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Is law and practice successful in enabling and facilitating children's participation in their health care? A critical analysis through the lived experiences of past-paediatric patients.

By

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A thesis submitted in partial fulfilment of the
requirements for the

degree of

Doctor of Philosophy in Law

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DEDICATION

This thesis is dedicated to
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DECLARATION

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctor of Philosophy. It has been composed by myself and has not been submitted in any previous application for any degree.

ABSTRACT

The law accords children the right to participate in their health care. However, within academic literature there has been growing concern that because of the complexity of the law of child consent, children are not meaningfully participating in their health care.

This thesis seeks to investigate whether law and practice are successful in enabling and facilitating children's meaningful participation in their health care. This study asks how do children participate in their health care, is it meaningful and why might children not be meaningfully participating in their health care? To address these research questions, I conducted an empirical qualitative research study using IPA methodology. This study interviewed 18 past-paediatric patients and four health care professionals seeking to document their 'lived experiences'. I conducted an analysis using typologies of participation as evaluative tools. The research findings suggest that children do participate in their health care, however, that their participation is often limited, tokenistic and inconsistent.

Where a child's ability is at the edge of their participation and they do not desire more, I claim that their participation was meaningful. Where a child's ability is beyond the level they are participating at and they desire more, their participation is not meaningful.

This study identified legal and practical barriers to meaningful participation including the ambiguity of the law in particular, the assessment of *Gillick* competency and 'due weight', the lack of guidance accompanying the law, doctor-child communication, physician and parental paternalism, selective information and the limited opportunity to participate at a higher level.

I recommend that law and practice are reformed to introduce tools to assist doctors in encouraging and facilitating children's meaningful participation in clinical practice. Further research is needed to find

effective methods for enabling and facilitating children's meaningful participation in their health care.

LIST OF ACRONYMS AND ABBREVIATIONS

| | |
|--------|--|
| A&E | Accident and Emergency |
| BMA | British Medical Association |
| CF | Cystic Fibrosis |
| CP | Cerebral Palsy |
| CT | Computed Tomography Scan |
| DMD | Duchene Muscular Dystrophy |
| ECHO | Echocardiogram |
| ECG | Electrocardiogram |
| FLRA | Family Law Reform Act 1969 |
| GMC | General Medical Council |
| GP | General Practitioner |
| HRA | Health Research Authority |
| IPA | Interpretative Phenomenological Analysis |
| IRAS | Integrated Research Application System |
| IV | Intravenous |
| MRI | Magnetic Resonance Imaging |
| ME | Myalgic Encephalomyelitis |
| NHS | National Health Service |
| OI | Osteogenesis Imperfecta |
| UNCRC | United Nations Convention on the Rights of the Child 1989 |
| UNCIEF | United Nations International Children's Emergency Fund |

REC

Research Ethics Committee

1. INTRODUCTION

1.1. Introduction

This thesis is based on a qualitative research study that asks is law and practice successful in enabling and facilitating children's meaningful participation in their health care? Using Interpretative Phenomenological Analysis (IPA), this thesis examines the 'lived experiences' of 18 past-paediatric patients who received therapeutic medical treatment as children on the National Health Service (NHS). For the purpose of this thesis, I define a child as a person under the age of 18.¹

This thesis aims to investigate how children participate in their health care. Through an exploration of the participants' 'lived experiences', I conduct an analysis seeking to assess whether the participants engaged in meaningful participation as children. I also investigate why children may not be meaningfully participating in their health care. During this introduction, I will articulate the origins of this project and why I sought to study it. In doing so, I draw out ideas, critiques and academic debate which will be analysed in greater depth during the subsequent chapters.

My interest in medical law and ethics originated from my personal experience as a paediatric patient. During my law degree (2013-2016), I had the opportunity to further this interest by conducting two pieces of independent research. The first, funded by the Undergraduate Research Support Scheme, analysed whether a doctor's fear of litigation will impact their employment of innovative medical treatment for their paediatric patients. The second project was my final year dissertation. I considered whether certain behaviours such as smoking and drinking should be criminalised during pregnancy. In both projects, I conducted an in-depth analysis of children's rights. Through this, I became aware that international and national Law values children's participation in all

¹¹ See further explanation in Chapter 1, Section 1.4.

decisions that impact them. On an International level, Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) states:

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.²

The guidance accompanying the UNCRC provided by the United Nations International Children's Emergency Fund (UNICEF), refers to a child's right to participate as one of the core values of the UNCRC.

In 1989, governments across the world adopted the United Nations Convention on the Rights of the Child (UNCRC), recognising that all children have the right to be treated with dignity and fairness, to be protected, to develop to their full potential and to participate.³

Article 12 of the UNCRC does not oblige a child to participate, rather provides them with the opportunity to do so.⁴ On a National Level, s1(1) of the Children Act states that when making a decision about a child, the child's welfare must be the paramount consideration.⁵ Part of this assessment includes giving consideration to the ascertainable wishes and feelings of the child concerned.⁶ In the area of medical practice, if a child under the age of 16 is deemed to have "sufficient understanding and

² United Nations Convention on the Rights of the Child (1989).

³ UNICEF, 'The Rights of Every Child: A summary of the United Nations Convention on the Rights of the Child' (*UNICEF UK*) <https://www.unicef.org.uk/child-rights-partners/wp-content/uploads/sites/3/2016/08/CRC_summary_leaflet_Child_Rights_Partners_web_final.pdf> accessed on 15 July 2019 at 1.

⁴ Lansdown, G, *Promoting children's participation in democratic decision-making* (UNICEF Innocenti Insight 2001) at section 1.1.4, 4-8.

⁵ Children Act 1989 c.51, s1(1).

⁶ *Ibid.*

intelligence”⁷ about a proposed medical treatment, they are considered *Gillick* competent and capable of consenting to therapeutic medical treatment without their parents’ consent.⁸ A child of 16 and 17 years is presumed capable to consent to therapeutic medical treatment.⁹ Where a child under the age of 18 is not competent to make decisions for themselves, their legal parents may act as surrogate decision-makers.¹⁰ If health care professionals and parents disagree on what treatment is in the child’s best interests, an application may be made to the courts for a judge to decide what treatment is in the child’s best interests. This occurred in the cases of Charlie Gard,¹¹ Alfie Evans¹² and Tafida Raqeeb.¹³

The General Medical Council (GMC) requires health care professionals to talk directly to the child, perceive children “as individuals...respecting their views”,¹⁴ “involve children and young people in discussions about their care”,¹⁵ provide paediatric patients with information, and create opportunities for children to ask questions.¹⁶ In 2003, the government

⁷ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] A.C. 112; [1985] 3 W.L.R. 830 at 189 per Lord Scarman.

⁸ *ibid.*

⁹ Family Law Reform Act 1969 c.46, s8.

¹⁰ Children Act (n 5) at s2(1).

¹¹ *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 1909 (Fam).

¹² *Alder Hey v Evans* [2018] EWHC 308 (Fam).

¹³ Wilkinson, D, ‘Press Release: Tafida Raqeeb, Medical Ethics, and Difficult Decisions’ (*University of Oxford Practical Ethics: Ethics in the News*, 1 August 2019) <<http://blog.practicalethics.ox.ac.uk/2019/08/press-release-tafida-raqeeb-medical-ethics-and-difficult-decisions/>> accessed 5 August 2019.

¹⁴ GMC, ‘0-18 years: Guidance For All Doctors’ (*GMC*, 25 May 2018) <<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/introduction>> accessed 16 June 2019 at para 3.

¹⁵ *ibid.*, at para 14.

¹⁶ *ibid.*, at para 14-21.

signed the UNICEF program “a world fit for children”,¹⁷ a scheme developed to promote and strengthen children’s rights during the 21st century in targeted fields including health. They argue that all children have the right to express themselves *and* “to participate in matters affecting them.”¹⁸

The law about children’s refusals of therapeutic medical treatment is unclear. There has been extensive academic debate on the distinction between consents and refusals of therapeutic medical treatment and whether the use of inherent jurisdiction is justifiable in these cases.¹⁹ In the majority of case law, children have not been considered *Gillick* competent thus, their refusal of therapeutic medical treatment has been overruled.²⁰ In *University Hospitals Plymouth Trust v B*²¹, Justice MacDonald held that the law entitles a judge to overrule a competent child’s refusal of medical treatment, where the refusal of treatment threatens the life of the child.

Gillick competency has been further critiqued for its ambiguous, subjective and context specific definition.²² Article 12 of the UNCRC has been

¹⁷ UNICEF, ‘A World Fit For Children’ (*UNICEF*, July 2008)

<https://www.unicef.org/publications/index_45482.html> accessed 8 December 2018 at 16.

¹⁸ *ibid.*

¹⁹ Gilmore, S & Herring, J, ‘No’ is the Hardest Word: Consent and Children’s Autonomy’ (2011) 23(1) *Child and Fam Law Quarterly*, 3; Cave, E & Wallbank, J, ‘Minors’ Capacity to Refuse Treatment: A Reply to Gilmore and Herring’ (2012) 20(3) *Medical Law Review*, 423.

²⁰ *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 F.L.R. 386; [1994] 5 Med. L.R. 73; *Re L (Medical Treatment: Gillick Competence)* [1998] 2 F.L.R. 810; [1999] 2 F.C.R. 524; (Fam Div); *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11; [1991] 3 WLR 592; *Re W (A Minor) (Medical Treatment: Courts Jurisdiction)* [1993] Fam 64; [1992] 3 WLR 758.

²¹ *University Hospitals Plymouth Trust v B* [2019] EWHC 1670 (Fam).

²² Cave, E, ‘Goodbye *Gillick*? Identifying and resolving problems with the concept of child competence’ (2014) 34(1) *Legal Studies*, 103 at 104-114.

criticised for failing to provide clear guidance on how to accord ‘due weight’ to a child’s views.²³ Where a non-*Gillick* competent child refuses therapeutic medical treatment, parents may lawfully act as surrogate decision makers overriding their child’s refusal. However, it has not been clarified whether parents are legally permitted to overrule their child’s refusal of medical treatment where their child is *Gillick* competent or aged 16 or 17. In instances where a competent child is refusing medical treatment, judicial opinion may be sought. Consequently, academics have speculated about the impact that an ambiguous law is having on the participatory activities of children in clinical practice.²⁴ It is not a huge logical leap to suggest that an ambiguous law may also be ambiguous to health care professionals. Thus, the application of the law may be patchy and inconsistent impacting the extent to which children participate in their health care. Unfortunately, absent from academic literature is sufficient evidence to confirm what happens in clinical practice.

In 1993,²⁵ Alderson sought to investigate whether children are capable of making decisions about their health care, including consenting to surgery.²⁶ Although, “Children’s Consent to Surgery”²⁷ focused on the capabilities of children, the empirical findings detailed some examples of children participating in their health care, such as, being informed and collaborating with their parents and health care professionals.²⁸ However, this study was not concerned with the extent to which children participated in their

²³ Daly, A, ‘No Weight for “Due Weight”? A Children’s Autonomy Principle in Best Interest Proceedings (2018) 26 International Journal of Children’s Rights, 61; Alderson, P, ‘Giving children’s views “due weight” in medical law’ (2018) 26 International Journal of Children’s Rights, 16.

²⁴ *ibid.*

²⁵ Alderson, P, *Children’s Consent to Surgery* (Open University Press 1993).

²⁶ *ibid* at 153 and 193.

²⁷ *ibid.*

²⁸ *ibid.*

health care and whether it was meaningful. Instead, Alderson called for more empirical research to further examine these findings.²⁹ In 2008, Coyne conducted a review of the academic literature examining the application of collaborative decision-making in Irish hospitals.³⁰ From this literature review, Coyne suggested that there is concern that children are not meaningfully participating in their health care.³¹ Nevertheless, Coyne's research was not supported with empirical data seeking the views of patients. Similarly, to Alderson, Coyne concludes there is a "need for further research to explore health professionals' and parents' perspectives on children's participation in consultations and decision-making".³² More recently, in 2018 Cumbria University conducted research into the participation of boys diagnosed with Duchene Muscular Dystrophy (DMD) who were deciding whether to enrol on a clinical trial.³³ These boys were found to have low level participation, in part because of the association between vulnerability, severe disability and presumed incompetency.³⁴ The project's conclusions imply that children without disabilities can participate in their health care because of an absence of vulnerability, although, there is a lack of empirical evidence which compares the findings from children with DMD with children who have other health conditions but not a disability, to examine whether a child's lack of participation is as a result of their disability.³⁵

²⁹ *ibid* at 197-199.

³⁰ Coyne, I, 'Children's participation in consultations and decision-making at health service level: A review of the literature' (2008) 45(11) *International Journal of Nursing Studies*, 1682 at 1682.

³¹ *ibid* at 1683.

³² *ibid* at abstract.

³³ Skyrme, S.L, & Woods, S, 'Researching disabled children and young people's views on decision-making: working reflexively to rethink vulnerability' (2018) 25(3) *Childhood*, 355 at 355-368.

³⁴ *ibid* at 359.

³⁵ *ibid* at 361-362.

Overall, children’s participation in their health care is an under-researched area. The perspective of patients has been largely overlooked. Academic literature which analyses the law is unsupported by empirical evidence of what happens in clinical practice and overlooks important issues unique to clinical practice such as, the practical barriers to participation, the long- and short-term impact of a child’s participation, and the voices of patients. Through an empirical research study, this thesis seeks to focus on the patient perspective, to understand whether children do meaningfully participate in their health care and to identify the reasons why children may not be meaningfully participating in their health care.

1.2. Why is it important to examine whether children meaningfully participate in their health care?

Academics have created typologies which define the term ‘participation’³⁶ as expressing one’s opinions, being actively involved in the decision-making process and ideally, exerting influence.³⁷ The typologies describe the levels of participation in a hierarchical structure, each rung of the ladder corresponding to increasingly more power. In a medical context, the ladders range from no involvement, to being informed, consulted, engaging in collaborative decision-making and finally, consenting to and

³⁶ Arnstein, S.R., 'A Ladder of Citizen Participation' (1969) 35(4) *Journal of the American Planning Association*, 24; Thomas, N, 'Towards a theory of children’s participation' (2007) 15(2) *The International Journal of Children’s Rights*, 199 at 199-218; Hart, R *Children's Participation: From Tokenism to Citizenship* (UNICEF International Child Development Centre, 1992) <https://www.unicef-irc.org/publications/pdf/childrens_participation.pdf> accessed 5 March 2019; Hart, R, 'Stepping back from "The ladder": Reflections on a model of participatory work with children' in J Reid, *Participation and learning: developing perspectives on education and the environment, health and sustainability* (SAGE 2008) 19, at 23; Hart, A, R, *Children's Participation: The Theory And Practice Of Involving Young Citizens In Community Development And Environmental Care* (Earthscan 1997, reprint 2008).

³⁷ Arnstein (n 36) at 24-25.

refusing therapeutic medical treatment.³⁸ Hart argues that a child's participation is meaningful where the child has an opportunity to participate at the child's highest potential in a manner that will influence a decision.³⁹

It is necessary to investigate whether all children are meaningfully participating in their health care because of the associative benefits. Meaningful participation empowers children, allowing them to influence the world in which they live, and to be considered as active and valued members of their community.⁴⁰ Article 12 of the UNCRC, the Children Act s1(1) and *Gillick* competency, acknowledges the child's right to "hold views, to make choices, and to take actions based on their views and beliefs" irrespective of their competency.⁴¹ Where this is respected not merely in attitude but in action, children's agency is upheld.⁴²

The principle of autonomy is one of the four fundamental bioethical principles.⁴³ Whilst a non-*Gillick* competent child does not have the competency to make an independent decision free from influence,⁴⁴ a child's emerging or existing autonomy ought to be protected. In medical practice, autonomy is associated with giving patients the opportunity to make voluntary choices about medical interventions. Meaningful participation enables *Gillick* and non-*Gillick* competent children to have the opportunity to voice their opinions and desires. This discourages doctor

³⁸ *Ibid*; Thomas (n 36); Hart, 'Stepping back from "The ladder": Reflections on a model of participatory work with children' (n 36) and Hart, *Children's Participation: The Theory And Practice Of Involving Young Citizens In Community Development And Environmental Care*.

³⁹ Arnstein (n 36) at 24-25.

⁴⁰ Sinclair, R, 'Participation in Practice: Making it meaningful, effective and sustainable' (2004) 18 *Children and Society*, 108 at 108; Lansdown (n 4) at section 1.4, 4-8.

⁴¹ Beauchamp, T & Childress, J, *Principles of Biomedical Ethics* (7th ed Oxford University Press 2013) at 106-107.

⁴² *ibid* at 107.

⁴³ *ibid*

⁴⁴ *ibid* at 102.

paternalism and is vital for a health care system that is moving towards a patient/child centred service. Where a child meaningfully participates in their health care, they have an element of control over their medical treatment. Thus, meaningful participation develops a child's emerging autonomy, enabling them in developing the skills required to make independent decisions. In participating, children develop their communication, debating and decision-making skills, they have choice, control, access to information and can bring their unique perspective.⁴⁵ For a *Gillick* competent child, being able to consent to and refuse therapeutic medical treatment goes some way to respecting their individual autonomy.⁴⁶

Thus, because of the international and national frameworks the law *should* be enabling children to meaningfully participate in clinical practice, all children *should* be meaningfully participating in clinical practice, and hospitals *should* be encouraging, promoting and enabling meaningful participation. It is therefore necessary to study what is happening in clinical practice and consider whether the law, policy, practice or all three, need reforming. This is of importance in an academic backdrop where concerns have been raised highlighting the weaknesses within the law and suggesting that children may not be meaningfully participating in their medical decisions.

1.3. What will this research do?

This thesis seeks to address one main and five secondary research questions.

Main Research Question:

- (i) Is law and practice successful in enabling and facilitating children's participation in all aspects of their health care?

Secondary Research Questions:

- (ii) How do children participate in their health care?

⁴⁵ *ibid.*

⁴⁶ *ibid.*

- (iii) Does an examination of the participants 'lived experiences' reveal that the participants in this study *meaningfully* participated in their health care as children?
- (iv) Does an examination of participants 'lived experiences' expose any barriers or enabling factors to meaningful participation?
- (v) What is the long- and short-term impact of the participation on the participants in this study?
- (vi) Have the 'lived experiences' of children evolved in accordance with the introduction of the law valuing participation in clinical practice?

Investigating whether the law is successful in enabling and facilitating children's participation from the perspective of patients is an under researched area. Previous studies have overlooked the barriers to meaningful participation experienced by patients and health care professionals and the long- and short-term impact of participation, or lack of, on children. Moreover, there is no knowledge about how children's 'lived experiences' have evolved and whether they have done so in accordance with legal and policy reforms. Simply addressing whether children participate in clinical practice - as has been done in academic commentary - negates the important issues behind children's struggle to meaningfully participate in clinical practice. Thus, this thesis makes an important contribution to academic knowledge by examining not only the participation of children in clinical practice and whether this participation is meaningful, but the barriers to meaningful participation.

My starting proposition for this thesis was that due to the ambiguities of the law, children are not meaningfully participating in their health care. To test this hypothesis, and further explore the reasons behind an absence of meaningful participation, I sought to conduct an empirical study that documented and examined the 'lived experiences' of patients. This study

only directly investigates the participants' experiences. Thus, the findings from this study, whilst important and significant, are not generalizable.

This study had 22 participants, 18 past-paediatric patients and four health care professionals. I organised these participants into four groups. Group 1 were past-paediatric patients between 18 and 25 years of age (eight participants). Group 2 were past-paediatric patients between the ages of 26 and 34 (five participants). Group 3 were past-paediatric patients aged 35 and above (five participants). Finally, group 4 were health care professionals (four participants).⁴⁷

I interviewed adults who, as children, had undergone therapeutic medical treatment. This was for two reasons. First, because interviewing past-patients was an effective method to answer the research questions that consider not only the 'lived experiences' of patients but the long- and short-term impact of their experience and the evolution of 'lived experiences' in accordance with changes in law and policy. Second, to satisfy the ethical principle that children must only be interviewed where the data gathered could not have been done in another manner.⁴⁸ I interviewed past-paediatric patients, half of whom have recently left paediatric health care. Their narratives were supplemented by four practising health care professionals. Collectively, they provide the modern-day perspective. The older past-patient participants provide insight into how the 'lived experiences' of children have evolved during a time when law and policy was being introduced to accord children the right to meaningful participation.

⁴⁷ See chapter 5 for background information of the participants.

⁴⁸ UCL, 'UCL Research Ethics Committee Guidance Note 1: Research Involving Children' (UCL) <<https://ethics.grad.ucl.ac.uk/forms/guidance1.pdf>> access 8 April 2019; Warwick University, 'The concordat to support research Integrity' (March 2019) <<https://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2019/revised-concordat-draft.pdf>> accessed 8 April 2019.

My research found that the participants in this study participated in their health care to a limited extent. Whilst one participant engaged in shared decision-making and five participants had an opportunity to assent to medical treatment,⁴⁹ neither shared decision-making nor assent were routinely sought and offered.⁵⁰ No participant under the age of 18 consented to therapeutic medical treatment.⁵¹ During an analysis of these findings in Chapter 8, I claim that the participants' participation in their health care was not always meaningful. The findings of this thesis illustrate the complexity surrounding children's participation in their health care that has before been overlooked. This thesis goes some way to laying the foundations for future research to consider how these barriers ought to be overcome to ensure law and practice are successful in enabling children to meaningfully participate in clinical practice.

1.4. Definitions

'Children'– There is an absence of academic and scientific agreement about the definition of 'children' and how it distinguishes from the terms 'young people' and 'adolescents' (section 2.2). *Gillick*⁵² and the FLRA⁵³ distinguish between children and young people, referring to young people as 16-17-year olds who enjoy a presumption of competency. Whilst I acknowledge this distinction, I will use the term children to refer to a person under the age of 18 as defined by the UNCRC.⁵⁴ However, where it is necessary to distinguish between the age groups, for example, during a discussion of the law, I will specify the age of the child.

'Therapeutic medical treatment'- 'Therapeutic' medical treatment, refers to medical interventions that have "a beneficial effect on the body or

⁴⁹ See Chapter 7, Section 4.4.

⁵⁰ *ibid*

⁵¹ *ibid*

⁵² *Gillick v West Norfolk and Wisbech Area Health Authority* (n 7).

⁵³ Family Law Reform Act (n 9).

⁵⁴ UNCRC (n 2).

mind” required to treat a disease or disorder.⁵⁵ I exclude non-therapeutic medical treatment because it raises different ethical and legal dilemmas. For the purpose of this thesis, ‘treatment’ is to be understood in its widest possible sense, incorporating any medical interventions including therapy, surgery, invasive procedures, intravenous (IV) therapy and investigations.

‘Consent’ – In all instances, the term ‘consent’ refers to a legally valid agreement. Consent requires three elements. First, the decision must be made voluntarily.⁵⁶ Second, the decision maker must be competent to make that decision.⁵⁷ Finally, the decision-maker must be informed. To protect against a tort of trespass, the doctor must inform the patient “what he intends to do, and its implications, in the way a careful and responsible doctor in similar circumstances would have done”.⁵⁸ To protect against a tort of negligence, the doctor must inform the patient of the material risks. A material risk is a risk that “a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor was or should reasonably be aware that the particular patient would be likely to attach significance to it”.⁵⁹

‘Assent’- Assent refers to a positive and voluntary agreement by a child who is not competent (either by reason of *Gillick*⁶⁰ or FLRA⁶¹) nor in

⁵⁵ Webster, M, ‘Therapeutic’, (MerriamWebster Medical Dictionary) <<https://www.merriam-webster.com/dictionary/therapeutic>> accessed 15 July 2019.

⁵⁶ *Freeman v Home Office* [1984] 1 ALL ER 1036.

⁵⁷ Mental Capacity Act 2005 c9, s3; *Gillick* (n 7).

⁵⁸ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582; *Chatterton v Gerson* [1981] 1 ALL ER 257 at 443.

⁵⁹ *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 at paras 39-87.

⁶⁰ *Gillick* (n 7).

⁶¹ Family Law Reform Act (n 9)

possession of a sufficient amount of information to meet the standards to provide a legally valid consent.⁶² Miller et al. states:

The concept of child assent emerged as a way to distinguish a child's "agreement" from a legally valid authorization. The requirements for assent are less strenuous than those for consent and include basic comprehension of procedures and purpose and the ability to indicate a preference.⁶³

Levesque laid down the four requirements for assent: (i) the child has awareness of their situation that is developmentally appropriate for them, (ii) as much as possible, the child is aware of "what they can expect during and after the procedures"⁶⁴, (iii) the health care professionals are aware of the child's understanding of their situation and (iv) the child is willing to act, their action is voluntary.⁶⁵ In many instances a child is not deemed capable to provide valid consent nevertheless they are deemed to assent. Throughout the empirical study that this thesis is based on, health care professionals were keen to emphasise the distinction between an assent and a consent arguing that assent is beneficial to the child in recognising their evolving competencies and autonomy, and encouraging their meaningful participation within their health care.

'*Competency*' - Capacity is the ability and power to do or understand something⁶⁶ and competency is using these abilities and powers to

⁶² The Research Ethics Guidebook: A Resource For Social Scientists, 'Research with children' (*The Research Ethics Guidebook*) <<http://www.ethicsguidebook.ac.uk/Research-with-children-105>> accessed 1 April 2019.

⁶³ Miller, V, Drotar, D & Kodish, E, 'Children's Competence for Assent and Consent: A Review of Empirical Findings' (2004) 14(3) *Ethics and Behaviour* 255, at 256.

⁶⁴ Levesque, R, 'Informed Consent and Assent' (2018) (*Encyclopaedia of Adolescence*, 28 February 2018) <https://0-doi-org.pugwash.lib.warwick.ac.uk/10.1007/978-3-319-33228-4_440> accessed 18 August 2019 at section 'Adolescents, Consent, and Assent'.

⁶⁵ *ibid.*

⁶⁶ "competency" OEC Online OUP <<https://www.oed.com>> accessed 4 March 2018.

complete the act or reach sufficient understanding⁶⁷ The Mental Capacity Act,⁶⁸ *Re C*⁶⁹ and *Gillick* competency⁷⁰ requires a competent person to have a sufficient understanding and appreciation of the proposed medical treatment, to develop a conclusion using reasoning and be able to communicate their decision to another person. (See section 3.4 for an analysis of the definition of competency).

1.5. Thesis structure

Mindful of the research questions identified in section 1.3, it is necessary to detail how my core argument develops in each chapter of this thesis.

Through a review of the literature, Chapter 2 establishes the theoretical assumptions upon which my empirical project is based, and the following chapters will draw upon. The chapter argues (i) that every child has a right to meaningfully participate in their health care, (ii) that children ought to have a right to meaningful participation and (iii) that some children are capable of making independent health care decisions. Second, this chapter presents a brief historical overview of the literature that has directly contributed to the discourse of childhood, and draws from scientific, historical and sociological discourse in order to show how the law has evolved to value children's participatory rights. This analysis does not intend to be exhaustive but seeks to go some way to establish the theoretical assumptions underpinning this empirical research.

Chapter 3 critically analyses the law. Despite the noble intentions of the creators of international and national legislation and case law, academic debate suggests that children do not meaningfully participate in clinical practice. Absent from the academic literature is sufficient empirical data supporting the assumption that children are not meaningfully participating

⁶⁷ Couden, M, *Children's Rights: From Philosophy to Public Policy* (Palgrave MacMillan 2016), at 38.

⁶⁸ Mental Capacity Act (n 56).

⁶⁹ *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819.

⁷⁰ *Gillick* (n 7).

in practice. Moreover, there is a lack of empirical research investigating why children do not meaningfully participate in their health care and the long- and short-term impact of this participation (or lack of participation) on children. Thus, this chapter justifies the empirical research that this thesis is based on.

Chapter 4 outlines the methodology and method for the empirical study. This chapter identifies and justifies the use of Interpretative Phenomenological Analysis (IPA) as the methodology for this study and the use of semi-structured interviews as the method to gather data. It details how I selected and recruited potential participants, the design of interview questions and how I conducted the interviews. I discuss my position within the research, the limitations of the study sample, the ethical considerations and the process of obtaining NHS ethical approval.

Chapters 5, 6 and 7 closely examine the lived experiences of past-paediatric patients. Chapter 5 reports the background information about the interviewees and introduces each participant using case reports which chronologically record the participants' medical experience in addition to their social background to provide a rich backdrop for the further discussions in Chapters 6 and 7. Chapter 6 focuses on relationships between the child and the clinical environment, their doctors, wider health care team and their parents. Chapter 7 delves deeper into how information is shared with children and the effects of this on their role in the decision-making process.

Chapter 8 analyses the empirical findings using Hart's ladder of child participation⁷¹. It argues that in the main, children's participation in their health care is routinely not meaningful. It identifies barriers to meaningful participation arguing they are multifactorial and caused by the law and clinical practice. For children's participation to be meaningful, law and practice needs to evoke significant and real change. Chapter 9 brings

⁷¹ Hart, *Children's Participation: From Tokenism to Citizenship* (n 36).

together the empirical findings and the analysis to provide a detailed review of the research questions and tentatively suggest recommendations for reform.

1.6. Conclusion

This research documents how children participate in clinical practice. From this evidence I evaluate whether the participants participation was meaningful. The empirical findings suggest that children's participation in their health care is limited. Shared decision-making and assent are not routinely offered or sought. This is a significant concern, most especially, as the right to participate is accorded children in a document that establishes the fundamental human rights of children. This research delved deeper, identifying numerous barriers to meaningful participation within the law and clinical practice. This thesis calls for future research to investigate and create recommendations for reform that could ensure that all children meaningfully participate in clinical practice. For now, this thesis turns to a review of the literature.

2. THE HISTORICAL EVOLUTION OF THE RIGHT OF CHILDREN TO MEANINGFULLY PARTICIPATE IN THEIR HEALTH CARE

2.1 Introduction

The purpose of this chapter is to show that the law has gradually evolved to value children's participatory rights in all decisions that impact them including their health care. This chapter will make three claims: (i) that every child has a right to meaningfully participate in their health care, (ii) that children ought to have a right to meaningful participation and (iii) that some children are capable of making independent health care decisions.

To assess whether the law is successful in facilitating and enabling children's participation in their health care, it is necessary to discuss how the law has developed to value children's right to participate. I aim to provide a brief overview of sources which contribute to the discourse of childhood which will provide context for later discussions on consent and refusals of therapeutic medical treatment. This review does not intend to be exhaustive but seeks to establish the theoretical assumptions underpinning this empirical research.

Section 2.2 discusses cognitive developmental psychology, neurological findings, and historical, social and cultural factors that are part of the discourse of childhood. Section 2.3 analyses the exceptions to the discourse of childhood. Section 2.4 and 2.5 considers the impact of the discourse on law and policy including parental authority, the hospital environment and the doctor-paediatric patient relationship. Finally, section 2.6 claims that the law has evolved to value children's participatory rights.

2.2 The Discourse of Childhood

Central to the discourse of childhood is the notion that adults and children are distinct.¹ Predominantly, adults are considered "mature, rational,

¹ James, A & Prout, A, *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* (1st edn, Routledge 2014), at 11.

competent, social and autonomous”,² whilst children are “immature, irrational, incompetent, asocial and acultural”.³ Cognitive developmental psychology, neurology and sociology contribute to this discourse.

2.2.1 Cognitive Developmental Psychology

Within psychology, there are many models that seek to depict the progress of a child’s cognitive development as they transition from childhood to adulthood.⁴ Vygotsky⁵ and Piaget and Inhelder⁶ present two prominent theories that remain influential in modern day psychology. Although fundamentally different, both models posit that children go through a transformational process that ends in adulthood where it is presumed that the individual has developed basic decision-making capabilities including the competency to make independent decisions. However, these models also illustrate that children develop their capabilities at individual rates, and thus, it is not possible to be clear at what age all children will develop the capabilities to make health care decisions. An independent competency assessment of each child is critical.

² *ibid*; MacKay, R.W, ‘Conceptions of Children and Models of Socialization’ in Waksler, F. C (ed), *Studying The Social Worlds Of Children: Sociological Readings* (Routledge 1991), at Chapter 3 at 23.

³ James & Prout (n 1) at 11.

⁴ Piaget, J & Inhelder, B, *The Growth of Logical Thinking from Childhood to Adolescence: An Essay on the Construction of Formal Operational Structures* (Psychology Press 1958); Piaget, J & Inhelder, B, *The Psychology of the Child* (Routledge 1969); Kohlberg, L, *The Philosophy of Moral Development: Moral Stages and the Idea of Justice* (Harper and Row 1981); Montessori, M, Claremont, C.A, (tr), *The Absorbent Mind* (Clio 1988); Rousseau, J.J, Bloom, A (tr), *Emile: Or On Education* (Penguin 1991).

⁵ Vygotsky, L, in Cole, M & others (eds), *Mind in Society: The Development of Higher Psychological Processes* (Harvard University Press 1978).

⁶ Piaget & Inhelder, *The Growth of Logical Thinking from Childhood to Adolescence: An Essay on the Construction of Formal Operational Structures* (n 4); Piaget & Inhelder, *The Psychology of the Child* (n 4).

Piaget and Inhelder developed “cognitive development theory”,⁷ which divides development into stages. They suggest that a child must progress through each stage chronologically to reach adulthood.⁸ By adulthood the child has transformed from the primary state of using reflexes, to thinking entirely for themselves and manipulating abstract ideas. The model has four stages; (i) sensio-motor stage (birth to two years); (ii) pre-operational (two-seven years); (iii) concrete operational (seven-11 years); and (iv) formal operational (11-18 years).⁹ During the first three stages, a child develops basic skills and functions such as object permanence, decentralisation of one’s self, communication, creative and sophisticated problem-solving, acting with intention, manipulating ideas and challenging authority. These capabilities culminate in stage four, the formal operational stage. At this stage the child develops the ability associated with adulthood such as, thinking rationally about hypothetical and abstract thoughts, using deductive reasoning, and making independent decisions.¹⁰ Piaget argues that during the formal operational stage the child develops concrete operational thought and the competency to engage in complex decision-making.¹¹

Piaget and Inhelder’s work continues to inform how psychologists, teachers and doctors are taught. Nevertheless, their work has been critiqued for its use of logic,¹² subjective methodology¹³ and the credibility of their data.¹⁴

⁷ Piaget & Inhelder were the first people to use the term “cognitive development theory”.

Piaget & Inhelder, *The Psychology of the Child* (n 4).

⁸ *ibid.*

⁹ *ibid* at chapter 1.

¹⁰ *ibid*, at 130-149.

¹¹ *ibid.*

¹² Parsons, C, ‘Inhelder and Piaget’s the Growth of Logical Thinking II A Logician’s Viewpoint’ (1960) 51(1) *Brit J Psychol*, 75 at 75-84; Ennis, R.H, ‘Children’s Ability to Handle Piaget’s Propositional Logic: A Conceptual Critique’ (1975) 45(1) *Review of Educational Research*, 7; Driver, R, ‘When is a Stage Not a Stage? A Critique of Piaget’s Theory of Cognitive Development and its Application to Science Education’ (1978) 21(1) *Educational Research*, at 54-60.

Academics who have repeated Piaget and Inhelder's experiments have found that children "operate at different levels in different contexts"¹⁵ thus, disproving the assumption that a child moves from stage to stage in a linear formation.¹⁶ Moreover, Driver found that a child's cognitive development level cannot be accurately ascertained from a child's performance in a task.¹⁷ Whilst there is a general pattern of evolving competency to which most children adhere, gradually increasing as they age, there are exceptions—with some children reaching stage four in tasks before being considered to operate at stage three.¹⁸ Therefore, it is not possible to determine an age where all children will be competent to make decisions. In terms of paediatric health care, the data from further research projects suggests that it is necessary to individually assess each child's developmental level before giving them the responsibility to make independent health care decisions.¹⁹

Vygotsky also proposes that a child develops in stages.²⁰ Like Piaget and Inhelder, each developmental stage is associated with a child developing the following functions which Vygotsky considers important milestones for development: (i) the role of speech in the organisation of higher functions, (ii) the ability to transform visual perceptions into language, (iii) memory and thought, (iv) an interaction with the internal and external world, (v) development as a tool for understanding,²¹ (vi) learning and

¹³ Lunzer, A, E, 'Problems of Formal Reasoning in Test Situations' (1965) 30(2) *Monographs of the Society for Research in Child Development*, at 19-46.

¹⁴ Driver, R (n 82) at 54-60; Wallace, J.G, *Stages and Transition in Conceptual Development* (National Foundation for Educational Research 1972); Cole, M & Scribner, S, *Culture and Thoughts: A Psychological Introduction* (Wiley 1971); Lunzer (n 13).

¹⁵ Driver (n 14), at 57.

¹⁶ *ibid*, at 56.

¹⁷ *Ibid*.

¹⁸ *ibid*, at 57-58

¹⁹ *ibid*; Wallace, (n 14); Cole & Scribner (n 14); Lunzer (n 13).

²⁰ Vygotsky (n 5) at 21.

²¹ *ibid* at 64.

development,²² and (vii) play and imagination in development.²³ Vygotsky explains how a child will develop these functions, often through social interaction. Unlike other models of cognitive development, Vygotsky does not correlate a function with a child's age nor does he detail how to assess an individual child's particular stage of development. Therefore, the application of this model is difficult to implement in practice.²⁴

Unlike Piaget, who believes development comes before learning,²⁵ Vygotsky believes that children develop through learning with guidance.²⁶ Vygotsky agreed with Piaget that at any given point, a child will be at a certain developmental level termed their "actual developmental level",²⁷ but he disagreed that this is the current extent of a child's capabilities. Instead, he believed that with guidance, a child can demonstrate further capabilities that have not yet matured.

Vygotsky uses the example of two 10-year-old children.²⁸ When these children were assessed, using standardised educational methods supported by Piaget, both children were said to be of a development level expected of an 8-year-old.²⁹ Rather than terminating the assessments at this point, as Piaget would expect, Vygotsky asked the assessor to provide guidance by showing and repeating methods of problem solving, using leading questions and helping the child with the task. After guiding the

²² *ibid* at chapter 9, 79.

²³ *ibid* at 93.

²⁴ Chaiklin, S, 'The Zone of Proximal Development in Vygotsky's Analysis of Learning and Instruction' in Kozulin and others (eds), *Vygotsky's Educational Theory in Cultural Context* (CUP 2003) at 42-46.

²⁵ Piaget & Inhelder were the first people to use the term "cognitive development theory". Piaget & Inhelder, *The Growth of Logical Thinking from Childhood to Adolescence: An Essay on the Construction of Formal Operational Structures* (n 4) at 281.

²⁶ Vygotsky (n 5) at 90.

²⁷ *ibid*, at 85-87.

²⁸ *ibid* at 85.

²⁹ *ibid* at 85-86.

child, the first child was re-assessed as having a developmental level equivalent of a 12-year-old and the second child was re-assessed as having a developmental level of a nine-year-old. Whilst in the first instance, Piaget would have argued that both children were similar developmentally, after guidance it was found that the children developed differently. The gap between 12 years of age and eight years of age, or between nine years of age and eight years of age is termed by Vygotsky as “the Zone of Proximal Development”.³⁰ Vygotsky clearly articulates the difference between the actual developmental level and the Zone of Proximal Development in this passage:

The actual development level only defines functions that have been established or already matured. The end products of development. The zone of proximal development defines the functions that are not yet matured but are in the process of maturing, functions that will mature tomorrow but are in an embryonic state.³¹ ...Actual developmental level characterises development retrospectively, but the zone of proximal development looks prospectively.³²

Wood et al. argue that the more capable peer, who guides the child through the Zone of Proximal Development, is providing the child with the scaffolding they need to learn and, consequently, promote development.³³ With this scaffolding in place, the child has the tools to learn, expanding their developmental capabilities.³⁴ Wood et al. considers that the role of the guider is to tailor their approach to the individual child, to understand their capabilities, so they are not stretching the person outside of their

³⁰ *ibid* at 86.

³¹ *ibid*.

³² *ibid*, at 87.

³³ Wood, D, Bruner, J.S, and Ross, G, ‘The Role of Tutoring in Problem Solving’ (1976) 17 *Journal of Child Psychology and Psychiatry*, 89 at 90.

³⁴ *ibid*.

Zone of Proximal Development.³⁵ The term 'scaffolding' was first introduced by Wood et al., and has since been linked with Vygotsky's Zone of Proximal Development, despite neither author citing the other. Vygotsky's model explains that children can complete activities beyond their actual developmental level with guidance, and this tells us a lot about the relationship between learning and development—i.e., that learning leads to and encourages development.³⁶

Within psychology there remains uncertainty as to which model is representative of how children truly develop. However, what is common among these theories is that, in general, children are considered to lack the competencies that most adults possess. Despite this, it is acknowledged that children develop at individual rates, and that it is possible for children to obtain the competency to make a complex decision before adulthood. Whilst the uncertainty of how children develop makes child development difficult to understand and document, it encourages the law to take an individualistic approach to development and learning rather than apply a 'one size fits all' ethos.

2.2.2 Neurological Development of the Child

Studying a child's brain as they develop became possible during the early 1990s, due to the implementation of revolutionary brain scanning technology.³⁷ Neuroscientists are particularly interested in the structural and developmental differences between child and adult brains. Angela Griffin's research explains how a child's brain develops up to adulthood, making the following assumptions.³⁸

First, a child's brain has a greater capacity for change in response to their environment than adults. The process of change is called neuroplasticity

³⁵ *ibid.*

³⁶ Vygotsky (n 5), at 88.

³⁷ Griffin, A, 'Adolescent Neurological Development and Implications for Health and Well-being' (2017) 5 *Healthcare MDPI Review*, 62.

³⁸ *ibid* 106.

and it describes the building and re-building of synaptic pathways in response to an experience.³⁹ The more experiences that we have of a similar nature, the stronger that pathway becomes. Whilst an adult's brain has capacity for change,⁴⁰ neuroplasticity is particularly marked during childhood as the brain strengthens pathways that are regularly used and removes pathways that are rarely used.⁴¹

Children with chronic conditions will have many experiences that other children may not have, and some will have these, in addition to experiences that those without chronic conditions may have. For children with chronic health conditions, their experiences and environment will cause change in the synaptic pathways, potentially improving their decision-making capabilities because of regular engagement in this activity.

Second, Griffin assumes that children react differently to fear than adults. As a result, they are considered more prone to trauma than adults.⁴² The amygdala is responsible for the self-regulation of emotions and fear processing. During adolescence, neurotransmitters such as dopamine accelerate in the brain, and this directly impacts the amygdala by increasing its activity.⁴³ When experiencing a stressful situation such as medical treatment, the hippocampus and amygdala affect our reactions, based on how we reacted to similar situations previously. This subsequently influences how we react in the future. When a person lacks a previous or similar experience, the brain struggles to process this information. The processing of this experience is therefore different to other experiences. Unlike adults, children may not have had as much experience, and as such, this is the first time that their brain is processing

³⁹ *ibid* at 61-62.

⁴⁰ Voss, P & others, 'Dynamic Brains and the Changing Rules of Neuroplasticity: Implications for Learning and Recovery' (2017) 8 *Front Psychol*, 1657.

⁴¹ Griffin (n 37) at 63.

⁴² *ibid*.

⁴³ *ibid*.

the information. Moreover, children are prone to trauma at a younger age because they experience heightened emotions and struggle to self-regulate these emotions. As such, children and adolescents have a greater sensitivity to stressful situations and chronic stressors can cause trauma in children.⁴⁴ Research has documented the impact of having a chronic health condition on the brain. Many academics argue it leads to loneliness, depression and feelings of rejection.⁴⁵ Consequently, it is important for children to meaningfully participate in their health care and to be fully informed so that they can prepare for medical procedures, thereby, reducing the anxiety and stress associated with invasive medical interventions.

Third, neuroscientists argue that the development of the brain peaks at adulthood.⁴⁶ Research suggests that 80 per cent of the total brain volume is reached by 1.5 years old, 95 per cent by six years old; girls' peak brain size is reached at 10.5 years old, and for boys, at 14.5 years old.⁴⁷ However, the brain continues to develop throughout a person's life.⁴⁸ Although the size of a person's brain is established in their early years, academics argue it is the continual formation of connections that promotes cognitive development—however, little is known about what age a person's cognitive development is reached from a neuroscientific perspective.⁴⁹ As such, neurologists are careful to make generalisations about a child's 'typical' neurological development.⁵⁰

⁴⁴ *ibid* at 66.

⁴⁵ Arana, A.A, 'The Impact of Social and Physical Peer Victimization on Systemic Inflammation in Adolescents' (2018) 64(1) *Merrill-Palmer Quarterly*, 12 at 15.

⁴⁶ Brown, D.R, *Neuroscience of Mathematical Cognitive Development: From Infancy through Emerging Adulthood* (Springer 2018) at 27.

⁴⁷ *ibid*.

⁴⁸ *ibid*.

⁴⁹ *ibid* at 13.

⁵⁰ *Ibid*.

Similarly, to cognitive development theories, this research remains contentious. There is much about the brain that we do not know, and academics warn about making generalisations.⁵¹ Every brain is different, they develop at various rates, and are affected by personal experiences. Brain development continues throughout a person's lifetime, as illustrated by adults who recover from significant brain injury, rebuilding, through repetition, the lost synaptic connections.⁵² Neuroscientists are unable to provide an accurate timeline of when childhood and adulthood begins and ends, as brain development is unique to each individual. Nevertheless, there is consensus that a child's brain is structurally different to an adult's.⁵³ This accounts for a lack of capabilities in young children, their vulnerability and dependency on adults around them. Overall, each child's capacity must be individually assessed, as assumptions cannot be based on the link between age and brain development.

2.2.3 Historical Variations

Although it is widely acknowledged that childhood is a period in a person's life of biological, cognitive and neurological change, the 'new sociological model of childhood' argues that a large element of childhood is socially constructed.⁵⁴ The model argues that our understanding of childhood is dependent on historical and cultural settings. Therefore, the presumptions that are made about a child's competency are, to an extent, dictated by societies' understandings of childhood. As such, it is necessary to challenge such presumptions.

Today children are viewed as vulnerable, dependent and lacking competency.⁵⁵ However, Aries believed that this modern understanding of childhood is relatively recent. In 1960, Aries made the controversial claim

⁵¹ *ibid* at 22.

⁵² Voss (n 40) at 5.

⁵³ Brown (n 46) at 27.

⁵⁴ James & Prout (n 1) at 17.

⁵⁵ *ibid* at 11.

that childhood did not exist until the 17th century in Western society.⁵⁶ An amateur historian, Aries was interested in the historical evolution of family. At the time of his research in the 20th century, a family was considered to be a private domestic circle, often with a central figure—the child. Aries chose to study the child as the nucleus of family life. Much of his work focused on the social narrative of childhood and its evolution since the Middle Ages in western society. The main premise of Aries' work is that childhood as a concept was not in the social consciousness until the 17th century, when social change distinguished between children and adults.⁵⁷ This, in turn, created the understanding of childhood as a period of innocence, dependency and vulnerability.⁵⁸

In medieval society the idea of childhood did not exist; this is not to suggest that children were neglected, forsaken or despised. The idea of childhood is not to be confused with affection for children. It corresponds to an awareness of the particular nature of childhood, that particular nature which distinguishes the child from the adult, even the young adult. In medieval society this awareness was lacking. This is why, as soon as the child could live without the constant solicitude of his mother, his nanny or his cradle-rocker, he belonged to adult society.⁵⁹

Around the age of seven, children would leave their mother and although they were recognised as biologically and cognitively different from adults, children took on adult responsibilities such as work.⁶⁰ They would be dressed in the same clothes and participate in the same recreational activities as adults.⁶¹ In 1600, “the specialisation of games and pastimes did

⁵⁶ Aries, P, Baldick, R (tr), *Centuries of Childhood* (Jonathan Cape 1962).

⁵⁷ *ibid.*

⁵⁸ *ibid.*

⁵⁹ *ibid.*, at 128.

⁶⁰ *ibid.*, at 84 and 329.

⁶¹ *ibid.* at 48-55.

not extend beyond infancy; after the age of three or four ...the child played the same games as adults, either with other children or with adults".⁶²

According to Aries, the recognition of childhood began in the late 16th century and early 17th century. This was primarily a result of decreased infant mortalities, changes to the education system, and a gradual shift from open public family homes to the closed private home with which we are more familiar today.⁶³ Aries places huge significance on the 17th century as a turning point, where society began to recognise the concept of childhood.⁶⁴

Aries reported that in the latter 17th century, activities, toys and clothes were being made specifically for children.

Focusing on dress, it was boys that were associated with childhood. It occurred solely in middle class or aristocratic families. The children of the lower classes, the offspring of the peasants and the artisans, those who played on the village greens, in the city streets, in the craftsmen's workshops, in the tavern taprooms and in the kitchens of great houses, went on wearing the same clothes as adults: they were never depicted in robes or false sleeves. They kept up the old way of life which made no distinction between children and adults, in dress or in work or in play.⁶⁵

Separation continued outside the family home, with the introduction of compulsory education for children. During the Middle Ages few people were educated in a school setting, most going out to work to provide for their families. Girls were domestic servants, whilst boys were apprentices and farmhands.⁶⁶ Education existed for men and boys to study at church to

⁶² *ibid*, at 71.

⁶³ *ibid*.

⁶⁴ *ibid*, at 46-47.

⁶⁵ *ibid*, at 61.

⁶⁶ *ibid* at 354.

become clerics.⁶⁷ The education system evolved from here, when students of all ages and abilities could attend school at any point in their lifetime, if they were able. Throughout the 17th and 18th century, people went to school as early or as late as they could, taking the opportunity when it arrived. As the education system developed, it became the norm for boys to attend school. Students were divided into ages, which contributed to the notion that the period of life now known as ‘childhood’ is a specific stage.⁶⁸ At first, education was only for the upper and middle classes; as such, for lower classes, childhood was a much shorter interlude. Moreover, education was predominately for boys.⁶⁹ As we go through the 18th and 19th century, education became available to girls, and compulsory for all students up to the age of ten, due to the Elementary Education Act 1870. After Forster's Education Act in 1893⁷⁰ this was increased to 11 years old, and in 1899, to age 13. The Education Act 1918 made education compulsory until 14 years of age⁷¹, and the Education Act 1944 increased this to 15 years.⁷² In 1972, this became 16, and in 2013—after years of campaigning—the school leaving age is now 18 years.⁷³ In the 19th century, child labour decreased in correlation with the introduction of a compulsory education system.

Aries noted that two concepts of childhood had evolved. Firstly, that children are “creatures to be coddled”,⁷⁴ childhood was now lasting longer than infancy. Secondly, he noted the realisation of the innocence and weakness of childhood and, therefore, the importance of adults to

⁶⁷ *ibid* at 148.

⁶⁸ *ibid* at 137.

⁶⁹ *ibid*.

⁷⁰ Elementary Education Act 1870 c 75.

⁷¹ Education Act 1918 c 39.

⁷² Education Act 1944 c 31.

⁷³ Education and Skills Act 2008 c 25

⁷⁴ Aries (n 56) at 316.

safeguard and protect such characteristics.⁷⁵ Aries argues that children are physically and cognitively different to adults, but that prior to the 17th century, society did not respond to these differences in the same way we do now. Children have not always been seen as vulnerable citizens, as they are today. Instead children were 'mini-adults' and, therefore, given adult responsibilities. Aries challenges whether the modern day understanding of childhood is fair, when we reflect on the capabilities of our ancestors.

Whilst Aries had many supporters and his work remains an important citation in studies relating to the history of childhood, his work also attracted a lot of criticism. In addition to being critiqued for his lack of logic, failing to draw attention to historical themes, and only describing rather than explaining his assumptions,⁷⁶ Wilson,⁷⁷ Smith,⁷⁸ and Cunningham⁷⁹ argue that a notion of childhood has always existed but that it is not the same notion that we refer to:⁸⁰ past "society may have lacked our awareness; but this is not the same as saying that it had no such awareness."⁸¹ There is little evidence that childhood did not exist at all—rather that the definition of childhood has evolved. Although many critics have interpreted Aries' claims as assuming that childhood did not exist at all,⁸² his explanation appears to point towards the understanding shared by

⁷⁵ *ibid.*

⁷⁶ Acocella, J, 'Little People: When Did We Start Treating Children Like Children?' (*The New Yorker*, 10 August 2003) < <https://www.newyorker.com/magazine/2003/08/18/little-people> > accessed 5 March 2019.

⁷⁷ Wilson, A, 'The Infancy of the History of Childhood: An Appraisal of Philippe Aries' (1980) 19(2) *History and Theory*, 132.

⁷⁸ Smith, R.S, 'The London Apprentices as Seventeenth-Century Adolescents' (1973) 61 *Past and Present*, 149 at 149.

⁷⁹ Cunningham, H, *Children and Childhood In Western Society Since 1500* (2nd edn, Pearson Longman 2005) at chapter 1.

⁸⁰ Wilson (n 77) at 134.

⁸¹ *ibid.*, at 142.

⁸² *ibid.*; Ozment, E.S, *Ancestors: The Loving Family in Old Europe* (Harvard University Press 2001), Acocella (n 76).

his critics: that childhood ideology has shifted over time in the way it is expressed by society. Aries was further critiqued for his “present-day view point”⁸³ of childhood. Aries wrote from the perspective of the modern-day notion of childhood, comparing the definition of childhood today: that children are vulnerable, dependent and immature, and illustrating the differences from this definition in the past. Wilson argues that Aries should have focused his research on investigating the childhood concepts which existed, rather than just how they differ to the modern-day definition. Wilson argued that Aries’ own attitude toward the modern-day family impacted his analysis and descriptions, idealising certain aspects of the Middle Ages rather than being descriptive and factual.⁸⁴

Nevertheless, what we can take away from Aries, and the books subsequently written critiquing Arie’s findings, is that the notion of childhood has evolved and uncertainty around when childhood begins and ends. Despite this, academics agree that childhood is a distinct part of a life, where a person is, in the main, perceived by those around them to be vulnerable, innocent, physically and cognitively immature and dependent, requiring protection from adults. However, because our understanding of childhood is, to some extent, a product of the historical context, Aries asks us to challenge this understanding and allow room for the notion that some children are mature and capable.

2.2.4 Cultural and Social Variation

In addition to historical variations of childhood, Prout and James argue that there are cultural and societal differences in the expression of childhood.⁸⁵ Prout and James do not dispute the biological, cognitive or neurological differences between adults and children, however, they argue that a society’s interpretation of this information *in itself* creates a unique

⁸³ Acocella (n 76).

⁸⁴ Wilson (n 77) at 142.

⁸⁵ James & Prout (n 1) at 7.

definition of childhood for the culture or society in which the child grows up.⁸⁶

Immaturity of children is a biological fact of life but the ways in which this immaturity is understood and made meaningful are a fact of culture. It is these 'facts of culture' which may vary and which can be said to make of childhood a social institution.⁸⁷

During her extensive research in Bolivia, Samantha Punch commented on the adult responsibilities and expectations accorded children there, in contrast to Western cultures.⁸⁸ She found education is only available for the first six years of a child's primary school life, and their normal day would comprise of a mixture of tasks including working alongside adults to maintain the family home and attending school. Children as young as five were expected to search for paid employment and take on household responsibilities, such as collecting water and looking after the family's cattle⁸⁹; parents depend on their children for financial stability.⁹⁰ Nevertheless, even though in Bolivia, children are accorded greater responsibilities than would be expected of children in Western cultures, Punch argues that they are still considered children.⁹¹ Thus, the expression of childhood is dependent on the cultural and societal environment.

Childhood and adolescence are fluid concepts. There is no universally shared definition of adolescence, as the parameters continue to shift and be a source of debate. In 1904, Stanley Hall argued that adolescence was

⁸⁶ *ibid* at 7-10.

⁸⁷ *ibid*, at 6.

⁸⁸ Punch, S, 'Negotiating Autonomy: Children's Use of Time and Space in Rural Bolivia', in Alanen, L and Mayall, B (eds), *Conceptualising Child-Adult Relations* (Routledge Falmer 2001) at 23-36.

⁸⁹ *ibid* at 94.

⁹⁰ Boyden, J, 'Childhood and the Policy Makers: A Comparative Perspective on the Globalization of Childhood' in James & Prout (n 1) at 178.

⁹¹ Punch (n 88) at 99.

from 12-24 years⁹². This was reduced in 1965 by the World Health Organisation to 10-20 years of age.⁹³ In 1969, Piaget referred to adolescence as being between 15 and 18 years.⁹⁴ In 1985, a formal definition was provided during the United Nation's First International Youth Year in their Barcelona Statement, which described adolescence as ending at 18.⁹⁵ This was agreed by the United Nations Convention on the Rights of the Child in 1990 (ratified in UK in 1992).⁹⁶ However, research by Arnett in 2000 increased the age of adolescence to 25 years of age.⁹⁷ In 2015, Bonnie et al. agreed stating that young adulthood lasts until 26 years of age⁹⁸; however, in 2016 the definition was once again re-established by the World Health Organisation (WHO) formally defining the period of adolescence as 10-18 years of age.⁹⁹

In 2018, Swayer et al. published a report re-examining the age of adolescence in Western culture¹⁰⁰, claiming that adolescence now lasts

⁹² Hall, S. G, *Adolescence: Its Psychology and Its Relations to Physiology, Anthropology, Sociology, Sex, Crime, Religion, and Education Vols I and II* (Appleton & Co 1904) at chapter 2.

⁹³ WHO, *Health Problems of Adolescents* Technical Report Series 308 (WHO, 1965) <<https://apps.who.int/iris/handle/10665/38425>> accessed 15 June 2018.

⁹⁴ Piaget & Inhelder, *The Psychology of the Child* (n 4) at 128-149.

⁹⁵ UNESCO, *World Congress of Youth* Final Report (UNESCO, 1985) <http://unesdoc.unesco.org/images/0006/000684/068409eb.pdf> accessed 5 March 2019.

⁹⁶ United Nations Convention of the Rights of the Child 1989.

⁹⁷ Arnett, J.J, 'Emerging Adulthood: A Theory of Development from the Late Teens Through the Twenties' (2000) 55 *Am Psychol*, 469 at 469.

⁹⁸ Bonnie, R. J, Stroud, C and Breiner, H (eds), *Investing in the Health and Wellbeing of Young Adults* (National Academies Press 2015) at Summary.

⁹⁹ WHO, *The Global Strategy For Women's, Children's, and Adolescents' Health (2016–30)* Report (WHO, 2015) <<http://www.who.int/life-course/partners/global-strategy/ewec-globalstrategyreport-200915.pdf?ua=1>> accessed 5 March 2019.

¹⁰⁰ Swayer, S.M and others, 'The Age of Adolescence' (2018) 2 *The Lancet Child Adolescent Health Journal*, 223.

until the age of 24 due to a shift in social and cultural factors.¹⁰¹ They establish that the length of time a person is a child is reducing, in part, because children are going through puberty at a younger age, and thus adolescence is beginning earlier.¹⁰² However, at the same time, adolescence is lasting longer, due to social factors that are typically associated with adulthood such as work, marriage, having children, living away from their family home and no longer being dependent on their parents.¹⁰³ As more people are going to university, formal education is continuing until a person's early to mid-20s. Consequently, young people are living with and remain financially dependent upon their parents for much longer than previous generations.¹⁰⁴ Swayer et al. suggest that social factors are extending the period of time that a person demonstrates the characteristics associated with childhood such as dependency, therefore, extending the time a person is an adolescent, in recognition of such societal changes.¹⁰⁵ There have been significant shifts in the boundary between adolescence and adulthood, in response to societal factors leading to uncertainty and consistent variation. Much of the distinction between adulthood and adolescence is dependent on social factors. Academics¹⁰⁶ use the social and cultural factors to distinguish adolescence from adulthood, arguing that the greater the responsibilities, the further away an individual is from the childhood characteristics of vulnerability, dependency and immaturity—and thus, childhood itself.

2.3. The Child as an Individual

Moving from generalised theories towards the nuances of the individual child, research has found that a child's unique circumstances can directly

¹⁰¹ *ibid* at 223.

¹⁰² *ibid*.

¹⁰³ *ibid* at 225.

¹⁰⁴ *ibid* at 226.

¹⁰⁵ *ibid* at 227.

¹⁰⁶ *ibid*; Bonnie (n 98); Arnett (n 97).

impact an individual's transition into adulthood. As established in psychology and neurology, the individual develops in their own unique way, and in many cases, personal circumstances can inhibit or encourage cognitive, neurological and social development. As Piaget explains, children are active learners, using their environment and social circumstances to grow.¹⁰⁷ Our interaction with more competent peers assists our movement through our Zone of Proximal Development.¹⁰⁸ In addition, life experiences create a new synaptic pathway which develops the brain in a unique way.¹⁰⁹ The general theories of childhood are helpful in appreciating children as a collective. However, they cannot consider the nuances within each child's life that may result in them being an exception to general theories of childhood. It is these nuances that allow us to understand that each child is unique in their development and transition to adulthood.

Although it is commonly accepted that children under 16 lack capacity and are dependent on adults, researchers continued to find exceptions to this expected rate of development.¹¹⁰ In 1982, Weithorn and Campbell conducted research into whether children have the capacity to make health care decisions. Presenting four hypothetical treatment dilemmas for 96 participants without health issues (24 at each of the four age levels: nine, 14, 18 and 19), Weithorn and Campbell measured the participants' competency according to evidence of choice, a reasonable outcome, rational reasoning and understanding capabilities¹¹¹. Their research concluded that the 14-year olds showed no difference in competency in comparison to the adults.¹¹² Moreover, whilst the nine-year olds lacked the

¹⁰⁷ Piaget & Inhelder, *The Psychology of the Child* (n 4)

¹⁰⁸ Vygotsky (n 5) at 85-87.

¹⁰⁹ Griffin (n 37).

¹¹⁰ Clark, A and Moss, P, *Listening to Young Children: The Mosaic Approach* (2nd edn, National Children's Bureau 2011).

¹¹¹ Campbell, S.B, and Weithorn, L.A, 'The Competency of Children and Adolescents to Make Informed Treatment Decisions' (1982) 53(6) *Child Development*, 1589 at 1591.

¹¹² *ibid* at 1594.

ability to reason and were unable to fully understand all the information provided, they were able to identify all “salient factors”¹¹³ within the decision¹¹⁴, and their reasoning was on a par with the adults in the study. Weithorn and Campbell’s’ data is open to academic critique, as it was carried out using hypothetical treatment dilemmas, however, Alderson’s research found similar findings. In 1993, Alderson conducted revolutionary research to investigate “at what age are children able to have the understanding and discretion [to] make wise decisions about consent to their health care?”¹¹⁵ During her two year extensive study, Alderson interviewed children, parents and hospital staff across four orthopaedic hospitals.¹¹⁶ Alderson interviewed 120 patients between the ages of eight and 15 years undergoing elective orthopaedic surgery, and spoke to their parents and surgeons.¹¹⁷ Evidence gathered by Alderson found that many paediatric patients, their surgeons and parents argue that mature children have the capabilities to consent to medical treatment. Irrespective of the general theories of childhood. Alderson reported that children as young as eight could be competent to make important health care decisions.¹¹⁸ “Competency develops, or at least is demonstrated, in response to experience and reasonably high expectations, rather than gradually over time through ages or stages”.¹¹⁹ The clinical environment meant that children were aware of the fragility of life and their health, and therefore were exposed to more than their peers which in turn, enables them to make decisions previously considered to be of an adult nature. Alderson hoped that her research would “encourage adults to assume that school-age children can be competent—informed and wise—and then to require

¹¹³ *ibid* at 1596.

¹¹⁴ *ibid*.

¹¹⁵ Alderson, P, *Children’s Consent to Surgery* (Open University Press 1993) at 3.

¹¹⁶ *ibid* at 4 and 43-56.

¹¹⁷ *ibid* at chapter 9.

¹¹⁸ *Ibid*.

¹¹⁹ *ibid*, at 198.

anyone who disagrees to demonstrate whether a particular child is incompetent”¹²⁰, rather than the child having to prove their competency. There is academic consensus that each journey is unique, and whilst it is useful to define and consider the child using a generalised theory, it is necessary to appreciate the nuances within this, and accept that children are individuals with different life stories and experiences, all of which impact the child’s maturity to adulthood. This research provides a sound argument to conclude that some children with medical conditions are capable of participating in their health care. This has since been supported by a 2018 research study by Cumbria University which investigated the lived experiences of boys with disabilities associated with Duchenne Muscular Dystrophy. They found that the boys were considered vulnerable because of their disability, and assumed to lack capacity because of their vulnerability.¹²¹ However, on assessment, the study found many of the children to be competent to participate in the decision-making process about their health care. They argue that we should consider the capability of children based on individual assessments.¹²²

2.4 Impact on the Law

The law seeks to strike a balance between acting in the best interests of the child and respecting the child’s emerging autonomy by enabling and facilitating children’s participation in their health care.¹²³ Autonomy is a person’s “freedom to decide what shall and shall not be done with their body”.¹²⁴ There are various definitions of autonomy in academic literature. Coggon and Cave argue that case law typically supports a liberal

¹²⁰ *ibid.*

¹²¹ Skyrme, S.L & Woods, S ‘Researching disabled children and young people’s views on decision-making: working reflexively to rethink vulnerability (2018) 25(3) *Childhood*, 355

¹²² *ibid.*

¹²³ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] A.C. 112; [1985] 3 W.L.R. 830; Children Act 1989 c.51 at s1(1); UNCRC (n 96) at Article 12.

¹²⁴ *R (Burke) v General Medical Council* [2005] EWCA Civ 1003 at 108 per Lady Hale

conception of autonomy that requires a person to have capacity.¹²⁵ As such, not every child is capable of making an autonomous decision. However, there is widespread agreement that children, irrespective of their competency, should be involved in decisions about their own health care.¹²⁶ To participate in their health care allows children to develop the skills necessary to make autonomous decisions when they are capable. Moreover, participatory rights seek to put the desires and wishes of the child at the centre of the decision-making process which in turn, protects against physician paternalism.

The UNCRC was developed as a specific framework for a child's fundamental human rights to protect the well-recognised differences between children and adults.¹²⁷ The UNCRC drafted in 1989 states, "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth".¹²⁸ The international and national frameworks are designed to support children at all stages of their development. This section will detail the law in relation to the non-*Gillick* competent child, the *Gillick* competent child and 16 to 17-year olds.

2.4.1. The Non-*Gillick* Competent Child

In the first instance, decisions about the child are taken by those with parental responsibility on behalf of the child with advice and guidance from the medical team. Parental responsibility is defined under the Children Act 1989 as "all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property".¹²⁹

¹²⁵ Coggon, J, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15(3) Health Care Analysis, 235; Cave, E, 'Goodbye Gillick? Identifying and resolving problems with the concept of child competence' (2014) 34(1) Legal Studies, at 103.

¹²⁶ Alderson, *Children's Consent to Surgery* (n 115) at chapter 4.

¹²⁷ UNCRC (n 96).

¹²⁸ Declaration of the Rights of the Child 1959 Preamble.

¹²⁹ Children Act 1989, c.51, s3(1).

Where a person does not have parental responsibility but still cares for a child they may still “do what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare”.¹³⁰

Where there is disagreement between the medical team and the child's parents' over whether a decision is best for the child's welfare, either side can seek the inherent jurisdiction of the court which will make a decision that is best for the welfare of the child. In the case of *Wyatt & Anor v Portsmouth Hospital NHS & Anor*,¹³¹ the judge summarised the position and role of the court:

“As a small child, Charlotte self-evidently lacks the capacity to make decisions about her medical treatment. In these circumstances, such decisions are, in the first instance, taken by those having parental responsibility for her (her parents) in consultation with, and on the advice of, the doctors treating her.

In the event of an important disagreement between doctors and a child's parents, however, either side can invoke the inherent jurisdiction of the Family Division of the High Court relating to children, and a judge of the Division will decide what course of treatment is in the best interests of the child.”¹³²

Where a judge makes a decision about what treatment is in the child's best interests, the Children Act requires the judge to place the welfare of the child as the paramount consideration.¹³³ Section 1(1) of the children act states:

- (1)When a court determines any question with respect to—
- (a)the upbringing of a child; or

¹³⁰ Children Act 1989, c.51 s3(5).

¹³¹ *Wyatt & Anor v Portsmouth Hospital NHS & Anor* [2005] EWCA Civ 1181

¹³² *Ibid* at Para 3.

¹³³ Children Act 1989 c.51, s1(1).

(b)the administration of a child’s property or the application of any income arising from it, the child’s welfare shall be the court’s paramount consideration.¹³⁴

For example, in the case of Charlie Gard and Alfie Evans, the role of the judge was to enact their power of inherent jurisdiction to decide what treatment, if any, was in the child’s best interests to protect their welfare.¹³⁵ Where the court is considering whether to make, vary or discharge a section 8 order, the court should give account to the following factors:

The court should give account to the following factors:

In the circumstances mentioned in subsection (4), a court shall have regard in particular to—

- (a)the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);
- (b)his physical, emotional and educational needs;
- (c)the likely effect on him of any change in his circumstances;
- (d)his age, sex, background and any characteristics of his which the court considers relevant;
- (e)any harm which he has suffered or is at risk of suffering;
- (f)how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs;
- (g)the range of powers available to the court under this Act in the proceedings in question.¹³⁶

¹³⁴ Ibid.

¹³⁵ *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 1909 (Fam); *Alder Hey v Evans* [2018] EWHC 308 (Fam)

¹³⁶ Children Act 1989 c.51, s1(3)(a).

Factors include giving weight to the child’s views in accordance with their capabilities. The courts role is to balance the factors in an assessment of the child’s best interests. The child’s views are considered as part of an assessment of their best interests, however, the weight given to these views is dependent on the judge’s independent assessment.

On an international level, the UNCRC provides guidance for how to make decisions about children.¹³⁷ The Convention requires special consideration to be given to decisions involving children to ensure that it is in the child’s best interests. Article 12 of the UNCRC requires children’s voices and beliefs to be incorporated into the best interest assessment.¹³⁸ The ‘due weight’ given to the child’s opinion is determined by the discretion of the judges as part of their analysis.¹³⁹

As a result of the recent cases *Great Ormond Street Hospital v Yates and Gard*¹⁴⁰ and *Alder Hey v Evans*,¹⁴¹ there has been tension between the parent’s right to family life¹⁴² and the intervention of the state. The wishes of the parents of Charlie Gard and Alfie Evans — to take their child to another country for experimental treatment, and to continue artificial ventilation—conflicted with the health care team treating their children.¹⁴³ The court held that Charlie and Alfie had serious life-limiting medical conditions that were untreatable.¹⁴⁴ As such, the court held that it was not in either child’s best interest to continue artificial ventilation or receive

¹³⁷ UNCRC (n 96).

¹³⁸ Ibid at Article 12.

¹³⁹ *University Hospitals Plymouth Trust v B* [2019] EWHC 1670 (Fam).

¹⁴⁰ *Great Ormond Street Hospital v Yates and Gard* (n 135).

¹⁴¹ *Alder Hey v Evans* (n 135).

¹⁴² European Convention on Human Rights 1950 at article 8.

¹⁴³ *Great Ormond Street Hospital v Yates and Gard* (n 135); *Alder Hey v Evans* (n 135).

¹⁴⁴ *Great Ormond Street Hospital v Yates and Gard* (n 135) at para 93; *Alder Hey v Evans* (n 135) at para 19.

alternative medical treatment.¹⁴⁵ Life support was withdrawn shortly after these judgments.

The court's decision put the child's welfare first. Parents do not have the authority to determine what happens to their child. Nevertheless, campaigners argued that these cases were controversial because they challenged the notion of parental authority.¹⁴⁶ Campaigners argued that it is for the parents to decide what is in their child's best interests.¹⁴⁷ The families of Charlie Gard and Alfie Evans continue to campaign for legislation to ensure parents are adequately supported and equipped with legal teams, medical experts and financial assistance to take a case to court against an NHS trust.¹⁴⁸ They seek to clarify the term 'best interests', to remove the complexities and provide parents with greater authority in the decision-making process. Academics have argued for greater parental authority, proposing models such as the Zone of Parental Discretion¹⁴⁹ and Constrained Parental Autonomy.¹⁵⁰ Gillam argues that parents should have the authority to make decisions about their children until "the effects [of a decision are] so bad as to constitute probable significant harm to the child".¹⁵¹ Similarly, Ross argues that parents ought to have absolute authority to decide what happens in their household, because the child is part of a family, and therefore, it is the head of the house that must fit competing priorities together, and compare one member's needs against

¹⁴⁵ *Great Ormond Street Hospital v Yates and Gard* (n 10) at para 5; *Alder Hey v Evans* (n 10) at para 66.

¹⁴⁶ Birchley, G, 'Charlie Gard and the weight of parental rights to seek experimental treatment' (2018) 44 *Journal of Medical Ethics*, 448

¹⁴⁷ *Ibid.*

¹⁴⁸ Dyer, C, 'Alfie Evans Case: Proposed Law Aims to Prevent Conflicts Between Parents and Doctors' (2018) *British Medical Journal*, 361.

¹⁴⁹ Gillam, L, 'The Zone of Parental Discretion: An Ethical Tool for Dealing with Disagreement Between Parents and Doctors About Medical Treatment for a Child' (2015) 11(1) *Clinical Ethics*, 1

¹⁵⁰ Ross, F.L *Children, Families and Health Care Decision Making* (OUP 1998).

¹⁵¹ Gillam (n 149), at 3.

others in their family, irrespective of a child's competencies.¹⁵² Ross proposes that parental authority should only be limited if there is harm to the child—in this instance, 'harm' means the deprivation of basic needs.¹⁵³ Despite such proposals, academics argue that such legislation will erode decades of progress on children's rights¹⁵⁴ where children are no longer the property of their fathers, with no legal rights.¹⁵⁵

Where a parent is the surrogate decision maker, and the case does not go to court, to provide valid consent that acts as a defence to the tort of trespass¹⁵⁶ and the tort of negligence, the parents must be competent to decide, must make a voluntary decision and must be informed.¹⁵⁷ To protect against a tort of trespass, "the duty of the doctor is to explain what he intends to do, and its implications, in the way a careful and responsible doctor in similar circumstances would have done".¹⁵⁸ In order, to protect against a claim for negligence, which is becoming "the dominant mechanism for protecting autonomy in medical treatment decisions",¹⁵⁹

¹⁵² Ross (n 150) at 131.

¹⁵³ *ibid* at 140.

¹⁵⁴ Willow, C.M, 'Alfie's Law Could Undo Decades of Progress on Children's Rights' *The Guardian* (10 May 2018) < <https://www.theguardian.com/healthcare-network/2018/may/10/alfies-law-childrens-rights> > accessed 20 May 2018.

¹⁵⁵ Blackstone, W, *Commentaries on the Laws of England* (4th edn, William Maxwell & Son, Henry Sweet, and Stevens & Sons 1869 originally published 1765) at Book 1, Chapter 15.

¹⁵⁶ There is some academic debate around whether valid consent is a defence to the tort of trespass or whether the lack of valid consent to the trespass that is the claimant's action. If the claimant argues that they did not provide valid consent, it is for the claimant to prove that valid consent was not obtained. The burden of proof is open to debate. Some case law suggests that it is for the claimant to prove whilst the majority argues that it is for the doctor to adequately record a valid consent to be used as proof that they did obtain valid consent.

¹⁵⁷ *Freeman v Home Office* [1984] 1 ALL ER 1036.

¹⁵⁸ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582; *Chatterton v Gerson* [1981] 1 ALL ER 257 at 443

¹⁵⁹ Cave, E and Purshouse, C, 'Think of the Children: Liability for Non-Disclosure of Information Post-*Montgomery*' (2019) *Medical Law Review*, 1 at 4.

the degree of disclosure must pass the test laid down in *Montgomery*. The *Montgomery* judgment increased the standard of disclosure required to protect the medical profession from claims of failure to disclose and many would argue this had the effect of increasing decision-makers' autonomy. *Montgomery* states that the decision-maker must be aware of all the material risks associated with the medical treatment.¹⁶⁰ Material risks are defined in *Montgomery* as risks which:

a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor was or should reasonably be aware that the particular patient would be likely to attach significance to it¹⁶¹

This high standard of disclosure is supported by the GMC, which states:

[Health Care Professionals] should do your best to understand the patient's views and preferences about any proposed investigation or treatment, and the adverse outcomes they are most concerned about. You must not make assumptions about a patient's understanding of risk or the importance they attach to different outcomes. You should discuss these issues with your patient.¹⁶²

Where parents are surrogate decision-makers, *Montgomery* strengthens the need for doctors to disclose to them adequate information.

2.4.2. The *Gillick* Competent Child and Young Person

In 1986, the case of *Gillick v West Norfolk and Wisbech AHA*¹⁶³ heard Victoria Gillick, a mother of a 15 year old daughter, who objected to the

¹⁶⁰ *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

¹⁶¹ *ibid*, at paras 39-87.

¹⁶² GMC, 'Consent: Patients and Doctors Making Decisions Together, Part 2: Making Decisions about Investigations and Treatment' (GMC, 2 June 2008) <<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/consent>> accessed 17 January 2018 at para 30.

¹⁶³ *Gillick v West Norfolk and Wisbech AHA* [1986] A.C. 112

DHSS Memorandum of Guidance which recommended to doctors that in exceptional circumstances it would be legally permissible to prescribe a young person under 16 years of age with contraception without their parents' consent or knowledge.¹⁶⁴ Victoria Gillick sought to argue that a doctor cannot lawfully "prescribe contraception for a girl under 16 years of age, without the consent of her parents".¹⁶⁵ The question the court had to address was whether it is ever legally permissible for a doctor to prescribe contraception to a young person under 16 years of age without their parents' consent.

In his leading judgment, Lord Fraser stated that where it is best for the welfare of the child, parental consent may be abandoned in favour of the child's consent.¹⁶⁶ Lord Fraser identified five pre-conditions as to when it would be best for the welfare of the child for a doctor to prescribe contraception to a person under the age of 16 without their parents' knowledge or consent:

- (i) the girl will understand the advice;
- (ii) the doctor cannot persuade her to inform her parents or to allow the doctor to inform her parents that she is seeking contraceptive advice;
- (iii) the girl is very likely to begin or to continue having sexual intercourse with or without contraceptive treatment;
- (iv) unless she receives contraceptive advice or treatment her physical or mental health or both are likely to suffer; and
- (v) her best interests require him to give her contraceptive advice, treatment or both without the parental consent.¹⁶⁷

As part of the inherent jurisdiction *parens patriae* power of the court, Lord Fraser's judgment recognises that in certain instances it is best for the

¹⁶⁴ *ibid* at 179-180; HN(80)46, section G

¹⁶⁵ *Gillick v West Norfolk and Wisbech AHA* [1986] A.C. 112

¹⁶⁶ *Ibid* per Lord Fraser at 162

¹⁶⁷ *ibid*

child's welfare to consent to medical treatment without their parent's knowledge or consent. Lord Fraser holds that a doctor, as part of their duty to protect the child's welfare, can in certain and exceptional circumstances abandon the requirement to obtain parental consent. Fraser's guidelines provide pre-conditions to when it would be best for the child's welfare to not require parental consent.¹⁶⁸

Focusing on the evolving child's autonomy and their relationship with parental rights, Lord Scarman's judgment stated that:

as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. It will be a question of fact whether a child seeking advice has sufficient understanding of what is involved to give a consent valid in law.¹⁶⁹

Unlike Lord Fraser whose judgment suggested that parental decision-making powers run alongside the *Gillick* competent child's decision making,¹⁷⁰ Lord Scarman suggests that the parent's decision making powers is passed from the parent to the child once they reach sufficient understanding and intelligence.¹⁷¹ Lord Scarman explains that it

is not enough that she should understand the nature of the advice which is being given: she must also have a sufficient maturity to understand what is involved. There are moral and family questions, especially her relationship with her parents; long-term problems associated with the emotional impact of pregnancy and its termination; and there are the risks to health of sexual intercourse

¹⁶⁸ *ibid*

¹⁶⁹ *Ibid* at 188 and 189.

¹⁷⁰ *Ibid* at 162.

¹⁷¹ *Ibid* at 189.

at her age, risks which contraception may diminish but cannot eliminate.¹⁷²

The case of *R (on the application of Axon) v Secretary of State for Health*¹⁷³ discussed Lord Fraser and Lord Scarman's judgments to seek clarification on whether the right to consent passes from parent to child when the child demonstrates 'sufficient understanding and intelligence'. *R (on the application of Axon) v Secretary of State for Health*¹⁷⁴ interpreted *Gillick* competency as an under 16-year-old can consent to medical treatment without their parental consent if all of the five pre-conditions laid down by Fraser have been met. The first condition is more stringent as a result of Lord Scarman's judgment which states that a doctor must be satisfied that the child has sufficient understanding and intelligence to understand the proposed treatment. In *Re S (Child as Parent: Adoption: Consent)*,¹⁷⁵ Cobb J slightly expanded Scarman's judgment linking the test for capacity laid down by Scarman to the requirements of the Mental Capacity Act 2005.¹⁷⁶ Cobb J states that a child who has "a sufficient understanding and intelligence to enable him or her to understand fully what is proposed" must be able to (i) understand the nature and implications of the decision, (ii) understand the implications of not pursuing the decision, (iii) retain the information long enough for the decision making process to take place, and (iv) be of sufficient intelligence and maturity to weigh up the information and arrive at a decision; (v) be able to communicate that decision.¹⁷⁷

In *Re R*, Lord Donaldson also considered whether parental rights are passed from parent to child once they reach "sufficient understanding and

¹⁷² Ibid at 191.

¹⁷³ *R (on the application of Axon) v Secretary of State for Health* [2006] EWHC 37 (Admin).

¹⁷⁴ Ibid.

¹⁷⁵ *Re S (Child as Parent: Adoption: Consent)* [2017] EWHC (Admin) 2729.

¹⁷⁶ Mental Capacity Act 2005 c.9.

¹⁷⁷ *Re S (Child as Parent: Adoption: Consent)* [2017] (n 175).

intelligence” or if they are concurrent.¹⁷⁸ In his judgment, Lord Donaldson reinforced Lord Fraser’s approach stating that the parents and child’s decision-making powers run concurrently. Donaldson clarifies that the child does not have an autonomous right to consent to medical treatment. Rather, if a child under 16 years of age does have “sufficient understanding and intelligence” and it is best for the child’s welfare to abandon the need for parental consent, using Lord Fraser’s five pre-conditions as a guide, then it is legally permissible for a doctor to abandon the need for parental consent. Nevertheless, parental consent can override a *Gillick* competent child’s decision where it is best for the child’s welfare.¹⁷⁹

Where there is disagreement between a capable child’s decision and the decision of their parent’s, the inherent jurisdiction *parens patriae* power of the court can be adopted.¹⁸⁰ The court’s role is to protect the child’s welfare and act in their best interests. Thus, the decision of a *Gillick* competent child forms part of this assessment, however, a *Gillick* competent child does not have the power dictate the outcome of the judgment in the same way that an autonomous adult’s decision would. A *Gillick* competent decision forms one element of the welfare checklist.¹⁸¹

How *Gillick* is incorporated in the welfare checklist can be demonstrated in refusal of medical treatment cases where children’s competency is considered within the wider picture of whether the treatment is in the child’s best interests and what treatment is best for their welfare. In *Re E*,¹⁸² a 15-year-old boy, a Jehovah’s Witness, sought to refuse a blood transfusion. Justice Ward stated that he “could not rule out the possibility that [E] may suffer diminution in his convictions”,¹⁸³ therefore, E did not

¹⁷⁸ *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam. 11.

¹⁷⁹ *Ibid.*

¹⁸⁰ *Re S (Child as Parent: Adoption: Consent)* (n 175).

¹⁸¹ *Gillick v West Norfolk and Wisbech AHA* [1986] A.C. 112.

¹⁸² *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 F.L.R. 386.

¹⁸³ *ibid* at 393.

satisfy the *Gillick* competency test. Moreover, as part of his assessment Justice Ward held that refusing a blood transfusion was not best for E's welfare even if he had been *Gillick* competent because a refusal of medical treatment would threaten E's life. Similarly, in *Re L*, L, a 14-year-old girl was held by the judge as unable to appreciate the "horrible" nature of her death¹⁸⁴ therefore, did not meet the requirements to satisfy *Gillick* competency. Again, it was held that irrespective of L's competency, a refusal of a blood transfusion threatened L's life, thus, was not best for her welfare. In *Re R*¹⁸⁵ and *Re W*,¹⁸⁶ Lord Donaldson held that the judge can use inherent jurisdiction as its role as *parens patriae* power to protect the welfare of the child. In *Re W*, Balcombe LJ said "one must start from the general premise that the protection of the child's welfare implies at least the protection of the child's life... if the child's welfare is threatened by a serious and imminent risk that the child will suffer grave and irreversible mental or physical harm, then once again the court when called upon has a duty to intervene"¹⁸⁷ Thus, Donaldson argues that he is permitted to overrule a refusal of medical treatment where a refusal threatens the life of the child.¹⁸⁸ The first case where a child had been considered *Gillick* competent and therefore, where it was necessary to overrule a child's refusal of medical treatment to protect their welfare, was in the case of *University Hospitals Plymouth Trust v B*.¹⁸⁹ B, a 16-year-old girl, refused insulin to treat ketoacidosis, a serious and life-threatening comorbidity of insulin dependent diabetes.¹⁹⁰ Justice MacDonald determined that B was *Gillick* competent, stating that she did possess the required capabilities to

¹⁸⁴ *Re L (Medical Treatment: Gillick Competence)* [1998] 2 F.L.R. 810 at 811.

¹⁸⁵ *Re R (A Minor) (Wardship: Consent to Treatment)* (n 178) at 16.

¹⁸⁶ *Re W (A Minor) (Medical Treatment: Courts Jurisdiction)* [1993] Fam 64 at 81.

¹⁸⁷ *ibid* at 12.

¹⁸⁸ *University Hospitals Plymouth Trust v B* [2019] EWHC 1670 (Fam) at para 12.

¹⁸⁹ *Ibid*.

¹⁹⁰ *ibid*.

refuse medical treatment.¹⁹¹ However, Justice MacDonald argued that irrespective of B's competency, the court could provide consent to the medical treatment exercising its role of inherent jurisdiction *parens patriae* power to protect the welfare of the child.¹⁹²

Unlike under 16's where a child must illustrate that they have "sufficient understanding and intelligence" and meet the Fraser guidelines for their consent to medical treatment, 16 and 17 year olds are presumed capable of consenting to medical treatment.¹⁹³ Section 8 of the Family Law Reform Act confers on 16- and 17-year olds the legal right to consent to their own medical treatment.¹⁹⁴ Unless their capacity is in doubt, they do not need to prove that they meet the standard in the Mental Capacity Act 2005.¹⁹⁵ The young person's consent "shall be as effective as it would be if he were of full age".¹⁹⁶ Thus, the consent of a 16 or 17-year-old is considered equivalent to the consent of an adult patient although, parental consent may still be obtained and there is no obligation for a 16 or 17-year-old to consent to medical treatment, parental consent would be valid. Nevertheless, once a child turns 16 years of age, the medical professionals turn to them for consent to medical treatment rather than their parents. Despite this, for any child under the age of 18, the court can use their powers of inherent jurisdiction to overrule any decision from either the competent child or their parents where their decision is not best for the welfare of the child.¹⁹⁷ Balcombe LJ said that in English Law, an individual of 18 years of age is free to do with their life as they wish. However, it is the "duty of the court to ensure so far as it can, that children survive to attain that age" by protecting their welfare until they are of an

¹⁹¹ *ibid* at para 2.

¹⁹² *ibid*

¹⁹³ Family Law Reform Act 1969 c.46, s8.

¹⁹⁴ *Ibid*.

¹⁹⁵ Mental Capacity Act 2005 (n 176).

¹⁹⁶ *Ibid*.

¹⁹⁷ *University Hospitals Plymouth Trust v B* (n 188) at para 12.

age where that decision making power is passed to them.¹⁹⁸ Where the 16- or 17-year old's capacity is in doubt, the doctors can rely upon the consent of a legal parent or seek the court's opinion.

If a child is 16 or 17, or is *Gillick* competent, before it is legally permissible to provide valid consent, they must also be acting voluntarily and be informed. To protect against a tort of trespass, the doctor must explain to the child what he/she intends to do and the implications of the treatment.¹⁹⁹ The doctor must provide information to the child as any reasonable doctor in similar circumstances would have done.²⁰⁰ If the child does not receive this information they can claim a tort of trespass.

With regards to a tort of negligence, it is uncertain whether *Montgomery* applies to *Gillick* competent children and children aged 16 and 17. Cave suggests that *Montgomery* is likely to apply to 16-17-year olds as the Family Law Reform Act (FLRA) treats them the same as adults.²⁰¹ However, for *Montgomery* to apply to under 16 year olds, Cave argues that it would "rely on the incremental extension from 'adult patients of sound mind' to children with *Gillick* capacity".²⁰²

Whilst Lady Hale's statement that the medical profession must respect the claimant's choice unless the claimant lacks capacity²⁰³ suggests that *Montgomery* applies to all children capable of consenting to medical treatment, Cave issues a caution that no assurances have been given.²⁰⁴ If *Montgomery* were to apply to *Gillick* competent children, the doctor must

¹⁹⁸ *Re W (A Minor) (Medical Treatment: Courts Jurisdiction)* (n 186) at 13.

¹⁹⁹ *Bolam v Friern Hospital Management Committee* (n 158); *Chatterton v Gerson* (n 158) at 443.

²⁰⁰ *ibid.*

²⁰¹ Cave and Purshouse (n 159).

²⁰² *ibid* at 4.

²⁰³ *Montgomery v Lanarkshire Health Board* (n 160) at 115; Cave and Purshouse (n 159) at 10.

²⁰⁴ *ibid.*

inform the child of all the material risks thus providing the child with more information than a “sufficient understanding” that *Gillick* requires.²⁰⁵ The higher standard of disclosure protects the *Gillick* competent child’s emerging autonomy to have some control over what will happen to their body.

2.5. Impact on Practice

As a result of the law seeking to protect the vulnerabilities associated with childhood whilst respecting the child as an individual with emerging autonomy, medical practice began to evolve. Research conducted as part of the Platt investigation into the welfare of children in hospital²⁰⁶ found that children’s wards failed to cater for the specific needs of children and young people. Wards were extremely regimented; children were not allowed to wear their own clothes or keep personal possessions; they did not receive an education; were unable to play, socialise or have positive stimulation.²⁰⁷ The Platt Report made 55 recommendations changing the hospital environment for children including having separate children’s departments,²⁰⁸ providing the child access to a multidisciplinary team, ensuring that the child is well informed about procedures, treatment and investigations, and is allowed to wear their own clothes, keep personal possessions and have access to education. The subsequent Court Report 1976²⁰⁹ proposed the separation of children under 16 and young people, accounting for their differing needs—most notably, a transition period

²⁰⁵ *Montgomery v Lanarkshire Health Board* (n 160).

²⁰⁶ Platt, H, ‘The Welfare of Children in Hospital: Report of the Committee’ (Ministry Of Health

Central Health Services Council, 1959)

<<https://ia800201.us.archive.org/8/items/op1266065-1001/op1266065-1001.pdf>>
accessed 12 February 2018 at 37.

²⁰⁷ *ibid* at chapters 6 and 7.

²⁰⁸ *ibid*.

²⁰⁹ Great Britain Committee on Child Health Services, ‘Fit for the Future: Report of the Committee on Child Health Services’ (*H.M.S.O.*, 1976).

from child care to adult services for children with long term medical conditions.²¹⁰ The Platt Report agreed with previous research on the negative impact of children being separated from their parents during hospitalisation. Bowlby and Robertson's research was disseminated through a documentary which showed children suffering extreme distress due to being separated from their parents during their hospital admission.²¹¹ In many hospitals, parents were unable to visit at all, some once a week and others once a day for one to two hours.²¹² Concern had been raised in the 1920s about the impact of separation from parents during a period of ill health and invasive procedures. Most notable of those concerned were Spencer, Cecily and Pickerill, who set up Glasgow's first mother and baby units²¹³, which admitted mothers alongside their children.²¹⁴ Robertson and Bowlby explain that when a child is separated from their parent, they experience a three-stage grieving process.²¹⁵ At first children protest by crying, showing visible distress. Secondly, the child enters a state of despair, where they may be quiet for some periods, able to interact with visitors but will cry when someone enters through the door by which their parents left, and evidence moments of distress. Finally, children will become detached, no longer displaying visible emotion (which at the time of the research was interpreted by nurses as being a sign of 'settling in'), nor interacting with visitors or reacting to stimulation.²¹⁶ This

²¹⁰ *ibid.*

²¹¹ Bowlby, J & Robertson, J, 'A Two-Year Old Goes to Hospital' (1953) 46(6) *Proceedings of the Royal Society of Medicine*, 425 at 426; Shields, L & Nixon, J, 'I want my Mummy: Changes in the Care of Children in Hospital' (1998) 5(2) *Collegian*, 16, at 17.

²¹² Shields & Nixon (n 211) at 17.

²¹³ Spence, J.C, 'The Care of Children in Hospital' (1947) 1(4490) *BMJ*, 125 at 125-130; L Shields & J Nixon (n 211).

²¹⁴ Pickerill, CM & Pickerill, H.P, 'Keeping Mother and Baby Together' (1946) 1(4509) *BMJ*, 126 at 826.

²¹⁵ Shields & Nixon (n 211) at 18.

²¹⁶ *ibid* at 17.

was a sign of serious suffering, and in many cases led to long-lasting emotional trauma.²¹⁷

The report concluded that children whose parents were present during procedures and hospital admissions suffered less or no trauma as a result²¹⁸. In contrast, children who were separated from their parents were more at risk from trauma in adolescence and adulthood. The Platt Report recommended allowing parents to stay with their child, and if this was not possible, encouraging them to visit every day for as long as the child wished.²¹⁹ The Platt and Court Reports required hospitals to build suitable accommodation and resources for parents, including common rooms and kitchens.²²⁰ The implementation of these recommendations was initially met with resistance from the nursing teams, who had previously been used to controlling their environment, and carrying out their practices without being challenged or questioned. Nurses complained that parents were interfering, asking questions and gaining too much knowledge.²²¹ There was initially resistance from the nursing teams, who had previously been used to controlling their environment, and carrying out their practices without being challenged or questioned.

As the parent-child bond became more understood, hospitals began to adopt a parent/family centred model.²²² In these models, parents would be active members of the health care team, being kept informed but also taught how to care for their child themselves.²²³ The extent to which the parent took control was dictated by their willingness or confidence to do so. However, the aim was to equip parents with the skills to care for their

²¹⁷ *ibid.*

²¹⁸ *ibid* at 18.

²¹⁹ Platt (n 206) at chapter 11.

²²⁰ *ibid*; Great Britain Committee on Child Health Services (n 209).

²²¹ Shields & Nixon (n 211) at 21.

²²² *ibid.*

²²³ *ibid.*

child both in and out of hospital. This led to shorter admissions, as hospital care could be provided at home.²²⁴ Gradually, more responsibility and expectation was placed on parents. In 1994, parents started to complain about the responsibility placed upon them, arguing that they had other children, jobs and responsibilities and were therefore unable to stay at hospital to care for a child whom they knew was being looked after by nurses whose job it is to care for them.²²⁵ Parents unable to live with their child in hospital felt a sense of stigma. There are many difficulties faced by parents when caring for an ill child, such as hospital accommodation, sleeping arrangements, a lack of personal space, and the need to take time off work for significant periods—these can make parent-care impossible for many families. Nevertheless, it continues to be encouraged where possible, as it is held to be most beneficial for the child.

The Platt Report's recommendations were important steps in the move towards placing the child at the centre of their healthcare. After recognising the importance of a sound parent-child relationship on children's wellbeing, parents were encouraged to actively participate alongside their child. Moreover, wards were being redesigned to meet the unique educational, social and health needs of children and young people. A crucial element of the move towards child centred health care was the doctor-paediatric patient relationship.

2.5.1. The Doctor-Child Relationship

Over the last three decades, clinical practice has sought to move away from a doctor paternalism towards a patient-led model²²⁶ where the patient has greater control and autonomy and the doctor less dominance. Patient- and child-centred care gained popularity during the 1960s, in response to liberation movements, civil rights campaigns, feminism movements,

²²⁴ *ibid.*

²²⁵ *ibid.*

²²⁶ Kabaa, R and Sooriakumaran, P, 'The Evolution of the Doctor-Patient Relationship' (2007) 5(1) *International Journal of Surgery*, 57 at 58.

freedom and fundamental human rights, and has grown in strength as a result of controversies, such as the treatment of mental health patients, and the Alder Hey organ scandal.²²⁷ For children specifically, this shift has been driven by increasing acknowledgement of children's capabilities and respect for their emerging autonomy.

In the medical model, the patient seeks the advice of a doctor who uses their skills to observe, investigate, diagnose, treat and cure a patient. Doctors provide a patient with selective information to encourage them to consent to the doctor's suggestions.²²⁸ In these instances, the power balance would be asymmetrical, in favour of the doctor. Academics have sought to categorise types of doctor paternalism.²²⁹ Szasz and Hollender divide doctor paternalism into two branches: activity-passivity and guidance co-operation.²³⁰ Activity-Passivity describes a helpless patient in need of medical expertise and knowledge, completely obedient to the doctor's guidance. Guidance co-operation describes a patient with

²²⁷ Royal Liverpool Children's Inquiry Royal Liverpool Children's Inquiry, 'The Royal Liverpool Children's Inquiry Report' (Royal Liverpool Children's Inquiry, 30 January 2001) <<https://www.gov.uk/government/publications/the-royal-liverpool-childrens-inquiry-report> > accessed 21 November 2016; Smith, R, 'Babies and Consent: Yet another NHS Scandal. But it Should Lead to Improvements in Research Governance Within the NHS' (2000) 320(7245) *BMJ*, 1285 at 1285; Kennedy, I, 'The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-199: Review of the Response of Heart of England NHS Foundation Trust to Concerns about Mr Ian Paterson's Surgical Practice; Lessons to be Learned; and Recommendations' (The Bristol Royal Infirmary Inquiry, 2001); Faden, R.R, Beauchamp, T.P, and King, N.P.L, *A History and Theory of Informed Consent* (Oxford University Press 1986) at Chapter 1, 3-22.

²²⁸ Royal Liverpool Children's Inquiry (n 227), at abstract.

²²⁹ Emanuel, E.J and Emanuel, L.L, '4 Models of the Physician-Patient Relationship' (1992) 267(16) *JAMA* 2221-6.

²³⁰ Szasz, T.S and Hollender, M.H, 'A Contribution to the Philosophy of Medicine: The Basic Models of the Doctor - Patient Relationship' (1956) 97(5) *AMA Arch Intern Med* 585, at 586.

awareness and consciousness, able to interact, seeking guidance from the 'expert', and expected to follow the doctor's guidance.²³¹

Parson's work on social disobedience depicted an unbalanced patient doctor relationship where the doctor was paternalistic and the patient vulnerable in need of expert advice. In Parsons's depiction of the doctor-patient relationship described in 1951, the patient lacks knowledge and the medical professional is the expert.²³² The patient is under an obligation to seek out and unwaveringly follow professional advice. It is assumed that doctors can provide a diagnosis, treatment plan and cure in all cases, and finally, patients will improve if they follow the medical advice. If they are not cured, it is the fault of the inexperienced and deviant patient, according to Parsons.²³³ Rather than acknowledge the limitations of medicine, Parson blames the lack of recovery on patients, believing them to have not properly complied with the doctor's treatment. In this doctor-led approach, it is assumed that doctors are the holders of all knowledge and cures and that a lack of recovery is due to the patient. In depicting the doctor patient relationship in this way, Parsons is illustrating the power that doctors have as experts in medicine in contrast to their patients.

Parsons²³⁴ explains that the medical profession has significant control over the population; this power imbalance is used to control and manipulate patients and society as a whole.²³⁵ Turner explains that where a profession has monopoly over an area, they can regulate themselves internally,

²³¹ *ibid.*

²³² Parsons, T, *The Social System* (Free Press 1951) at chapter 10.

²³³ *ibid* at 321.

²³⁴ It is noted that academics such as Foucault provided theories that also make this point. However, as this thesis is not critiquing Parsons or Foucault's work, rather using it as an example of what physician paternalism is said to look like, it was not necessary or relevant to provide an in-depth investigation of Foucault's work that would inevitably be unsatisfactory in its analysis due to its limited links to the main body of this chapter.

²³⁵ Foucault, M, *The Birth of the Clinic: An Archaeology of Medical Perception* (Routledge, 1989), at chapter 6.

produce their own knowledge, and control what knowledge is divulged to the public.²³⁶

During the last three decades, the depiction of paternalism by Parsons has been challenged in favour of a patient-centred model. Szasz and Hollender describe the patient-led approach as mutual participation.²³⁷ Here both the doctor and patient gain something mutually advantageous, there is mutual satisfaction, equal power, and both are dependent on the other. Emanuel and Emanuel refer to three types of patient-centred care: (i) Informative/Consumer, (ii) Interpretive and (iii) Deliberate²³⁸. Informative, otherwise known as the consumer model, characterises the patient as the consumer seeking consultation to get all the facts on proposed treatments.²³⁹ The doctor must convey all the information, set out the facts and allow the patient to decide on the basis of such facts. The interpretative approach requires the doctor to know the patient and their values. They lay out the facts, but seek to understand the true desires of the patient according to their values and help the patient to realise this. Moreover, the 'deliberative' type of care is a relationship where the doctor educates the patient on health, values, and aspirations. The doctor is the teacher, and the patient enters into a dialogue with the doctor. The doctor is interested in the life of the patient, not just their diagnosis, and seeks to work with the patient.²⁴⁰

The desire to move towards a patient-led model has been reflected in child law and clinical practice. The 20th century has seen significant changes to the relationship between doctor and child. Child-centred care also gained popularity during the 1960s liberation movements, civil rights campaigns,

²³⁶ Turner, B.S, *Medical Power and Social Knowledge* (2nd edn, SAGE 1995).

²³⁷ Szasz & Hollender (n 230) at 587.

²³⁸ Emanuel & Emanuel (n 229) at 2221-2222.

²³⁹ *ibid.*

²⁴⁰ *ibid* at 2222-2223.

feminism movements, freedom and fundamental human rights.²⁴¹

Collaborative decision-making and children-led approaches are promoted by law, policy and academics.²⁴² For example, Article 12 UNCRC and s1 of the Children Act states that children ought to participate in decisions about their welfare and be able to express their views and opinions. Moreover, *Gillick*-competent children can consent to medical treatment without parental consent. The GMC also established extensive guidelines to health care professionals stating health care decisions are a “partnership” between doctor and patient.²⁴³ Whilst there is a shift away from doctor paternalism, there is a role and a time for the paternalistic model in medical practice, for example, in emergency medicine, where the patient is unconscious and requiring urgent medical care. However, in general, the patient-centred model is desired in law and practice. Child involvement has evolved, with child-centred care and collaborative decision-making favoured by the NHS and English law.²⁴⁴

2.6. The ‘Right to Participate’

The 20th century marked the “age of children’s agency”,²⁴⁵ which placed the participation of children in society high on the policy agenda.²⁴⁶ As outlined above, this has led to the introduction of international and national legislation that values protecting the agency of children.

²⁴¹ Royal Liverpool Children’s Inquiry (n 227); Smith (n 78); Kennedy (n 227); Faden, Beauchamp, and King, (n 227) at chapter 1 Foundations, 3-22.

²⁴² Coynea, I, Amorya, A, Kiernanb, G, and Gibsonc, F, ‘Children’s participation in shared decision-making: Children, adolescents, parents and healthcare professionals’ perspectives and experiences’ (2014) 18(3) *European Journal of Oncology Nursing*, 273 at 273-280.

²⁴³ GMC, ‘Consent: patients and doctors making decisions together’ (n 162) at Part 1: Principles

²⁴⁴ *ibid.*

²⁴⁵ Oswell, D *The Agency of Children: From Family to Global Human Rights* (Goldsmiths University of London 2013), at 3.

²⁴⁶ Baraldi, C and Cockburn, T, *Theorising Childhood: Citizenship, Rights and Participation* (Palgrave Macmillan 2018).

The UNCRC²⁴⁷ protects (i) a child's right to non-discrimination and the devotion to their best interests, (ii) a child's right to life, (iii) survival and development, and (iv) respects the views of the child.²⁴⁸ Sinclair argues that the UNCRC gives children "the rights to participate in decisions that affect them, most notably through Article 12".²⁴⁹ Article 12 of the UNCRC is a guiding principle of the convention and affirms the child's right to express their views, for these to be heard and respected.²⁵⁰

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.²⁵¹

The guidance alongside the UNCRC recognises that children have a legal right to participate in decisions that impact them.

In 1989, governments across the world adopted the United Nations Convention on the Rights of the Child (UNCRC), recognising that all

²⁴⁷ UNTC, 'Convention on the Rights of the Child' (UNTC)

<https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-11&chapter=4&lang=en> accessed 19 August 2019.

²⁴⁸ The UK ratified the convention on 16th December 1991, and it came into force on 15 January 1992.

²⁴⁹ Sinclair, R, 'Participation in Practice: Making it meaningful, effective and sustainable' (2004) 18 Children and Society, 108 at 107.

²⁵⁰ UNCRC (n 96), Article 12

²⁵¹ *ibid.*

children have the right to be treated with dignity and fairness, to be protected, to develop to their full potential and to participate.²⁵²

Fundamentally, article 12 validates the child's opinion and ensures that they are considered within an evaluation of the child's best interests. Article 12 of the UNCRC "obligates the state to ensure the child's seat at the table".²⁵³ Article 12, "theoretically empower[s] children to be stakeholders in the pursuit of their own health and well-being".²⁵⁴ Article 12 of the UNCRC encourages a continual dialogue between the parents, the child and the health care team where the role of the adults is to consider the child's views, guiding and encouraging their development. The existence of Article 12 of the UNCRC recognises the value that a child can bring to the decision-making process and the importance of collaborative decision-making between parents, the child and their health care team. International law accords children a legal right to have their voices heard and due weight to be given to their opinions. The law values the participation of children in decisions that impact them including health care.

²⁵² UNICEF, 'The Rights of Every Child: A Summary of the United Nations Convention on the Rights of the Child' (UNICEF UK) <https://www.unicef.org.uk/child-rights-partners/wp-content/uploads/sites/3/2016/08/CRC_summary_leaflet_Child_Rights_Partners_web_final.pdf> accessed on 15 July 2019 at 2.

²⁵³ Ford, A, 'Do Children Have the Right to Contribute to Medical Decisions about their own Care? An Analysis of Policy and Practice in the United Kingdom and the United States' (2017) Health and Human Rights Journal < <https://www.hhrjournal.org/2017/08/do-children-have-the-right-to-contribute-to-medical-decisions-about-their-own-care-an-analysis-of-policy-and-practice-in-the-united-kingdom-and-united-states/>> accessed 15th July 2019.

²⁵⁴ Ibid.

The right to participate is a rhetoric shared within policy. The 2003 UNICEF program, “a world fit for children”,²⁵⁵ a scheme developed to promote and strengthen children’s rights during the 21st century in targeted fields including health. They argue that all children have the right to express themselves *and* to participate in matters affecting them.²⁵⁶

Children and adolescents are resourceful citizens capable of helping to build a better future for all. We must respect their right to express themselves and to participate in all matters affecting them, in accordance with their age and maturity²⁵⁷.

Schemes such as “Getting the right start: National Service Framework for Children Standard for Hospital Services”,²⁵⁸ the introduction of a Children’s Commissioner for England in 2004,²⁵⁹ and charities including the National Children’s Bureau and ‘Get Your Rights’ further encourages participation in all decisions affecting the child.²⁶⁰ Such policy extends to a clinical setting. In 2004, the Department of Health published the “National Service Framework” that outlined the core values of health care for children and their mothers. The framework referenced Article 12 of the UNCRC and

²⁵⁵ UNICEF, ‘A World Fit For Children’ (UNICEF, July 2008)

<https://www.unicef.org/publications/index_45482.html > accessed 8 December 2018 at 16.

²⁵⁶ *ibid* at 16 para 9.

²⁵⁷ *ibid*.

²⁵⁸ Department of Health, ‘Getting the Right Start: A National Service Framework for Children. Standard for Hospital Services.’ (Department of Health, April 2003)

<<https://www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services>> accessed 2 December 2017.

²⁵⁹ Children’s Commissioner, ‘The Children’s Commissioner for England’

<<https://www.childrenscommissioner.gov.uk/about-us/the-childrens-commissioner-for-england/>> accessed 5 January 2019.; Children and Families Act 2014 c 6.

²⁶⁰ National Children’s Bureau, ‘About Us’ (*National Children’s Bureau*)

<<https://www.ncb.org.uk/>> accessed 1 January 2019

stated that “children have a right to be involved in decisions about their care”.²⁶¹ For clinicians, the GMC guidance states:

Doctors must safeguard and protect the health and well-being of children and young people. Well-being includes treating children and young people as individuals and respecting their views, as well as considering their physical and emotional welfare.²⁶²

Law and policy provides children the right to have their views heard and respected. Children have a right to be the decision-maker where they are capable of doing so. Children have a right to be treated as active citizens and to participate in their health care. However, what does it mean to participate and what does participation look like in a clinical setting? From a clinical perspective, the World Health Organisation states:

Meaningful participation requires that individuals are entitled to participate in the decisions that directly affect them, including in the design, implementation, and monitoring of health interventions. In practice, meaningful participation may take on a number of different forms, including informing people with balanced, objective information, consulting the community to gain feedback from the affected population, involving or working directly with communities, collaborating by partnering with affected communities in each aspect of decision making including the development of alternatives and identification of solutions, and

²⁶¹ National Health Service Wales, *Core document: National Service Framework for Children, Young People and Maternity Services in Wales* (Wales: National Health Service, 2004), 92.

²⁶² GMC, ‘Introduction, 0-18 years: guidance for all doctors’ <<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/introduction>> accessed 16 June 2019 at para 3.

empowering communities to retain ultimate control over the key decisions that affect their wellbeing.²⁶³

The National Health Service (NHS) defines successful and meaningful participation in terms of shared decision making which involves patients being active partners with their medical team, working together to determine what treatment options would be acceptable to the patient and in deciding which medical treatment is the preferred course.²⁶⁴ In recent years, the NHS has introduced frameworks within many of its trusts to implement shared decision making into adult care. However, there is a lack of unifying definition as to what is meaningful participation.

Clinical practice relies heavily upon academic interpretations of participation, most notably Arnstein and Hart's work. Hart's work in particular is routinely referenced with regards to children and young people.

In seeking to define participation for the purpose of a variety of academic disciplines, academics began creating typologies for participation to provide guidance as to what participation means and the spectrum of participation. To 'participate' is defined by the Oxford English Dictionary as being involved or taking part.²⁶⁵ Academics refer to two types of participation: social and political.²⁶⁶ Social participation is primarily concerned with human interaction and the degree to which a person is embedded in the community. Melucci argues that social participation "means both taking part that is, acting so as to promote the interests and

²⁶³ World Health Organisation, 'Participation' <<https://www.who.int/gender-equity-rights/understanding/participation-definition/en/>> accessed 12 July 2018.

²⁶⁴ NHS, 'Shared Decision Making' <<https://www.england.nhs.uk/shared-decision-making/>> accessed 18th November 2018.

²⁶⁵ "participate, n." OED Online, Oxford University Press, March 2019 <<https://www.oed.com/>> 27 April 2019.

²⁶⁶ Carpentier, N, 'Beyond the Ladder of Participation: An Analytical Toolkit for the Critical Analysis of Participatory Media Processes' (2016) 23(1) *Javnost The Public*, 70, at 71.

the needs of an actor as well as belonging to a system identifying with the general interests of the community.”²⁶⁷ Here, power is not a primary consideration. In contrast, political participation refers to the power relations and inequalities within the decision-making process. Arnstein considers political participation as acknowledging the difference between the power holders and the non-privileged citizens who are unable to make an impact with their participation.²⁶⁸ Arnstein argues participation is expressing one’s opinions and, ideally, exerting influence.²⁶⁹ Participation is about all citizens being able to recognise and express their needs and rights, where the beneficiaries take an active role in the decision-making process.²⁷⁰ In terms of health care, a person can participate in the wider context through public and patient involvement in the health care system, or through their individual patient health care choices. This thesis is concerned with the individual patient health care choices.

Nigel Thomas²⁷¹ divides participation into taking part in an activity (such as in education), or taking part in decision-making (as in medical law).²⁷² A person may participate in the process or the outcome of the decision-making process.²⁷³ Moreover, participation can be collective (about decisions that may affect a group of people) or about an individual’s life (as in the majority of medical decision-making cases).²⁷⁴ Finally, Thomas distinguishes between ‘consultation’ and ‘participation’. Whilst many

²⁶⁷ Melucci, A, *Nomads of the Present: Social Movements and Individual Needs in Contemporary Society* (Temple University Press 1989) at 174.

²⁶⁸ Arnstein, S.R, 'A Ladder Of Citizen Participation' (1969) 35(4) *Journal of the American Planning Association*, 216 at 31-32.

²⁶⁹ *ibid* at 29-30.

²⁷⁰ *ibid* at 25-26.

²⁷¹ Thomas, N, 'Towards a theory of children’s participation' (2007) 15 *The International Journal of Children’s Rights*, 199.

²⁷² *ibid* at 199.

²⁷³ *ibid*.

²⁷⁴ *Ibid* at 204.

academics refer to consultation as a sub-category of (and low level) participation, it is important to note the difference between the terms which may be incorrectly assumed to be the same.²⁷⁵ Sinclair's research found that, in practice, participation means only to be consulted or to be listened to, as distinct from 'active participation', where people "have reason to believe that their involvement will make a difference".²⁷⁶ Hill et al. elaborates, defining consultation as "seeking views", and participation as "the direct involvement of children in decision-making".²⁷⁷

Whilst it is argued that there has been a shift in understanding of childhood and adolescence, there remains limited research into the 'lived experiences' of children in understanding whether they meaningfully participate in clinical practice. These typologies provide a useful tool to analyse the extent to which children participate in their health care.

Although not a typology specific to children, Sherry Arnstein created a ladder consisting of three categories: (i) non-participation, (ii) degree of tokenism and (iii) citizen power.²⁷⁸ These categories are further divided into eight rungs.²⁷⁹ Arnstein's ladder is based on the understanding that there is an essential difference between "going through the empty ritual of participation and having the real power needed to affect the outcome of the process".²⁸⁰ Arnstein's ladder is composed of eight graduations of citizen participation, where "nobodies in several areas are trying to become somebodies with enough power to make the targeted institutions responsive to their views, aspirations and needs".²⁸¹

²⁷⁵ *ibid* at 208-209.

²⁷⁶ Sinclair (n 249) at 110-111.

²⁷⁷ Hill, M & others, 'Moving the participation agenda forward' (2004) 18(2) *Children and Society*, 77 at 83.

²⁷⁸ Arnstein (n 268) at 25-26.

²⁷⁹ *ibid*.

²⁸⁰ *ibid* at 24.

²⁸¹ *ibid* at 25.

Non-participation consists of manipulation and therapy, where citizens are informed but have no influence in the decision-making process.²⁸²

Tokenism includes informing, consultation and placation.²⁸³ Where a person is participating at a tokenistic level, they have no real power or legitimate function. Finally, citizen power includes partnership, delegate power and citizen control.²⁸⁴ Partnership refers to shared decision-making with citizens and power holders. Delegate power is the negotiation stage, where the majority of the power is with the citizens. This leaves the power holders in a position to negotiate to try and resolve their differences.²⁸⁵

A leading typology in the field of children's participation, created by Roger Hart, sought to adapt Arnstein's ladder of participation, placing children's agency at its core.²⁸⁶ Hart's ladder of children's participation was "the first real attempt" to recognise child agency within this typology.²⁸⁷

2.6.1. Hart's Ladder of Participation

Hart and his colleague Robin Moore recognised that designers like themselves, were struggling to successfully involve children in the designing, planning and research of environmental community projects.²⁸⁸ As such, Hart sought to start a dialogue in this area, writing an article for

²⁸² *ibid.*

²⁸³ *ibid.*

²⁸⁴ *ibid.*

²⁸⁵ *ibid.*

²⁸⁶ Hart, R, 'Children's Participation: From Tokenism to Citizenship' (UNICEF International Child Development Centre 1992) < https://www.unicef-irc.org/publications/pdf/childrens_participation.pdf > accessed 5 March 2019 at 3-4.

²⁸⁷ Kellett, M, 'Children and Young People's Participation' in Montgomery, H and Kellett, M, (eds.) *Children and Young People's Worlds: Developing Frameworks for Integrated Practice* (Policy Press 2009) at 43-60.

²⁸⁸ Hart, 'Stepping back from "The ladder": Reflections on a model of participatory work with children' (n 36) at 21.

the “Childhood City Newsletter”,²⁸⁹ in which the ladder of participation first appeared. The ladder was used as a metaphor to encourage designers to self-reflect and evaluate their current practices to give children the opportunity to participate at the highest of their capabilities, where they desired to do so.²⁹⁰ During the early 1990s, when the UNCRC was in its infancy, UNICEF, like many international non-governmental organisations, were having difficulty interpreting the Convention, in particular, Hart argues, the parts of the convention about child participation.²⁹¹ Thus, published by UNICEF, Hart adapted his ladder of participation for a book which brought to a wider audience a critical perspective to child participation stimulating a conversation.²⁹²

Sherry Arnstein’s ladder of citizenship participation²⁹³ was influential in Hart’s work. Hart adapted Arnstein’s ladder to be applicable to children. Where Arnstein’s ladder composed of eight rungs divided into three segments – no power, degrees of tokenism and degrees of citizen power²⁹⁴ – Hart divided the eight rungs into two segments – non-participation and participation.²⁹⁵ Each rung is associated with a higher level of competency required to participate at this level and is an expression of different degrees of child agency. Although not equal - as suggested by Jensen who redesigned the ladder into a circle to signify the equivalence of each

²⁸⁹ Childhood City Newsletter, ‘Special Issue: Participation Methods’ (1980) New York: Children’s Environments Research Group, Graduate School of the City University of New York

²⁹⁰ Hart, R, ‘Stepping back from “The ladder”’: Reflections on a model of participatory work with children’ in J Reid, *Participation and learning: developing perspectives on education and the environment, health and sustainability* (SAGE 2008) 19 at 21.

²⁹¹ *ibid.*

²⁹² *ibid.*

²⁹³ *ibid.*

²⁹⁴ *ibid* at 25.

²⁹⁵ Hart, *Children’s Participation: From Tokenism to Citizenship* (n 288) at 8.

rung²⁹⁶ - Hart does not believe that a higher rung is superior to a lower rung, nor that the highest rung is the goal for all children. Instead Hart emphasises the element of 'choice'. Hart believes that every child ought to be given the opportunity to access the highest degree of participation that they are capable of.²⁹⁷ However, a child is under no obligation to participate to the maximum of their capabilities. It is the presence of the opportunity that is important. Thus, meaningful participation is having an opportunity to participate at the child's highest potential in a manner that will influence a decision.

Non-participation represents the first three rungs of Hart's ladder; manipulation, decoration and tokenism.²⁹⁸ Manipulation and decoration refer to using children as a means to an end. Hart uses the example of children holding a placard that they do not understand the meaning of. In this example, adults are using children to campaign for a cause they do not understand.²⁹⁹ In manipulation, adults are pretending that children are the inspiration behind the project, whereas decoration does not make this pretence. Manipulation and decoration also refer to consulting children but not providing feedback.³⁰⁰ In a medical context, this may include seeking the opinions of a child, but failing to go back and communicate to the child how those concerns have been addressed.

A child's participation is described as tokenistic where it is perceived that the child has a voice, but in reality, they have little or no opportunity to

²⁹⁶ Jensen, B.B, 'Participation, commitment and knowledge as components of pupils' action competence' In Jensen, B.B, Schnack, K and Simovska, V (eds), *Critical Environmental and Health Education: Research Issues and Challenges*, (Copenhagen: Danish University of Education 2000) at 219–238

²⁹⁷ Hart, 'Stepping back from "The ladder": Reflections on a model of participatory work with children' (n 290) at 24.

²⁹⁸ Hart, *Children's Participation: From Tokenism to Citizenship* (n 288) at 8.

²⁹⁹ *ibid* at 9.

³⁰⁰ *ibid*.

formulate an opinion and have this respected.³⁰¹ This includes informing a child about the treatment they are going to receive but providing no opportunity for the child to influence the design or execution of the treatment.

The following five rungs represent degrees of participation. Where a child is acting at the level of rung four, being 'assigned but informed', the child (i) understands the intentions behind their treatment, (ii) knows who made the treatment decisions and why, (iii) has a meaningful, not decorative, role in the treatment and (iv) volunteers or assents to the treatment suggested by the health care professionals.³⁰² Rung five, 'consulted and informed', refers to a child who is consulted about the treatment being proposed.³⁰³ Rather than merely assenting and volunteering for the treatment, the child has an active involvement in the design process through consultation with the adults working with them. Rung six, 'adult-initiated shared decision-making', involves health care professionals designing the initial treatment idea, but, incorporating the child at every step of the process including deciding which treatment is most appropriate.³⁰⁴ Shared decision making is to be distinguished from rung seven, 'young people initiated and directed', where the child initiates the idea and leads the decision-making process.³⁰⁵ In child-led participation, adults are limited to a supportive capacity. Finally, rung eight, 'collaborative decision-making between children and adults', is where all parties involved in the decision-making process have an equal role.³⁰⁶

³⁰¹ *ibid*, at 10.

³⁰² *ibid*, at 11.

³⁰³ *ibid*, at 12.

³⁰⁴ *ibid*.

³⁰⁵ *ibid* at 14.

³⁰⁶ *ibid*, 14-15.

There has been much debate surrounding the hierarchy of rungs seven and eight.³⁰⁷ Hart values shared decision making above child-led decisions, in contrast to academic literature which often cites a child led decision as the ultimate power because there is the least adult involvement.

The highest possible degree of citizenship in my view is when we, children or adults, not only feel that we can initiate some change ourselves but when we also recognise that it is sometimes appropriate to also invite others to join us because of their own rights and because it affects them too, as fellow-citizens. When people recognise the rights of others to have a voice and involve them, then this, in my mind, is morally superior to children being 'in-charge'.³⁰⁸

Hart values shared decision-making as the highest level of participation because he subscribes to Vygotsky's theory of child development, that a child develops through their interactions with those more capable than them.³⁰⁹ As such, a child choosing to involve adults who can assist their decision-making is, to Hart, a sign of maturity and sophisticated decision-making.

In a similar typology structure to Arnstein and Hart, Alderson and Montgomery state that there are four levels at which a child can participate:

- (i) Being informed
- (ii) Expressing a view
- (iii) Influencing a decision

³⁰⁷ Hart, 'Stepping back from "The ladder": Reflections on a model of participatory work with children' (n 290) at 24.

³⁰⁸ *ibid*

³⁰⁹ Vygotsky (n 5) at 85-87.

(iv) Being the main decider³¹⁰

These levels represent varying and valid degrees of participation, however, the first three levels are required before the child can be the main decider. Kirby et al. criticised these typologies for their hierarchical nature, presuming that being the main decider is the desired objective. Yet, there are many children who do not wish to have autonomy in the decision-making process and, therefore, this ought to be respected. To remove the pressure of a hierarchical model, Kirby et al. developed a typology that considers methods of participation instead of levels.³¹¹ For example, they reference the need to create mutual trust and respect, have an ongoing dialogue with the child, provide action and feedback, reduce the power imbalances between children and health care professionals, support young people throughout the process, and provide the opportunity for choice.³¹²

With the typologies in mind and with regards to children making health care decisions, I define participation as the opportunity for a child to participate in decisions about their health care. Participation is meaningful when the child has the opportunity to participate in accordance with their capacity. If a child chooses not to participate at this level, in accordance with their capacity, their participation is nevertheless meaningful. Their participation is not meaningful, however, where the child does not have the opportunity to participate in accordance with their capacity.

2.7. Conclusion

This chapter lays down three assumptions that form the foundation to the empirical study at the centre of this thesis: (i) that every child has a right to meaningfully participate in their health care, (ii) that children ought to have

³¹⁰ Montgomery, J, & Alderson, P, *Health care choices: making decisions with children* (IPPR, 1996)

³¹¹ Kirby, P and others, *Building a Culture of Participation: Involving Children and Young People in Policy, Service Planning, Delivery and Evaluation' Research Report* (London, Department for Education and Skills, 2003a).

³¹² *ibid.*

a right to meaningful participation, and (iii) that some children are capable of making independent health care decisions. Moreover, this chapter engaged with some academics who have contributed to the discourse of childhood which directly impacts law and policy. It considers the evolution of childhood taking in turn cognitive developmental psychology, neurological development, and historical, social and cultural factors. It analysed how this notion of childhood has impacted law and policy which has evolved to value children's participatory rights. The purpose of this chapter is to show how the law has gradually evolved to place value on the right of children to meaningfully participate in their health care. With this in mind, it is now of importance to critically analyse the law and ask whether the law adequately upholds this value.

3. A CRITICAL ANALYSIS OF THE LAW

3.1. Introduction

The law has evolved to value children's participatory rights. However, the extent to which children participate in medical practice has been debated by academics who argue that the law acts as a barrier to participation. This chapter presents and critically analyses the academic debate surrounding the law of child consent. Section 3.2 examines Article 12 of the UNCRC and section 3.3 critically analyses *Gillick* competency and the Children Act. These sections conclude that the ambiguity of the law and the lack of guidance accompanying the law is a barrier to participation. Finally, section 3.4 presents previous academic research on children's participatory rights concluding that further empirical research examining the 'lived experiences' of patients is necessary to understand whether law and practice are successful in enabling and facilitating children's participation in their health care.

3.2. The 'Right to Participate'

As we saw in the previous chapter, the purpose of Article 12 of the UNCRC, *Gillick v West Norfolk and Wisbech Area Health Authority* and the Children Act is to give children the right to participate in their health care in accordance with their developmental level. A critic may argue that the law is to be celebrated for valuing and promoting the right to participate, and that therefore, no change is required from a legal perspective. However, despite valuing the right to participate, academics have suggested that the law is a barrier to children's participation.

In a 2018 special issue in the *International Journal of Children's Rights*,¹ concerns were raised about (i) the wording of Article 12 of the UNCRC, (ii) the role of adults in interpreting and according 'due weight' to children's opinions and (iii) the lack of methods for measuring whether a child's

¹ International Journal of Children's Rights Special Issue (2018) Vol 26 Issue 1.

decision has been given 'due weight'. Alderson² identified the stark difference between the choice of wording in the UNCRC³ in contrast to the United Nations Declaration of Human Rights (UNDHR).⁴ In the UNDHR, the Declaration states "everyone is entitled to" make decisions for themselves.⁵ However, the UNCRC stipulates that "states parties shall assure to the child" the following rights. Therefore, unlike adults who are entitled to make decisions for themselves where they are capable to do so, children only have their voice and opinions heard if state parties incorporate this right into their national Law.

Article 12 of the UNCRC has been further criticised for failing to define 'due weight'.⁶ Daly asks, what is it that we are measuring? Competency, wisdom of the decision and accuracy of perception? Moreover, how do we measure this?⁷ Because of the lack of definition the weight credited to children's views is subjective, unfair, lacking precision, gravity and consistency, despite the implications that 'due weight' can be weighted in a mathematical and accurate manner.⁸ In case law, judges do not state how they give 'due weight' to a child's opinion.⁹ As such, there is a lack of

² Alderson, P, 'Giving children's views "due weight" in medical law' (2018) 26 *International Journal of Children's Rights*, 16 at 23.

³ United Nations Convention on the Rights of the Child 1989 ratified in 2001.

⁴ United Nations Declaration of Human Rights 1948 ratified in the UK 10 December 1948.

⁵ *ibid.*

⁶ Daly, A, 'No Weight for "Due Weight"? A Children's Autonomy Principle in Best Interest Proceedings' (2018) 26 *International Journal of Children's Rights*, 61 at 65; Daly, A, *Children, Autonomy and the Courts: Beyond the Right to be Heard Vol 3* (Brill | Nijhoff 2018).

⁷ Daly, 'No Weight for "Due Weight"? A Children's Autonomy Principle In Best Interest Proceedings' (n 6) at 63.

⁸ Alderson 'Giving Children's Views "Due Weight" in Medical Law' (n 2) at 23-24.

⁹ *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 F.L.R. 386; *Re L (Medical Treatment: Gillick Competence)* [1998] 2 F.L.R. 810 ; *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11; *Re W (A Minor) (Medical Treatment: Courts Jurisdiction)* [1993] Fam 64.

transparency as to how to weigh children's views alongside expert evidence. In the recent case *University Hospitals Plymouth Trust v B*,¹⁰ a 16-year-old desired to refuse therapeutic medical treatment for her diabetes. The judge acknowledged the views of B in the following simple and short statement: "I have also borne in mind B's stated wishes and feelings".¹¹ Justice MacDonald did not expand with an explanation of how he incorporated B's views alongside expert witnesses; this omission adds to the lack of clarity around the requirement to accord 'due weight' to the views of children.

According to Alderson, the lack of clarity and subjective nature of the term 'due weight' means that judges may fall back on the presumption of child incompetency to discount the views of the child.¹² Daly discusses how the courts do not often concern themselves with the voice of the child:

Great importance is now placed on the need to understand, support and value the decision-making of adults where capacity is in question, yet little effort is expended on trying to determine where the courts should and should not uphold children's decisions. Courts generally do not concern themselves with such matters, and where they do (usually in medical law cases) the emphasis is on some notion of competence, and it is easy to determine that children do not have it, because competence is so little understood. In fact, there is an argument to be made that Article 12 has actually compounded the low status accorded to children in their own proceedings, whilst permitting adults to claim that they are

¹⁰ *University Hospitals Plymouth Trust v B* [2019] EWHC 1670 (Fam).

¹¹ *ibid* at para 18.

¹² Alderson, 'Giving children's views "due weight" in medical law (n 2) at 23.

committed to children's rights because of the rhetoric of the right of children to be heard.¹³

As a result of the discourse of childhood, characteristics such as vulnerability, incompetency and dependency are inextricably linked with children. Consequently, it is easy for judges to apply this discourse and determine that children lack the competency to make a decision, especially as the term 'competency' is also ambiguous and subjective.¹⁴ Aside from *University Hospitals Plymouth Trust v B*,¹⁵ all other case law about child-refusal of therapeutic medical treatment has had judgments built on the premise that children lack competency to make a decision.¹⁶

3.3. Gillick and the Children Act

As described in chapter 2, the Children Act requires the court to deliver a judgment that is best for the child's welfare. As part of this assessment, the child's views, irrespective of their competency should be taken into account. The case of Gillick works alongside the Children Act. Where a child is Gillick competent, and makes a decision, it is for the judge to decide how much weight is to be accorded their opinion in light of other factors to be considered when assessing a child's welfare. However, the Children Act and the case of Gillick do not provide any guidance as to how much weight a child's opinion ought to accord. For example, should a Gillick competent child's opinion carry more weight than a non-Gillick competent child? How does the court weigh the welfare factors and what method is used to ensure each welfare assessment is universally applied? Unlike with adults, the link between competency and authority is not as clear for children. For adults, if they demonstrate competency the law of consent gives them the

¹³ Daly, 'No Weight for "Due Weight"? A Children's Autonomy Principle in Best Interest Proceedings' (n 6) at 66-67.

¹⁴ *Re E (A Minor) (Wardship: Medical Treatment)* (n 9).

¹⁵ *University Hospitals Plymouth Trust v B* (n 10).

¹⁶ *Re E (A Minor) (Wardship: Medical Treatment)* (n 9); *Re L (Medical Treatment: Gillick Competence)* (n 9); *Re M (A Child) (A Refusal of Medical Treatment)* [1999] 2 FLR 1097.

authority to make autonomous decisions. However, with children, “being competent only enables minors to authorise decisions which relevant others determine to be in their best interests”.¹⁷ Gillick competency does not respect a child’s autonomy or independence, rather, allows children to contribute their opinions in an environment where their decisions can be overruled to prevent long term harm or severe consequences that may negatively impact the child’s welfare.

In her article, “Goodbye Gillick? Identifying and Resolving Problems with the Concept of Child Competence”,¹⁸ Emma Cave discusses the issue of competency, in particular, the lack of a clear definition. Lord Fraser states that a Gillick competent child can consent to medical treatment if, among other factors, the child will understand the advice given by their doctors.¹⁹ In contrast, Lord Scarman says that a *Gillick* competent child can consent to medical treatment if they have ‘sufficient understanding and intelligence of the proposed treatment’.²⁰ Case law has combined these definitions however, “sufficient understanding and intelligence” is difficult to define. Does this mean that the child understands all the information needed to make a valid consent or just the information given to them by their doctor? Do they need to demonstrate that they are academically, emotionally, cognitively, or socially intelligent? Emma Cave argues that whilst it has been necessary to keep *Gillick* competency broad to allow flexibility in assessing the welfare of each child independently, “too much flexibility enables those assessing competence to focus less on the minor’s functional ability to make the decision and more on the outcome of the decision. In

¹⁷ Cave, E ‘Goodbye Gillick? Identifying and resolving problems with the concept of child competence’ (2014) 34(1) Legal Studies, 103.

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] A.C. 112.

some cases, because the outcome of the minor's decision would be so serious, it is difficult to see how the minor could prove competence".²¹

The definition of competency is ambiguous both in law and academic debate. The following section discusses the evolution of the term competency, its ambiguity, how it relates to capacity and the definition of competency that will be used for the purpose of this thesis.

3.4. Competency

Referring to the competency of vulnerable adults, Herring and Wall state it is extremely important to accurately assess a person's competency.²² It is a "terrible thing"²³ to have a decision taken away from a person when that person has the capability to make an autonomous decision. Likewise, it is a "terrible thing"²⁴ to burden someone with a decision they are not capable of making. Therefore, it is of great importance to be able to assess a person's competency.

The term 'competency' is often used interchangeably with 'capacity'.²⁵ However, academic discourse suggests capacity and competency are distinct concepts that link together. Couden argues that having capacity is possessing the characteristics which provide an individual with the current

²¹ Cave, E 'Goodbye Gillick? Identifying and resolving problems with the concept of child competence' (n 17) at 6.

²² Herring, J & Wall, J, 'Autonomy, capacity and vulnerable adults: filling the gaps in the Mental Capacity Act' (2015) 35(4) *Legal Studies*, 698.

²³ *ibid* at 698.

²⁴ *ibid*.

²⁵ Academic literature focuses on capacity rather than competency. However, I have chosen to talk about 'competency' for the purpose of consistency.

McFarlane, A, 'Mental Capacity: One Standard for all Ages' (2011) 41(5) *Family Law*, 479; Cave, E 'Maximisation of a Minors Capacity' (2011) 23 *CFLQ*, 4431; Cave, E & Wallbank, J, 'Minors' Capacity to Refuse Treatment: A Reply to Gilmore and Herring' (2012) 20(3) *Medical Law Review*, 423; Scott-Moncrieff, L, 'Capacity, Choice and Compulsion' (2004) 11 *Journal of Mental Health Law*, 142; Donnelley, M, *Healthcare Decision Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (CUP 2010).

potential to act, if the optimising factors are present.²⁶ Beauchamp and Childress,²⁷ Bunchanan and Brook²⁸ and Grisso, Appelbaum and Berg²⁹ refer to capacity as the current presence of capabilities that, if exercised, would result in a competent action.³⁰ As such, competency is possessing and using the necessary capabilities to act. The Oxford English Dictionary defines capacity as the “ability or power to do or understand something”³¹ and competency as “the ability to do something successfully”.³² In other words, capacity is having the skills and tools to complete or understand something if the person so desired, and competency is using those skills or tools to go on to complete the act, or reach a sufficient understanding.³³

Couden believes that competency requires a person to understand something to a level of excellence.³⁴ However, legislation has simplified the definition of competency: a person either reaches the threshold or they do not. The Mental Capacity Act,³⁵ *Re C*³⁶ and *Gillick* competency³⁷ do not refer to standards of competency, but rather the presence of four capabilities: understanding, appreciation, reason and communication.

²⁶ Couden, M, *Children’s Rights: From Philosophy to Public Policy* (Palgrave MacMillan 2016) at 42.

²⁷ Beauchamp & Childress, *Principles of Biomedical Ethics* (7th ed Oxford University Press 2013) at 71.

²⁸ Bunchanan, A, & Brook, D.W, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press 1990).

²⁹ Appelbaum, Grisso, & Berg, ‘Constructing Competence: Formulating Standards of Legal Competence to Make Medical Decisions’ (2006) 48 Rutgers Law Review, 345

³⁰ *ibid*; Bunchanan & Brook (n 28).

³¹ Trumble, W.R and Stevenson A (eds), *Shorter Oxford English Dictionary* (first publish 1933, OUP 2002).

³² *ibid*

³³ Couden (n 26) at 38.

³⁴ *ibid* 43.

³⁵ Mental Capacity Act 2005 c.9.

³⁶ *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All ER 819.

³⁷ *Gillick* (n 20).

These four capabilities are supported by academic literature.³⁸ Buchanan and Brook recommend adding an additional capability, 'value',³⁹ and Appelbaum, Grisso and Berg suggest adding 'rationality'.⁴⁰

In medical practice, 'understanding' requires a patient to have an awareness of their diagnosis, prognosis, the doctor's recommendations and a knowledge of the risks and benefits for a specific treatment.⁴¹ 'Understanding' is to be distinguished from 'appreciation', which involves being able to evaluate the information disclosed by health care professionals in relation to the whole situation.⁴² 'Reasoning' is said to involve the manipulation of the relevant information by the employment of a logical thought process which will aid the formulation of a decision within the mind.⁴³ However, as Appelbaum and Berg argue, the rationality of a decision often forms a crucial part in establishing the presence of reasoning.⁴⁴ If a patient's decision is irrational, then there is an assumption that they have failed to apply a logical thought process to come to a reasoned decision. McLean argues that if he were to only buy milk on days where it was sunny then he would, given the weather in England, have too

³⁸ Appelbaum, Grisso & Berg (n 29); Appelbaum, P.S, Grisso, T & Hill-Fotouhi, C, 'The MacCAT-T: A Clinical Tool to Assess Patients' Capacities to Make Treatment Decisions' (1997) 48(11) *Psychiatric Services*, 1415 at 1415-1419; Appelbaum, P.S, & Grisso, T, 'The MacArthur Treatment Competence Study I: Mental Illness and Competence to Consent to Treatment' (1995) 19(2) *Law and Human Behaviour* 105-126; Appelbaum, P.S, & others, 'The MacArthur Treatment Competence Study II: Measure of Abilities Related to Competence to Consent to Treatment' (1995) 12(2) *Law and Human Behaviour* 127-148; Appelbaum, P.S & Grisso, T, 'The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments' (1995) 19(2) *Law and Human Behaviour*, 149 at 149-174.

³⁹ Buchanan & Brook (n 28).

⁴⁰ Appelbaum, Grisso & Berg (n 29) 351, at 345.

⁴¹ *ibid.*

⁴² *ibid.*

⁴³ *ibid* 220; Buchanan & Brook (n 28) at 350.

⁴⁴ Appelbaum, Grisso & Berg (n 29) at 367.

much milk most of the time and not enough milk at other times.⁴⁵ Because the decision is based on an unrelated variable—the weather—the decision is irrational.⁴⁶ A rational decision would be to buy milk when the agent is running out of milk.⁴⁷ Therefore, rationality refers to a logical connection between a decision and the reasoning behind this decision. Establishing whether a person has developed a logical thought process in their reasoning can be used to assess the presence of this factor. However, as it is a subjective factor, whereby what may appear irrational to one person is rational to another, rationality is not a reliable or appropriate method for measuring reasoning. For example, you may only make a milk shake on a sunny day and only use milk for milkshakes – hence the decision is rational. As such, the law concludes that irrationality is not a sign of incompetency—although fear or phobia is, as this interferes with a person’s ability to take on information, understand and reason in response to it.⁴⁸ A phobia may prevent a person acting as they would like to, whereas irrationality is a subjective perception about another person’s decision, which to them is rational.

Buchanan and Brook conclude that a person is competent when their decisions are based on a consistent moral basis.⁴⁹ This has been widely rejected in academic debate, as it is important to acknowledge that people’s values change and evolve throughout their life in accordance with their experiences. As such, it is not unusual for individuals to suddenly change the values on which they base major decisions. This is especially true in medicine, where individuals are facing life-changing diagnoses.⁵⁰ It

⁴⁵ McLean, A, *Autonomy, Informed Consent and the Law: A Relational Challenge* (CUP 2009) at 13-14.

⁴⁶ *ibid.*

⁴⁷ *ibid.*

⁴⁸ *Re T (Adult) (Consent to Medical Treatment)* [1993] Fam 95.

⁴⁹ Buchanan & Brook (n 28) at 103.

⁵⁰ Wall, G, ‘Defining Our Values Can Change Who We Become’ *Journal Review* (23 June 2017) <www.journalreview.com> accessed 25 June 2017

cannot be said that a dramatic shift in values indicates a lack of reasoning. However, Buchanan and Brook are correct to argue that a sudden and rapid change in values may indicate a change of reasoning.⁵¹

Whether a person has engaged in a coherent thought process can be assessed through the fourth capability, 'communication'. Here, a person must effectively make known to another their decision and associated thought process. Applebaum and Berg conclude that a person's inability to communicate their decision suggests that they lack competency.⁵²

However, academic debate and medical literature emphasise that medical professionals must exhaust all methods of communication prior to deeming an individual to be incapable of communication.⁵³

Academics have created models standards of competency. The MACT test assesses a patient's competency using the four capabilities.⁵⁴ For each capability, the patient is allocated a number from zero-six (zero being the lowest and six the highest level of competency in this area).⁵⁵ A total is produced, symbolising the patient's overall competence, thereby inferring that there are lower and higher standards, and that it is important that a certain standard is achieved to conclude that the individual is competent.⁵⁶ However, Appelbaum, Grisso and Berg state that there is no minimum score that establishes competence.⁵⁷ In other words, a score above zero in all capabilities is enough to establish competence. Therefore, their

⁵¹ Buchanan & Brook (n 28) at 103.

⁵² Appelbaum, Grisso & Berg (n 29) at 351.

⁵³ British Medical Association, *Medical Ethics Today: The BMA's Handbook of Ethics and Law* (3rd edn, Wiley-Blackwell 2012).

⁵⁴ Appelbaum, Grisso & Berg (n 29) at 345; Appelbaum, Grisso & Hill-Fotouhi (n 388); Appelbaum & Grisso, 'The MacArthur Treatment Competence Study I' (n 38); Appelbaum & others, 'The MacArthur Treatment Competence Study II' (n 38); Appelbaum & Grisso, 'The MacArthur Treatment Competence Study III' (n 38).

⁵⁵ *ibid.*

⁵⁶ *ibid.*

⁵⁷ *ibid.*

threshold of competency is the ability to perform the act using all four capabilities. Whilst there are levels of competency from zero-six that would distinguish between the individuals, they are all competent.

The threshold for competency is decision-specific, as the extent of the four capabilities required is dependent on the complexity and gravity of the decision. Some decisions require a greater understanding than others. In *Re R*⁵⁸ and *Re W*,⁵⁹ Lord Donaldson's judgment concluded that a mature child has the capability to consent to medical treatment, yet may not be capable of refusing treatment as a higher standard of competency is required.⁶⁰ This is because there is a practical distinction between refusing and consenting to medical treatment, whereby a refusal of treatment requires a higher standard of competency. This is because the child is refusing therapeutic medical treatment which is often considered to be in the child's best interests. Gilmore and Herring argue that there are several types of refusals, from refusing to consent to a specific treatment to declining all medical interventions.⁶¹ Here each choice asks "very different questions"⁶² of the patient, and this is reflected in the difficulty to meet the standard of competency expected in *Gillick*. Drane shares these conclusions, stating that there is a "sliding scale"⁶³ of capacity that is dependent upon the risk of harm.⁶⁴ "As the consequences flowing from the patient's decisions become more serious, competency standards ... become more stringent".⁶⁵

⁵⁸ *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11.

⁵⁹ *Re W (A Minor) (Medical Treatment: Courts Jurisdiction)* [1993] Fam 64 at 71-84.

⁶⁰ *ibid*; *Re R* (n 58).

⁶¹ Gilmore, S & Herring, J, "No' is the Hardest Word: Consent and Children's Autonomy' (2011) 23 Child and Fam LQ, 3at 8.

⁶² *ibid*.

⁶³ Drane, J.F, 'The Many Faces of Competency' (1985) 15(2) *The Hasting Centre Report*, 18.

⁶⁴ *ibid*.

⁶⁵ *ibid*.

Gilmore and Herring considered whether a child found capable to consent to therapeutic medical treatment is also capable to refuse therapeutic medical treatment.⁶⁶ They argue that to consent to medical treatment or refuse a particular treatment does not require a child to “understand the consequences of a failure to treat”.⁶⁷ However, where a child is refusing all medical treatment, they must turn their mind to all the consequences of refusing all therapeutic treatment.⁶⁸ Thus, it is harder for a child to meet the standard of competency if they are refusing all therapeutic medical treatment, in part, because the consequences that a child must understand and appreciate become more serious and complex.

Although, consents and refusals are fundamentally different, it can be argued that a child who is competent to consent to medical treatment must also be aware of the consequences of refusing all therapeutic medical treatment. To consent to a procedure that carries a significant risk to life, the child must have given careful thought and consideration to the alternative, including the refusal of all medical treatment. Without giving thought to what would happen if they did not have a surgical procedure the child would not put themselves through the significant harm caused by the surgery. Therefore, it is arguable that a child who is competent to consent to medical treatment must have considered the consequences of consenting to medical treatment, refusing their consent to a specific procedure and refusing all therapeutic medical treatment in order to have decided to consent. Cave and Wallbank state:

in order to consent to treatment, a minor might need to understand one or all of the following:

- (i) A specific treatment and not having that treatment;

⁶⁶ Gilmore and Herring (n 61) at 10.

⁶⁷ *ibid* at 5, 10 and 11.

⁶⁸ *ibid* at 7.

- (ii) A range of alternative treatments and their respective risks and benefits;
- (iii) The risks and benefits of having no treatment at all.⁶⁹

To consent to a procedure requires an understanding of the consequences of a refusal, so that the person fully understands the true potential benefits of having the procedure. Moreover, for a child to illustrate that they are *Gillick* competent they must have an understanding and appreciation of the risks and benefits of consenting to a medical procedure. Therefore, if a procedure has grave consequences, then to illustrate that they are *Gillick*-competent a child must have an understanding and appreciation of those risks and benefits. The graver the consequences, the more there is to understand and appreciate and the more challenging it may be to satisfy the standard in *Gillick*. However, as discussed in chapter 2, section 2.4 the law remains ambiguous on whether a child is lawfully allowed to refuse therapeutic medical treatment where their refusal threatens their life. Precedent suggests that in cases where there is risk of significant harm to the child, then the *Gillick* competent child's decision can be overruled in a process known as inherent jurisdiction.⁷⁰

Harvey asks, "should adolescents be allowed to refuse medical treatment such that death/serious disability will most likely be a consequence of their refusal?"⁷¹ In law, there is a precedent towards intervening when children are seeking to make decisions that will cause serious harm or a risk to life.⁷² Consequently, there is yet to be a case in England and Wales where a child has been allowed to refuse medical treatment, primarily because they are deemed not competent to do so. Moreover, where the consequences are grave, case law illustrates that it is permissible for a judge to override a

⁶⁹ *ibid* at 443.

⁷⁰ *ibid*.

⁷¹ Harvey, M.T, 'Adolescent Competency and the Refusal of Medical Treatment' (2003) 13 *Health Matrix*, 297.

⁷² *University Hospitals Plymouth Trust v B* [2019] EWHC 1670 (Fam).

Gillick competent child's wishes, in a process known as inherent jurisdiction.⁷³ This was recently illustrated in *University Hospitals Plymouth Trust v B*⁷⁴ where Justice MacDonald stated that "there is no evidence that B lacks capacity",⁷⁵ however, "the law is clear that the court is not mandated to accept the wishes and feelings of a competent child where to honour those wishes and feelings would result in manifest, and even fatal, harm to that child."⁷⁶

There is much academic debate on whether competent children's refusals of medical treatment should be overruled by judges. Whilst Gilmore and Herring agree that it is more challenging to meet the standard of competency when the child is refusing all medical treatment, they disagree with overruling a competent child's refusal of particular medical treatment.⁷⁷ This argument is supported by many academics who believe that all children should be assessed individually, and if they are found to be competent, they ought to be the decision-makers.⁷⁸ This is known as "presumptive decisional capacity".⁷⁹ These academics agree on the theoretical foundations to this claim, although they disagree on the threshold of establishing competency. The threshold for competency is an ongoing and unresolved dispute. However, it is often variable, set high for paediatric cases, and linked with the consequences of the decision.

⁷³ *Ibid.*

⁷⁴ *Ibid.*

⁷⁵ *ibid* at para 2.

⁷⁶ *ibid* at para 18.

⁷⁷ Gilmore & Herring (n 61) at 15.

⁷⁸ Ross, F.L, *Children, Families and Health Care Decision Making* (OUP 1998); Elliston, S, 'If You Know What's Good For You: Refusals of Consent by Children' in McLean, S, *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth 1996) at 29-55; Hartman, R.G, 'Adolescent Decisional Autonomy for Medical Care: Physical Perceptions and Practices' 8 U CH L Sch Roundtable 87 (2001) 88-89; Hartman, R.G, 'Adolescent Autonomy: Clarifying an Ageless Conundrum' *Hastings LJ* 1265 (2000) 51

⁷⁹ Harvey, M.T, 'Adolescent Competency and the Refusal of Medical Treatment' (2003) 13 *Health Matrix*, 297.

As a result of the ambiguous definition of *Gillick* competency, a high standard of competency has been set in paediatric cases. In *Re E*⁸⁰, Justice Ward highlighted the consequences of refusing a blood transfusion, and despite previously establishing that the patient was mature, argued that he “could not rule out the possibility that [E] may suffer diminution in his convictions”⁸¹ due to the life-threatening consequences of refusing a blood transfusion.⁸² It is argued that the possibility of regret is a sufficient factor for finding that E is not *Gillick*-competent.

In *Re M*⁸³, a 15-year-old wished to refuse a heart transplant. In assessing her maturity, it was held that M understood that she would die without the operation, and that although she did not wish to die, she also did not want to have another person’s heart or be on anti-rejection medication for the rest of her life.⁸⁴ Whilst the presiding High Court judge recognised that M was mature, “she had gone through a traumatic experience and was struggling with a very difficult decision”.⁸⁵ Therefore, the “risks posed by the operation and by her possible future resentment at her wishes being overridden were both outweighed by the need to preserve her life”.⁸⁶

Coggon argues that the flexibility and ambiguity of the term autonomy has been “inadvertently”⁸⁷ used to “take advantage of the equivocal nature of the concept to come tacitly to decisions that reflect their own moral judgments”.⁸⁸ Similarly, it can be argued that the ambiguous nature of the term competency has been inadvertently used by judges to justify a higher

⁸⁰ *Re E* (n 9).

⁸¹ *ibid.*

⁸² *ibid.*

⁸³ *Re M (A Child) (A Refusal of Medical Treatment)* [1999] 2 FLR 1097; [1999] 2 FCR 577

⁸⁴ *ibid.*

⁸⁵ *ibid.*

⁸⁶ *ibid.*

⁸⁷ Coggon, J, ‘Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?’ (2007) 15(3) *Health Care Analysis*, 235 at 235.

⁸⁸ *ibid* at 235.

standard of competency for children. This is illustrated when comparing paediatric and adult case law. In *Re R*⁸⁹, a 15-year-old patient who suffered from a mental health condition that, at times, affected her capability to consent, was held unable to refuse drug therapy—a treatment option for her condition.⁹⁰ The judges held that because of the presence of her mental health condition, the medical decisions made during those times could not be relied upon.⁹¹ In contrast is *Re C*,⁹² C was an adult patient also suffering from a mental health condition who wanted to refuse an operation.⁹³ The judge stated:

Although his general capacity is impaired by schizophrenia, it has not been established that he does not sufficiently understand the nature, purpose and effects of the treatment he refuses. Indeed, I am satisfied that he has understood and retained the relevant treatment information, that in his own way he believes it, and that in the same fashion he has arrived at a clear choice.⁹⁴

C appeared to be suffering from some impairment of competency during the decision-making process⁹⁵ unlike the patient in *Re R*⁹⁶. However, C's impairment was not considered to prevent an understanding of the purpose and effects of treatment. Therefore, C was held to have competency and entitled to refuse medical treatment.⁹⁷ On the other hand, the judge in *Re R* stated that R's mental health condition was not impacting her decision-making capabilities,⁹⁸ yet R was held to be

⁸⁹ *Re R* (n 58).

⁹⁰ *ibid.*

⁹¹ *ibid.*

⁹² *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819.

⁹³ *ibid.*

⁹⁴ *Ibid.*, 295

⁹⁵ *ibid.*

⁹⁶ *Re R* (n 58)

⁹⁷ *Re C* (n 92).

⁹⁸ *Re R* (n 58).

incompetent.⁹⁹ This suggests that paediatric patients must achieve a higher standard of competency than their adult counterparts.

Beauchamp and Childress argue that there are seven levels of incapacity, namely: (i) the inability to evidence a preference or a choice; (ii) the inability to understand one's situation or relevantly similar situations, (iii) the inability to understand disclosed information, (iv) the inability to give a reason, (v) the inability to give a rational reason, (vi) the inability to give reasons where risk and benefit have been weighted, and (vii) the inability to reach a reasonable decision, as judged, for example, by a reasonable person's standard.¹⁰⁰ As Freeman argues, "if rights were to hinge on competence at any of the higher levels depicted here, few would have them. But of course, we do not do this".¹⁰¹ Speaking after *the Re R (A Minor) (Wardship: Consent to Treatment)*¹⁰² Bainham argues:

The decision also confirms the suspicion that the acquisition of capacity by children is capable of manipulation by adults. The test propounded by the Court of Appeal is sufficiently exacting that many adults might fail it. We ought perhaps to question whether the law should demand a greater level of appreciation and understanding of the implications of decisions from children than it appears to require of adults who are assumed to have, but not required to demonstrate, emotional or intellectual maturity.¹⁰³

The ambiguous definition of competency leaves mature paediatric patients under the age of 16 in a position where they are only able to make a decisions when the adults around them believe it is in their best interests

⁹⁹ *ibid.*

¹⁰⁰ Beauchamp, T & Childress, J, *Principles of Biomedical Ethics* (7th ed Oxford University Press 2013).

¹⁰¹ Freeman, M 'The Right to be Heard' (1998/9) 22(4) *Adoption and Fostering* at 50-51.

¹⁰² *ibid.*

¹⁰³ Bainham, A, 'The Judge and the Competent Minor' (1992) 108 *LQR*, 194 at 200.

or where they can prove that they have met the high standard of competency to make such decisions.

Daly has proposed the removal of competency testing, and suggested an approach that refers only to the likelihood of causing significant harm.¹⁰⁴

Daly heavily criticised the UNCRC, due to the lack of definition for according due weight to children's views.¹⁰⁵ Daly's criticism is applicable to *Gillick*-competency, where there are no definitions within case law or legislation to define or measure whether a child has sufficient maturity and intelligence. As such, Daly proposes an alternative model, in order to give children a voice and ensure that they are heard, and that the true and noble intentions of Article 12 of the UNCRC are invoked.¹⁰⁶

Although competency is often the gateway to autonomy, Daly argues that everyone should have autonomy regardless of competency.¹⁰⁷ Daly states:

autonomy is taken here to refer to the liberal ideal that we should all have personal freedom in our lives to the extent possible, not that we can always get what we want, nor that we should only get it if we meet some standard or measure of competence.¹⁰⁸

Even if a child does not want to be involved, Daly believes that it is the role of the judge to ensure autonomy is respected. Daly campaigns for his "children's autonomy principle" to be adopted.¹⁰⁹ According to this principle, regardless of competency in legal decisions in which the best interest of the child is the primary consideration, children should get to choose, if they wish, how they are involved (process autonomy) and the

¹⁰⁴ Daly, 'No Weight for "Due Weight"? A Children's Autonomy Principle In Best Interest Proceedings' (n 6).

¹⁰⁵ *ibid* at 70.

¹⁰⁶ Daly, *Children, Autonomy and the Courts: Beyond the Right to be Heard* (n 6) at Chapter 2.

¹⁰⁷ *ibid* at 21-22.

¹⁰⁸ *ibid*.

¹⁰⁹ *ibid* at Chapter 2.

outcome (outcome autonomy), unless it is likely that significant harm will arise from their wishes.¹¹⁰ They should have “autonomy support” to ensure that, with greater influence in proceedings, they simultaneously have additional assistance to negotiate and understand proceedings and options.¹¹¹

However, in medical law, significant harm may be interpreted widely. For example, if a child refuses a blood test, it is easy and logical for a health care professional to argue that in refusing a blood test they are unable to test for suspected diseases and as such, the child may go on to suffer significant harm. In order to prevent significant harm, the child’s decision can be overridden and they would have to have the blood test. Therefore, Daly’s ‘children’s autonomy principle’, whilst noble in attempting to accord greater authority to children’s decisions and wishes, in the context of medical law may have no more success protecting a child from having their refusal of medical treatment overridden, than the current best interest or competency based tests. For example, *Gillick*-competent children, inherent jurisdiction used to override their refusal of treatment where this is likely to cause serious harm or death because of the risk of serious harm rather than on the grounds of their lack of capacity. This theory only switches the grounds for refusal, rather than, suggesting a workable/practical definition of competency that can be used in clinical practice.

In seeking clarity for *Gillick* competency, Cave called for a test case to be brought before the court.

Cave argued that if a case on refusals of medical treatment were brought before the court then one of three options would occur.¹¹² First, the court may argue that the child is not competent thus, avoiding the need to clarify whether a competent child’s refusal can be overruled. Second, the court

¹¹⁰ *ibid* at 69.

¹¹¹ *ibid* at 418 and 432.

¹¹² Emma, C & Stavrinides, Z, ‘Medical Practitioners, Adolescents and Informed Consent project’ (2013) Final report University of Leeds.

may challenge judicial statements predominantly in the case of *Re R*¹¹³ and *Re W*¹¹⁴ stating that the court and parents cannot overrule a child's competent refusal of medical treatment. Finally, the court may provide advice on how to assess competency for lawyers, health care professionals and families. However, in *University Hospitals Plymouth NHS Trust*,¹¹⁵ none of these occurred. Instead, the judgment complied with *Re R* and *Re W* and overruled a competent child's refusal of medical treatment. In doing so, the rights of the child were limited and the relevance of *Gillick* competency as a legal rule designed to respect the autonomy of the child is undermined.

3.4. Previous Academic Research

The extent of children's participation in health care decisions has been questioned as a result of the language used in Article 12 UNCRC, the Children Act and *Gillick* competency, all of which place adults as the gatekeepers to meaningful participation. Moreover, the definitions of competency and due weight are ambiguous, and case law has led to an unusually high standard of competency demanded of children that is not seen in adult law. In part, this is because of the understandable desire to protect children who are associated with characteristics discussed in the discourse of childhood. Whilst case law is important and has a wide-reaching impact, the law only refers to refusals of therapeutic medical treatment which is a small part of children's participation in their health care. Thus, it is necessary to investigate how children participate every day in clinical practice. After all, it is the everyday interactions that provide children with the skills to make more advanced decisions, such as, a refusal of therapeutic medical treatment.

¹¹³ *Re R* (n 58).

¹¹⁴ *Re W* (n 59)

¹¹⁵ *University Hospitals Plymouth Trust v B* (n 72).

There is limited research evaluating whether such policy and law is successful from the perspective of patients.¹¹⁶ Some of the literature investigating the experiences of children in medical practice has been primarily focused on another research objective. Nevertheless, their insights provide evidence to suggest that children experience low levels of participation, of a type that Hart and Arnstein would describe as non-participation: manipulation, decoration and tokenism.¹¹⁷ Moreover, much of this research is outdated.

Alderson's 1993 research "Children's Consent to Surgery"¹¹⁸, sought to investigate whether children are capable of making decisions about their health care, including consenting to surgery. She interviewed 120 children, health care professionals and parents on an orthopaedic ward.¹¹⁹ She found that children as young as eight can be capable of making decisions about their health care.¹²⁰ An analysis of Alderson's data found examples of participation in health care including being informed and shared/collaborative decision making. Moreover, it is noteworthy that doctors felt that they had adequately included children in the decision-making process and children reported being satisfied with their participation.¹²¹ Alderson called for further empirical research to further examine the extent of children's participation and whether it was meaningful. As the extent of participation was not the centre of Alderson's project, and this project was concluded in 1993, further research must be conducted to assess whether children currently participate in health care decisions, given the significant policy and legal changes in recent years.

¹¹⁶ Sinclair, R, 'Participation in Practice: Making it meaningful, effective and sustainable' (2004) 18 *Children and Society*, 106 at 112.

¹¹⁷ *Ibid.*

¹¹⁸ Alderson, P, *Children's Consent to Surgery* (Open University Press 1993).

¹¹⁹ *Ibid.*

¹²⁰ *Ibid.*

¹²¹ *Ibid.*

In 2008, Coyne conducted a review of the academic literature examining the application of collaborative decision-making in Irish hospitals. Coyne argued that children's participation in their health care is limited and their views "rarely sought nor acknowledged".¹²² Despite this, there was a lack of empirical data supporting such findings, most of which were speculative, originating from an in-depth analysis of legislation and case law. Like Alderson, Coyne states that there is a "need for further research to explore health professionals' and parents' perspectives on children's participation in consultations and decision-making"¹²³ arguing that such information can lead to a development of guidelines assisting health care professionals "in facilitating and supporting children's participation".¹²⁴

In 2010 to 2013, the 'Medical Practitioners, Adolescents and Informed Consent project'¹²⁵ conducted focus groups with health care professionals seeking to ascertain whether the *Gillick* competent child's refusal of medical treatment is lawful and should be respected. During the focus groups they found that doctors struggle with the ambiguity of the law and supporting guidance from the GMC and BMA. As such, it is likely that children's participatory rights will be impacted. They call for more research to investigate this further.

More recently, in 2018, a further literature review was conducted. This review investigated when and how children should participate in their health care concluding that the "inclusion of children in medical decision making, to the extent of their ability and interest in doing so, should be the

¹²² Coyne, I 'Children's participation in consultations and decision-making at health service level: A review of the literature' (2008) 45(11) *International Journal of Nursing Studies*, 1682 at 1683.

¹²³ *ibid* at abstract.

¹²⁴ *ibid*

¹²⁵ Emma, C & Stavrinides, Z, 'Medical Practitioners, Adolescents and Informed Consent project' (2013) Final report University of Leeds.

default position, ensuring that children are routinely given a voice”.¹²⁶

Whilst academics agree with this default position, the presence of this position in clinical practice has not been tested by analysing whether children are meaningfully participating in their health care.

Research conducted by Cumbria University in 2018 investigated the participation of boys with Duchenne Muscular Dystrophy (DMD) when deciding whether to enrol on a clinical trial. They found that boys with DMD had low levels of participation in health care, due to the association between vulnerability, severe disability and presumed incompetency¹²⁷. The project implies that children without disabilities can participate in health care decisions, because of an absence of vulnerability. However, there is a lack of empirical evidence to examine whether or not children without a disability participate in their health care. Furthermore, the project’s conclusions are context specific; focusing solely on one condition, DMD, one gender, boys and one specific context, children undergoing clinical trials, thus, not considering a variety of medical conditions and less severe procedures such as blood tests, scans and routine medical treatment outside of a clinical trial.¹²⁸

Sinclair argues that law and policy value children’s participation in all matters affecting them, however, there is a significant lack of research evaluating whether such policy and law is successful from the perspectives of patients.¹²⁹ As such, it is unknown whether children participate in their health care and whether this participation is meaningful. Whilst it is suggested that children do not meaningfully participate in their health

¹²⁶ Olszewski, E.A. and Goldkind, F.S, ‘The Default Position: Optimizing Pediatric Participation in Medical Decision Making’ (2018) 18(3) *The American Journal of Bioethics* 4, at 8.

¹²⁷ Skyrme, S.L & Woods, S ‘Researching disabled children and young people’s views on decision-making: working reflexively to rethink vulnerability (2018) 25(3) *Childhood*, 355.

¹²⁸ *ibid.*

¹²⁹ Sinclair (n 116) at 112.

care, there is a lack of knowledge investigating *why*. What are the barriers impacting the extent to which children participate in clinical practice? Have the experiences of children evolved in accordance with the law, or remained the same? Finally, what is the impact of a lack of meaningful participation on children? This thesis seeks to answer these questions.

3.5. Conclusion

Chapter 2 claimed that international and national law accorded children the right to participate. Chapter 3 critically analysed the law suggesting that the law is a barrier to children's participation. Findings from this literature review indicate that children may not participate in their health care. However, there is limited academic research providing sufficient empirical data to provide a comprehensive understanding of how children participate in clinical practice and why children may not meaningfully participate in their health care. This thesis seeks to address these questions.

Academic debate and case law exclusively focus on refusals of life-saving therapeutic medical treatment. However, this thesis is interested in all forms of participation including everyday participatory activities. This is because, children's participation in every-day activities is more common and more relevant to the experience of most patients.

4. METHODOLOGY AND METHOD

4.1. Introduction

To provide a comprehensive understanding of children's participation in their health care it was necessary to conduct an empirical research study with patients and health care professionals. This thesis seeks to address one main research question and five secondary research questions.

Main Research Question:

- (i) Is law and practice successful in enabling and facilitating children's participation in all aspects of their health care?

Secondary Research Questions:

- (i) How do children participate in their health care?
- (ii) Does an examination of the participants' 'lived experiences' reveal that the participants in this study *meaningfully* participated in their health care as children?
- (iii) Does an examination of participants' 'lived experiences' expose any barriers or enabling factors to meaningful participation?
- (iv) What is the long- and short-term impact of the participation on the participants in this study?
- (v) Have the 'lived experiences' of children evolved in accordance with the introduction of law valuing participation in clinical practice?

This chapter details my research methodology and seeks to justify the decisions that I made during the process of planning and carrying out this empirical study. This chapter is composed of six sections. Section 4.2 introduces and justifies the selection of Interpretative Phenomenological Analysis (IPA) as the methodology underpinning this project. In section 4.3 I discuss the methods used in this empirical study and justify the decisions that I made. I then reflect in section 4.4, on my position as a legal researcher and person with a visible disability and consider how these characteristics may have impacted or influenced the research process. In

section 4.5 I identify the ethical considerations that were raised during this study and detail how I responded to these ethical considerations. Section 4.6 confirms that this project received full NHS ethical approval. Finally, section 4.7 acknowledges the limitations of this data.

4.2. Interpretative Phenomenological Analysis

To address the research questions and provide a comprehensive understanding of how law and practice impacts children's participation in their health care, it was necessary to investigate the 'lived experiences' of patients who have been directly affected by such laws and practices. Exploring the 'lived experiences' of patients is valuable because the impacts of law and practice on a patient's participation in their health care can often be complex, multifactorial and wide-reaching, all of which needs to be captured to adequately understand the phenomenon being studied.¹

Interpretative Phenomenological Analysis (IPA) is a qualitative methodology that seeks to explore detailed accounts of a person's 'lived experiences'.² IPA seeks to use 'lived experiences' (instead of theory) as a lens through which to examine a phenomenon.³ IPA is composed of three constructs: (i) phenomenology, (ii) hermeneutics and (iii) ideography.⁴ Phenomenology is the process of removing the preconceptions and biases that we all carry, to expose the "taken for granted"⁵ and the "essence of

¹ Eatough, V & Smith, J.A, 'Interpretative Phenomenological Analysis' in Williy, C and Stainton Rogers, W, *The SAGE Handbook of Qualitative Research in Psychology* (SAGE 2017) at 193.

² Blandford, A, Makri, S & Furniss, D, *Qualitative HCI Research: Going Behind the Scenes* (Morgan and Claypool 2016); Creswell, J.W, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (SAGE 2014).

³ *ibid.*

⁴ Smith, J.A, 'Interpretative Phenomenological Analysis: Getting at Lived Experience' (2017) 12(3) *The Journal of Positive Psychology* 303-304

⁵ Harper, D & Thompson, A.R, 'Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners' in Larkin, M & Thompson, A.R

the phenomenon whilst transcending the contextual and personal”.⁶ IPA documents a person’s narration of their ‘lived experiences’ as *they* saw it, and how *they* experienced it. IPA has a “commitment to understanding phenomena of interest from a first person’s perspective and its belief in the value of subjective knowledge for psychological understanding”.⁷ Hermeneutics means “to interpret” or “to make meaningful”.⁸ The role of the researcher is “to make sense of the participants trying to make sense of their world”.⁹ This requires the researcher to explore the participants’ experience *and* the meaning the participant attributes to that experience. The meaning a person attributes to an experience and how they interpret that meaning “tells us something about the individual and their individual intentions”.¹⁰

The ideography element of IPA requires the researcher to evaluate the ‘lived experiences’ of the participants on a case-by-case basis. IPA encourages close reading of the data, most often in the form of a verbatim transcript, pulling out codes before examining the data set as a whole. The detailed examination of single transcript allows researchers to record unique and individual perceptions of the phenomena being studied. Within such transcripts researchers can identify vital data, “a singular remark which jumps out at the researcher or a small extract from an entire interview that the researcher is drawn to and has a hunch might be key to understanding ‘a person’s grasp of their world’”.¹¹ This data unlocks the

Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research (Wiley-Blackwell 2012) ch 8.

⁶ Eatough & Smith (n 1).

⁷ *ibid* at 193.

⁸ *ibid* at 196.

⁹ *ibid* 193; Harper & Thompson (n 5); Smith, J.A, Flowers, P & Larkin, M, *Interpretative Phenomenological Analysis*. (London: Sage, 2009) at 46.

¹⁰ Eatough & Smith (n 1) at 194.

¹¹ Ashworth, P ‘Conceptual Foundations of Qualitative Psychology’ in Smith, J.A (ed) *Qualitative Psychology: A Practical Guide to Research Methods* (SAGE 2008) at 4-5.

participants' experience for the researcher to understand, "offering a way of seeing that illuminates and affirms 'the centrality of certain general themes in the lives of all particular individuals'".¹² It is a transformative process where the participant's experience illuminates a way of viewing a phenomenon. The researcher is moving from a specific experience to a universal experience. The value within the specific is that it enables shared human experiences to be understood. Identifying the universal concepts allows generalisations to be drawn, which in turn justify policy or legal reforms. IPA begins with the "particular and ensures that all generalisations are grounded in this".¹³

Research that has successfully used IPA gives a voice to the participant which elicits rich and detailed first-person accounts of experiences and the phenomena under investigation.¹⁴ The research captures the meaning that participants give to their experience, in turn, explaining universally shared experiences. When using IPA, it is expected that the research study has a small sample size to enable a researcher to obtain quality data and explore the participants' 'lived experiences' in depth.¹⁵

4.3. Semi-Structured Interviews

Semi-structured interviews are the sole data source for this qualitative research project. Unlike structured interviews, where the researcher rigidly follows an interview schedule having decided in advance the direction and topics of the interview and asking short and specific questions designed to elicit specific answers, semi-structured interviews are constructed with broad open questions which are led by the participants narratives and

¹² Evans, M 'Reading Lives: How the Personal Might Be Social' (1993) 27 *Sociology* 8.

¹³ Eatough & Smith (n 1) at 200.

¹⁴ Pietkiewicz, I & Smith, J.A, 'A Practical Guide to Using Interpretative Phenomenological Analysis in Qualitative Research Psychology' (2012) *Czasopismo Psychologiczne—Psychological Journal*, 20 at 15.

¹⁵ *Ibid.*

responds to them.¹⁶ In designing the interview schedule, I created a pre-determined general structure outlining which topics must be covered during the interview.¹⁷ The basic research question was “sufficiently focused so that a relatively homogenous group will have shared experiences about the topic”.¹⁸ This question was supplemented by a number of more specific follow up questions that were used to engage more deeply with an issue.

The substantial detail of the interviews were decided on during the interview, by the participant. This is important because “in this relationship, the respondents can be perceived as the experiential expert on the subject and should therefore be allowed maximum opportunity to tell their own story.”¹⁹ It is the role of a researcher to take a neutral and facilitative role that provides participants with an opportunity to tell their narrative.²⁰ Thus, I was prepared to depart from the interview guide to follow the interviewee’s interests.²¹

The first question was intentionally broad and open-ended (see Appendix 14 and 15 for the interview schedules). For past-paediatric patients, I began by asking “in as much detail as you feel comfortable, can you explain what medical treatment you had as a child?” This question was designed to “reflect the nature of the research and be non-threatening”²² so to put the

¹⁶ Drever, E, *Using Semi-Structured Interviews in Small-Scale Research: A Teacher’s Guide* (SCRE 2003) at 10-16.

¹⁷ Ibid.

¹⁸ Eatough & Smith (n 1) at 201.

¹⁹ Smith, J.M & Osborne, M, ‘Interpretative Phenomenological Analysis’ in Smith, J.A, (ed) *Qualitative Psychology: A Practical Guide to Research Methods* (2nd edn, Sage 2007) at 59.

²⁰ Harper & Thompson (n 5) at 104.

²¹ DiCicco-Bloom, B & Crabtree, B.F, ‘The Qualitative Research interview’ (2006) 40(4) *Medical Education*, 314 at 315.

²² Ibid at 316.

participant at ease. This was crucial in assisting the development of a rapport which is an essential component of the interview process.²³

The following questions were tailored in response to the participants' answers and often took the form of probes and prompts such as, "how did you feel about that?" to elicit further clarification without leading the participant.²⁴ My role was to probe how they felt about their experiences and the meaning they attributed to their experiences. As the interview went on, the participants became more relaxed and comfortable in the research environment which then made it possible to discuss topics that were too sensitive to broach at the beginning of the interview.²⁵

To ensure the data could be transcribed into a verbatim transcript for a close examination,²⁶ all the interviews were audio recorded and subsequently transcribed. I chose to transcribe the data myself and not rely on transcription software to increase the likelihood that the transcriptions were accurate. This was also beneficial in enabling me to become familiar with the data. As recommended by McGrath et.al all transcripts were double checked before I carried out my analysis.²⁷

Participants could choose between a face-to-face interview in an accessible room at the University of Warwick or a skype/facetime interview. The latter was particularly beneficial for the participants with disabilities and health conditions who were more comfortable in their own home.

Each interview lasted between one to three hours including the discussions prior to and after the recorded interview.

²³ Ibid.

²⁴ Ibid at 315.

²⁵ Ibid at 310-217.

²⁶ Drever (n 16) at 10-16.

²⁷ McGrath, C, Palmgern, P.J & Lilijedahl, M, 'Twelve tips for conducting qualitative research interviews' (2019) 41(9), 1002 at 1002.

4.3.1. Selection of Potential Participants

This study interviewed adults who, as children, underwent therapeutic medical treatment in England or Wales. I chose to interview past-paediatric patients instead of children currently receiving therapeutic medical treatment for two reasons. First, interviewing past-paediatric patients was the most effective way to answer the research questions that focus not only on the 'lived experiences' of these patients but considers the short- and long-term impact of their participation in their health care, and seeks to determine whether the 'lived experience' of paediatric patients has changed in accordance with the participatory rights accorded children over the last 50 years.

Second, selecting past-paediatric patients rather than children as potential participants upholds the ethical principle that we must only interview children if the data cannot be obtained in another manner. The "UCL Research Ethics Committee Guidance Note for Research with Children" states that research with children should only occur if "the participation of children is indispensable because information available from research on other individuals cannot answer the question posed in relation to children."²⁸ Furthermore, Warwick University's ethical and research duty requires researchers to use appropriate methods and only work with vulnerable groups when this is the appropriate method for collecting data.²⁹

The past-paediatric patients were split into three groups, (i) aged 18-25, (ii) aged 26-35 and (iii) aged 36 and above. Group one was composed of young adults who have recently left paediatric health care and are currently still transitioning to adult services. The NHS considers patients up to the age of

²⁸ UCL, 'UCL Research Ethics Committee Guidance Note 1: Research Involving Children' <<https://ethics.grad.ucl.ac.uk/forms/guidance1.pdf>> access 8 April 2019 at section 1.1.

²⁹ University of Warwick, 'The concordat to support research Integrity' (March 2019) <<https://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2019/revised-concordat-draft.pdf>> accessed 8 April 2019) at 10.

25 as 'in transition from child to adult services'. As such, the participants in group one (alongside the health care professionals) provide a perspective that has been confirmed by health care professionals to represent how paediatric health care is today.³⁰

To be eligible to participate in this, the past-paediatric patients had to be aged 18 or over, capable of consenting to their participation in a research project and had received therapeutic medical treatment as a child in England or Wales. As discussed in Chapter 1, section 1.4, therapeutic medical treatment is defined in its broadest sense, as an interaction with the health care profession that resulted in interventions such as (amongst others) physiotherapy, occupational therapy, mental health treatment, surgery, blood tests, scans and investigations. The treatment must have been for a medical need rather than for a non-therapeutic reason such as cosmetic treatment. This definition was provided in all participant-facing documentation. As the law underpinning this thesis is English and Welsh law, and this thesis was not conducting a comparative analysis between jurisdictions, it was necessary that the participants had received medical treatment in either England or Wales as a child.

I sought to "maximise the potential richness of the data through maximum variation sampling"³¹ regarding age, geographical location, type of medical condition and gender. Unlike previous empirical research, this project did not restrict the selection of participants to people with specific or complex medical conditions.³² This is because this project seeks to carry out a holistic examination of children's participation in their health care. To focus

³⁰ The narratives of past-paediatric patients were collaborated by health care professionals currently working in the NHS. Thus, their narratives are representative of how paediatric health care operates today.

³¹ DiCicco-Bloom & Crabtree (n 21) at 317.

³² Skyrme, S.L, & Woods, S, 'Researching disabled children and young people's views on decision-making: working reflexively to rethink vulnerability' (2018) 25(3) *Childhood*, 355 at 355-368.

solely on participants with complex or specific medical conditions would neglect to investigate whether children's participatory rights are being respected in all aspects of health care including the treatment of minor medical complaints. As children have the right to participate, regardless of the severity of the medical intervention, all health care experiences are valid and need to be considered.

As the research question seeks to investigate the long- and short-term impact of past-paediatric patient experiences, and whether the experience of paediatric patients has changed in accordance with the development of children's participatory rights, I did not target a specific age range.

I sought to recruit as many potential participants as possible. Originally, I had planned to work closely with local charities and hospitals. However, I felt that this would only reach patients who are currently undergoing medical treatment thus, neglecting adults who may have had treatment as a child and recovered, thus, no longer requiring the support of local charities and hospitals. Therefore, to reach as many potential participants as possible, I chose to recruit at the University of Warwick, an organisation that has 27,278 students and 6,947 staff.³³ Moreover, in recruiting at Warwick University, the needs of the participants were better met. Many of the participants had an ongoing health condition and/or disability which restricted their travel. As the participants lived and worked in and around the University, all the participants felt comfortable in the interview environment.³⁴ Although the past-paediatric patients were recruited at the University of Warwick, 17 did not receive medical treatment in or around Coventry as a child. Rather, they received their paediatric medical care in 16 different hospitals around England and Wales.

In addition to recruiting past-paediatric patients, I chose to recruit health care professionals. This was because health care professionals provide an

³³ University of Warwick, 'People', <<https://warwick.ac.uk/about/profile/people/>> accessed 1st Jan 2019

³⁴ See Chapter 4, Section 4.3.6. for a discussion on the limitations of the project.

alternative perspective that was necessary to document to provide a holistic appreciation for what happens in clinical practice. During the interviews, the past-paediatric patients shared similar factual experiences to those of the health care professionals. Therefore, the health care professionals validated the reliability, accuracy and relevancy of the data gathered from past-paediatric patients.

Health care professionals were eligible to participate in this study where they were aged 18 or over, capable of providing consent to participate in this study and who had worked with children in their role as a health care professional for at least one year in England or Wales. It was necessary that the health care professionals involved in the study had at least one year's experience to ensure that their narratives presented an accurate representation of paediatric medicine. This accuracy may not be gained during a one-off work experience placement commonly conducted during medical rotations, as rotations may not provide enough exposure to accurately state what happens in clinical practice and how this impacts health care professionals, the child and their family and friends.

4.3.2. Recruitment of Potential Participants

Recruitment is an essential part of the research study and can impact the data that is obtained.³⁵ Although I sought to recruit individuals with a particular characteristic - those who had been paediatric patients - it was not possible to identify a specific organisation or institution that was solely for adults who had had medical treatment as children. Thus, to recruit participants who had been a paediatric patient I needed to distribute my recruitment material to as many people as possible. I used numerous advertising platforms to reach as many potential participants as possible.

³⁵ Kristensen, G.K & Ravn, M.N, 'The voices heard and the voices silenced: recruitment processes in qualitative interview studies' (2015) 15(6) *Qualitative Research*, 722 at 726.

To recruit past-paediatric patients I used the Warwick Insite page as a main source of recruitment. Warwick Insite is a hub for staff and students which advertises ongoing research projects at the University to recruit potential participants. In addition, I approached academic departments, the Students Union and Warwick Library to ask if they would be able to distribute my recruitment material to those who had signed up to their newsletters. I also contacted Warwick Enable, and Warwick Wellbeing and Support Services who provide support to staff and students with disabilities and medical conditions. I did this to increase the likelihood of my recruitment material reaching people who may have had medical treatment as a child. Where a department or society agreed to distribute my recruitment material, my participant-facing documentation was added to newsletters and distributed to all staff and students on the departments or societies' mailing list via email. In line with GDPR, all potential participants who received the recruitment material had consented to receiving such emails and were able to unsubscribe at any point.

Finally, some participants were recruited as a result of contact with me or my supervisors. Whilst meeting people across the university in my roles as Postgraduate tutor at Warwick Medical School and Warwick Law School, students and staff would often approach me about my research and their interest in participating.

If a potential participant was interested in being interviewed for this study, they would have to self-select by contacting me to register their interest. I would then check that the participants met the eligibility criteria and had read all the participant-facing documentation before arranging an interview.

There were two recruitment rounds for past-paediatric patients, the first in June 2018, which attracted 13 potential participants, and the second in September 2018 which attracted seven potential participants. Of the 13 potential participants in the first-round, two withdrew due to health reasons. All participants in the second recruitment phase progressed to the

interview stage. The recruitment of participants ended once no more participants came forward.³⁶ Overall, there were 18 participants.

To recruit health care professionals, I created another research page on Warwick Insite and distributed the recruitment material via newsletters to the Psychology Department, Warwick Medical School and their sub departments such as, General Practice, Child Health Care and Adolescent Mental Health. Health care professionals were also recruited via local hospitals through the Director of Research. All participants were contacted by email and newsletters. They had consented to this contact and were able to unsubscribe at any point. As with past-paediatric patients, the health care professionals had to self-select to participate in this study.

There were two recruitment rounds for health care professionals. The first in September 2018, recruiting two potential participants, and the second in January 2019, recruiting three further potential participants. Of those recruited, one withdrew due to career commitments. Overall there were four participants. The recruitment of healthcare professionals was a challenging aspect of this empirical study. Due to limited time and work commitments, health care professionals were unwilling to self-select for an interview. This was further compounded by the nature of paediatrics which is a highly specialised area of medicine with fewer staff numbers than in other more popular areas of medicine. Moreover, to interview health care professionals at a local hospital required a member of staff at the host hospital to act as a Principal Investigator. Whilst full ethical approval had been obtained, the hospital's Research and Development teams were unable to recruit a Principal Investigator due to the degree of resources required to conduct such research. As such, the health care professionals who self-selected were members of the University of Warwick.

³⁶ Kumar, R, *Research Methodology: A Step-By-Step Guide for Beginners* (SAGE, 2014) at chapter 12.

4.3.3. Representation and Limitations of the Research Data

Whilst Oppenheim stated that “exact representativeness is not usually necessary”,³⁷ it is noteworthy at this point to consider the representation of this data and acknowledge that it is not representative. I acknowledge that because the interviews were conducted with participants who had self-selected by expressing an interest in being interviewed, that sample justification issues arise.

It is an undisputed fact that the persons whose lives, experiences and meaning-making processes researchers are able to study in interview-based projects are those who respond positively to requests for interviews; the rest remain unknown.³⁸

The past-paediatric patients who came forward did so in part, because they had either a positive or negative experience as a paediatric patient and wished to share their narrative. Half the participants expressed a positive overall health care experience as a child, and the other half expressed a negative overall health care experience. Initially I assumed that the participants would represent both extremes and not the middle ground. Consequently, it would have been likely that these participants would have an overwhelming positive or negative health care experience as a child. However, on probing what the participant meant about a negative and positive health care experience it became clear that they were talking about their relationships with health care professionals, how welcome and comfortable they felt in their company and whether their medical treatment was successful. The participants were not measuring their overall experience by how they participated in their health care. Moreover, when asked why they self-selected to be interviewed, they explained that they wanted their narrative to be heard because they felt that the spotlight is rarely on paediatric patients. Therefore, whilst I do not propose that this

³⁷ Oppenheim, A.N., *Questionnaire Design, Interviewing and Attitude Measurement* (2nd edn, Pinter Publishers, London 1992), 42-44 at 68.

³⁸ Kristensen & Ravn (n 35) at 726.

data is representative, the fact that the participants self-selected due to a desire to share their narrative, suggests that the participants who self-selected to be interviewed were not motivated by an overwhelming positive or negative experience of participating in their health care.

The health care professionals who came forward did so because of their passion for paediatric medicine and improving the experience of paediatric patients. Therefore, the health care professionals who self-selected were unlikely to represent the majority opinion. Thus, the health care professionals interviewed were most likely representing the best-case scenario of how health care professionals encourage and facilitate children's participation in clinical practice.

Moreover, I acknowledge that because the recruitment method was only received by persons at the University of Warwick, the data is likely to be limited in terms of its geographical demographic. However, due to the wide geographical demographic of staff and students who work and study at the University of Warwick, the geographical demographic is not as limited as it initially appears.

As this study is only focused on the lived experiences of the participants in this study. The findings of this study are not generalizable, however, due to the infancy of the area on child participation, these findings are of significance.

A further limitation is the presence of research variables that are likely to impact how children participate in clinical practice and whether it is meaningful. For example, acute versus chronic health conditions, treatment by a specialist or a non-specialist doctor, receiving treatment through private health care or the NHS. I made a choice not to explore the impact of these variables in this study. Instead I sought to capture a holistic appreciation of children's participation in their health care. However, I acknowledge that these variables are likely to have influenced the

qualitative data. The following chapters should be understood in terms of these caveats in the representation of this data.

4.3.6. Data Analysis

I used guidelines by Larkin and Thompson³⁹ and Johnny Saldana⁴⁰ as a tool to analysing transcripts. For each transcription I began with 'free coding', writing initial ideas, thoughts and opinions over the transcript. I would then set aside this transcript and proceed with a clean copy. Here I would carefully examine the transcript line by line. I would identify objects of concern such as events, relationships, feelings and values that mattered to the participant. From this I would begin to thicken out the interpretation to create a code and analysis. I recorded this in a table which included the code, the section of transcript the code referred to, the object of interest, and my interpretation of the data and code. At the end of the transcription I would identify emerging codes and exceptions, collecting them to create broader themes. Time must be given to each case study before moving on to notice the patterns and commonalities among the participants' narratives. After a close analysis of each transcript, I drew comparisons between the transcripts, linking and cross-examining the transcripts to create general themes. To validate the codes and subsequent themes, I spoke to supervisors, peers, and repeated my analysis.

4.4. My Position as a Researcher

It is widely established in academic literature that it is of importance for the researcher to reflect on their background, status and perspective:

A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered

³⁹ Larkin, M & Thompson, A.R, 'Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research' in Harper, D & Thompson, A.R, *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (Wiley-Blackwell 2012) at 104-115.

⁴⁰ Saldana, J, *The Coding Manual for Qualitative Researchers* (SAGE 2016) at 67-291.

most appropriate, and the framing and communication of conclusions.⁴¹

Such factors may create bias and a lack of objectivity. Phenomenology acknowledges that researchers are subject to bias and personal characteristics that must be brought to the forefront and examined. Malterud argues, “preconceptions are not the same as bias, unless the researcher fails to mention them.”⁴²

Throughout this study I was aware of my own position as a white female researcher in my early-to-mid-twenties. I identify as having a disability, born with a progressive medical condition, I have been a patient since birth, and received a variety of medical interventions including physiotherapy, occupational therapy, surgery, infusions, invasive medical procedures and investigations requiring frequent hospital admissions. This has accorded me an insight into how the law of consent is applied in daily practice, the complexities of applying the law in a pressured, challenging and ever-changing health care profession, an awareness of the pressures faced by the NHS, and the impact of this on patients, professionals and the quality of care. I was also aware that every participant has an individual story, and as such, I was keen to document the participant’s background and context, as this is crucial to unpicking and understanding the meaning participants gave to their experiences.

However, being a wheelchair user means my health condition is visible, and therefore I was conscious that participants may deduce that I had received medical treatment as a child and that this may influence the narratives of the past-paediatric patients. Participants often asked about the motivation behind the project, and due to the visibility of my health condition, were intrigued to hear my story. However, where a participant asked, I chose

⁴¹ Malterud, K, ‘Qualitative Research: Standards, Challenges and Guidelines’ (2001) 358 *The Lancet: Qualitative Research Series* at 483-488.

⁴² *ibid.*

not to disclose any information until their interviews were completed. Having documented and listened to their stories, it was appropriate to reciprocate this when asked. Throughout the interview, I was conscious to avoid any verbal or non-verbal gestures that may imply approval or otherwise at the participants' account. I wrote notes on *all* the participants' narrative, to avoid implying favouring some parts over others.

The interview process was challenging, as many participants' experiences were distressing for them. It was necessary to protect the participants, repeating that the interview could be stopped whenever they wished. However, it was these moments that the participants were most keen for me to record. This was the reality of their experience, and the impact on their physical and mental health. Their experiences were reminiscent of some of my own, and I found some interviews challenging. As Lincoln and Guba suggested, I kept a journal where I was able to reflect on each interview, the journal being a private place to document my feelings and thoughts. I wrote a second journal which recorded the context, non-verbal discourse, methodological decisions and reasoning⁴³.

It is well acknowledged that the power balance is often in favour of the interviewer: the person with the questions who appears to be controlling the interaction.⁴⁴ For participants who have had treatment as a child, this power dynamic may be reminiscent of welfare assessments and doctor patient relationships. I sought to avoid this by being guided by the participants' answers, allowing them to control the direction of the study, a core feature of IPA.⁴⁵ To encourage this, my interview structure was fluid and responsive to their experiences, rather than directed by a list of closed questions. I found that my own disability meant that the participants viewed me as a peer or 'insider', rather than an outsider researching a

⁴³ Lincoln, Y.S. & Guba, E.G, *Naturalistic Inquiry* (SAGE 1985).

⁴⁴ Oliver, M, 'Emancipatory Research: Realistic Goal or Impossible Dream?' in Barnes, C, Mercer, G (eds), *Doing Disability Research* (Disability Press 1997) at 14-31 Chapter 2.

⁴⁵ *ibid.*

community of which I was not a member. The assumption that I was an insider contributed to participants feeling comfortable to share their stories in an environment that they described as 'non-judgmental'. This improved the richness, volume and credibility of the data.

In my detailed field notes, I documented participants stating that they felt 'able' and 'comfortable' to share their experiences with me. All the participants referred to 'us', using language such as 'as you know', and 'I'm sure you felt the same', suggesting that they believed us to have a shared experience. About half of the participants stated at the beginning of the interview that they felt as though their experience would not be valid due to the lack of severity of their condition. However, on meeting me, and assuming that I too had gone through a health care experience, they felt that I would appreciate the hidden challenges within a 'minor' procedure, and give them a voice within the research. Many participants expressed relief that they could speak to someone who 'understands', stating it was their first opportunity to be 'heard'.

Whilst being an 'insider' is beneficial on a number of counts, it can also lead to the researcher failing to notice points of importance in analysing the data because they may take this for granted.⁴⁶ To combat this, I analysed the transcripts on numerous occasions, and spoke to colleagues to see if they saw something I had failed to notice due to my position within the research.⁴⁷

The effects of my condition meant that it was at times challenging to conduct the field work, due to the physical effort required. Sitting for long periods of time increases my pain and can affect my concentration. Traveling to meet participants was a challenge, and I had to balance my work around regular hospital admissions, delaying the writing process and

⁴⁶ Saidin, K & Yaacob, A, 'Insider Researchers: Challenges and Opportunities' (2016) 1 ICECRS, 849 at 849-954; West, C & others, 'Accidental Insider: Living the PhD Study' (2013) 20 *Collegian*, 61 at 61-65.

⁴⁷ *ibid.*

making it difficult to complete interviews in a set time frame. It was therefore vital to record the interviews and where necessary arrange a second interview. Whilst second interviews were for participants who required a break or wished to provide more information, participants were also willing to have a second interview if I had missed something, or where there were gaps in their narratives.

I was also aware that my academic background—which is exclusively in law—may be a barrier to acceptance by the medical professionals I sought to interview. I completed my LLB in 2016 and began this PhD two months later. I have taught in the Law School over the past two years and have sought to extend my academic knowledge by teaching in the Medical School.

During the IRAS ethical approval process, the reviewers asked, “If you notice anything during your research that is potentially unlawful how would you respond?” I explained that my role is one of a researcher; I am not there as a lawyer. However, if I was concerned about anything, this would be fed back to my academic supervisors. The panel were concerned that my legal background meant that I would be seeking to critique the activities of the health care professionals through a legal lens, searching for negligence and litigating against the NHS. This concern from the reviewers, who were health care professionals themselves, highlighted that my legal background would alter the power balance within an interview in favour of myself. As previously established, the aim is neutrality, wherein the participant feels empowered and able to share their story without fear of potential litigation or judgment.⁴⁸ To achieve this, I introduced myself as a researcher. I disclosed my background in law to prevent any form of deception. I explained the purpose of my study and reiterated that I was not there to judge or search for avenues to pursue litigation. When I met the health care professionals, I was pleasantly surprised that due to the

⁴⁸ *ibid.*

visibility of my disability they acknowledged that I was a patient, and said that they felt that I had a certain empathy to their situation, having seen first-hand the pressures health care professionals are under on a daily basis in an understaffed, underfunded, chaotic and ever-changing environment where the patient demand has never been higher. My field notes document the health care professionals stating, 'as I am sure you will understand', 'as you see on the ground' and 'as a patient you will know', suggesting they saw me not as an outsider but as an insider. This shifted the balance of power and resulted in the doctors feeling comfortable to tell their narratives in a non-judgmental environment. One doctor did initially feel uncomfortable with my legal background, and as such, I took some time prior to the interview to discuss their concerns. After explaining my role as a researcher, they felt reassured, and from this point began to willingly disclose detailed narratives. At the end of the interview they stated that they felt it was refreshing to meet someone who wanted to help rather than criticise.

4.5. Ethical Considerations

During this research project I dealt with the following ethical considerations.

4.5.1. Informed Consent

During the recruitment process all the participants were given a participant information sheet outlining the interview process and the purpose of the project. If the participant wished to continue with the project, a suitable time and place was then arranged for the interview. Participants would decide the time and place. In those cases where the participant had no preference, I booked an accessible room on central campus. Three interviews were conducted by skype, and 15 in person. The decision as to the nature of the interview was decided by the participant.

All participants, as far as it is possible to tell, were capable of consenting to their participation in the study. They received information well in advance

and voluntarily self-selected to be interviewed. Moreover, I checked that the participants understood the project, what was required from them, and whether they were happy to be interviewed. They were fully informed at all stages about what was going to happen and were informed of their right to withdraw from the project at any point. I gave all participants a month after their interview to withdraw from the project, enough time for them to make a decision, whilst ensuring that thereafter I could confidently use the data without the concern that it may be withdrawn.

Informed and written consent was obtained from each participant prior to the interview. Where written consent was not appropriate due to the participant's medical condition, their informed consent was audio recorded using a separate Dictaphone to that being used to record the interview. All participants were given the choice of providing written or verbal consent; two participants provided verbal consent. The consent forms were kept in a locked filing cabinet in a locked room in accordance with the University of Warwick's data protection policy.⁴⁹ The forms were kept separate from personal information about the participant and the transcriptions.

4.5.2. Confidentiality and Data Protection

Once a potential participant had expressed an interest in the project by responding to the recruitment material, they were assigned a unique identification number and their name was replaced with a pseudonym. To protect the identity of participants, only personal information that was necessary for the project (such as contact details for sending thank you letters and a letter of results) was collected. The transcripts, registration log, consent forms and demographic information were stored separately.

All interviews were audio recorded to ensure detailed data analysis could be conducted on verbatim transcripts. The recordings were encrypted

⁴⁹ University of Warwick, 'Research Data Management Policy' (*University of Warwick*, 2011)
<https://warwick.ac.uk/services/ris/research_integrity/code_of_practice_and_policies/research_code_of_practice/datacollection_retention/research_data_mgt_policy/> accessed 5 September 2016.

requiring a passcode to listen to the transcript. After the transcripts were completed the audio recording was deleted. The transcripts were anonymised and the data analysed. All the data was stored on the University of Warwick MyFiles, an encrypted data storage system backed up every 24 hours. This was in line with the University of Warwick's Data Protection and Confidentiality guidelines.⁵⁰

As the participants were disclosing potentially identifiable medical histories, the names of rare medical conditions and interventions were replaced with general terminology such as a 'cardiac condition'. Where the job title of health care professionals and past-paediatric patients could lead to identification, this was also changed. Although each case report is specific to the individual, all data that could possibly identify the participant was removed, or rendered unidentifiable where its incorporation was vital to the participants' context.

4.5.3. Interview Environment

The location and method of the interview was chosen by the participant to create the most comfortable environment possible. Participants were informed that they could stop the interview at any point, have rest breaks, and split the interview over several sessions. It was necessary to be aware of health factors that may affect a participant such as fatigue and pain. I regularly offered rest breaks to ensure participants felt able to take them if needed.

4.5.4. Emotion of the Participants

The participants were keen and willing to disclose sensitive and emotive information. Many of the past-paediatric patients were visibly upset during the interview, and it was necessary to protect the participants, repeating that the interview could be stopped whenever they wished. These moments are an ethical challenge. On one hand, self-disclosure means "re-

⁵⁰ Ibid.

opening wounds without the opportunity to work them through”,⁵¹ potentially harming the participant. Whilst participants were prepared for the interview, after receiving all the information and approaching me to sign up for an interview, it is acknowledged that participants can be unprepared for the emotions they may experience during the interview.⁵² “The process of qualitative health research is not always predictable for either participants or researchers”.⁵³ On the other hand, the participants described sharing their experiences as a relief and therapeutic, as someone was willing to listen. In all cases, participants were pleased to have taken part. The consequences of talking about sensitive issues always poses a risk to the participant. All participants had the opportunity to withdraw their contribution up to a month after their last interview, and were able to remove parts of the transcript if they desired. All participants voluntarily signed up and were not approached directly by the research team. This ensured that only those participants who felt able to share their experience would come forward.

As sensitive information was being discussed, semi-structured interviews in a one-to-one setting created a safe environment to share such experiences. Through this approach, I was able to collect facts, record participants’ opinions, uncover the meaning participants attributed to their experience and explore in-depth their reasoning, thoughts and feelings. I was able to follow the interests or concerns of the participants, and felt free to probe areas of interest as and when they arose.

⁵¹ Raheim, M & others, ‘Researcher-Researched Relationship In Qualitative Research: Shifts In Positions And Researcher Vulnerability’ (2016) 11 *International Journal of Qualitative Studies on Health and Well-being*, 1 at 1-12.

⁵² Richards, H & Schwartz, L ‘Ethics of Qualitative Research: Are There Special Issues for Health Services Research?’ (2002) 19(2) *Family Practice*, 135 at 135-139.

⁵³ Kidd, J & Finlayson, M, ‘Navigating Uncharted Water: Research Ethics and Emotional Engagement in Human Inquiry’ (2006) 13(4) *Journal of Psychiatric and Mental Health Nursing*, 423 at 423-428.

4.5.5. Benefits to the Participant

It is unlikely that there was any direct benefit to taking part in the project. However, the purpose of the data collection was to add knowledge to the existing academic debate. Therefore, there is a potential future benefit to others, as well as the opportunity for the participants to have their experiences listened to. The participants described being 'heard' and having the opportunity to share their narrative as a benefit.

4.5.6. Time Commitment

The interviews required participants to commit unpaid time towards the project. For health care professionals it was important to schedule the interview during their working hours, and for past patients it was necessary to schedule the interview outside of their working hours, to ensure that they could attend. All interviews were conducted at a time and date chosen by the participant and mutually agreed. The length of the study was initially designed to stay within one hour—however this was not always possible, and many participants required more time. Where a longer interview was required, the session was either extended or split into two sessions.

4.6. Ethical Approval

NHS ethical approval is required where the project involves:

potential research participants identified in the context of, or in connection with, their past or present use of services (adult and children's healthcare within the NHS and adult social care), including participants recruited through these services as healthy controls.⁵⁴

To gain ethical approval, University Sponsorship was required. Once obtained, the Health Research Authority (HRA) and Research Ethic Committee (REC) applications were submitted together via the Integrated

⁵⁴ NHS Health Research Authority, 'Do I Need REC Approval?' (*NHS HRA*) <<http://www.hra-decisiontools.org.uk/ethics/>> accessed 21 July 2018.

Research Application System (IRAS). HRA approval was required to interview health care professionals, as recruitment occurred within NHS hospitals. After submission, it was necessary to attend a Research Ethics Committee Meeting, after which recommendations were made for improvements to the applications. Amendments were submitted and REC approval granted. Any further amendments required a separate submission for approval. Details of the amendments are provided in 4.1 below. All certificates can be found in the thesis appendix.

| Table 4.1: Ethics Approval | | | | | | |
|--|--|-------------------------------|--|---------------------------------|-------------------------------|--|
| | University Sponsorship Approval | HRA initial assessment | Research Ethics Committee Meeting | Provisional REC Approval | Final Approval | Amendments |
| Health care professionals IRAS ID: 238834 | 3 November 2017 | 10 th January 2018 | 16 th January 2018 | 25 th January 2018 | 25 th January 2018 | 27 th July 2018- New site at Warwick Medical School |
| Past-paediatric patients IRAS ID: 242598 | 21 March 2018 | N/A | 27 th April 2018 | N/A | 17 th May 2018 | 16 th August 2018 – recruitment through InSite |

4.7. Conclusion

This chapter presented the methodology underpinning this project and justified the choice of methodology and method. It discusses my position as a researcher, ethical considerations and the ethical approval process. Subsequent chapters are dedicated to the presentation of the data

obtained during the interviews. I begin with an overview of the participants' background information and case reports, justification for which can be found in the following chapter.

5. INTRODUCING THE PARTICIPANTS

5.1. Introduction

The purpose of Chapters 5, 6 and 7 is to closely examine the 'lived experiences' of 18 adults who underwent therapeutic medical treatment as a child, and four paediatricians who each have around 25 years' experience working with children. This study only directly investigates the participant's experiences. The past-paediatric patients' narratives are concerned with their experiences when receiving therapeutic medical treatment whilst in paediatric health care, before their transition to adult services. This chapter introduces the participants. First, dividing the participants into four groups: (i) aged 18-25 (11 participants), (ii) aged 26-35 (three participants), (iii) aged 36+ (four participants) and (iv) paediatricians (four participants) which can be visualised in Table 5.1. Second, each participant will be introduced through a case report.

Section 5.2 details the background information about the interviewees. Although the results of the study are significant, they are not generalizable. Nevertheless, I introduce the background information of the participants to provide context. For past-paediatric patients, this section reports their age, sex and occupational demographics, the number of times each participant was interviewed, the length of time they were treated under paediatric health care and the age at which they transitioned to adult services. For health care professionals, their age, job title and years' experience are documented. The geographical demographics of all participants will be discussed separately from the tables, to protect the participants' identities. Section 5.3 introduces each participant using case reports, chronologically recording their paediatric medical experience, and their background, to provide a rich backdrop for the further discussions in Chapters 6 and 7.

5.2. Background Information

During this study, I interviewed 22 participants, 18 past-paediatric patients and four health care professionals. As Table 5.1. illustrates, I organised the participants into four groups.

| Group 1 18-25 | Group 2 26-34 | Group 3 35 and above | Group 4 Health care professionals |
|--------------------------|--------------------------|---------------------------------|--|
| Abigail | Faye | Bethany | Chris |
| Anjali | James | Faith | Daniel |
| Emily | Lee | Maddison | Jonathan |
| Hannah | Logan | Rachel | Julie |
| Kate | Megan | William | |
| Liam | | | |
| Susan | | | |
| Zoe | | | |
| Total 8 | Total 5 | Total 5 | Total 4 |

Group 1 is composed of individuals between the ages of 18 and 25 who have recently left paediatric health care. Paediatric care is typically from birth to 18 years.¹ Subsequently, patients are considered as ‘young adults’ until the age of 25.² For the participants in this study, their transition to adult health care occurred between the ages of 16 and 21. They are currently being treated as ‘young persons’ in an adult hospital until their 25th birthday.³ Group 4 are practising health care professionals. Together, group 1 and 4 provide a representation of paediatric health care today. Group 2 are participants aged 26 to 34 and group 3 are participants aged 35 and above. Group 3 provides insights into the evolution of paediatric patients’ ‘lived experiences’ since the introduction of law that accorded

¹ GMC, ‘Introduction, 0-18 years: guidance for all doctors’ < <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/introduction>> accessed 16 June 2019 at Appendix 1.

² Quality Care Commission, ‘From the Pond into the Sea: Children’s Transition to Adult Health Services’ (QCC, 2014) < https://www.qcc.org.uk/sites/default/files/CQC_Transition%20Report.pdf> accessed 5 September 2018, at 4.

³ *ibid*

children the right to meaningful participation. As established in Chapter 1 section 1.4, I use the term ‘children’ to refer to any person under the age of 18. I will not use the terms ‘young persons’ or ‘adolescents’. Where it is necessary, I will specify the participants’ age at the time of their narrative.

| | | Sex | Age | Occupation | Times Interviewed | Ages under paediatric services | Age transitioning to adult services |
|----|----------|------------|------------|--------------------------------|--------------------------|---------------------------------------|--|
| 1 | Abigail | F | 19 | Undergraduate Student | 2 | 0-18 | 18 |
| 2 | Anjali | F | 25 | Administrator | 1 | 12-17 | 17 |
| 3 | Bethany | F | 45 | Academic | 1 | 8-18 | 18 |
| 4 | Emily | F | 21 | Undergraduate Student | 2 | 0-19 | 19 |
| 5 | Faith | F | 65 | Academic | 1 | 8 | n/a |
| 6 | Faye | F | 25 | Pharmacist and medical student | 1 | 8-18 | n/a |
| 7 | Hannah | F | 19 | Undergraduate Student | 2 | 0-18 | 18 |
| 8 | James | M | 27 | Office Manager | 1 | 11-16 | n/a |
| 9 | Kate | F | 21 | Undergraduate Student | 1 | 0-18 | 16 |
| 10 | Lee | M | 26 | PhD Student | 1 | 0-18 | 18 |
| 11 | Liam | M | 18 | Undergraduate Student | 1 | 0-18 | 18 |
| 12 | Logan | M | 26 | Medical Student | 1 | 8-9 | n/a |
| 13 | Maddison | F | 49 | Administrator | 1 | 8-10 | n/a |

| | | | | | | | |
|----|---------|---|----|-----------------------|---|------|-------|
| 14 | Megan | F | 26 | PhD Student | 1 | 0-18 | 16-18 |
| 15 | Rachel | F | 54 | Administrator | 1 | 10 | 18 |
| 16 | Susan | F | 21 | Undergraduate Student | 1 | 7-18 | 18 |
| 17 | William | M | 35 | IT and Cyber Security | 1 | 8-18 | 18 |
| 18 | Zoe | F | 23 | Undergraduate Student | 1 | 0-16 | 16 |

Table 5.2 provides background information of the past-paediatric patients. All the names are pseudonyms. Where the participants were interviewed twice, their age and occupation is their status at the first interview. Of the 18 past-paediatric patients, 15 had chronic health conditions which required ongoing therapeutic medical treatment and maintenance. For eight of these participants, a genetic cause was identified for their condition. They entered paediatric health care at or shortly after birth.⁴ The remaining seven participants developed a chronic health condition during their mid- late childhood.⁵ Three participants had an acute health condition that once resolved, did not require any further treatment.⁶ 13 of the 18 past-patients transitioned from paediatric to adult health care between the ages of 16 to 21. Five participants did not transition to adult health care because their medical treatment was completed during their childhood.

As illustrated, just over half the participants are students: seven undergraduates and four postgraduates. Two postgraduate students are also in part time employment, Logan, a lifeguard and Faye, a pharmacist. Four participants have administrative positions, two academic positions

⁴ Emily, Hannah, Abigail, Isabella, Liam, Lee, Zoe, Megan, Rachel.

⁵ Susan, William, Faith, James, Bethany, Anjali.

⁶ Maddison, Logan, Faye.

and William is a cyber-security engineer. Two participants, Abigail and Hannah were interviewed twice due to the extensive content within their initial interviews. Notably, of the 18 participants, 13 are female and five are men. It is unknown why only 27% of the participants were male. After conducting a review of the recruitment material and methods, gender bias could not be found. Whilst it would have been preferable to have an equal gender split, on analysis of the data, there was no variation between the male and female responses, and gender was not mentioned by participants as a theme during the interviews. All the participants were treated by the NHS. Lee was the only participant to have been treated by private health care. This treatment was for one symptom of his condition which could not be accessed on the NHS.

| Table 5.3: Background Information, health care professionals | | | | |
|---|----------|------------|------------|---|
| | | Sex | Age | Occupation |
| 1 | Chris | M | 58 | Paediatric consultant in general paediatrics with a specific interest in infectious diseases and immunology and an academic |
| 2 | Daniel | M | 55 | Child protection, general paediatrics and disability |
| 3 | Julie | F | 55 | General Practitioner with a specific interest in paediatrics |
| 4 | Jonathan | M | 55 | General Practitioner with a specific interest in paediatrics |

Table 5.3 provides an overview of the health care professionals and as above, pseudonyms are used. Due to the small number of health care professionals interviewed, it was of importance that they represented a variety of clinical specialities.

5.3. Participant Case Reports

Ideography is a core element of IPA and requires the researcher to conduct a close analysis of the data on a case by case basis.⁷ The purpose is to identify what is meaningful for each participant, pulling out codes before analysing the data set as a whole, transitioning from specific to general. In closely examining each participant's experience, I identified the context and background developing a rich and detailed backdrop necessary for the accurate reporting, understanding and analysis of the subsequent data. To replicate this effect within this thesis, I introduce each participant through a brief biography. The case reports detail the participants' background, medical conditions and treatments in addition to their thoughts and feelings, highlighting and introducing the themes prior to an in-depth discussion in the following chapters. The reports are composed of information collected from the interview transcriptions and my detailed field notes. I organised the case reports in the participant groups discussed in section 5.2, so that comparisons can be drawn.

5.3.1. Group 1 (18-25-years)

Anjali is a 25-year-old woman who works in administration. As a child Anjali enjoyed an active and independent lifestyle. At the age of 12, and previously healthy, Anjali was diagnosed with a life-threatening cyst in the fourth ventricle in her brain for which she underwent major brain surgery. Her rehabilitation comprised of a one to two months inpatient admission followed by a further six months of speech, language and physiotherapy. She was offered further surgery for her double vision which had been unresponsive to routine treatments. Keen to avoid surgical options, Anjali chose to investigate alternative therapies including Botox injections. The first two injections were conducted under general anaesthetic, however, the third was administered under local anaesthetic during a routine

⁷ Eatough, V & Smith, J.A, 'Interpretative Phenomenological Analysis' in Williy, C and Stainton Rogers, W, *The SAGE Handbook of Qualitative Research in Psychology* (SAGE 2017) at 200.

appointment. After exhausting all treatment options and seeking a second opinion, at 15, Anjali had what was to be her final major surgery as a child. Anjali describes her participation as unsatisfactory. She desired meaningful information and greater involvement in the decision-making process. At 17, Anjali transitioned to adult services where she continues to be monitored. She found the transition abrupt and felt unprepared although she reports she has now settled into the service.

Emily is a 21-year-old woman, studying Law with ambitions to be a barrister. As a child, Emily had a wide friendship circle and was really engaged with her education describing it as of extreme importance and an illustration that her disability is not a barrier to success. Emily was born with Osteogenesis Imperfecta (OI). She was diagnosed shortly after birth and immediately began medical and surgical treatment. At age two and a half, Emily started a newly introduced IV drug specifically for children with Osteogenesis Imperfecta that had previously been used by adults in the UK and children in Canada. During regular consultations with her medical team, the dosage of the drug would be reviewed and at times changed in accordance with Emily's symptoms. At 15, the IV drug was discontinued in favour of a tablet form to allow Emily to spend more time at school. Emily had three major operations at the age of 10, 14, and 17. Further surgeries were suggested, the primary aim of which was to help her walk. Emily declined these due to the disruption in her education, the long recovery process, and the minimal benefit that could be achieved. Emily required regular casting changes, x-rays, physiotherapy, occupational therapy and blood tests. Of importance to Emily is the positive relationship that she has with her parents, in particular, her mother. A major milestone in Emily's life was starting secondary school. Here, Emily says she found her voice and became more confident and independent. She believes that this change in her character was reflected in her participation and interaction with health care professionals. From the age of 11, Emily felt at the centre of her health care, comfortable and confident in declining treatments which did

not marry with her goals and her ambitions to excel academically. Emily transitioned to adult care between the ages of 16 and 21 where she continues to receive treatment.

Hannah, 19, is studying English literature at university. As a child, Hannah was incredibly active, participating in numerous sports such as rock climbing and Irish dancing. Hannah describes herself as “strong willed and mature for her age”. She believes this originated from her difficult childhood and poor relationships with her parents. Hannah’s parents separated whilst she was a young child and at age nine, Hannah had to attend court to argue for visitation rights with her father. Born with a unilateral cleft lip palate, at three weeks of age, Hannah underwent a palate repair, and a few months later a lip repair. At the age of nine, Hannah had a second major reconstruction surgery. Since then, Hannah has undergone a significant amount of dental work, requiring regular orthodontist appointments. Doctors recommended that Hannah have a further operation. Hannah declined and due to feeling pressurised into having the surgery moved to a different hospital to seek a second opinion. Hannah preferred the experience at this hospital, feeling involved, respected and listened to. Hannah was monitored until adulthood at which point, she was discharged from the cleft lip palate service. Hannah did not transition to adult services as her condition no longer required treatment or monitoring.

Kate, 21, is in her final year at university with ambitions to be a counsellor. Born with Spina Bifida, Kate underwent her first surgery at two days old. Over the next five years, Kate underwent five further surgeries culminating in a brain surgery at the age of five. Since birth, Kate has had ongoing physiotherapy, the frequency of which varies in accordance with her health needs. At 14, Kate began experiencing new symptoms and after two years of independent research, was diagnosed with vertigo and water retention. As an adolescent, Kate struggled with the treatment being pursued by her medical team. Her health care professionals were working towards the goal

of walking with crutches. However, Kate did not share this goal. Despite a desire to walk, Kate felt that the side effects of physiotherapy, such as extreme tiredness and minimal impact, meant that the benefits of a wheelchair outweighed the attempts to walk. Moreover, Kate wished to spend time with her friends and participate in her hobbies. The physiotherapy prevented Kate from achieving these aims and took her away from the things she valued in her life. As Kate struggled to articulate this internal conflict to her health care team, she would go to her appointments but not do her therapy at home. She quietly refused treatment by not complying. Kate describes herself as lacking confidence and shy when around health care professionals due to their formality and because she felt uncomfortable with the treatment goals. Kate felt that the professionalism and authority prevented her having an open discussion with her health care team. Instead, her parents primarily interacted with her consultants and physiotherapists. Kate describes a positive relationship with her parents who were very involved in her health care. From the age of five, Kate's parents would explain to her the nature of treatments, the risks and benefits. With her parents, Kate was very articulate about her feelings and values. Her participation in her health care progressed as she got older and since moving to adult services at 16, Kate now feels more comfortable sharing her opinions with her consultants. Kate speaks of a smooth transition period to adult services where she continues to receive ongoing support.

Susan, 21, is a student at university studying psychology. At the age of eight, Susan developed an eating disorder and regularly saw a dietician. Throughout her childhood and teenager years, Susan continued to struggle with her mental health. However, due to a poor relationship with her mother, Susan felt that she was unable to get the right medical treatment for her condition. Susan has been a carer for her siblings since the age of 15. As such, Susan explains that she feels that she was very mature for her

age. In her teenage years, Susan was diagnosed with sinus headaches and gynaecological conditions for which she still receives ongoing treatment.

Abigail, 19 is studying law at university. Born in Poland, Abigail was diagnosed with a congenital heart condition which required two open heart surgeries, one at two months of age and the other at five years of age. Abigail briefly remembers elements of her second admission, particularly her parents' distress. Abigail was extremely close to her parents. Since moving to England at the age of eight, her parents signed up and met with her GP who referred Abigail to the children's hospital for regular monitoring of her condition via outpatient appointments. Each appointment would require Abigail to have an Echocardiogram (ECHO), an electrocardiogram (ECG) and an examination by the cardiologists. At 18, Abigail transitioned to the adult clinic. This was a significant moment for Abigail who had previously lacked involvement in her health care. At the transition clinic, a health care professional spent an hour with Abigail explaining her condition. It was at this appointment that Abigail was told the name of her condition and the impact that it may have on her life now and in the future. Abigail appreciated this information and felt that the transition clinic was at the right time in her life. Abigail continues to be monitored as an adult.

Zoe is an active and ambitious 23-year-old woman who at the time of the interview was finishing her final year at university. Now, fulfilling her ambition, Zoe is living in Germany and working as a tour guide whilst studying part time for a Master's degree. Zoe described herself as a quiet, calm, mature, and thoughtful child. At six weeks old, Zoe was diagnosed with Cystic Fibrosis (CF) and immediately started upon a treatment plan. Zoe was required to do percussion therapy twice a day to clear her lungs, have physiotherapy, nebuliser antibiotic treatments and oral medications including antibiotics, steroids, and enzymes. Initially Zoe's parents delivered these treatments and organised her medication. However, as Zoe got older, she gradually took over the responsibility. From the age of four,

Zoe would require consultations every six weeks with her medical team and a two-week hospitalisation roughly three times a year. She required additional hospital admissions when her condition flared-up. Here she would receive more effective physiotherapy and IV antibiotics. During some admissions, Zoe would also undergo a bronchoscopy procedure. Zoe's weight required ongoing monitoring. As CF affects the digestive system, Zoe would often lose weight so further treatment would be needed to help her maintain it. Much of Zoe's treatment was unscheduled and in response to flare-ups in her condition. In addition to her regular treatment, Zoe took part in gene therapy clinical trials. If the trial was successful, because she had participated in the trial, Zoe would have first access to any new treatments that were a result of the trial. Zoe is currently on one such medication. Zoe describes a positive relationship with her parents. Her parents were very involved in her treatment until Zoe moved to adult care. Zoe explains that her parents struggled with this transition as they had always looked after Zoe and were aware of the fragility of her condition. Zoe transitioned to adult care at the age of 16. Initially she found this process overwhelming and felt unprepared, although, overall, Zoe believes this process was beneficial as she grew in independence. Adult care was the first time Zoe felt in control of her medical treatment.

Liam is an articulate 19-year-old man in his first year at university studying modern languages and culture. As a child Liam describes himself as a creative and arty person with an interest in literature. Liam has a close relationship with his parents, in particular his mother who was Liam's primary carer throughout his childhood. Liam was diagnosed with Juvenile Arthritis at 18 months. Liam was treated at a specialist children's hospital by the same consultants, nurses, physiotherapists and neurologists. Liam had regular Botox injections from the age of four or five until the age of 16. At the age of 15 and 16, Liam underwent two medical procedures under local aesthetic to remove the fluid surrounding his knee joint and to

receive a steroid injection. During his teenage years, Liam had his appendix removed and had a severe form of pneumonia for which he required further treatment including antibiotics. Liam describes himself as a quiet child. He was content with his mother taking the lead in conversations and making decisions on his behalf. Liam trusted his mother as she was a nurse. Liam would engage in the conversation between his doctor and mother by explaining to the doctor what symptoms he was experiencing. As such, it was not until 16 or 17 where Liam began assenting to medical treatment. Liam transitioned to adult care between the ages of 16 and 18. He found the transition to adult services particularly difficult as he had a strong relationship with his medical team and found making decisions for himself overwhelming. Liam continues to seek his mother's advice before consenting to any medical procedure as an adult. Liam describes a positive paediatric health care experience.

5.3.2. Group 2 (26-34 years)

James is a 27-year-old man who works in his dad's business as an office manager specialising in business growth. James has always had a close relationship with his parents. Before the age of 11 James describes himself as a very active and sporty child. At the age of 11, James became unwell after contracting a virus. After months of extreme exhaustion and a variety of other symptoms affecting his whole body, James's parents took him to the GP for a diagnosis. James underwent numerous tests including scans and blood tests to rule out anaemia, vitamin and mineral deficiencies, and hepatitis among other conditions. James recalls visiting numerous hospital and consultants, trying a variety of treatments in the hope that one would be successful. In the early days, James was being admitted into hospital every four to six weeks whilst they tried to find a diagnosis. Eventually, James was diagnosed with ME. James tried many treatments but as relatively little is known about ME, many of the treatments did not work and James's condition continued to fluctuate. In many instances there was concern for James's weight, which required James to have prescribed

nutrition drinks. At the age of 15, James's health significantly deteriorated, and he spent four to five months bed-bound, off school, and unable to partake in any activity. Between the ages of 16 and 18 James was discharged from child services but was not picked up by adult services. James describes the period between the ages of 16 and 18 as "a gap in the system" and was, in part, the cause of a flare-up in his condition whilst at university. As an adult, James actively looked for alternative treatments and has since seen specialists in ME. However, he remains out of routine hospital care.

Lee, 26 has an interest in classics and historical artefacts relating to World War II. He is currently studying part time for a PhD alongside voluntary work. As a child, he describes himself as "rather quiet" preferring solitary activities such as kayaking, horse riding, and reading. Lee is very close to his parents and values their relationship. Lee is a non-identical triplet and unlike his sisters, Lee was born with Cerebral Palsy. Since birth, Lee has required regular physiotherapy, most of which was done at home by his grandmother, a physiotherapist. Lee's father is also a doctor. Lee's condition was primarily overseen by a specialist orthopaedic surgeon who he saw every six months. Between the ages of six and 18, Lee often underwent surgery which involved Botox injections into his Achilles tendons to increase movement. After an operation, Lee's foot would be in a plaster cast which, once the cast was removed required further physiotherapy at the hospital. Lee had splints to improve the alignment of his leg and foot. He also had a Femoroacetabular Impingement on his right hip which required several surgical procedures to correct. Lee describes himself as an intelligent and mature child who desired to be involved in his health care, however, felt that his involvement was limited as the doctors would mostly speak to his mother. Nevertheless, he had a positive relationship with his doctors and nurses and was very knowledgeable about his medical condition. Lee's participation increased once he started university as he became more independent. Lee transitioned to adult care

at 18 and describes the process as abrupt and challenging. Lee continues to receive treatment as an adult.

Faye is a 25-year-old woman. She is a pharmacist and is training to become a doctor. Faye has a very close relationship with her mother who has provided unwavering support throughout her treatment. Faye's first experience of medical care was at the age of 12 when she was referred to a psychiatrist for the nightmares she was experiencing. Faye subsequently received counselling for about 12 months which she found incredibly beneficial. Throughout her childhood, Faye experienced regular ear infections which caused a burst ear drum requiring two surgeries at the age of 16 and 17. At the age of 14, Faye was diagnosed with mild scoliosis which required regular monitoring as she grew. Faye had a positive health care experience where she felt listened to and respected.

Logan is an active 26-year-old who is currently studying to become a doctor, fulfilling his life-long ambition. As a child, Logan was interested in football. He was a huge fan of gaming and loved spending time with his friends playing the latest computer games. A happy and healthy child, Logan had not experienced ill health until he was eight years old. During the summer holidays he experienced sudden and crippling pain in his legs and hips. His parents took him to hospital where Logan stayed for two to three weeks. At first, Logan's medical team thought he may have a joint infection or bone cancer. Both of these were ruled out after several tests including blood tests, Magnetic Resonance Imaging (MRI), and x-rays. Throughout his admission, Logan continued to be in considerable pain, and his temperature and inflammatory markers would be raised every couple of days. This was indicative of an infection which the doctors believed had progressed to sepsis. Although his medical team could not find the location of the infection, they started Logan on IV antibiotics. Logan was then transferred to a specialist children's hospital for a more in-depth examination. Logan was eventually diagnosed with hypermobility, alongside a mild infection or inflammation that caused spikes in

temperature and potential sepsis. Over time, Logan's condition improved, and he was discharged from hospital. Due to his loss of muscle mass through inactivity, Logan used a wheelchair for a couple of weeks before using crutches for nine months. Logan received regular physiotherapy and consultations to check on his condition throughout this period. Later in the year, Logan was readmitted into hospital due to further pain in his hips, however, this resolved itself relatively quickly and he did not require further treatment. Logan is very close to his parents who took the lead in his care as a child. Logan did not desire to be involved due to being so unwell. Logan was discharged as a child and did not transition to adult services.

Megan, 26, is studying for a PhD in theatre studies. Megan is an avid campaigner for the rights of people with disabilities and has a passion for theatre, combining these two interests in her research. At birth Megan was diagnosed with Cerebral Palsy, affecting all four limbs. As a young child, Megan's family moved from South Africa to England to access a conductive education - a specialist education that equips people with the capabilities to live an active lifestyle. As part of this education, Megan required daily physiotherapy and at times used a wheelchair. Prior to the age of 11, Megan's treatment consisted of routine appointments with her health care team, physiotherapy and occupational therapy, blood tests and scans. At 11, Megan began using her wheelchair more as she was struggling to walk. Her orthopaedic surgeon recommended an operation to inject Botox into the tendons in her ankle. This improved Megan's pain and range of movement. Shortly after, Megan required a major operation called a tendon transfer surgery. During this procedure her calcaneus was broken requiring a cast for many months. From the age of 11 to 18 Megan received regular support for her mental health conditions. She describes this as a positive and beneficial experience. Whilst at primary school, Megan was severely bullied due to her disability. As a result, her parents moved Megan to a specialist secondary school designed to assist young

people with conditions such as Cerebral Palsy. Although this form of education ensured Megan's condition was better understood, Megan felt that she was not challenged academically and did not receive the required amount of physical input. Consequently, she developed severe muscle spasms causing joint deterioration and a spinal curvature. Megan moved back to mainstream education. Megan's spinal curvature was first diagnosed at the age of 14 for which she underwent further physiotherapy and wore braces in an attempt to improve the curve. Spinal fusion surgery was explained as the inevitable option by her orthopaedic consultant. Megan reports feeling under significant pressure to agree to a spinal fusion, a standard treatment for those with her condition. However, Megan's parents declined the surgery after Megan had experienced the loss of a close friend who had undergone this operation and because the medical team could not guarantee the surgery would improve her pain - Megan's primary motivation for the treatment. Megan's parents changed consultants to seek a second opinion and this consultant who agreed to observe rather than operate. Throughout her teenage years, Megan continued to receive Botox injections as a form of pain relief and to increase joint function. She reports feeling involved in her medical treatment from the age of 11 however, due to her disability, involvement was often limited by other people's perceptions of Megan's capabilities. Megan transitioned to adult services between the ages of 16 and 18 and continues to receive treatment. She describes the transition as a challenging period where she struggled to receive the required support from her medical team. Megan reports a very close relationship with her parents.

5.3.3. Group 3 (35+ years)

Bethany is a 45-year-old lecturer and academic specialising in the development of children. Bethany is a sociable and bubbly person who lives with two of her friends and has a very close relationship with her mother and younger siblings. Bethany had a challenging childhood as her

father suffered from alcoholism leading to the separation and eventual divorce of her parents. Bethany praises her mother for her strength and support and believes that these shared experiences strengthened their relationship which was important during her ill-health. As a child, Bethany describes herself as very smart and hardworking, a sensitive child, a deep thinker, and very socially aware. Bethany enjoyed singing, playing the piano, and sport. However, at the age of eight Bethany came down with the flu. Due to her extreme fatigue, muscle weakness and being cognitively and physically drained, Bethany's mother took her to the GP where she was tested for a variety of conditions such as glandular fever. This required multiple blood tests. Bethany found her first blood test traumatic as she was not aware of what was happening. Bethany describes the experience as deeply unpleasant. This event led to a long-standing needle phobia. At the age of nine, Bethany developed an idiopathic skin condition, similar to impetigo which caused small growths on her joints that periodically would become infected. Her GP recommended a minor surgical procedure. In contrast to her blood test, Bethany remembers this to be a very positive experience as she felt involved and safe with familiar people. Bethany also developed an allergy to plasters and was diagnosed with a compromised immune system. Throughout Bethany's teenage years she continued to suffer from severe exhaustion which led to many weeks off school. After many years, Bethany was eventually diagnosed with Myalgic Encephalomyelitis (ME) during her mid 20s. Bethany continues to receive monitoring and treatment for her condition.

Faith is a 65-year old academic with an interest in the arts. As a child Faith had one experience of being a patient in paediatric health care. At the age of 8, Faith was taken to hospital via ambulance. She was suspected of having appendicitis which was later found to be a mild gastroenterological condition. Faith spent about a week in hospital undergoing investigations. She states that her experience of paediatric health care was negative because of the poor relationship that she had with the nurses. Faith did not

feel part of the process and was often distressed at not knowing what was happening. She was in a ward of children who had been in hospital for a long period of time and her mother was not allowed to stay with her. However, her mother would travel great distances to see her every day until she was well enough to go home. She was extremely close to her mother which added to the distress. On recovering Faith went home and did not receive any medical treatment as a child since. She has been left with a lifelong apprehension of hospitals.

William, 35, works in cyber security. As a child, William had a close relationship with his parents and describes himself as an avid gamer, with an interest in technology. William acknowledges he adopted a 'class clown persona' to hide his lack of confidence and insecurities. At the age of seven he suffered a hip injury. His parents took him to the GP who carried out an x-ray and made a referral to an orthopaedic consultant. The consultant diagnosed William with Perthes Disease. William was treated with restriction therapy. This required a hospital admission to use traction to pull his hip joints into the right place for the brace to fit correctly. His leg and hip were then cast, and his leg held at an angle. William was in a cast and used crutches for 18 months. After this, William required physiotherapy and a yearly x-ray until he was 18. Unfortunately, the restriction therapy was unsuccessful, and he continued to suffer significant pain. At the age of 17, William was started on tramadol and anti-inflammatory medication. As a child, William felt that his concerns about his health were not taken seriously and that he was not listened to. Despite consistently visiting his GP and consultants, it was not until his mid-20's that William was diagnosed with arthritis. William felt disbelieved, ignored, and has lost trust in the medical profession. William continues to receive ongoing monitoring and treatment as an adult.

Rachel is a 55-year-old woman who works in administration. Rachel describes herself as an incredibly sporty but painfully shy child. Rachel had a difficult childhood. For many years Rachel and her family were homeless,

living in hotels or on friends' sofas. At the age of 10, Rachel began to experience pain and swelling in her knee joint. After several visits to her GP, Rachel was admitted into hospital for two weeks. During her inpatient admission, Rachel underwent numerous investigations which she found extremely distressing. After the conclusion of the tests Rachel was diagnosed with Rheumatoid Arthritis. Rachel was immediately transferred to a rehabilitation hospital, however, her parents discharged Rachel after one night due to her extreme distress. For the remainder of her childhood, Rachel had intense physiotherapy, joint injections and hydrotherapy. She transitioned to adult services at the age of 18 where she continues to be monitored and receive ongoing medical treatment.

Maddison is a 49-year-old woman who works with young adults with disabilities. As a child, Maddison describes herself as fairly shy, not a particularly outgoing child, bookish but friendly and happy. Maddison had three periods of hospitalisation due to three acute medical conditions. The first was at 11 months after she had broken her leg. The second was at the age of four where she required surgery to pin her ear back. This was connected to a wider condition, Torticollis. This stemmed from a breach birth but was diagnosed at the age of seven. At the age of eight, Maddison had an operation on her neck and had a three-week inpatient admission at a specialist orthopaedic hospital. Following this operation, Maddison had 12 months of regular physiotherapy as an outpatient and daily physiotherapy at home, carried out by her mother. Maddison describes her medical experiences as challenging although positive in contrast to her husband who was severely traumatised by his experience of medical treatment as a child. Maddison valued the relationship that she had with her mother, although, remembers her mother struggling with the daily physiotherapy as it would cause Maddison great pain and distress. Due to the improvement in Maddison's health, she was discharged as a child and did not enter adult care.

5.3.4. Group 4 (Health Care Professionals)

Chris is a 58-year-old man. Since 1986 he has worked as a paediatric consultant in general paediatrics with a specific interest in infectious diseases and immunology. Chris has recently left this role and is now an academic training medical students. As a consultant much of Chris's workload involved children under five, teenagers, and in recent years, children with mental health conditions. Chris is very passionate about involving parents and children in health care decisions and saw the collaboration with the family as of extreme importance.

Julie is a 55-year-old woman. She is a practising General Practitioner working in England. During her training in the 1990s Julie went to New Zealand and Australia where she specialised in paediatrics. On returning to England she completed her training as a General Practitioner where she still works today. Julie has been a GP for 25 years where 1/5 of her patients are children and adolescents. Julie is also a volunteer counsellor for children and adolescents and has an interest in mental health and wellbeing of paediatric patients. As such, many paediatric patients choose to see Julie. She firmly believes in putting the child at the centre of care. It is of extreme importance to Julie that she builds a good relationship with all her patients as she believes this is the key to success.

Daniel is a 55-year-old man. Daniel has worked in paediatric medicine since 1989. Daniel specialises in child protection, general paediatrics, and childhood disability. As part of his role, Daniel conducts forensic medical examinations and investigations providing reports for social services and courts. Daniel has worked with children with a variety of medical conditions including Attention Deficit Disorder, Selective Mutism, and mental health conditions. Daniel's work involves working with a wide team around the child including their parents, families who are divorced or separated, schools, and social workers.

Jonathan, 55, has worked as a General Practitioner for over 25 years. As part of his role, Jonathan typically treats five to six children a day. This

includes providing vaccinations for babies, referring children to paediatric consultants for further tests and safeguarding. Jonathan is incredibly passionate about children participating in their health care. Alongside his role as a GP, Jonathan is an academic, teaching medical students about how to obtain consent from children under the age of 18.

5.4. Conclusion

This chapter has provided the background information about the interviewees in this study. It has reported the age, sex and occupational demographics, the times each participant was interviewed, the length of time they were under paediatric health care and the age at which they transitioned from paediatric to adult services. Furthermore, this chapter provided a detailed case report about each participant which provides the context and background information necessary to understand and analyse the data reported in the following chapters.

6. RELATIONSHIPS

6.1. Introduction

This chapter focuses on the relationships between the participants' and their doctors, wider health care team and parents. All the participants' narratives refer to their 'lived experiences' as paediatric patients. Chapters 6 and 7 present the research data using a thematic approach and verbatim quotes. The themes were created during the IPA coding process as described in Chapter 4. Verbatim quotes are used in the reporting and presentation of this data, to place the 'lived experience' of the participants at the centre of this thesis. Section 6.2 reports an overview of the therapeutic medical treatment that the participants underwent as children and the hospital departments they were treated by. This is to provide context for the remainder of Chapters 6 and 7. Section 6.3 discusses the participants' relationships with their clinical environment, doctors and wider health care team and section 6.4 focuses on the parent-child relationship.

6.2. The Therapeutic Medical Treatment Participants had as Children

The past-paediatric patients were asked about the therapeutic medical treatment that they had as a child. Tables 6.1, 6.2 and 6.3 summarise their replies, identifying the medical contexts, departments they were treated under and the medical treatment they received.

| | Outpatient Clinics | Inpatient Admissions | Day Care | Accident and Emergency | General Practice | Ambulance |
|-----------------|--|--|----------------------------------|---|-------------------------|----------------------------|
| Children | 16: Abigail, Anjali, Bethany, Emily, Faye, | 14: Abigail, Anjali, Emily, Faye, Hannah, Kate, Lee, | 4: Anjali, Bethany, Liam and Lee | 7: Abigail, Anjali, Emily, Faith, Kate, | 18: All | 3: Anjali, Emily and Faith |

| | | | | | | |
|--|--|---|--|------------------|--|--|
| | Hannah, James, Kate, Lee, Liam, Maddison, Megan, Rachel, Susan, William and Zoe | Liam, Logan, Maddison, Megan, Rachel, William and Zoe | | Logan and Zoe | | |
|--|--|---|--|------------------|--|--|

| Table 6.2: Hospital Departments | |
|--|--|
| Departments | Children |
| Respiratory | 1: Zoe |
| Rheumatology and Muscular Skeletal | 4: Kate, Liam, Maddison and Megan |
| Neurology | 5: Anjali, Faye, Kate, Lee and Megan |
| General Medicine | 6: Bethany, Faith, Hannah, James, Logan, Rachel |
| Mental Health | 2: Susan, Faye |
| Dentistry | 1: Hannah |
| Cardiology | 1: Abigail |
| Orthopaedic | 6: Emily, Faye, Kate, Lee, Megan and William |
| Ophthalmology | 2: Anjali and Susan |
| Dietician | 1: Susan |

| Table 6.3. Therapeutic Medical Treatments | |
|--|-----------------------------|
| Therapeutic Treatments | Children |
| Surgical | 11: Abigail, Anjali, Emily, |

| | |
|-----------------------|--|
| | Faye, Hannah, Kate, Lee, Liam, Maddison, Megan and William |
| Procedures | 18: All |
| Physiotherapy | 13: Abigail, Anjali, Emily, Faye, Hannah, Kate, Lee, Liam, Logan, Maddison, Rachel, William and Zoe |
| Occupational therapy | 2: Emily and Kate |
| Mental health therapy | 1: Susan |
| IV therapy | 13: Abigail, Anjali, Emily, Faye, Hannah, Kate, Lee, Liam, Logan, Maddison, Megan, Rachel, William and Zoe |
| Examinations | 18: All |
| Investigations | 18: All |

As illustrated in Table 6.1, all the participants had regular appointments with their General Practitioner (GP), 16 of these participants being referred by their GP to a hospital consultant for an outpatient appointment to have further investigations, treatments and a diagnosis. 14 participants required at least one inpatient admission for medical examinations and treatment. Eight of the 14 participants required routine inpatient admissions for their condition. Zoe (group 1), experienced the most inpatient admissions, having on average four planned admissions annually. Day-care refers to a one-day admission for a pre-determined surgical procedure, IV medication and/or invasive procedures. Seven participants attended Accident and Emergency (A&E) departments as a child. For Logan (group 1), Anjali (group 2) and Faith (group 3), A&E was their first experience of paediatric health care as previously, they had been active and healthy children. Anjali and Faith were transferred via ambulance from their local hospital's accident and emergency department to a specialist children's centre where they received urgent and specialist medical treatment. One participant, Emily, born with Osteogenesis Imperfecta (OI), regularly fractured and broke bones requiring an ambulance to take her to hospital for urgent scans and

treatment. As Table 6.2 illustrates, participants were treated under a wide variety of paediatric departments.

To clearly distinguish between the types of procedures, I define 'surgical procedures' as operations conducted in an operating theatre under local or general anaesthetic. In contrast, 'procedures' encompass a range of invasive medical events that do not require an operating theatre including blood tests, endoscopy, cast changes, bone marrow biopsies and bronchoscopies. As seen in Table 6.3, 13 participants had IV therapy - medication delivered through a canula in the vein directly into the blood stream. All participants had examinations and investigations such as X-rays, MRIs, Computed Tomography Scans (CT), ECHO's and ECG's.

All participants describe the paediatric hospital as child-centred, designed to be friendly and welcoming with beautifully painted walls that make the space feel immediately comfortable. There were toys in every room, bright and colourful furniture, low level desks designed to meet the child's eye level and seating for all ages. Participants in group one and two, recall that their parents were encouraged to stay with them. There was 24 hours visiting and parent accommodation onsite. Zoe (group 1) has Cystic Fibrosis (CF), a life-limiting genetic condition. As a child, Zoe was admitted into hospital once a month for inpatient treatments composing of IV antibiotics and nebulisers. The National Institute for Health and Care Excellence (NICE) provides guidance on the management of patients with CF.¹ To prevent cross-infection, hospitals are required to separate patients with CF from one another.² Consequently, Zoe spent a significant portion of her inpatient admissions in isolation. She fondly recalls the activities the

¹ National Institute for Health and Care Excellence, 'Cystic Fibrosis: Diagnosis and Management' 25th October 2017 <
<https://www.nice.org.uk/guidance/ng78/evidence/full-guideline-pdf-4610685853>>
accessed 9th July 2019

² *ibid*

hospital organised and the approachability of the staff who helped her through these days.

It was so friendly. It was all painted beautifully, and we had hospital school, and because I was so geeky, I actually loved going into hospital. I loved it! We had teachers, and people came around and played musical instruments in the paediatric ward. As a child I had a really positive experience. There was one consultant, he would wear really brightly coloured ties and be so friendly. The paediatric team always tried to make you feel at ease. They work on their bedside manner. I had appointments every 6 weeks, so, I knew the team really well. They were like another family.

With ease Zoe recalled her favourite doctors and nurses, describing their welcoming personas. All the participants remember being asked about their lives, hobbies and interests, “a sign” Liam (group 1) says, of genuine compassion, “that they aren’t just there for the medicine”. Born with Juvenile Arthritis, Liam had spent much of his childhood in hospital attending outpatient appointments, day care for IV treatment, inpatient admissions for surgical interventions, and regular visits from the home nursing team for blood tests. Like Zoe, Liam valued the compassion shown by his paediatric nursing team.

I remember walking out of that operating theatre to a round of applause, nurses giving me hugs. It means something. Because when you give someone human contact it’s a level of intimacy, but it’s also showing that you matter. You know, “we care about you”. My local nurses, they were pretty good. There was one lady ... everyone, even the other nurses used to call her Aunty Jose, and she just gave all the kids hugs, give them sweets, treat them well... Everyone had fond memories of her because she cared.

Liam tells me that it was the nurses that “show[ed] a level of love” and supported the whole family.

All the participants recalled the care and compassion of nurses and the welcoming nature of the children's ward. However, unlike the younger participants, those in group 3 described how their parents were unable to stay with them during their inpatient admissions, and that visiting hours were restricted to a few hours in the day. For those parents who worked or lived a distance from the hospital, visiting their child everyday was not a possibility. Faith (group 3) was admitted into hospital with suspected appendicitis and recalls the isolation brought about by the lack of a family member during her week-long admission. Faith's father worked long hours and her mother had to take several bus rides with a new-born child to visit her. "I was aware of being isolated in the hospital and it was a steady procession of being visited by doctors and having procedures administered by nurses." These participants aged 36 and over and born between 1954 and 1984 also recalled mixed gender wards and no separation between adolescents and young children. Their narratives are in line with the findings of the 1959 Platt Report.³ Following the reports of the distress suffered by children separated from their parents during inpatient hospital admissions, it was recommended that parents should be encouraged to remain with their child throughout their child's medical treatment. The subsequent 1976 Court Report⁴ introduced separate wards for older and younger children.

6.3. Relationships Between Health Care Professionals and Children

The participants were asked to describe their experience as a paediatric patient. Half of the participants recalled an overall positive health care

³ Platt, H, 'The Welfare of Children in Hospital: Report of the Committee' (Ministry Of Health Central Health Services Council, 1959)
<<https://ia800201.us.archive.org/8/items/op1266065-1001/op1266065-1001.pdf>>
accessed 12 February 2018 at Chapter 11.

⁴ Great Britain Committee on Child Health Services, 'Fit for the Future: Report of the Committee on Child Health Services' (H.M.S.O., 1976).

experience,⁵ and half reported a negative health care experience.⁶ The participants who had a positive health care experience stated it was because of the strong rapport they had with their doctors. Where the participants had a negative health care experience, they explain this was in part, because they had no rapport with their doctors.

Health care professionals emphasise the need to establish a strong rapport with children and their parents. Daniel (group 4) believes that a positive doctor-child relationship affirms the child's self-worth, esteem and confidence. This is particularly important, Daniel explains, in his area of work, supporting children with disabilities and conducting medical reviews for child protection cases. In these instances, Daniel describes how the child's background impacts their confidence, self-worth and esteem. Therefore, before examining a child and conducting an assessment, Daniel believes it is crucial to build a sound rapport with the child.

I remember really clearly a young girl who was brought to me with selective mutism. So, not communicating verbally at all, and the parent was clearly wanting a full assessment and my medical opinion. I think, the first two clinic appointments I had with that child, I saw her in the waiting room. She wouldn't even come into the clinic room. Then eventually, having built up a bit of a relationship, she was able to come into the consulting room. After three years, when I last saw her, she was actually speaking to me.

Having built a rapport with his patient, Daniel explains that the child subsequently cooperated with medical examinations and treatments. The health care professionals agreed that a sound doctor-child relationship was vital to ensuring the child cooperates and complies with their therapeutic medical treatment.

⁵ Liam, Lee, Emily, Maddison, Abigail, Faith, Zoe, Logan and Faye.

⁶ Susan, Hannah, Kate, William, Bethany, Megan, Rachel and Anjali.

If you are negotiating some kind of treatment program, or even an assessment or investigation, you will only achieve that if you've got the child's cooperation. Cos children are very good at keeping their mouths closed, folding their arms, sitting back and not doing anything. If they don't want to it, it then becomes a real battle. It's not going to happen. Communication, negotiation and relationship is absolutely central to this and I think where it is being treated as a one off thing, it doesn't work, and for parents particularly, knowing that the person that is taking the consent and giving the information knows what they are talking about is important. For children what I think is more important is, "is this somebody I can trust?" There are bits of it for both of them, but for children it comes much more from a relationship. With parents it's, "is this somebody who is knowledgeable, knows what they are doing, talking about?" (Daniel, group 4).

Like Daniel, all the health care professionals assume that children would primarily desire a strong rapport with their doctor above receiving information. Moreover, they believe that parents desire accuracy of information and clinical expertise above a rapport with their child's doctor. As such, they focus on building a rapport with the child and giving parents the sufficient information. However, the empirical evidence detailed in Chapter 7, Section 7.3 suggests that the participants desired more information. Whilst a sound doctor-child rapport is of value to the participants, they also desired accurate and extensive information about their medical treatment.

However, only half of the participants stated that, in the main, they had a consistently positive relationship with their doctor.⁷ Of these participants, five had received their medical care at specialist paediatric centres and were treated by experts in their conditions. Emily's (group 1) and Zoe's

⁷ Emily, Zoe, Abigail, Lee, Liam.

(group 1) doctors were leading experts in their fields at the forefront of medical knowledge. Emily and Zoe engaged with clinical trials, thus, had access to innovative surgical techniques and potentially life-saving drugs. Because of their doctors' expertise, Emily and Zoe trusted their doctor's recommendations. Having been treated by experts since birth, they had built a strong rapport with their doctors'. However, they did not trust non-specialist paediatricians. Zoe explains that unlike her specialists, non-specialist doctors lacked sufficient understanding of CF. Consequently, they suggested inappropriate and potentially harmful medical treatment.

I went to [location] A&E once. Never again! Because they're not specialists, I was explaining to them about my condition. They didn't really understand. They didn't know how to deal with me. They put me on a saline drip to hydrate me and I was like, "This is absolutely not what I need" and they kept me overnight, unnecessarily which was really ridiculous. So, since then I've vowed to stay clear of general A&E. It never pays off. I call my CF team. For me I think it's better to be with my team.

Participants were advised by their specialist paediatricians to only seek the advice of specialist health care teams. Because many of the participants' conditions are rare and complex, their doctors expressed concern that they would receive inappropriate treatment for their condition that could cause a risk of harm if they were to attend a non-specialist hospital.

Similarly, Emily recalls an instance where she had broken her arm. The doctors recommended a surgical procedure to insert a rod, correcting the break, however, due to the width of her bone canals, this would have caused further damage. Emily's mother informed the doctors of their concern. A CT scan was taken which confirmed the narrow width of Emily's bone canals. Consequently, the surgery was abandoned. Emily felt that her mother's knowledge and authority as a practising nurse protected her because "[the doctors] were quite willing to cut me open. In a way we kind of saved ourselves from what could have been a big surgery". Where the

participants' parents worked in health care, they had more authority to challenge the recommendations of doctor's and have their opinions respected. In contrast, the participants whose parents did not work in health care report instances when their parents were not listened to when they sought to raise a concern about their child's treatment.⁸

Emily felt lucky to be treated by experts in OI. "I'm very lucky that I just happened to be born in the city where the specialists were but I know several people with my condition that weren't discovered for quite a while because they weren't born in the right place which is really bad". Emily reports a level of inequality within the health care system, a "postcode lottery" where not all patients have access to the specialists. Participants with chronic and rare medical conditions, who had been treated in specialist children's hospitals, emphasised the importance of being treated by experts in their condition. They report being listened to, valued and included within conversations. They felt knowledgeable about their conditions because of their doctors' expertise and enthusiasm to share their knowledge.

James (group 2) and Hannah (group 1) initially struggled to locate specialists in their conditions. For many years, their doctors had not understood their conditions. Hannah explains that she had felt "pressured" into having medical treatment that she believed to be inappropriate and unnecessary. James described how his medical team were unaware of how to manage his condition resulting in James being bed bound until a specialist could be located. On meeting experts in their conditions, James and Hannah describe feeling relieved. Both felt understood for the first time. They felt the experts were more personable, with a genuine interest in their condition. These doctors would provide detailed explanations of the science behind their condition and share the reasons behind the need for their medical treatment. James felt a greater sense of trust towards his

⁸ William, Anjali, Abigail, Hannah, Kate, Zoe, Faith, Faye and Rachel.

specialists, who, because of their extensive knowledge and experience, portrayed a sense of assurance.

They're coming at it from being an expert and seeing lots of people with your condition, so they know lots of things. You perhaps have to describe things to them less, as they understand it more. They can ask more probing questions on specific areas because they know in depth rather than the overarching questions that you tend to get from GPs. I think that comes across massively and gives that level of assurance, and that level of comfort that this person, you can trust them. You can trust that they are at the forefront of trying to help whole waves of people like yourself and that they have a chance at being able to do it more than others do.

It is notable that participants described a positive doctor-patient relationship when they were treated by experts in their conditions, suggesting that poor doctor-patient relationships are founded on a lack of knowledge, understanding and thus empathy of a child's medical condition.

6.3.1. Wider Health Care Team

Irrespective of whether the participant had a rapport with their doctor, all participants explain that they did not always feel able to share their feelings, worries or concerns with their doctors. Rather, they preferred to confide in and seek advice from their wider health care team. Whilst Emily (group 1), describes a positive relationship with her clinicians, she explained that this relationship was extremely formal and limited to social niceties at the beginning of a consultation. For example, Emily would be asked about school, family and her hobbies. Because Emily was treated in a specialist children's hospital with a multidisciplinary team, Emily had an extensive support network. This network composed of physiotherapists, occupational therapists and clinical nurse specialists. Emily had a particularly close relationship with her physiotherapist who provided her with emotional support.

We would go into the doctor's appointment and come out and then we would be sat in the clinic. I'd be chatting with my physio and it was more kind of natural. I get on with my doctors but for me with the physio especially, she has known me since I was 11 days old, so she really gets me. She also understands what affect it might have on my life. The hospital as a whole made sure that there was a lot of support, it wasn't just you and the doctor. It was unusual that if I was having an appointment it would just to be with my surgeon, that I wouldn't see at least one of my medical team in the hospital. If they saw me, they would come and say "hi". I could just talk to them, so that was really valuable, and it helped me make better decisions. Doctors are aware that when you're in that doctor's room it's a very different environment. I think they are aware that it's hard for them to really know someone. For me it was really useful and whenever I went to an appointment it almost made me less worried because I was going to have the support there. Obviously, my mum's there but sometimes I know that she's upset as well. It was always good having someone who was there for me if I needed it.

For the participants, emotional support was delivered by their wider health care team. In Section 6.2 Liam (group 1) recalled the care and compassion shown by his nurses. He explains, that this level of care is not necessarily attainable with doctors due to the limited time patients spend interacting with them. Nurses "are the ones that take blood, give the medication and see more of you", thus, they are the people with whom children form relationships. Liam explained, the interactions that nurses have with children can have a huge impact on making hospital "a less scary place" and creating "good memories".

Unfortunately, eight participants did not have access to a wider health care team. This was a concern for the participants that had a challenging relationship with their parents and so did not have anyone to talk to. Asked

how she coped, Susan (group 1) explains that she didn't. Instead she would "bottle up" her feelings. Susan believes the lack of support contributed to the severity of her eating disorder.

6.3.2. Consistency and Continuity of care

NICE guidelines recommend that all patients experience consistency and continuity of care.⁹ Eleven participants, across both past-patient groups, experienced and valued consistency in care, having the same medical team, as far as possible, throughout their paediatric health care experience. Those that did not experience consistency in care had acute medical conditions which did not require long term follow up.

Although NICE recommend continuity of care for all patients (adult and paediatric),¹⁰ the participants in this study explained that in their experience, consistency of care is a unique feature of paediatrics which is lacking in adult care. The 13 participants in this study who transitioned to adult services, stated that consistency of care ended once they entered adult health care.

The participants with a chronic health condition benefited the most from consistency in their care. Over time, these participants describe building a comfortable rapport with their medical teams. Participants felt reassured by their doctors' vast knowledge about their medical condition and were impressed by doctors who knew their patients' goals, ambitions, hobbies and interests. As their doctors and wider health care team saw them regularly, they could provide tailored and individualised treatment. Liam (group 1) describes having the same physiotherapist, neurologists and nurses throughout most of his time in paediatric health care. He tells me

⁹ NICE, 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services' (NICE, 2012) <<https://www.nice.org.uk/guidance/cg138/chapter/guidance>> accessed 4 April 2019 at Section 1.4.

¹⁰ *ibid*

that, although consistency in care “is not possible in adult services” due to a high demand and lack of resources, it is necessary for children.

James (group 2) explains the benefit of having consistency in his care:

Seeing a new face every single time, you’re less likely to be open with them. Whereas if you see the same face again and again and again, you treat them like a friend. It was a continuous narrative. It was the same people seeing me and they knew what was going on in my life. We weren’t repeating my history over again. (James, group 2).

Over the course of his treatments, James saw a variety of clinical specialists and local practitioners. He recalls the repetitive nature of these conversations which James believes was caused by a lack of consistency.

You end up having the same conversations so many times. You end up having to repeat stuff, and as we grow older there’s always a greater sort of backlog of everything you’ve got to get through isn’t there?! That’s the script that you’ve got to tell everybody about.

Having the same doctors assisted Abigail (group 1) who found her scans extremely uncomfortable and embarrassing as she became more body conscious during adolescence. She tells me how having the same doctor helped her build a “connection” which made her “feel more comfortable”. Participants describe a link between consistency in their care and a meaningful and trusting relationship with their doctors and wider health care team.

Although, consistency of care was typically a positive experience for the participants, Emily (group 1) recalled how her treatment improved when she had a new consultant after her previous consultant retired. Whilst she had a good relationship with her previous consultant, he had treated her since birth, and therefore Emily felt that his expectations and understanding of her capabilities had not evolved in accordance with her

maturity. On the other hand, Emily's new consultant was keen to listen to her opinion. He encouraged Emily to participate in discussions alongside her parents. This was because he recognised Emily's maturity.

It just so happened that the doctor retired, and he was lovely, but I don't think he would have been the right doctor for me going [forward], because he, in his mind, I would always be that two year old that he first met. I think it's hard on doctors to progress. My new doctor came in...he saw me with fresh eyes.

In retrospect, Emily felt that the length of time her doctor had known her had limited her doctors' expectations of her capability. Similarly, Kate's (group 1) physiotherapists had known her since birth and whilst her therapist was quickly able to assess Kate's needs and design a suitable and effective treatment program, Kate expressed feelings of frustration as her therapist continued to treat her in a "childlike" manner. Participants whose capacity was evolving, yet felt that this was not being recognised by their health care team, saw benefits in changing doctors, nurses and therapists as they matured.

6.4. Parents

All the participants recalled that their parents were present for consultations with their health care teams. In all cases, their mothers took the role of primary carer and decision-maker. Whilst fathers were crucial support, work commitments prevented their regular attendance at consultations and inpatient admissions. Liam (group 1) recalls a strong relationship with both his parents who took an active role and interest in his medical care. However, he describes that his medical needs were met primarily by his mother.

Dad was involved but because he works a lot, and he travels a lot, when it comes to health, or in fact anything else, me and my brother would always go to mum first. Go to mum first, mum knows what she's talking about, mum was the one who stayed up when I

was unwell. Not that [dad] wouldn't. Obviously, he would, but mum was the one who was there, every single time.

Participants explained that during periods of ill-health, they preferred and desired their mother's presence. Whilst their fathers were willing and eager to be their child's primary carer, participants asked that their mothers were present during their medical appointments, surgeries, treatments and investigations. Where a consultation involved receiving scan or test results, their fathers would attend where possible. Aside from the two eldest participants whose mothers did not work outside the home, all the other participants had mothers who were employed outside the home. They would take long periods of time off work to look after their unwell child.

In some instances, the participants' wider family were heavily involved in their health care. Born with Cerebral Palsy, Lee (group 2) required daily physiotherapy. His grandmother would often assist him. James (group 2), diagnosed with ME at the age of 11, frequently sought his grandparents' advice about possible treatment options. It was after one discussion with his grandmother that Liam declined statins: "I'd always grown up with my Grandma telling me how bad statins are and so I remember at that stage saying, 'no I'm not having any statins'. The ingrained opposition towards [statins], what was said by my Grandmother, probably still stays true to this day." Julie (group 4), a General Practitioner, stated it is commonplace for grandparents to attend an outpatient consultation in place of a parent. Where children do not feel comfortable with their parents, they will often invite grandparents, friends and older siblings to their appointments. Such companions, whilst trusted by the paediatric patient, usually do not have parental responsibility and in some cases, may be aged under 18. As Julie explains, this creates a unique challenge for doctors as they do not wish to turn the child away who is seeking medical advice yet are under a duty of care to ensure an adult with parental responsibility consents to any

treatment or examination where a child is not *Gillick* competent or aged 16 or 17.

6.4.1. Parental Support

Fourteen participants described strong and positive relationships with their parents. Throughout their paediatric health care, their parents acted as support and reassurance. For children like James (group 2), whose condition affects his speech, memory and causes word finding difficulties, their mothers would assist them during conversations with their health care team. From the age of 16, James explains it was his decision to have his mother in the room.

I had the option whether to have my mother in the room. I chose to have her there because it was a sense of reassurance. One of my concerns at that age was with ME, you have a thing called 'brain fog', which means that sometimes, you either struggle with the words, or struggle to remember what has been said. So, for me, there has always been that level of reassurance that there was a person in the room, that if I could not fully form what it is I was trying to say, they would be able to help. Or they would be able to remember the salient points.

Parents undertook a practical role, remembering medical information, assisting their child in articulating their concerns to a doctor and in many instances, acting as the voice of the child. Participants describe rarely speaking during consultations. Prior to outpatient appointments and inpatient ward rounds, they would collaborate with their parents, informing them of their concerns and what they wished to articulate to their doctors. During the conversations with the health care professionals, their parents would lead the conversation and "translate" their child's thoughts and feelings into "adult language". Anjali (group 2), was concerned that she would be unable to meaningfully articulate herself in an "adult way" that would be respected by her doctors.

As a child you can't translate all that to an adult. A medical professional is not always listening to everything that you're saying. I used my parents as a translator. I would tell them my opinions and they would basically back me up.

At the heart of the parent-child relationships was trust. Bethany (group 3), recalls the immense trust that she had for her mother who Bethany describes as a "quiet advocate" who provided gentle "encouragement".

I had such a good relationship with my mum. I trusted her. I didn't question it. She was the person I trusted most in the world and I trusted her to do what was right for me and I knew that she wanted me to be healthy and well. If she thought it was a good idea, then I trusted it not to be a bad idea. I'd say she was a quiet advocate. Quiet but reassuring. She wouldn't be one of these mega pushy mums, or she wouldn't be one of these people grabbing the doctor by the throat going "you will make my daughter healthy" but it was, "come on, let's go and get this sorted".

Bethany's mother provided emotional support. Bethany tells me of the many occasions she would talk to her mother about her worries and concerns where her mother would listen and comfort her. On an emotional level, parents were an outlet for the participants who felt comfortable to openly discuss their concerns about their medical conditions with their families. Together they would unpick and work through these worries. Emily (group 1) describes her parents helping her appreciate the bigger picture, putting her fears into perspective. Abigail (group 1) sought great comfort from having another person to share her experience with, who intimately understood what she was going through.

It helps with comfort, emotional support. A relationship between a mum and her daughter is really important. Having that person with you, it's very helpful to have someone there. It's definitely comforting. I've always felt this. It's the support, that they are there

for you, they are going through it with you, they might not have it physically but the emotions are there and they are going through it with you because you are their child.

For most participants, their parents were the only other people to witness and experience the impact of their medical treatment. They would sleep on the hospital floor, be with their child through the extreme side effects of their treatment and be present for each step towards rehabilitation. Parents continue caring for their child once they had been discharged from the hospital. They are the people alongside them through the sleepless nights, anxiety and the highs and lows.

Daniel (group 4) emphasised the expertise that parents build as they support their child during periods of ill-health.

In the majority of cases [parents] have the child's best interests at heart. They know their child far more than I do, they know far more what they want for their child and what the child wants for themselves. So, they'll bring that, they will, I guess, in a sense be advocates for their child so they will often ask some of those hard questions that a child will be unable to ask, so, "what are the side effects?", for example. They might be able to express some of the fears that a child might have. Particularly with disabled children that's even more so. And often they can be a translator of communication, so, where I might be limited, particularly with a child with communication difficulties, in understanding what they are trying to tell me, the parent may end up translating that in effect.

The health care professionals articulated great respect for parents, their expertise and their role in supporting their child throughout their diagnosis, treatment and recovery. The participants' relationships with their parents extended to adult care, testament to the strength of those relationships. Liam (group 1), told me that he is now independently

attending outpatient appointments although he continues to consult his mother prior to appointments to seek her opinion and receive emotional and practical support.

I went to the GP yesterday. I called my mum up before and I said look, "this is what I'm going to say, this is what I'm going to get across, do I need to add anything? Are there any symptoms that you've thought of, that I haven't?" Nowadays I'm far more independent. I will go to consultants and just speak myself. I can't remember the last time she came to an appointment with me. I would call her afterwards and say this is what happened, this is what they said, this is what I need to do. She likes to be kept in the loop but also in case I missed anything.

Although Liam transitioned into adult care, his relationship with his mother continues to be strong. Liam consults his mother because of the expertise she accumulated during the many years of caring for Liam. Participants described how these experiences brought them closer to their parents.

6.4.2. Challenging Parent-Child Relationships

Susan (group 1), Hannah (group 1) and Rachel (group 3) reported challenging relationships with their parents. Susan's and Rachel's parents were absent from their lives and as such, they were responsible for day to day tasks including cooking, cleaning and caring for their young siblings. Hannah's relationship with her parents broke down at the age of nine when her mother and father divorced. Hannah lives with her mother and stated that whilst they attend outpatient appointments together, their relationship is "poor", "we don't get on". Bethany describes a strong relationship with her mother although tells me that she does not have a relationship with her father. Bethany's father suffered from alcoholism which eventually led to her parents' divorce during Bethany's mid-teenage years.

These participants describe that their parents were present during inpatient admissions and outpatient consultations. However, Susan and Rachel recall having to encourage their parents to take them to see their GP or consultants. Aside from Bethany, Susan and Rachel explain how their parents were uninterested in their health care. From the age of eight, Susan developed an eating disorder, gynaecological conditions and in her mid-teenage years, severe headaches. Susan describes her relationship with her parents as “destructive”. Her parents were often absent and unable to care for their children. Susan, being the eldest, took on the household responsibilities such as cleaning, cooking, washing, caring for her siblings, attending her siblings’ parents’ evenings, and taking and collecting them from school. She reports that her parents do not believe in mental health conditions and thus did not recognise that she required medical treatment. Susan recalls attempting to attend her GP appointments alone, which she was prevented from doing by her GP who would not see her without parental support. Susan tells me of the distress she experienced at her parent’s presence during her consultations and explains how they prevented her voice being heard.

As a child they would talk to my parents and not me. I am an expert in my own body and my parents didn’t know shit. I didn’t tell them anything and you’re still asking people who do not know anything about me. I knew in myself that something wasn’t right, and I knew in myself that was an issue. Having parents who do not believe in mental health, who do not believe in stuff like that, they were just like “oh yeah she just eats so much, whatever she’s a fat one”. [Doctors] didn’t try to understand the issue from my perspective, it was all from what my parents saw. [My parents] were just more destructive than helpful.

Like Susan, Hannah and Rachel describe a medical environment where, as children, they are more aware of their symptoms than their parents. Nevertheless, their doctors directed the conversation to their parents. Due

to the poor parent-child relationship, they felt inhibited from speaking openly and honestly to health care professionals when their parents were present and that this often led to an incorrect diagnosis causing a delay in receiving the correct medical treatment. For all these participants, the recollection of poor relationships with their parents and the impact of this on their health care, continues to cause distress.

6.4.3. A Complex Dynamic

Typically, academic literature refers to the decision-making process as a parent – child – health care professional triangle, “in which power shifts back and forth, as it is contested or shared between parents and professionals and, more recently, children”.¹¹ However, the health care professionals have challenged this notion, describing a more complex dynamic. During any decision-making process, health care professionals emphasise that they have to navigate family dynamics, relationships and external support services whilst performing their job to “society’s and GMC’s expectations”. In the majority of circumstances, the assumed doctor-child-parent triangle is embellished with grandparents, older siblings, social services, educators, paediatricians, nurse specialists and general practitioners. Where families are fragmented, this adds another dimension which too must be navigated. Daniel (group 4), a paediatric consultant, uses the example of the ongoing management of a child diagnosed with Attention Deficit Hyperactive Disorder (ADHD) to illustrate the numerous services and professionals involved in any decision-making process.

[The] management of ADHD is often not just the child’s perspective, there is the parents’ and the school’s perspective as well and that adds another dimension where school is clearly saying “this child is not coping”, and the parent may or may not see that, the child may or may not see that. Then you’ve got other situations where the parent is

¹¹ Alderson, *Children’s Consent to Surgery* (n 25) at 34.

saying, “My child is completely out of order and off the rails and I must have him on Ritalin”, and the school is saying, “Well, actually he is an angel in class and gets on with everybody”. Then you’ve got a difference. You’ve got that triangle, but that triangle often has other bits coming off it. I have certainly had situations where estranged parents have disagreed with each other. So, I have had one parent wanting treatment and another parent refusing treatment, and then it comes down to who has primary responsibility and that is not always clear in the law. And there have been other situations where I have passed it back to social services but then it’s been their responsibility to resolve it. A very cohesive family that clearly has good family dynamics and relationships and the parents are clearly acting in the child’s best interests, it’s very different from one which is fragmented.

6.4.4. Parents’ Understanding

Both doctors and participants credit parents for their exceptional understanding and knowledge of their child. Participants with chronic health conditions recall how their parents would spend hours researching and exploring innovative medical treatments and clinical trials. At the age of 11, and after a serious viral infection, James (group 2) developed extreme fatigue and widespread pain which was eventually diagnosed as ME. Due to the rarity of ME, James’s GP struggled to find a leading specialist in the local area and they were unclear on how to manage his symptoms. Consequently, James’s health continued to deteriorate leaving him bed bound. Desperate for answers, James’s mother located an ME specialist. “This was the turning point” James explains. With the assistance of his ME specialists, James began attending school and interacting with his peers.

My mom had done research into ME specialists and found a doctor, the doctor was one of the leading specialists in ME and got us booked in there. I read up on a lot of things. I think my mum did a lot more of the reading and the research, and the understanding.

She helped track down this specialist in [location] so, in some ways, she was slightly more qualified in an aspect than I would have been.

Fifteen participants expressed that their parents were experts in their condition having conducted a significant volume of research in an attempt to appreciate their child's symptoms, what to expect in the future, to seek support from patient groups and to locate specialist teams where their child's GP were unable to. Nine participants had at least one parent who worked in health care. These parents understood the health care system and felt confident and able to navigate it. Those participants whose parents did not work in the health care system, but had a child with a chronic health condition, independently conducted research to find second opinions and specialist doctors. Three participants describe how their parents lacked sufficient understanding and awareness to engage in meaningful discussions with their health care team. Susan (group 1), Rachel (group 3) and Hannah (group 1) explain that their challenging parent-child relationship was a contributing factor to their parents' lack of knowledge. Hannah recalls having to answer questions on behalf of her mother during consultations.

They would talk to my mum. My mum would spend the entire time looking at me so to try and direct the conversation to me. It was basically a triangle and I'd spend the entire time looking at the consultant and they would talk about me. I remember now this was one of the main reasons why we left [location], they'd talk about me as if I wasn't there. [My mother] wouldn't really say anything. She would just nod. We felt very like we couldn't say anything. It was futile.

Despite her mother's lack of understanding, Hannah describes how her mother contacted a local Cleft Palate support group to find a specialist when they had concerns about the proposed treatment plan from their local doctor. Abigail (group 1), had a positive relationship with her parents,

however, felt that her mother and father were unaware of her precise diagnosis or the complications associated with her condition.

They were making decisions on my behalf because I was a child.

They knew a lot more about my condition than I did. I found this a little bit weird because I think they didn't know exactly what it was because it was very medical. The transition thing, that's when I was told like the name of my condition, what it really is and everything.

Abigail remembers her parents' understanding that she had a chronic and life-threatening congenital heart disease but that it was not until Abigail's transition to adult services where she was informed of her diagnosis, that her parents understood Abigail's diagnosis and the necessary life-style changes required to protect her heart.

6.5. Conclusion

The 18 past paediatric patients were treated for a wide variety of medical conditions across ten departments. Participants underwent surgeries, procedures, IV treatments, in addition to scans, investigations and other procedures. All participants recalled a positive clinical environment with friendly and supportive staff and nurses. Participants aged 36 and above, detailed a similar clinical environment to participants younger than 36. However, there were fundamental differences in the running and management of paediatric wards. For example, for participants in Group 3, parents were unable to remain with their child during an inpatient admission and visiting times were limited.

With regards to the relationship between doctors and children, half of the participants describe a positive relationship with their doctors. All the participants preferred and valued the company of their wider medical team who, in the main, were their core support network for themselves and their families. In the main, participants valued consistency within their care, and report that it created trust and strengthened the relationships with their medical team.

In all cases, parents were present for all consultations with doctors. After the initial niceties, consultations would involve a dialogue primarily between parent and doctor. In the main, parents were viewed as the main decision-maker throughout their child's paediatric health care. This only changed once the participant reached adult services. However, most of the participants desired greater participation within their consultations. They explain there are two primary reasons behind their lack of participation: (i) parents desire to take the lead in conversations and (ii) doctors predominantly direct the conversation, questions and decisions towards parents.

Despite this, most participants valued their parents' participation in their health care, describing them as a translator, supporter and advocate. Four participants detailed a challenging parent-child dynamic. Whilst Bethany did not feel that her poor relationship with her father impacted her medical care, the remaining three participants were concerned that treatment opportunities and diagnoses were missed as a result of the breakdown in their parent-child relationship. Health care professionals emphasised the impact of a strong parent-child relationship on the treatment and care of a child. They explain that where this is fractured, particularly when fractures occur between parents, medical decisions become more complex. In addition, health care professionals challenged the assumed parent- doctor- child triangle, stating that medical decisions involve many more services and individuals than previously assumed. This is particularly the case in families with challenging parent-child relationships.

With these findings in mind, the following chapter will delve deeper into the communication that a child has with their health care professionals. I will also consider what information the participants received, including the source of such information and the role of the child in the decision-making process.

7. A CHILD'S PARTICIPATION IN THEIR HEALTH CARE

7.1. Introduction

This Chapter will present the empirical evidence about how the interviewees participated in their health care and the long-and-short-term impacts of their participation (or lack of). The empirical evidence identified three broad methods of participation: communication, information and decision-making.

Section 7.2 considers the communication between the doctor, the participant and their parents. Section 7.3 asks how much information was given to the participants, what are the sources of this information and are the participants satisfied with this information. Section 7.4 discusses the role of the participants in the decision-making process. Section 7.5 focuses on the 'lived experiences' of the participants as they transitioned from paediatric to adult health care. Finally, Section 7.6 conducts a comparative analysis between the 'lived experiences' of the participants in the three groups of past-paediatric patients.

7.2. Communication with Health Care Professionals

NICE states that effective communication with health care professionals impacts the extent to which patients' participate in their health care.¹

Although in relation to adults, NICE reports that good communication is an essential tool in "enabling patients to actively participate in their care".²

This section considers how the past-patient participants in this study participated in their health care and the meaning these participants attribute to their experiences.

¹ NICE, 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services' (NICE, 2012) <
<https://www.nice.org.uk/guidance/cg138/chapter/guidance>> accessed 4 April 2019 at Section 1.5.

² Ibid.

7.2.1 Dialogue with Health Care Professionals

Describing a typical conversation, the participants' detailed that their health care teams would primarily engage in a dialogue with their parents. Zoe (group 1) recalls her doctors directing their questions and explanations to her parents in formal manner and in adult language that excluded Zoe from the conversation.

I do think it was mainly my mum talking to the doctor and engaging in what was going on and I was sort of accepting it. I was the recipient rather than part of the conversation.

Obviously, my medical terminology is good for the condition that I have but what I know is very narrow and they will use terms that I haven't heard yet and be so professional that it's almost quite insulting. If the doctors had spoken more to me and I had been encouraged to be involved, I was quite a mature child, I think I could have been involved from a much younger age, so 11 upwards.

Due to Zoe's complex and life-threatening medical condition, Zoe's mother desired active participation, "My mum was so nosy and involved in it all. She would want to know everything so she would be part of the conversation." Having a child with a life-threatening medical condition left her mother feeling protective of Zoe. She took on the responsibility for Zoe's medications, home treatments, physiotherapy and supporting her daughter during inpatient admissions and outpatient clinics. Zoe explains that her doctors would speak to both of them and although they did not address Zoe as much as she desired, she feels this was, in part, because of her mother's need to take an active role in her health care. Zoe believes this was a result of her mother's anxieties associated with looking after a seriously unwell child.

Parental health anxieties were a common feature in all the participants' narratives. Before his hospital admission at the age of eight, Logan (group 2), was a healthy and active child. His sudden episode of ill-health and the

continued deterioration in his condition caused great distress for his family, motivating them to take the lead in dialogues with doctors. Logan believes that had his doctors engaged with him, unlike Zoe, he would not have been able to participate due to his health.

I was just basically floppy and in bed and not really that involved. Limitations set by my capacity for understanding and I guess the position I was in. I was in bed. I couldn't move around. They would come and talk to me, but mostly they would talk to my mum, so I would just be sat there. I wasn't in a position where I would want to pay attention. And, also scared to be honest, and genuinely in a lot of pain, a lot of the time. So my thought process wouldn't go beyond this hurts, I need some tablets for it.

The extent to which the participants were spoken to by their doctors varied. For 16 participants, communication with doctors was unusual. Aged eight, Maddison (group 2), was about to undergo a major surgical procedure to correct the muscles in her neck. This required intense physiotherapy for up to a year post surgery. Whilst the main discussions were between consultants and her parents, Maddison recalls the one time she was spoken to by a consultant.

I do remember the consultant who spoke directly to me. I didn't feel that I was being treated as a kid who didn't understand stuff. Clearly, he must of had conversations with my parents, but he also spoke directly to me, which I remember thinking, "I feel quite kind of grown up that he assumed that I would understand what he was kind of saying". I remember him explaining what was going to happen in an age appropriate way. I don't remember being particularly scared by it. I think there was some explanation of what needed to be done. I know there was mention of the fact that I would need physio afterwards. I trusted him, and I liked the fact that he talked to me directly, because previously when I had been to the doctors, I hadn't particularly felt that. He addressed me by

name and talked to me directly. I remember being sort of quite impressed.

For Maddison, as with the rest of the participants, being spoken to directly was unfamiliar. Maddison details how her GP would normally exclude her from the conversation.

It was more talking over my head, mainly spoke to my mum. I do remember having a consultation with my mum and dad when they were there, but he very much talked to them rather than to me, I don't really remember my GP talking directly to me at all, but I do remember the consultant.

Sixteen participants described their participation during outpatient clinics until the age of 16 as limited to "reporting their symptoms and wellbeing". Liam (group 1) was asked by his doctors to express how his week had been in terms of the symptoms he was experiencing and the effect that this had on his quality of life. At school, Liam's teachers developed a sticker system to inform his teachers of his pain levels caused by his Juvenile Arthritis. During hospital outpatient appointments Liam shared his weekly symptom log.

That was good because that encouraged me to say to consultants, "Look, the past couple of days I have average faces or sad faces" and then they came to learn what that meant.

During his teenage years, Liam verbalised his experiences, increasingly having greater input.

I would go into the consultation; I would sit down and [mum] would rattle off everything that happened. Obviously, she would look at me for collaboration as I got older and then eventually, as I sort of reached my mid-teens, so we are talking about 14,15, I sort of said "I can go now". In fact, I probably said it a bit earlier than that, taking responsibility for telling the doctors what had happened in

the past months, days, weeks. Keeping them informed and then eventually, it came to a point where my mum wouldn't be in the room. That was 16,17. She was a bit clingy my mum.

Emily (group 1), was the only participant to report feeling "at the centre of discussions". Emily's case was unique compared to the other participants as her symptom reports were crucial in determining the dosage and frequency of her IV infusions.

From the age of 10 I was like "oh shall we go for four months rather than three say?", because it was an IV and I'd be like, "oh yeah because I'm feeling alright at the moment". And then, especially when I went through teenage years I had it a bit more often because of puberty, I don't know how it works but somehow it affects your genes. It made me more tired, so I had [IV treatments] more often. It was just based on how I was feeling at that point rather than what medically was in front of them.

Fourteen participants describe doctors asking questions such as "does this hurt?" which provided information to assist a diagnosis and treatment plan. William (group 3) had a hip condition caused by an accident at the age of eight. He regularly attended outpatient orthopaedic appointments at his local hospital. William describes feeling like "an object of medical interest" stating that he was only spoken to during examinations.

[The doctor] didn't really talk to me or deal with me. He spoke to my parents. He dealt with my mum. He was very clinical, is the best way of describing it, in how he dealt with me. He went through physical examination with me and all the manipulation of my leg, "Does this hurt, does that hurt, what if I do this, is it a problem for you, can you cope?", but that was about it. There was no, "How are you feeling, or do you like to play football?" or anything which could give him a picture of activity. They explained what they were going to do in X-ray because they needed my participation. Move

my legs in the correct format and having my body in the right shape to be X-rayed to see the right things.

Julie and Jonathan (group 4) explain that, in a normal conversation, a doctor must give both the parent and child an opportunity to be heard. First, they state that doctors should ask the child to provide their story. They tell me that it is useful hearing the narrative from the child as the parent may be stressed and anxious, therefore, may have missed important components. Equally, some parents may be unduly concerned about their child's symptoms, thus placing greater than necessary emphasis on such symptoms. Julie explains that this is understandable, and often occurs where a parent has another child who has been seriously unwell, or they themselves had a life-threatening medical condition as a child. As such, it is always important to hear from the child. Where a child is shy and hesitant to tell their story, the doctors explain that they will ask about school, the child's hobbies and interests to encourage the child to talk about something that they are confident and comfortable with. This then allows them to open up to talk about their medical concern. Second, Julie and Jonathan describe entering into a dialogue with the child's parents about the treatment plan.

William (group 3) felt that he would have preferred to have been asked his opinions and thoughts instead of merely reporting symptoms or complying with examinations. All participants recall that their opinions were rarely sought. During her appointments with a dietician, Susan (group 1), describes the conversation being between her parents and doctors. Her health care team were attempting to understand where Susan's relationship with food had originated. Susan was keen to share her experiences with the consultants, and therefore, feels angry that her opinion was not considered. Especially as she had lived with this condition for many years and felt "best placed" to inform them.

I would have liked them to have asked me questions about how I was feeling, my relationship to food, not just how much I was

eating. I would have liked them to ask me why I think I was experiencing pain. I would have liked them to ask me about my compulsive exercising, because it's on record, they know it is an issue. They didn't ask for my opinion - they basically just asked me questions and I would tell them, but they didn't let me explain or they didn't let me actually engage with them. They treat me like I was stupid. It's weird if you think about it. The person themselves is the expert in their own medical history, what's happening in their own body, but they didn't give me that sort of insight, they didn't ask for that insight. They didn't care about it to be honest.

I'm angry. I'm very angry because I'm now at a point where I've done so much damage to myself and it could have been prevented. It could have very easily been prevented if they were actually engaging with me.

Participants describe how they are experts in their own health, and as such, they feel that their opinions ought to have been sought due to the valuable insight they could share. As children, they were keen to share their concerns with their health care team and felt frustrated when their opinions were not sought. Hannah (group 1) felt that her doctors "had no time for me or my opinions" leading to a deep frustration, "I felt like [my doctor] didn't respect me at all. I used to feel very angry and frustrated when I came out of those appointments".

Four participants recall their parents encouraging them to participate.³ Emily describes how her mother initiated her independence, to prepare Emily for adult care where health care professionals would expect Emily to be the decision maker. Emily's mother was wary of the potential damage a "sudden" transition to adult services could cause. Her mother may have had an increased awareness about the need to facilitate Emily's

³ Emily, Kate, Liam and Rachel.

participation because she was a nurse. Emily credits her parents as the reason her transition to adult care was smooth.

It was like “well now you’re a bit older we are going to try and do your appointments yourself”. My mum came in with me and she left halfway, we had a half and half thing. I am quite happy on my own unless it’s something quite emotional. Because my condition is long term as well, my parents knew that at some point I was going to have to do it myself. And if they did it kind of suddenly...if I was having a lot of assistance and then all of a sudden I went to the adult hospital and I was having nothing, that wasn’t going to be effective. I think they realised that it needed to be a gradual process.

James (group 2) recalled his doctors encouraging his participation in the discussions by deflecting questions back to him.

I think that he would always try and answer towards me and try and reflect the question back on me. I think that probably my mum at every session she would be the one that would very much talk about the issues that had happened but then he would reflect it back onto me and have those questions with me. I think that it was nice for him to reflect it back at me. I think that at that stage in my life that I probably needed that support and strength from my mum to be able to put it in.

These participants gradually increased their involvement, taking the lead in consultations prior to the transition from child to adult services. The remaining 11 participants describe their doctors continuing to engage with their parents until they turned 18 years of age. Moreover, where the participant would be required to assent to their medical treatment, the dialogue would extend to the risks and benefits of a procedure and the treatment plan. However, usually this treatment plan had already been

established and doctors were expecting the child to comply. Information was given in this instance to ensure compliance.

7.2.2. Being Told What Will Happen

Participants report that doctors have a “blanket way” of treating children with the same condition. Once diagnosed, their doctors immediately commenced a standard treatment plan with parental agreement.

Participants described the planning process as fast moving, with unwavering momentum, where it is extremely challenging to stop or change direction. Participants recall how their consultants would approach their parents with the treatment plans in a tone of informing their parents of what *will* happen next, under the assumption that parents would consent and that the child would comply.

For the participants who developed their condition during their childhood and early teenage years, their first experience of paediatric health care was being informed by a doctor of a treatment plan, pre-agreed with their parents prior to child being informed. At the age of 12, Anjali (group 2), was referred to her local A&E department by her GP. After an urgent MRI scan showing a cyst in the fourth ventricle, Anjali was transferred by ambulance to a specialist children’s hospital. She recalls being informed that she would be undergoing a serious operation later that day.

I remember being in the hospital, that first scan at midnight and then waking up the next morning to the consultants sitting us down saying “there’s a cyst, we need to remove it”. That’s the outcome of this situation. My parents were sat down and I wasn’t told initially. Then when it was explained to me, my consultant did tell me but with my parents. They didn’t at no *[sic]* point tell me that if you don’t have the surgery you will die which is what they had told my parents. I felt very out of control. It felt as though I wasn’t involved in anything. In my mind, I wasn’t been treated like I knew what was going on. I was intelligent and smart enough to understand what was happening, so that was quite hard. It’s a sense of feeling out of

control of the situation, and even though my parents were always very supportive, and they would run every decision past me, there was no real control over the situation, they were gonna do what they were gonna do. My parents, I don't think they had a decision either. That's the impression I got. It very much felt like this is what's going to happen, you're just going to have to deal with it and that was that.

Due to the medical urgency of Anjali's life-threatening brain condition, her doctors implemented a treatment plan without seeking Anjali's assent. Moreover, the doctors informed her parents, seeking their agreement before approaching Anjali. Chris (group 4), an immunologist explains the theory behind this technique.

Usually what you'd do is share information first, and then, once you've got a plan, a strategy, then the child would become involved at that point. Because otherwise what would happen is, if you are going off at tangents, the child has the opportunity to put a spanner in the works in multiple different ways. So usually it is about developing consensus first and then bringing the child on board and trying to persuade them it's a good idea.

At the time Anjali recalls feeling angry and frustrated, that she ought to have been informed at the same time as her parents. She explains to me that her parents and doctors presented a united front when informing her of what was "going to happen", making it challenging for her to object.

I think it would have been at the time I definitely felt as though I could make a decision. That I should have been told first. You know, it's me, it's my body and not my mum and dad's body.

The imposition of a treatment plan left Anjali feeling a loss of control and disempowered. Anjali acknowledged that had she been involved in the decision-making process, she would have agreed with the proposed treatment, however, for Anjali, there is a fundamental difference from

being “told” what is going to happen and being “asked” her opinion. Similarly, James felt that his doctors were focused on directing care and implementing a pre-determined plan, rather than assisting his understanding of his diagnosis and seeking his consent to the treatment plan.

I understood the basics of it, but I didn’t really understand it. I knew the impacts that it had on me. I didn’t really understand what may be causing it or how I could potentially alleviate some of the symptoms, it was just very much directed rather than understanding. I’ve seen doctors for issues impacting mental health where I think that they have been very much “right this is what you need to do”. It feels very much straight down the line and not that friendly conversation. It felt very stern and strict and not the same level of amicability that I was perhaps used to growing up. It was like “bang, bang, bang this is what you need to do”. There’s plenty of times in life in the working world where I want people to be “bang bang bang” you know, get this all sorted, end the meeting as quickly as you can, everyone knows their actions, go away. When it comes to healthcare, I’m not sure I want that action orientated approach. I very much want to feel as if somebody’s going to give me a bit of comfort, but also be acting in a way where it feels like they’re doing what is in the best interests of my health, which I don’t think action orientated ways of doing things is.

Participants diagnosed with their condition before or shortly after birth also describe being directed and lacking control over their health care. However, they did not report strong feelings either way. Having already been on an established and predetermined treatment plan for many years, these participants accepted direction as the norm, not realising that they could challenge or question the established treatment plans. Zoe (group 1) informs me how her life was being made to fit around her treatment rather than her treatment being made to fit around her life.

I was told that I wasn't very well and needed to come into hospital. It wasn't, "We don't think you're doing very well; do you want to come into hospital?" It was very much more this is happening. It would just be more, "You need to come into hospital now". So, I would be in over my GCSEs and they wouldn't say, "Would you like to sit your GCSEs in the school then work it out?" or anything like that. My life fitted around my treatments. Because I have been doing it all my life, it's just been how I've grown up and never stopped to question it.

Unlike the participants entering the health care system later in their childhood, these participants expressed that direction of their health care was to be expected. Moreover, whilst they felt excluded from the decision-making process, they did not express the same injustice the other participants described.

7.2.3 Authority

Whilst most participants describe having a sound relationship with their health care teams, when discussing their health care, all participants describe feeling uncomfortable around their doctors, unable to ask questions and challenge decisions. Participants reported complying with treatment because they were "worried" about being perceived as a "challenging patient". They describe their health care professionals as experts and explained that they felt inferior to this medical knowledge. Susan (group 1), was brought up in a Nigerian culture and tells me how her upbringing instilled in her that children do not challenge, interrupt or contradict adults, including doctors. During discussions about her medical treatment, Susan felt unable to honestly communicate with her doctors.

It is very disempowering being in that situation because in high school or in general society as a child, you're not taught to speak up for your own rights. You're not taught what your rights are, and you're not taught to speak up. From my perspective coming from a Nigerian culture, it's very authoritative where children do not talk,

they're not talked to. It's like, "I didn't ask you to speak, so don't talk to me". It's very "respect your elders", if they are saying something, even if it's wrong, do not intervene, mind your own business. I feel very disempowered; I feel very angry. Cause obviously I get that I was a child and didn't understand the whole technical bases of what was happening but at the same time, even as a child, you do have an awareness of what is happening, when it's happening, you know. As a child, I didn't know that I could ask... because they're doctors, I can't ask them what I need.

Susan's awareness of authority in the family home translated into health care: a setting where doctors would only speak to Susan's parents, where she was not asked, included in the consultations nor approached about her opinions. For Susan, these experiences reinforced the notion of authority and she felt inferior to adults. Consequently, Susan's engagement with the health service diminished. All participants reported that they were not in a position to decline or challenge therapeutic medical treatment proposed to them because the doctors are "the experts". Lee (group 2) recalls feeling inferior to his consultants. He describes feeling unable to ask questions because he does not have enough knowledge to meaningfully contribute to the conversation. Participants reported "going along" with the medical treatment even in instances where they felt it was not right for them. Kate (group 1) has Spina Bifida. As a child, Kate's doctors and physiotherapists proposed extensive physiotherapy. Their aim was to maintain Kate's ability to walk for as long as possible. At the time, Kate relied upon a wheelchair and walker to mobilise, however, her medical team wished to transfer her to crutches due to their flexibility. Because of the instability of crutches and the difficulty in moving around a school building, Kate felt unsafe, regularly tripping over and injuring herself. Moreover, the intensive physiotherapy was causing severe fatigue and pain. As a result, Kate did not socialise and rarely left the house. Kate did not believe that the effort required to walk on crutches outweighed the benefits from the

physiotherapy. Kate wished to decline the new physiotherapy regime. She felt that her doctors desired for her the ability to walk, similarly to her peers. However, Kate who had accepted her disability as a core part of her identity, did not believe that the benefits outweighed the negatives from the proposed treatment. Nevertheless, Kate was unable to communicate her inner conflict, concerns and thoughts to her medical team due to their status as experts in her condition.

I think they have wanted me to be able to live my life doing things that I would do without conditions. I think partly there was a bit of this, "Oh we want you to be able to keep walking". I'd wanted to bring in my chair, it took me a long time to have that discussion even saying, "Actually I want to do this". In the appointment I probably would say, "Yeah 'I'll do that" and then I just don't do it. I think because as a child you have this professional image. I suppose if you're at school you listen to your teachers and it's kind of the same thing as with your doctor. And then as a teenager I suppose you start to shift those authority boundaries a bit and be like, "No I can say my opinion a bit more". I think it's partly a growing up thing. I don't think I was super open with either [my parents or doctors]. I was a lot more open with my parents for sure. There was a lot more open discussion. I was still keeping it to myself, but with doctors it was definitely a different thing than talking to my parents. You kind of feel that they are the expert in it. You feel it's wrong to go against a doctor's opinion. You feel you should do that, but I didn't necessarily always agree with their opinion. I would do my own thing at home even if I'd said, "Oh yeah I'd do it" in the session. As an adult you are able to say no and have that opinion respected. When you're a child or a teenager and you don't do what they want, it's their job to convince you it's the right thing.

Kate felt powerless and inferior preventing her from openly discussing her concerns. She felt the role of health care professional was to "convince"

her that she ought to follow their treatment plan. Like the majority of participants, Kate did not verbally express her thoughts through fear of being labelled a “difficult patient”. However, this fear of authority did not deter Kate from not complying with her treatment program. Instead, Kate communicated her dissatisfaction by non-compliance. In Kate’s experience, she did not feel that her health care professionals considered her a “difficult patient”. Kate’s health care team may have misinterpreted her non-compliance as laziness thus, not ideal for the amelioration of her condition, but not confrontational to their treatment plans.

As Zoe (group 1) reached adolescence, she describes growing in maturity and developing her own opinions that conflicted with her health care team. Zoe feared challenging authorities, in the belief that she would be denied treatment options.

The way the doctors give you the options and give you the treatments, it’s up to them. I wouldn’t know how to force more involvement into the situation, and when something is presented to you, I would find it quite difficult to reject it. Just because they think I’m impatient, or because I might have some weird motivation behind it. I would be worried that they would block me from other treatments. I just want to be a good patient; someone who does all their treatments.

Zoe shared that she had never had the opportunity to be involved in the decision-making process and had always complied with the process. Therefore, to challenge medical professionals caused concern that she may be rejected by her health care team. Fearing being “blocked” out of new treatment options, Zoe states that she did not express her opinion until she reached adult services where, like Kate, she felt safe in the knowledge that her decision had to be respected.

7.3. Information

| Satisfied | Dissatisfied | Neutral |
|-------------------------------|---|-------------------------------|
| 4: Emily, Maddison, Liam, Lee | 10: James, William, Anjali, Bethany, Susan, Hannah, Kate, Faye, Megan, Rachel | 4: Abigail, Faith, Zoe, Logan |

| Table 7.2: Sources of information | | | | | | |
|--|---|---|--|-----------|------------|------------------------|
| Child Led | | Parent led | Doctor and Health Care Team Led | | | |
| Personal research | Asking questions | Parents | Doctors and health care team | Leaflets | Letters | Scan results |
| 4: Susan, Anjali, Abigail, Emily | 6: James, William, Anjali, Emily, Megan, Rachel | 11: Abigail, Emily, Maddison, Kate, Lee, Zoe, Bethany, Liam, William, Faye, | 4: Emily, Maddison, Hannah, Lee Faith, Liam, Zoe | 1: Anjali | 1: Abigail | 3: Emily, Hannah, Liam |

Valid consent requires a child to be informed. This section investigates who informs the child, the importance of informing children and the child's satisfaction with this information. Tables 7.1 and 7.2 report the results.

| | | | | | | |
|--|--|-------|--|--|--|--|
| | | Faith | | | | |
|--|--|-------|--|--|--|--|

7.3.1 The “Delicate Balance Between Meaningful Information and Overload”

The GMC cites the exchange of information between doctor and patient as “central to good decision making”⁴. Health care professionals are expected to inform patients about their diagnosis, proposed investigations and treatments. The risks and benefits of such treatments are to be presented in a “clear”⁵ and “accurate”⁶ manner, which patients can understand⁷. The extent of disclosure depends on the patient’s individual characteristics, including their capability to understand. The GMC explains that “children and young people usually want or need to know about their illnesses and what is likely to happen to them in the future.”⁸ Chris (group 4), a paediatric consultant for 30 years, describes how over the course of his career, there has been an increasing emphasis placed on informing children. Despite this, Chris tells me that there remains no standards or guidelines detailing how to inform children. Consequently, there is a significant variation in the extent to which children are being informed.

⁴ GMC, ‘Consent: Patients and Doctors Making Decisions Together, Part 2: Making Decisions about Investigations and Treatment’ (GMC, 2 June 2008) <<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/consent>> accessed 17 January 2018.

⁵ Ibid.

⁶ Ibid.

⁷ Ibid.

⁸ GMC, ‘Introduction, 0-18 years: guidance for all doctors’ <<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/introduction>> accessed 16 June 2019) at para 17.

Daniel (group 4) highlights the delicate balance between providing the right amount of information to a child without overloading them.

With drug treatment, knowing the whole range of side effects that could occur in relation to a particular drug, how do we convey all of that without overloading people? Consent forms; you want to try and cover everything comprehensively, but, the more you try and do that, the more unwieldy it becomes, and actually becomes self-defeating because you are overloading. So, getting that balance between appropriate informed consent and overload is a real challenge, with that added complexity of the developmental stage and level. And I mean, for example, all the drug information leaflets will list coma and death as potential side effects. Now the last thing you want to say to a child is that you might be in a coma or you might die! It's very, very unlikely. I think there's a huge dilemma here, because prospectively, people don't want to know too much, but retrospectively, if a child dies and they haven't been warned that it is a potential complication of the treatment, then [their parents] will tear you apart.

Amongst the medical professionals interviewed for this project, there was a concern that they are "treading a very fine rope" between meeting the guidance and avoiding litigation. Daniel explains how society's expectations of doctors have changed during his 25-year career. He is now expected to fully inform patients, record all information given to patients in medical notes and at the same time, balance the need to protect patients from unnecessary worry and anxiety.

It can get overwhelming at times, and inevitably I don't think we do fulfil all the expectations, and we do accept that there's a risk, in that the next inspection might tear us apart for that, but that in the majority of cases that's going to be ok.

Asked how he deals with this dilemma in clinical practice, Daniel informs me that he and his colleagues will provide a basic level of information to the child but will only provide additional information if a child asks for it.

7.3.2. Absence of Information

Asked how satisfied the participants felt with the information that they received as a child, ten participants reported feeling dissatisfied, predominantly due to an absence of information. Bethany (group 3) was eight years old when she had her first blood test at the local hospital in what she describes as a “deeply unpleasant” experience. Accompanied by her mother, Bethany recalls not being informed about the forthcoming procedure.

There was no real talking through the procedure. There was no sense of actually this is something somebody’s doing to my body...there was no sense of me being part of the process. There was no explanation as this was happening. There was me just sitting there and this thing just being, not gently pushed into a vein, but dug into my flesh, wiggled around and I’m just watching my blood go like this [illustrates blood going out of needle]. And then just complete shock. There was no “don’t worry” or reassurance or “you might want to look at your mum, or you might want to take a deep breath now” Nothing.

For Bethany, who describes herself as a “smart” and “engaged child with an interest in how things worked and a desire and curiosity for information”, an absence of information and preparation time led to a feeling of violation of her bodily integrity.

I definitely wouldn’t have known about bodily integrity or violation at that point in time but I knew that something had got through to me in a way that I hadn’t wanted it to. That felt really bad. I was technically kind of psychologically traumatised by it because of the fact it wasn’t explained to me properly. It was deeply unpleasant, and I actually went into shock and had a panic attack after.

Bethany identifies this event as the cause of her life-long needle phobia. Similarly, at 15 years old, and during what was expected to be a routine appointment to discuss further treatment for her ongoing eye condition, Anjali (group 2) underwent a minor operation under local anaesthetic. Previously, Anjali's Botox injections had been planned and conducted under general anaesthetic. Anjali explains that neither herself nor her mother, were aware that she would be undergoing this procedure on that day.

I had no preparation time... I was going in for [the consultation] to just say, "Yes, it's not fixed". But [the procedure] was on the spot. Nobody had been told, my parents hadn't been told, I hadn't been told and it was very traumatic because I hadn't had time to mentally prepare for that.

At the time I was really angry! I felt like I had completely lost trust in my consultant. Kind of in the whole process, I just didn't trust anybody then, I didn't feel that they were doing what was right for me. I felt like I had been let down by these people who were meant to be caring for me.

Anjali's perception of her medical team shifted from trust to apprehension. Eventually, the mistrust caused a breakdown in the doctor-patient relationship causing Anjali's parents to seek a second opinion shortly after this event. Susan (group 1) also expressed that an absence of information led to an increase in anxiety. After undergoing a CT scan, Susan was not informed of the results until she enquired many months later.

When you have no idea of what's happening it could be anything. And if you do not know what it is, then you don't know how to act. For instance, with my muscle pain, I didn't know what it was, so I made the pain worse by exercising on it. I could have arthritis, I could have fibromyalgia, I could have something that's chronic that could literally be there for the rest of my life or I could have

something that has a simple treatment to do and it could be fine. There's just that much scope. So, having that answer, being able to know there's nothing wrong, your body's just doing what bodies do and sometimes being like "Yes this is what's wrong you know".

I would have liked to know the risks. I just wanted a CT scan, but I didn't even know what a CT scan was. I would have liked if they'd told me, "This is what we'll be doing, this is how it happens, this is what you should expect, are you happy with this?"

Although, a complete absence of information is rare, Chris (group 4), a paediatrician, explains a lack of information as described by the participants is not uncommon nor limited to paediatric health care.

One of the GP's said, "One of my commonest things is a patient will come to me with a discharge summary and get me to explain what it means". And that struck me as really worrying, particularly if somebody has had a surgical procedure and they are then wanting someone to explain what the surgical procedure has been. Because it suggests to me that the consent that they gave to the operation wasn't full and informed. I think it's an area that we really need to work on...I can remember when I first started, this is back a long time ago, back in 1983, we would have to take consent off about 120 day cases per week. You would go round taking 40, 50 consents in about less than half an hour. You would spend a minute each. You were basically saying, "Do you want the operation or not? Sign on the dotted line". There's no way that you had the time to go through fully informed consent. The assumption was that it had been explained to you beforehand, in the outpatient clinic, and this was just the formal procedure of doing that. And you were doing it after you had checked the person's heart and lungs were ok for the anaesthetic. There was a big assumption being made that the explanation had been given beforehand.

Asked whether this assumption was still present in today's healthcare, Chris stated:

I think a lot of surgeons do like to explain things in clinic, but if you go to something like an orthopaedic clinic and they've got a three-hour clinic and they've got 80 people to see, then it means this business of taking fully informed consent is going to be a difficult thing. You've got a broken leg, it needs to be fixed, you need an operation, fair enough, sign on the dotted line.

Chris explains that a challenge for health care professionals is assessing how much a patient understands and therefore, how much information you ought to give, particularly where the patient is unknown to the doctor or does not disclose a lack of understanding.

Really it is a question of getting to know the person well enough. Because what you are talking about is trying to get two minds as one. That's what it boils down to. And in order to understand a person, you need to get to know them. You need to get some feel for how they are understanding something. And often we make assumptions about the level of knowledge that people have. Secondly, people may be unwilling to admit that they don't know something. So, they will be busy sort of doing the nodding dog stuff and saying, "Oh yes I fully understand, thank you doctor you explained that really clearly", and you ask them some later question which shows that they haven't a clue of what you just said. But they just want to sign the form and get on with it. What often happens, is that you go as far as you think is necessary on your individual instincts and it depends a bit on the procedure. As I've mentioned before there is a spectrum from implied consent right the way through to formal consent. And the more serious the procedure, the more serious the process, the more you go through it formally. If it's just a routine thing then you tend to be much more at the end of the spectrum.

The health care professionals stated that the extent to which patients are informed varies as to the complexity and gravity of the medical procedure; the more serious a procedure the more important it is to fully inform a patient. However, where the procedure is routine, there is less pressure and necessity to ensure a sufficient level of understanding. All the health care professionals openly recognised that most patients only receive partial information, and that in paediatrics, it is not uncommon for children to be uninformed. Whilst importance is placed on the delicate balance between meaningful information and overload, in this study, the participants often received no information and doctors in group 4 explained that this finding is commonplace.

7.3.3. Sources of Information

Where participants were informed, as table 7.2 illustrates, a wide variety of sources are used; the most common source were parents. Maddison (group 2) recalls and valued the discussions that she had with her mother prior to the surgical procedure.

When I was eight, I do remember quite a bit of discussion with my mum explaining that I was going to need an operation, and that it was going to be important, and I don't remember feeling scared. I knew that there was something wrong that needed to be corrected because it was becoming quite obvious, in photos mainly, actually that I was a bit kind of lopsided. So, I knew it had to be done really. I think my mum explained that I needed to go into hospital, but that it wasn't something I needed to be concerned about. I do remember having a clear idea that was going to happen.

For most participants, the journey to and from hospital was a common place to talk about the outpatient appointments or inpatient admissions, sharing concerns with their parents and receiving information.

Occasionally, Abigail (group 1) asked her parents for information, however, she did so sparingly out of concern that she may offend her parents who found the subject of her health challenging. In the main, Abigail states that

she did not desire information, however, as she entered adolescence and became body conscious, she sought to understand the stories behind her scars in order to make sense of her condition. Abigail felt that her parents were open and honest.

[Talking to my parents] helped me understand because when I was younger, I had a lot of confidence issues because of my scars. I had two operations, so I've got two scars. I had a lot of confidence issues with that. There were times when I went to [my parents] to try and understand why I have them, and it definitely did help. I've actually asked my dad last week what I was like right after the operation, how I was in hospital, little things like that. I've never sort of held back any questions that I've had. They'll always answer it, but there is an element where I do feel guilty because, for my parents it must hurt a lot knowing your child's at risk. So, I do feel a little bit guilty asking.

Abigail states that her parents were initially her only source of information. As she approached adulthood, Abigail received information about her condition via letters. Abigail attended hospital for routine scans every six months, moving to every 12 months as her condition improved. She explains that although she rarely saw a consultant for scan results, she would always receive a letter from the hospital detailing the results. Abigail has never felt as though her treatment team were holding back information which is of importance. She describes how all information, significant or otherwise, is within these letters.

I've always been in the loop about my condition. They've never hidden anything from me. Even the slightest of change, even if it's not significant, it's not important, it doesn't affect me, they still tell me.

Abigail was the only participant to receive medical reports via letter. All other participants describe attending outpatient appointments to be

informed of their results before receiving a summary letter weeks later. Until the age of 18, Abigail relied upon her parents for information. She describes being unaware of the name of her condition and the risks associated with this condition. It was at the transition clinic, at the age of 18 where Abigail was provided with this information. Abigail does not feel satisfied or dissatisfied with the information she received as a child, "I didn't have a longing for knowing every single detail. It's life, it's a condition and I just have to live with it, it's not something like ok if I google it, it's not going to change anything, it is what it is, so I think I just didn't think there was a point".

Information was shared with children and parents by the health care team including doctors, clinical nurse specialists, physiotherapists, occupational therapists and occasionally, psychologists. A common method of sharing information was through scan results. Maddison (group 2), Emily (group 1), Abigail (group 1) and Liam (group 1) valued seeing their scans, feeling as though they were participating in the process. From a young age, Emily remembers always being shown x-rays of her legs, providing her with the information about her condition that justified the treatments being proposed by her health care team. Having information was crucial in assisting Emily's understanding of her condition, reducing anxieties and worries.

When my doctor used to come around, he would be like, "Do you want to look at your scans to see how you're doing medication wise?" I was very involved in that kind of conversation and I don't think they kind of hid things. I didn't feel like they weren't telling me stuff. I was aware of all the information more so than you would think some adults might be, because [my doctors] knew that I knew what was going on at that point, and I think they knew that I liked being involved and liked knowing. It's easier as a child to know. For me it was a lot easier to handle if I knew what was going on. Whenever I wasn't told things, I wouldn't like it. Like, "Why aren't

you telling me?”, “Why wouldn’t you tell me that?” So, I think sometimes surgeons forgot that cos they maybe didn’t know me as well, wouldn’t give me as much information and I would just ask the questions and we would get there. I think it may be fear that they don’t want to make a child that scared. Which I kind of get, but I think at a certain age it kind of becomes, especially when you’re at secondary school, well you’re kind of like “I understand”, and “I know what’s going on and why I want to know what’s going on with my body”.

Similarly, to Emily, Anjali (group 2) had a desire for information. At age 15, Anjali was told she required a surgical procedure on her eyes since the Botox injections had been unsuccessful. Anjali recalled receiving information about her operation through leaflets.

I was given a leaflet on “this is what happens in surgery and you will wake up and have some toast and juice afterwards”. You know, it was very basic because it was a children’s leaflet and it did not, there was no kind of [someone] there to talk to, even talk me through the process of what was going to happen. I had no idea of what medicine was going to be given. They explained a little bit about what they were going to do but I felt that at 15 I needed to know a bit more than just, ‘Oh you’re going to go to sleep and we just cut a muscle and then you wake up and everything’s fine!’ I think, at 15 I needed, I wanted more, I needed more information for myself.

I would like to have known what medicine I would have been given, how long the surgery was gonna take, who was gonna be involved in the surgery, because I knew my consultant was gonna be there, but were there going to be junior doctors there, kind of registrars there or whoever else? You know it’s kind of the little pieces of information that, probably, to a medical professional don’t seem that important but at that point, for me, were very important.

Anjali was dissatisfied with the level of information she received in the leaflet, thus approached her doctors with a list of questions in an attempt to gather further information. On approaching her consultants, Anjali did receive the information she desired, however, explains that she “shouldn’t have had to ask for it”. Of the participants that felt able to consult their doctors, all were provided with the information. Emily explains, “I would just ask the questions and we would get there”. Those participants reported having a level of confidence enabling them to ask questions. However, in the main, participants were hesitant to seek further information. Overall, the majority of participants were dissatisfied with the information that they received, explaining that it was not meaningful. William (group 2), Anjali (group 2) and Kate (group 1) felt that they were only informed to ensure compliance.

It was more discussing it with me to get me to agree to it, rather than to get me to decide whether I wanted to do it or not. I don’t think it was necessarily a discussion to see whether I would say no to it, it was a discussion to try and get me to do it. It was more to get me to understand it to the point where it’s useful to you, rather than, to get you to decide if it is actually right for your lifestyle.

(Kate)

Four participants conducted independent research to seek answers to their questions, as most of the participants felt unable to ask questions, due to apprehension around authority figures, not being spoken to or afforded permission to ask questions. Many describe a lack of opportunity to ask questions primarily because the conversations were between their parents and doctors. Four participants including James (group 2), describe there being an opportunity to ask questions, yet due to feeling inferior, they did not engage until they were older teenagers.

I probably didn’t ask many questions in the early days, but I definitely did over the years. I think again that’s growing up in terms of maturity and understanding. You can challenge and

scrutinise and ask questions that I think, in the early days, my mum would ask the questions. As I grew towards adulthood then I would ask questions and try to understand things.

The participants explained that asking questions were the only way to receive the information they required to feel adequately prepared for a medical procedure, however, they describe that they had to initiate the questions as they would not be initiated by their medical team.

Participants believe that there is a presumption that children do not want to be informed, or cannot understand due to fear of the risks, and the enormity of some medical procedures. Like Emily, however, all the participants desired to be adequately informed.

For me not knowing makes me think the worst-case scenario. Whereas the reality was fine and I would have been fine with what was actually going on, in my head I didn't know what was going on, the worst thoughts, I can come up with the worst case scenarios. I am aware of what it could be. So I think when they don't tell me what it is, my mind is automatically like, "Oh its clearly awful" and it made me more anxious in a way, than I think the truth would have.

Four participants describe being satisfied with the information that they received. These participants reported receiving meaningful information when they were under a specialist medical team. Zoe (group 1) states that she would regularly be informed whilst under her CF specialists, however, if she attended another hospital, she would not receive adequate information, if any at all. The 11 participants that reported being dissatisfied with the information they received were being treated by non-specialist doctors in their condition. Participants believed there was a direct link between expert doctors and the type and extent of information delivered to them as children. All participants placed value on being informed, stating that it accorded them an element of control over their medical treatment. Maddison (group 3) believes that all children ought to be informed.

I think you should explain to a child what's going on so that they understand it and make sure that if there are any choices, that they are explained so that they have a chance to have some kind of control. I think it's really important that the full situation is explained to you and that has happened in my case, but I am not sure that happens every time. In terms of all of the implications that you might be going through and perhaps detailing about what is going to happen. I think some people consent to a procedure without being entirely sure maybe about what it involves.

Bethany (group 3), believes that children must be informed to a standard they are satisfied with, prior to undergoing medical treatment, as it is a crucial element of the decision-making process.

I think it's important for kids to understand about bodily integrity, psychologically and legally and medically. Of course, you can't say it in those words. And you don't want to. You don't want to put them on their guard. If a child is quite open and is, in want for a better word, innocent, you don't want them to suddenly start to think of boundaries. So, you don't want to impute boundaries, but at the same time you want them to know that they are an important part of this. And it is their body, and it is their wishes, that is an important part of the process decision making.

There was no link between the era in which the participants received their medical care and their satisfaction with the information they received. As Chris (group 4) and Daniel (group 4) explain, the extent to which children are informed has been a continuing challenge throughout their careers. Children receive varying amounts of information dictated by the ethos of the health care team they are under.

7.4. Decision-Maker

This section focuses on the participation of children in the decision-making process, considering when children are capable of consenting to and

refusing therapeutic medical treatment, the barriers and enabling factors that children and health care professionals navigate in clinical practice, and the importance of meaningful participation to children.

7.4.1. When Are Children Capable of Making Decisions About Their Health Care?

Participants defined competency as the ability to understand and appreciate information, including the risks and benefits of a decision. The past-patient participants referred to emotion as an indicator that they had fully appreciated the severity of their medical decision. For example, Megan (group 2) explained that when considering whether to have scoliosis surgery, she experienced a significant amount of fear. She feared this surgery because her friend had died shortly after having the same surgical procedure. Whilst she had been aware that all surgeries had a risk of mortality, it was not until her friend had died that Megan says she *understood* the risks of this operation. Megan believes that emotion can be an indicator that a person is truly aware of the risks of a procedure. The participants drew comparisons between themselves and peers of the same age. Based on their comparisons, all past patients argued that age is not a useful tool for assessing competency. Instead they argue that a competency assessment ought to be an individual process. These conclusions were echoed by all the health care professionals.

Lord Fraser in *Gillick v West Norfolk and Wisbech Area Health Authority*⁹ created guidelines to assess a child's competency. This framework, now known as the 'Fraser Guidelines', has been extensively applied in subsequent case law, and by health care professionals in clinical practice. The doctors interviewed for this study state that the guidelines are "ambiguous", "context specific" and, consequently, not easily applicable to the full range of clinical contexts necessary to ensure a universally consistent assessment of competency for every child; "you have to go to

⁹ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] A.C. 112; [1985] 3 W.L.R. 830 at 165, per Lord Fraser.

the next level of abstraction to get a sort of sense of the Fraser guidance before you can apply it to different contexts” (Chris, group 4).

The assessment of children’s competency varied considerably between the health care professionals being interviewed for this study. Daniel (group 4) describes assessing a child’s capabilities using an ‘intuitive’ approach: “I can gauge they have seemed to have grasped this, or ok they have seemed to have missed this out”. Chris adopts a multidisciplinary approach, seeking advice from his colleagues and occasionally using a clinical psychologist where he is concerned about a patient. As GPs, Jonathan (group 4) and Julie (group 4) described that it is rarely necessary to assess a child’s competency, however, they refer patients to clinicians at local hospitals if they have ongoing concerns. Daniel believes that the inconsistent assessment of competency is widespread in clinical practice because of the ambiguous guidance and an absence of formal training.

There probably is quite a lot of personal perspective and experience. I think certainly going back to my training, and a lot of training I have been involved with, there has not been formal training in how to assess competency. I think one of the challenges of that is how do you develop something like that, that can take into account different developmental stages. So, I think ways of, pointers towards, okay this is ways you can tease out particular aspects of competency could be quite helpful, but it has to not be within a framework. Also understanding that competency is not a fixed concept, so a child may be competent to make a decision in one area of their lives but not in some other area, or on one occasion but six months later things are quite different.

The health care professionals requested an innovative model for assessing competency that was flexible to different medical contexts and appreciative of the unique challenges each context presents. Daniel believed that any framework for competency ought to appreciate the full scope of their role as medical practitioners.

I think being aware of the different sort of situations and scenarios, so there's a huge difference between consent for an acute surgical procedure and a long-term assessment process in a community clinic. So, actually, sort of recognising in terms of what we are doing as medical practitioners, covers a huge spectrum right through from a simple consultation, through to an investigation and assessment, through to medical treatment, through to surgical treatment, through to emergency treatment.

Chris emphasises the unpredictability of A&E, using this context as an example of where assessing competency to seek consent is not always appropriate.

From an emergency point of view, often you just have to get on with it. People have brought the person to you, you've got somebody who's collapsed, they've got no blood pressure, you don't sit down for half an hour explaining. You just crack on with it, resuscitate the person and then when you've got a moment, you go and sit and say this is what we've had to do. The implied consent is somebody's brought in a collapsed child, and they've brought them in because they want you to do something about it rather than sort of get all legalistic about it. They just want you to do something.

In addition, the health care professionals stated that any framework for assessing competency must be appreciative of the extreme fluctuations in children's capacities and developmental level which they explain, is vulnerable to the child's ill health, pain and fatigue, the clinical environment and parent-child relationships as illustrated by Logan (group 2), who was too unwell to participate in his health care (see section 7.2.1). Any model of competency must recognise the continuing narrative of a child's competency and be flexible to sudden changes.

7.4.2 Presumption of Incompetency

The health care professionals stated that they begin with the presumption that children lack competency. Chris (group 4) discusses the evolution of competency, explaining that throughout the course of his career he rarely meets a “truly competent” child or adolescent.

Parents usually decide for their child, often before 12. Children between, depending on maturity, 12 to 14 up to adolescents, that's where the shared decision-making fits in. So this is where the parents tried to persuade it's a good idea. Then after 16, usually it's mainly the child that decides things with the parents' support, 16 to 18. I think the difficulty with paediatrics is that you are covering a wide age group and the majority of patients that present to paediatricians are actually under the age of five. So it means that for those it's the parents you are dealing with most of the time. Neonatal practice: it's going to be parents all the time, there's not a lot of assent you can get off the kids at that age. The other group that tend to cause probably most of the problems around consent are adolescents. Particularly if they've got some degree of sort of mental type illness. I would have [cases] across the spectrum so an emergency admission, the patient with learning difficulties, the patient with mental illness, the stropky adolescent and a baby, the child protection case or query child abuse or something like that.

The past-patients expressed sympathy towards their doctors' predicament. “In a way I get it cause if they give you really complicated information and you don't understand, it could be quite overwhelming”, nevertheless, Emily (group 1), felt that doctors ought to tailor their approach in accordance with the capability of the child in front of them.

In my mind it would be better if doctors started with the low presumption and carried on talking, then quickly realise that I do know more and then gave me more [information] rather than gave me the stupid information and then left.

Emily described being treated in a “childlike manner” throughout her care and that doctors struggled to recognise her emerging competency. Zoe (group 1) reported that it was not until the end of primary school that her doctors appreciated that she was capable of taking responsibility for her medical needs. The responsibilities for Zoe’s health had previously rested with the adults around her. Whilst Zoe desired to take on greater responsibility, her doctors did not feel that she was capable to do so.

When I was at primary school, the lunch time staff, the receptionists would come to me with my tablets at lunchtime and if I was coughing a lot in class they would take me aside and help me do physiotherapy, so I had no responsibility there. I didn’t keep tablets in my backpack. They were kept at school and given to me. Maybe one of the first times, actually it’s quite a vivid memory, we did one of these things called “the year six journey” where everyone in year six went away, for I think it was three days, to an activity centre. And it was to prepare you for secondary school, and this was my first time going away without my parents. And my parents and someone from my CF team came into my school to teach my teacher about my medication, my physiotherapy, my nebulisers and I think at that point they realised how much I knew and that I could teach my teacher. And then I was responsible for it when I went on this little trip.

Zoe’s doctors responded to her increased competency by according her responsibility for her medical needs, which continued after the residential. Participants described how their medical teams were often surprised at their level of capacity and would regularly describe them as mature and intelligent. James (group 2) felt that his consulting team had faith in him and his abilities.

I think that they clearly recognised my academic ability. I think that they wanted to see what they could do to help to make sure that shone through, and that I could make that potential into something.

They were always supportive of me as a person, whilst recognising the impact that the ME was having on me.

All the participants report being informed by their health care teams that they were mature, intelligent and capable young people. Each participant recalled a defining moment in their lives which they attribute to the time where they considered themselves capable to make a medical decision. Chris (group 4) shared two exceptional clinical cases where he supported the decision of two children of seven and eight years of age who he believed were capable of deciding to refuse therapeutic medical treatment.

Sometimes you do get children, I remember there was this lovely little lad who was about seven, who was dying from leukaemia who had been through everything and it failed, failed a bone marrow transplant, failed his chemotherapy all that sort of stuff. Sometimes what will happen is that the child will eventually say I've just had enough. What you find is that people can learn quite a lot you know through personal experience. So, if you explained in abstract terms to the eight-year-old they wouldn't have understood anything. Having been through it from a personal point of view they have a much greater understanding of what is involved. They can sort of say we are going to have to go through that all over again and they go "oh no I don't want to do that. I've had enough mum".

There was one lovely little chap who I had dealt with who had a terrible immunological disorder, he had a condition where the lungs fill up with puss and eventually, they go into respiratory failure. And he, although his parents wanted us to continue to treat him actively, he would do things like pull out his drip, and you know deliberately contaminate sterile surfaces, he knew what he was doing, he was perfectly conscious he just did not want active treatment. Eventually he made it clear to us. His parents wanted to keep going, we tried everything, and then we all accepted that we'd

tried everything, consensus developed, and we realised it was pointless.

The children had been through extensive medical treatment and there was no realistic positive prognosis from continuing medical treatment. Chris believed that their experiences led them to make competent decisions about their future, despite their age. Chris explains that a child's decision alone is not enough. However, through talking to their parents and assisting their understanding of their child's suffering and distress, health care professionals and parents can form a consensus to withdraw life sustaining medical treatment. Chris emphasises that cases involving children being capable to consent to medical treatment and capable to refuse life-sustaining medical treatment such as these, are rare in any medical career.

7.4.3. Personal Development

All the participants with long term conditions described secondary school as a "turning point" in their lives. They reflect on this time as their first independence, where they had to take responsibility for their health needs. Emily (group 1) credited her move to secondary school with attaining the confidence to articulate to her doctors what she desired and what medical treatment was right for her.

I think as I was going through secondary school, I really found my voice, and found that I could stand up for myself and that it's alright for me to go against what [my doctors] say. Not rebelling against, I was not a rebel at all, but I think through school I found my voice and I think that reflected medically. I was much more able to have a proper conversation and make it clear that I wasn't just going to do as they say and be like, "yeah of course you're right". Although I do trust my doctors, I was much more able to be like "well this is what I want".

Emily, Zoe (group 1), Kate (group 1), Susan (group 1), Lee (group 2), Liam (group 1), Anjali (group 2) and Megan (group 2) explained how they personally developed as a direct consequence of their medical experience. Anjali recalled the difference in her capabilities when she underwent her second major surgery at 15 in contrast to her first at 12 years of age.

In terms of my medical treatment I actually gained confidence in knowing what I wanted, what questions I could ask, not necessarily challenge things, but I asked what treatment options are available. I wouldn't have done that if I hadn't had that experience at 12, I don't think.

In comparing themselves to their peers, participants recall that due to their medical knowledge and experiences, they were more mature. Emily believes that her experience of having a serious medical condition and balancing her health care with her school career made her mature quicker than her peers. She explained how her peers would struggle to cope if they required an X-ray or blood test, procedures that were routine to Emily.

When I was in Year 10 making these massive decisions about "do I want to walk?", I didn't tell a single friend at school. I just did it myself and no one knew. I was literally crying in the hospital one day and back at school smiley and normal the next. I was able to really separate, and I think, compared to my peers, if something medical happened it was a much bigger deal in their lives.

In addition to her health condition, Susan had to take on the responsibility as a carer to her siblings.

I was very mature cause I was a carer for my siblings. I had a lot of responsibility and I was handling that responsibility. And I wasn't the best psychologically, but I was handling that responsibility. I was dealing with that, I was cooking, cleaning, I was going to parents' evenings, I was providing emotional support and things. I clearly had the capacity to obviously not take on more, but I clearly had

the capacity to actually to be mature and reason. Helping me mature meant that in general, especially as I was going to university, I was a lot more competent. I was a lot more organised with my priorities. I was volunteering, I was meeting people. I integrated very well into university cause I wasn't shocked because actually I had a lot less responsibility once I started university than I ever did at home. Like a lot less, it just meant "oh I can relax now and breathe".

All participants believe that they would have been capable of contributing positive consent prior to starting secondary school, however, stated that the level of information provided prevented this. The participants describe how secondary school enabled them to conduct their own research, feel able to ask questions and contribute to the discussions even if the consultation was primarily between their parents and doctors.

7.4.4. Consent and Assent to Therapeutic Medical Treatment

As established in Chapter 1, Section 1.4, legally valid consent sufficient to protect against claims of trespass or negligence requires a decision to be made voluntarily,¹⁰ for the decision maker to be fully informed, aware of the nature and quality of the act,¹¹ the risks and benefits associated with the proposed treatment and the significance and likelihood of those risks.¹² Finally, the decision maker must be competent to make that decision¹³.

Verbal and written consent are the two most common methods of consent. Daniel (group 4) explains that verbal consent is most appropriate for "everyday" clinical interactions such as physical examinations of children.

¹⁰ Faden, R.R, Beauchamp, T.P, and King, N.P.L, A History and Theory of Informed Consent (Oxford University Press 1986) at Chapter 1 Foundations, 38.

¹¹ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582; *Chatterton v Gerson* [1981] 1 ALL ER 257 at 443; *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

¹² Faden, Beauchamp, and King, (n 10) at Chapter 1 Foundations, 38.

¹³ *Ibid.*

Everyday clinic interactions and seeing a patient in for assessment you don't obtain consent in a more formal way, but it is that engagement. Most medical treatment we wouldn't obtain any formal consent, but I would make sure that I talked through what the treatment was that we were doing, why we were doing it, what the potential risks were, to document that in the notes but I wouldn't ask for any signatures or anything. It can actually be quite off putting for teenagers to be presented with a thick 20-page consent form. It's just crazy. And for most of the parents that I'm dealing with, actually they don't want that, and it can actually be quite restricting.

Asked why consent forms can be restricting, Daniel stated that the forms are generic, long and can appear very intimidating when detailing the whole process, before it has happened. Daniel finds it more effective to engage in a step by step verbal consent process asking the child's permission before moving on to the next step. Daniel predominantly uses verbal consent for permission to conduct physical examinations, blood tests and referrals to other colleagues. Julie (group 4), a General Practitioner, explains how verbal consent is most appropriate for her line of work, however, as with all health care professionals, she does use written consent for medical procedures or treatments.

In general practice most of it is verbal, but if you were doing something more formal such as some minor surgery, so if you were having for example a joint injection or a removal of a mole something like that, then written consent. So, we do tip into written consent then for those procedures.

Health care professionals reported using verbal consent for most of their interactions with children and parents: parents would provide verbal consent whilst children provide verbal assent. Consent is to be distinguished from assent. Assent is a positive agreement that is not legally binding. It is not binding because the decision maker is not required to be

fully informed nor competent.¹⁴ Levesque established the following four requirements for assent: (i) the child has awareness of their situation that is developmentally appropriate for them; (ii) as much as possible, the child is aware of “what they can expect during and after the procedures”;¹⁵ (iii) the health care professionals are aware of the child’s understanding of their situation, and (iv) the child is willing to act, their action is voluntary. Nevertheless, for a child, it is argued that the benefit of assent is the empowerment to meaningfully participate in their health care.¹⁶

The health care professionals in this study keenly emphasised the distinction between a child’s consent and assent to therapeutic medical treatment. Although, Julie sought to seek consent from all her child patients prior to examinations and minor procedures, such as blood tests, Julie stated that this was not possible for more serious procedures, or where a child is unwell. Unlike Julie, the remaining health care professionals explained that in the main, children assent to medical treatment, not consent. This is because, they claim, it is rare to meet a child who is truly competent to consent to therapeutic medical treatment. Thus they prefer to seek child assent and parental consent (dual consent). Daniel tells me that dual consent is the norm for practitioners as children are assumed rarely capable of consenting independently of their parents.

It’s uncommon, we do get some situations. Probably no more than half a dozen cases in my career where actually it’s been the child making a decision on their own without involvement from their

¹⁴ Miller, V, Drotar, D & Kodish, E, ‘Children’s Competence for Assent and Consent: A Review of Empirical Findings’ (2004) 14(3) *Ethics and Behaviour*, 255 at 256.

¹⁵ Levesque, R, ‘Informed Consent and Assent’ (2018) (*Encyclopaedia of Adolescence*, 28 February 2018) < https://0-doi-org.pugwash.lib.warwick.ac.uk/10.1007/978-3-319-33228-4_440 > accessed 18 August 2019 at section ‘Adolescents, Consent, and Assent’.

¹⁶ A Sibley, M Sheehan & A Pollard, ‘Assent is not Consent’ (2012) 38(1) *Journal of Medical Ethics* 3; Leikin, S, ‘Minors’ Assent, Consent, or Dissent to Medical Research’, (1993) 15(2) *Ethics and Human Research*, 1.

parents. It's very rare. So normally you would be looking for that dual consent, combined consent.

No doctor recalled an instance where a child under the age of 16 years was capable to consent to a therapeutic medical procedure independent of their parents. The only circumstances where a child was deemed capable was for minor examinations and routine investigations such as blood tests. The health care professionals explained that parents desire involvement in their child's health care, and that it would be a great disservice to the child to exclude parents from this process. Seeking parental consent and child's assent encourages shared decision making which contributes to strengthening the parent-child relationship, ensuring the child is supported throughout their medical treatment. As Daniel (group 4) notes, "a cohesive family that clearly has good family dynamics and relationships are clearly in the child's best interests."

All past patients reported providing verbal assent for everyday interactions with health care professionals, such as, having an MRI or echocardiogram, undergoing a physical examination or having blood tests. For procedures and operations, five participants provided their assent.¹⁷ All past patients state that formal written consent was sought from their parents, however, no past patient reported consenting to therapeutic medical treatment before the age of 16. Instead, all participants' doctors sought dual consent, the formal written consent of the parents and the written or verbal assent from the child.

Academic literature argues that assent empowers children by enabling them to meaningfully participate in their health care.¹⁸ However, in this study, all past patients reported frustration at being unable to provide legally valid consent to procedures including, surgical procedures. Lee

¹⁷ Emily, Anjali, Hannah, Lee and James.

¹⁸ A Sibley, M Sheehan, A Pollard, 'Assent is not Consent' (2012) 38(1) *Journal of Medical Ethics* 3; Leikin, S, 'Minors' Assent, Consent, or Dissent to Medical Research', (1993) 15(2) *Ethics and Human Research*, 1.

(group 2) has Cerebral Palsy and at 15 and 16, required major surgical procedures to maintain his ability to walk. Lee informs me that his consultants believed Lee to have full awareness, understanding and an appreciation for the medical procedure. Consequently, Lee had assumed that he would be the decision maker and therefore, was “shocked” and “disappointed” when he was informed that he could not consent to either procedure.

I was perfectly aware of what was going on. I understood the medicine as it was explained to me, all the risks as they were explained to me, all the benefits as they were explained to me. I felt that I could make that decision, but legally I wasn't allowed to. The doctor said, “You're just too young to sign your name to consent for yourself, so your mum will have to do it”. The doctor did explain to me that it was important that my mother consent on my behalf, to provide a legal agreement for the procedure. I would still write my name, but it was my mother's signature that really counted there.

All participants reported being informed that prior to the age of 16 they would be “too young” to consent to medical procedures irrespective of their capabilities. No participant had been informed of the existence of *Gillick* competence, the legal exception that a capable child can provide legally valid consent to therapeutic medical treatment prior to the age of 16 without parental consent. Aside from the participants that now study law or medicine, all other participants remained unaware of the existence of *Gillick* competency, its concept, or application in child health care.

For past-paediatric patients, the inability to consent was a contradiction from the “mature young adult” rhetoric they were hearing from their health care professionals. Whilst the health care professionals in this study state the majority of children are not capable to consent to medical treatment, the past-patients reported being informed by their consultants that they did have a high level of maturity and capability. Despite this, they were informed that they could not consent to medical treatment, only

assent. As a triplet, Lee compared his inability to make decisions with his sisters' increasing independence; able to go on holiday with their friends and make decisions about their lives distinct from their parents. Lee was unable to engage in these activities due to his condition, and therefore, sought independence and control in his health care.

I did feel a bit put out, slightly annoyed but there was nothing I could do. I think that my control had been taken away, that I didn't have the independence, despite the fact I had the maturity or understanding of the procedure. Legally I couldn't sign for myself which was a shame cause I would have liked to have that independence, particularly, at a time when my sisters who were able bodied were going off and doing things by themselves and increasingly having more independence. I felt like I was being left behind, and had I been given this decision I could have felt a bit more independent.

Having been informed by their doctors of their capabilities and encouraged to sign, participants, such as Megan (group 2), expressed confusion at the need to have their parents' signature also.

I did find it weird that mum was still signing because it was my body, so surely, I'm the one. If I'm being allowed to give that signature then surely that's enough. If they're considering that I can give that signature, then surely that should be enough.

Megan stated that even if she had been allowed to consent to medical treatment, her ability to do so would have been limited as it is in adult services. Megan explains that hospitals do not have the equipment to enable her to consent. A symptom of Megan's condition is being unable to write, and therefore, she requires audio equipment to provide formal verbal consent.

[As an adult] I'm just given the form and then I fill it in. Although, what's interesting is that mum normally fills in my name because

giving consent in different ways, signing forms is not always the most accessible way to do it. So, at the beginning of this interview I read the statement and said that I consented, that was easier than me printing out the form and signing it. However, within [the clinical] environment those alternative methods of consent are not necessarily considered.

For Megan, the lack of accessible methods of consent is a barrier to providing formal consent, both as a child and as an adult. Like Megan, Emily (group 1), described the parental signature as a “formality” and referred to her signature as “tokenistic”. Despite this, Emily felt confident that her parents would not have “forced” her to undergo any medical procedures. Prior to consenting, Emily and her parents would always discuss the procedure and Emily’s parents sought her permission; “[mum] is literally just signing it because I have. If I hadn’t have signed it, she wouldn’t have.” Emily recalls the sense of frustration at the presence of an age limit.

I think when the child is judged to be able to consent themselves, there is no need for the parents to consent as well, because I don’t really know what it achieves. To me it achieves absolutely nothing because, if the child is saying, “Yes I want this” and is able to do it...well if I’m competent why would anyone else need to sign? In a way it felt that the doctors, I don’t even think it’s your personal doctors, but the system as a whole doesn’t trust you to do it yourself yet. You still need your parents. I’m quite happy to sign it myself, and then you get it’s so arbitrary when you get to 16 and suddenly now you’re like, nothing had changed really for me, it was all of a sudden you can do it yourself. And then when you get to 18 your parents aren’t meant to be in the room.

Despite academic debate arguing that assent empowers children, the participants in this study reported feeling disempowered, undervalued and their autonomy and competency unrecognised. They argue that their

assent is meaningless, as it holds no legal value. Some participants with a strong relationship with their parents were satisfied that their parents would only consent to therapeutic medical treatment if they had agreed to undergo the procedure. This was not the case for all participants. Lee explains that had he disagreed with his mother and sought to decline medical treatment “it would have been a different story. I would probably have been told very firmly that legally I did not have a leg to stand on and that she would consent on my behalf.” As such, a child appears to be respected where they assent to medical treatment. Where they dissent, their opinions may be overturned by the legal decision makers, their parents. In this study, whether or not a child’s assent or dissent is respected is not based on their ability to assent, rather on their parent’s willingness to listen to their child’s wishes and desires.

After the age of 16, participants Lee (group 1), James (group 2) and Emily (group 1), recalled providing legally valid consent to therapeutic medical treatment. Zoe (group 2), Kate (group 1) and Liam (group 1) stated that their mothers continued to consent until they reached adult services where they now provide legally valid consent. Abigail (group 1), Anjali (group 2), Faith (group 3) and Megan (group 2) continued to provide verbal assent to investigations such as MRIs and CT scans. They do not recall providing any formal written consent until they reached adult services. The remaining participants did not require any therapeutic medical treatment between the ages of 16 and 18.

7.4.5. Refusals of Therapeutic Medical Treatment

Medical professionals report that it is extremely uncommon for children to dissent and for parents to refuse therapeutic medical treatment. Where children do express a desire to refuse treatment, the doctors state it is a sign that children have concerns about their treatment. Daniel (group 4) explains that no child’s concerns should be dismissed or overridden, rather it is important to understand these underlying worries and resolve them through communication and negotiation.

In my experience [refusal is] very uncommon, very rare. We've had the children who have closed their mouths and refused to take tablets, and that is a nightmare for the parents, but, very rarely where they have sort of turned round and said I am not going to do that.

In most situations, particularly with young children you are relying on the parents' consent and assume that the child will go along with that, but, if I'm picking up from the child, actually I don't like that idea, even if the parents say yes, I would then try and tease that out a bit more. We've had situations where I have talked about starting some treatment and so on, and the child has been clearly very reluctant so I have tried to talk through: "was it the fact that it's pills?", "would you prefer liquid medicine?", things like that so it's again trying to pick up on those clues that the child might be sending out. Often very non-verbal signals but actually this is not going to work, they are not going to comply with this - I need to take a different tact.

I guess there have been situations where I've sort of negotiated, and actually, where the specific treatment might be flexible I can say, "if we put your child on this medication it is likely to resolve things quicker, but, you're clearly reluctant or not wanting that, so let's try some other ways or give it a bit longer to observe what happens naturally". So, I have had situations like that fairly commonly, I guess. Much more common actually is "I'm unhappy about that" so let's talk that through and work out if there are any alternative routes. That's not uncommon.

Emily (group 1) recalls negotiating with her surgeons, when at 16, she sought to refuse a ground-breaking surgery that could assist her walking. She remembers her doctor's excitement about the opportunity to perform the surgery, however, due to the risks of the operation and the impact on her education Emily declined the operation.

When I was 16, there was a potential discussion of me being able to walk. It's always been in the background that I would walk. We had always been working towards, from every aspect of treatment, physio, medical, everything was about [Emily] definitely walking. But when it came to it and they realised why I couldn't walk, the operation was going to be massive. They were going to have to literally break my bones and then move them. There will be a 60% chance that you'd be able to walk a few steps. And I was like, "you know what, you're alright! I'll take a pass!" It was just on the boundary of GCSEs and A-levels and we were going to do it over the summer of year 11 to year 12. But then I was probably going to take more than the summer to recover.

I think there is obviously the perception that everyone should want to walk, and so, it confused [my surgeons] a bit, which I get. It's more of a wider disability perception issue. I think they were maybe confused, but then, they kind of accepted. They knew that I knew what I was doing and that I understood the consequences. I think they were confused why I wouldn't want it. I think they were maybe concerned that I just didn't want the big scary operation, it was going to be a big job, and because there were probably going to be frames involved it was going to be, I don't know if they were thinking maybe she doesn't want to have to deal with them. I think they wanted to do the operation as well, because it was cool.

Doctors are like that though; I find that all the time.

After consulting with her doctors, Emily and her parents refused the treatment and their choice was respected. Emily, James, Megan and Anjali were the only participants that worked with their health care team about medical treatment they were uncomfortable or apprehensive about. This is a form of shared decision-making.

In the majority of cases, the participants did not feel comfortable to challenge their doctors. However, seven participants' parents, refused

therapeutic medical treatment. These participants believed that they would have been capable of refusing medical treatment instead of their parents. These participants described themselves as fully aware of the risks and emphasised the importance of careful consideration. Emily was prepared to take on risks and described her approach and perspective on risk as “practical”.

When it comes to risks to surgery, I’m quite happy knowing everything, I am very able to quickly balance it out. If they say there might be blood loss I’m not like, “That’s it I’m done!” No, I understand that, I get it kind of thing. I think decision making wise I was able to think through things more and like the consequences, the long term, rather than just, cause I think when people have medical procedures I think in my mind they are just like what’s going to happen in surgery like kind of short term, like how long they are going to be in hospital for, whereas I know how it’s going to affect my life, not even long term, like for the next 6 weeks I’m going to be in a cast, how is it going to affect me then like, I’m very much I think forward, I really think about the decision and it’s a big thing. I really consider it.

When engaging in shared decision making with their parents, all seven participants had to balance significant risks. Throughout her life, Megan’s doctors recommended spinal fusion surgery to correct the curvature of the spine. Megan (group 2) describes the complexity of the decision she had to make.

It was ultimately me who said I am not comfortable with this, largely because one of my friends died, and obviously, I knew intellectually we were very different and that it was a result of her condition, and that the operation was successful, but once that’s happened you can’t shake it off as a teenager. Because the pain was as a result of a muscular skeletal issue, they couldn’t guarantee that having the surgery would make a difference to my pain. So, I said

“Well if its, if it’s completely cosmetic then I’m not really that bothered”. My lung function was ok ish so they weren’t unduly concernedthere was a really big kind of push and a lot of pressure, not from my parents or my family but from the medical professionals around me because, they very much seemed to think that they knew what was best. I ended up changing consultants because I wanted to get a second opinion, and it was actually at the [name] children’s hospital that they were more receptive to my opinion. Medicine is so often presented as this objective field that is very clear cut of what needs to happen but there is all sort of ethical and interpersonal factors that need to be considered, as two different surgeons can look at the same X-ray and that is not something that is really considered.

Refusing medical treatment through seeking a second opinion was a path taken by the majority of participants with chronic health conditions which required regular treatment. For example, Anjali (group 2) sought multiple opinions before having her final Botox injection surgery. It may be that these participants had much more knowledge of their medical treatment and their rights, as patients who have been in the health care system longer. Therefore, they are more familiar with how to seek second opinions and confident to challenge doctors’ suggestions. Anjali explained that had her life-saving brain surgery at the age of 12 not happened, she would not have been as clear and settled in her decision to exhaust all treatment options before having her Botox surgery. She explained that her experiences as a patient added up to make her capable of refusing treatment at 15.

At 12, I think it was this is the procedure, cause it was the first time in any kind of hospital environment, or any sort of serious kind of medical circumstance, so I didn’t know, I had no idea what my rights were at all, if I had any. Nobody really explained anything and it was all just happening, and you just, it was like firefighting

essentially with the situation, and so I just didn't get a say. But then at 15 I was much more like no this is what I like, this is what I don't like, I don't appreciate this particular type of treatment.

For these participants, dissenting treatment and subsequently obtaining a second opinion, was based on the assumption that there are alternative treatments and that the current options were not necessarily in their best interests. These participants dealt with risks, both the short and long term.

7.4.6. The Right to Consent to and Refuse Therapeutic Medical Treatment

In the main, participants were unaware that they could consent to or refuse therapeutic medical treatment. All were informed by their doctors that 16 is the age of consent. For Zoe (group 1) not being able to consent was not a concern as a child. However, as she leaves paediatrics and enters adult care, she expresses concern about the extent of her participation in future life-changing decisions such as a double lung transplant.

It's not that I've never consented. It's that I never thought I had the option to consent or not consent. I've just done it. I've always had the relationship with my condition and my treatment that I get on with it, and so far, I have been happy to do it. It's never been a problem because I've never been uncomfortable with the treatment that I'm getting, but as I've said before, I have been thinking about transplants a lot recently and I'm worried about the future. When my treatments become more invasive and more difficult whether I will still not have much consent.

Zoe desires for her consent to be sought in an attempt to regain control over her medical condition. Although she does not believe that she would refuse medical treatment, she would like to have a choice.

Just being told "these are the options, would you like to take up the treatment?", "am I able to come into hospital at this point?" and obviously, they can very strongly recommend that I do these things, but ultimately, I would like to feel as if I can say no. I would never

reject treatment, but I would like to feel that I would have that opportunity. And I am quite nervous about. I have been thinking about this a lot lately because CF is a big recipient of double lung transplants. And I am nervous that I will be told that I need a transplant, rather than, that is discussed whether that is something that I would want, because I'm not sure it is. I would like to think that they would say "we really think you should have one, but do you want to be on the list?" I would like to have that choice. I'm nervous that I won't.

Similarly, Maddison (group 3) felt as though she did not have a choice. Maddison assumed that she needed the treatment and as such, the possibility of consenting or refusing medical treatment "did not occur" to her. Like the majority of participants, Maddison expressed no desire to refuse treatment, nevertheless, believed that she was unable to, irrespective of her intentions, because she was not adequately or meaningfully informed.

7.4.7. Desiring to be the Decision Maker

The health care professionals in this study were keen to involve children in decisions about their care by encouraging children to assent to medical treatment and informing children. To do so, they inform me, improves the doctor patient relationship, ensures patients comply with medical treatment and builds trust.

If you get a patient involved, they are going to be more likely to comply with treatment, you're going to build a better relationship. If you feel active in your treatment, then you've got more stock in it basically, and you're going to try and make it work and try and take your tablets on time, if you've got problems you will feel that you can speak to your doctor about it, and then I think from a medical student perspective, being involved, having patients involved, makes for a better relationship. (Logan, group 2, medical student)

Logan, a medical student, believes that patient participation is extremely important, particularly in the current climate where health care upholds patient autonomy, the right of patients to make decisions for themselves. To respect autonomy, doctors must adequately inform their patient and provide choice, thus patients ought to meaningfully participate in their health care.

Gone are the days where the doctor is this all-powerful knowledgeable person. I think there's less of a gap between understanding and people have a lot more choice nowadays, and at least can find out about different treatment options. I think this element of choice means that they should be involved. And it's just more ethical nowadays. Everything is just sort of going away from the paternalistic doctrine, it's more a shared decision making. I think it's good. For the most part it's better for the patient. Autonomy is really important, and actually, if you can know and understand what's going on, it can for the most part be a better experience. (Logan).

Most participants were dissatisfied with the level of participation they experienced as children in their health care. The participants expressed a desire for meaningful participation, where they had an impact, either as the ultimate decision maker or collaborating with their health care professionals and parents to make a joint decision, citing autonomy as a primary reason. James (group 2) diagnosed with ME at 11 years of age, states that because the medical treatment is happening to his body, he ought to be the ultimate decision maker to ensure respect of his bodily integrity and personal autonomy.

I think that ultimately, it's the only person that lives in the body is you, and you've got to be able to make those decisions. I'd like to think that my family would have respected any decision I would have made, even though legally they are guardians and can make those decisions for me. We are the ones that have to live our own

lives. The consequences of anything on the body, the main impactee is ourselves, and so I think I've always been a bit uncomfortable with people trying to impose things onto your body, even though they often have your best interests at heart. I think ultimately, you've got to be able to make that decision based on the rational options that are there in front of you.

The effects of any decision directly impacts the life of the child. During her brain surgery, Anjali (group 2) had been excluded from the decision-making process, and as such, felt a loss of control. Anjali believes that the lack of control over the decision-making process exacerbated the trauma she experienced at the unexpected symptoms and challenges in recovery. Lee (group 1) has Cerebral Palsy and tells me of the challenges that he faced accepting his disability. He valued meaningful participation as it accorded him a level of ownership over his condition and better prepared him for the outcome of medical decisions.

Involvement is and was important because I felt I needed to understand both the medicine and treatment but also to feel involved in my treatment. It's about being able to take ownership of one's life as a human being. If it's just somebody else telling you what to do and taking the information on your behalf, and then keeping you in the dark, the world becomes quite a scary and difficult place. One is really faced with the difficulties that one has in one's life, and therefore, what one can't understand, why one has the difficulties, and why one has to alter and modify the way in which one does to make things easier, and also to understand why one is different from everybody else, and why one does things differently to everybody else. And so that involvement means one has the knowledge to be able to understand all those things.

To have influence and power over the decisions made about their health care, accords the patients a sense of ownership, control and involvement in their care. They are better prepared and thus, experience fewer symptoms

of trauma such as anxiety. For Emily (group 1) influence over her health care extends to being informed and able to make independent decisions. She explains that this would improve trust, reduce her anxieties around her treatment, allowing her to accept and cope with her medical condition.

I like being involved. If I'm not involved it means that I don't trust them. When you have big operations it's not nice, even after you've had several, and so for me knowing that I've been involved and knowing that I had the chance to see my scans and knowing exactly what they are doing, you accept it don't you? I think knowing it really helped me accept it almost. I think being involved is really important. It helps psychologically, knowing what's going on helps a lot.

As Anjali explains, having power and influence within your health care "gives you a sense of confidence in your treatment, that you are getting what is right for you, the confidence to know what is happening to your body and you're making choices about your body. It's not someone making a decision for you." Once Zoe entered adult services, she felt recognised as a person with rights, instead of a child, passive to the decisions of others. Reflecting on her experiences as a child and comparing them to her adult care, Zoe explains the importance of having influence over medical decisions:

I feel if you are more involved in your treatment then you feel more human in the process. You feel more that they actually care about you as a person and getting you better so that you can live your life more. Whereas, I find when I meet a consultant that I don't like, they are really abrupt and make me quite upset, and to them, I feel I am just an object and a medical viewpoint, and it does make me quite upset. When I meet a health team that I feel is quite rude it really affects me.

To meaningfully participate is a recognition of a child's emerging competency. In the main, participants describe a lack of power, influence and control over their decision, being treated as a child and their emerging competency going unrecognised by doctors who were acting under the presumption of incompetency. "I was having all this medical treatment and being treated like a child everywhere I went", Anjali explains. "It made me feel like a child for longer so at 15, 16 I was still feeling like a 12-year-old, because I was being treated like a 12-year-old". All participants reported feeling "childlike" until they reached adult services, at which point, they were the decision-makers, presumed capable to consent to therapeutic medical treatment and meaningfully participate in their health care.

7.5. Transition to Adult Services

In England and Wales, children from the ages of 16 can transition to adult health care.¹⁹ The transition process is governed by NICE guidance before, during and after transition.²⁰ Among other requirements, transition to adult services should occur at a time that is developmentally appropriate for the child.²¹ The transition must be planned from as early as 13 years of age.²² The child should have support from a named key worker,²³ the child must be involved in the process,²⁴ building their independence²⁵ and the transition should include parents.²⁶ Prior to a transition to adult services, it is recommended that children have a transition clinic.²⁷ This may include

¹⁹ NICE, 'Transition from children's to adults' services for young people using health or social care services' (*NICE*, 2016) at 1.1

²⁰ *Ibid.*

²¹ *Ibid* at 1.1.2

²² *Ibid* at 1.2

²³ *Ibid* at 1.2.5

²⁴ *Ibid* at 1.2.11

²⁵ *Ibid* at 1.2.13

²⁶ *Ibid* at 1.2.19

²⁷ *Ibid* at 1.3

“pairing a practitioner from children’s services and adult services”²⁸, allowing the new practitioner to meet with the child, or providing an opportunity for the child to ask questions about this new phase in their medical care.

Thirteen participants transitioned to adult services between the ages of 16 and 21. For the majority, Emily (group 1), Abigail (group 1), Kate (group 1), Zoe (group 1) and Lee (group 2), the move to adult services composed of a one-off clinic called the ‘transition clinic’ which was a routine appointment at the children’s hospital attended by the participants, their parents, current health care team and their adult team. The purpose was to hand over medical notes and meet the new team prior to the first outpatient appointment in the adult hospital. Participants were given an opportunity to ask questions and discuss long term goals and aims. Zoe’s transition clinic included a tour of the adult hospital where she met the wider support network. For Abigail, it was at this clinic that she learnt the name of her medical condition and understood the medicine behind it, “once they told me the name and what actually happens, they had a little diagram, and they explained what’s wrong. It just meant that I understood it more”. Abigail believes that she learnt this information at the right time in her life. At this point, she desired to learn about her condition and felt open to taking responsibility for her health.

It made me understand about myself. It just made me understand the past and why it happened, and how it affects my life and how it could affect the future. It was intense. I had a meeting with an advisor or supervisor, and she really explained the whole impact that my heart condition would have. The impact that it had on my life in terms of pregnancies, contraception, exercise, literally everything. She sat down and it was a good hour that she talked to

²⁸ Ibid at 1.3.1

me. It was a lot of information, but it was very useful, I came out with leaflets as well.

Abigail describes the process as “overwhelming”, as she was being “overloaded with information” crucial to her medical history and her future wellbeing. She conducted independent research after the meeting to cement the information she had been given and learn as much as she could about her condition. Whilst Abigail valued the information that she received, she did not feel that the clinic adequately prepared her for the transition to adult services particularly as she did not feel able to be the decision maker. Abigail shared that she would have desired more information sooner, so that she could have avoided smoking and drinking, potentially damaging her heart, and understand the reason behind her scars and admissions into hospital. Similarly to Abigail, Anjali felt let down by her paediatric team stating that they had failed to prepare her for the sudden transition to adult services, from passive observer to decision maker. “It’s a culture shock, going from somewhere where everyone knows what’s going on, even if you don’t, to going to somewhere where you’re supposed to know what’s happening”. Anjali tells me that in adult services, she requires support in making decisions because she does not have the experience in decision making, “I still need someone to tell me if I am ill or not”. During her paediatric care, Anjali recalls that decisions were made on her behalf by her doctors and parents, thus, when it came to adult care, where the burden of decision making was hers, she felt anxious and required parental support.

Because of the experiences that I had had, I felt nervous about making decisions on my own, that I needed someone to tell me what decisions to make. So, if they asked if I wanted to continue, I thought no was my honest answer because I didn’t know enough about what my treatment was originally. Some parts of the treatment I didn’t know anything about, so I feel like, if you ask me

a question about it now, I couldn't tell you anything. So, I couldn't make an informed choice because of that.

All participants felt ill equipped to transition to adult services, in part, due to the lack of information they possessed, thus preventing them from making informed medical decisions. Lee shared that he lacked the skills having not previously been the decision maker. Lee noticed the absence of his parents and struggled without their support during consultations with doctors.

I actually, to be honest, found it quite difficult. Because I could consent and legally consent the doctors didn't talk to my parents. It meant that I had to be much more aware of the conditions that emerged. As an adult I developed a seizure condition, and because the doctors just talked to me about it, I found it quite stressful having to make those decisions myself without having the opportunity to confer with my parents, and suddenly, having to talk to doctors I'd never met before, and to trust them and the treatments that they were suggesting. I was intelligent enough to understand what was going on and the treatment that was being suggested, but I was perhaps unsure and lacking in confidence rather than lacking intelligence to understand my medical condition and treatment. I had not sort of grown up with making those decisions myself and when it came to suddenly making those decisions, I was lost I didn't know what to do.

Whilst participants valued the transition clinic, they felt that it was not extensive enough to improve the transition to adult health care. Of the 13 past-patients who transitioned to adult services, five had a transition clinic. All the participants felt ill equipped for being a decision-maker in adult services, irrespective of whether they had attended a transition clinic. They all experienced anxiousness prior to the transition and took many admissions and outpatient appointments to settle in.

Transition to adult services is more challenging as it occurs at an important and critical stage in a child's life, during their GCSE examinations, where they are making decisions about college, A-levels and jobs. These children must balance transitioning to the next stage in their life, in addition to having the responsibility to make life-changing medical decisions. Past patients and health care professionals believe that a lot more needs to be done to improve the transition from paediatrics to adult care. Primarily, they believe that transition should start at a much younger age, as soon as the child is illustrating capability for shared decision making. Daniel (group 4) states that a child's emerging autonomy must be recognised and respected by encouraging them to make decisions and supporting them in that process, "rather than reaching 18 and congratulations you're on your own". After transition, the doctors propose that there needs to be recognition that a young adult may not be as capable as an older adult, therefore, they may require parental contributions. The Care Quality Commission have conducted an extensive review into the transition to adult services, citing many of these concerns within their paper.²⁹ Nevertheless, of note for this thesis, to be analysed in the subsequent chapters, is how a child's participation in their paediatric care, has impacted their ability to make decisions as an adult.

7.6. The Impact of Law and Policy on the 'Lived Experiences' of Children Over Time

The past patient participants were divided into three groups, distinguishing between participants aged 18-25, 26-35 and 36 and above. The purpose was to seek to identify whether there were differences between the 'lived experiences' of the younger and older participants, to ascertain whether the 'lived experiences' of children have developed in accordance with the introduction of law enforcing the right to participation. This data does not

²⁹ Care Quality Commission, 'From the pond into the sea' (CQC, 2014) <https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf> accessed 2 February 2019.

show any identifiable variations in the experiences between the age groups aside from the clinical environment. The participants above the age of 36 stated that their parents were unable to stay with them during inpatient admissions and there was no separation between adolescent and children on wards.

However, it is necessary to acknowledge the limitations of this data. The small sample size means that it is not possible to draw any conclusion about the impact policy and law has had on the 'lived experiences' of children. It is, therefore, only possible to draw tentative conclusions that there does not appear to be a difference between the extents to which children participate in their care, nor the frustrations experienced by the participants. The data provides a strong argument for further research, specifically, investigation of the sixth research question: have the lived experiences of children evolved in accordance with the introduction of law valuing participation in clinical practice?

7.7. Conclusion

This chapter discussed the communication between doctors, parents and children, considered how children received information and what information they received. It examined the role of the child as the decision-maker and documents their experiences when transitioning to adult services. This chapter found that for the participants in this study, doctors predominantly communicated with the participants' parents. As children, the participants' communication with their doctor was limited to four instances: (i) informal niceties at the beginning of a consultation, (ii) explaining why they have visited their doctor, their concerns and symptoms, (iii) during examinations conducted by health care professionals, and (iv) direction of treatment.

Participants explained that after reviewing their medical history and new symptoms, health care teams would collectively decide on a treatment plan, first communicating this to their parents and when consent had been

obtained, informing them as to the treatment they required. The participants in this study felt unable to challenge their health care professionals due to their authority and status as expert medical professionals.

Out of concern for overloading a child with too much information, and thereby causing unnecessary fear, participants describe how their doctors gave them selective information. In some cases, there was an absolute absence of information. The types of information a child received from their health care professionals included being shown scan and blood test results, and an explanation of the treatment they were about to undergo. Despite this, when the participants were children, their parents were the participants' main source of information. Moreover, parents were the decision-makers.

Participants recall a strong presumption of their incompetency. Doctors express lacking confidence in assessing a child as competent out of fear of litigation. The health care professionals explained that children do not consent to medical treatment. No participant consented to medical treatment as a child. Only assent was sought. Whilst assent was assumed to empower a child, this study found that assent was also dependent on adults as gatekeepers to children having their voices heard and respected.

An outright refusal of all medical treatment is uncommon in paediatric health care. However, within this study many participants parents declined medical treatment in favour of alternative treatments, sought second opinions and refused medical treatment the child and parents deemed unnecessary. In the main, participants were and remain unaware of their rights. Nevertheless, all the past-patient participants desired to have been a decision-maker as a child and to have had an impact on the health care decisions discussed whilst they were a child. As a result of their experiences in child health care, participants expressed feeling ill-equipped to be the decision maker when they transitioned to adult services.

Throughout Chapters 5, 6 and 7, there was no notable differences between the findings from group 1 and 2, implying that the lived experiences of children have not changed in accordance with evolving legislation according children the right to participate. Chapter 8, Section 8.4 will analyse this finding, to ascertain the impact of *Gillick* on the extent to which children participate in clinical practice. Furthermore, the following chapter will analyse the findings from Chapters 5, 6 and 7 in greater depth, examining whether the participants' participation was meaningful and to unpick the barriers to meaningful participation.

8. CHILDREN'S PARTICIPATION IN THEIR HEALTH CARE

8.1 Introduction

The previous three chapters have closely examined the empirical data. The data documents how the interviewees participated in their health care as children and identified the long- and short-term impact of their participation (or lack of participation). This chapter seeks to deepen this examination to answer the main research question, does an examination of the participant's 'lived experiences' expose any barriers to meaningful participation? This chapter seeks to ascertain through an in-depth analysis, whether the interviewees' participation was meaningful and, if not, why participants were unable to meaningfully participate in their health care.

This chapter uses Roger Hart's ladder of participation as an evaluative aid (see Chapter 2, Section 2.7.1 for a discussion of Hart's ladder of participation).¹ Due to its "simplicity of form and clarity of goals",² Hart's ladder of participation provides a pre-determined and recognised language through which to evaluate the participation of children in clinical practice. Hart's ladder was chosen over similar models because it was designed specifically for children's participation and is considered "the first real attempt"³ to recognise child agency. Section 8.2 analyses the findings in Chapters 5-7 to consider whether the participants meaningfully participated in their health care and to identify barriers to meaningful participation. This analysis only focuses on the experiences of these

¹ Hart, R, 'Children's Participation: From Tokenism to Citizenship' (UNICEF International Child Development Centre 1992) < https://www.unicef-irc.org/publications/pdf/childrens_participation.pdf > accessed 5 March 2019.

² Hart, R, 'Stepping back from "The Ladder": Reflections on a model of participatory work with children' in J Reid, *Participation and Learning: developing perspectives on education and the environment, health and sustainability* (SAGE 2008), 19 at 23.

³ Kellett, M, 'Children and Young People's Participation' in Montgomery, H and Kellett, M, (eds.) *Children and Young People's Worlds: Developing Frameworks for Integrated Practice* (Policy Press 2009) at 44.

participants. It yields significant findings, however, they are not generalizable. This chapter should be read with these caveats in mind.

8.2. Does an Examination of the participant's 'Lived Experiences' Reveal that they Meaningfully Participated in their Health Care as Children?

The empirical data presented in Chapters 5-7 illustrates that children do participate in their health care. Primarily the participants received information and occasionally engaged in the decision-making process.⁴ Four participants (Emily, Anjali, Megan and James) engaged in shared decision-making.⁵ All the participants assented to minor medical interventions, such as, blood tests, scans and examinations.⁶ Five participants (Emily, Anjali, Hannah, Lee and James) were given the opportunity to assent to therapeutic medical treatment.⁷ No participant under the age of 16 consented to therapeutic medical treatment.⁸ In this section, I use Hart's ladder of participation to assess whether the interviewees' participation in their health care was meaningful. I analyse each form of participation identified in the empirical evidence: - communication,⁹ information¹⁰ and decision-making.¹¹

8.2.1. Rapport with Doctors

At the beginning of the interviews, the past-paediatric patients were asked to describe their overall paediatric health care experience.¹² Half of the

⁴ See Chapter 7, Section 7.3.3. about the information that participants received and Chapter 7, Section 7.4.4 about the participants engagement in the decision-making process.

⁵ See Chapter 7, Section 7.4.5.

⁶ See Chapter 7, Section 7.4.4.

⁷ Ibid.

⁸ Ibid.

⁹ See Chapter 7, Section 7.2.

¹⁰ See Chapter 7, Section 7.3.

¹¹ See Chapter 7, Section 7.4.

¹² Appendix Interview Schedule and Chapter 6, Section 6.3.

participants stated that their experience was positive.¹³ The other half reported a negative experience.¹⁴ When asked what they meant by a positive or negative experience, the participants referred to the rapport that they had with their doctors.¹⁵ The participants who had a strong rapport with their doctors respected, liked and looked up to their clinicians.¹⁶ Unfortunately, only half of the participants remembered a sound rapport with their doctors. In Chapter 6, Section 6.3 Liam fondly describes a positive rapport with his nurses, however, emphasised that this level of care and compassion shown by his nurses was not “necessarily attainable with doctors due to the limited time spent interacting with them”.¹⁷

Whilst all the participants reported a positive rapport with their wider health care team,¹⁸ only the participants who did not have a rapport with their doctors reported an overall negative health care experience.¹⁹ This data suggests that a sound rapport with a child is crucial to an overall positive health care experience and ought to be encouraged and sought.

However, irrespective of the rapport that the participants had (or did not have) with their doctors, all the participants reported the same frustrations such as, a lack of information,²⁰ communication²¹ and involvement in the decision-making process.²² Thus, a sound rapport can act as a smoke screen, covering up the limited participation that a child has in their health care.

¹³ Liam, Lee, Emily, Maddison, Abigail, Faith, Zoe, Logan and Faye.

¹⁴ Susan, Hannah, Kate, William, Bethany, Megan, Rachel and Anjali.

¹⁵ Chapter 6, Section 6.3.

¹⁶ *Ibid.*

¹⁷ See Chapter 6, Section 6.3.1.

¹⁸ See Chapter 6, Section 6.3. and Section 6.3.1.

¹⁹ See Chapter 6, Section 6.3. and Section 6.3.1.

²⁰ See Chapter 7, Section 7.3.2 and 7.3.3.

²¹ See Chapter 7, Section 7.2.

²² See Chapter 7, Section 7.4.

Moreover, of those participants that had a positive experience, all received medical treatment in children's hospitals.²³ Where the children were treated in a specialist children's hospital, they had a sound rapport with their doctors. Because they were treated by specialists, they had access to innovative medical treatments. Unfortunately, this was not available to nine of the participants. Emily describes it as a postcode lottery, stating that she was lucky to be born in an area where the specialists were. Participants with chronic and rare medical conditions, who had been treated in specialist children's hospitals, emphasised the importance of being treated by experts in their condition. They report being listened to, valued and included within conversations.²⁴

8.2.2. Communication

The participants remembered the paediatric clinical environment as friendly and welcoming.²⁵ At the beginning of every consultation, their doctors would greet them and pleasantries would be shared.²⁶ Most commonly, their doctor would ask them about school, hobbies and family to put them at ease on a topic that they felt comfortable with, prior to asking about their health condition, a topic that was unfamiliar and daunting. Subsequently, their doctors would ask them to explain why they have come to see a doctor.²⁷ Jonathan (a paediatrician) and Julie (a GP) tell me that it is important that children tell their story in their own words to ensure that the health care professional is able to ascertain the complete picture undisturbed by parents who might not provide an accurate or complete narrative.²⁸ A physical examination was sometimes conducted

²³ See Chapter 6, Section 6.3.1.

²⁴ Ibid.

²⁵ Chapter 6, Section 6.2.

²⁶ Chapter 6, Section 6.3.1

²⁷ Chapter 7, Section 7.2.1

²⁸ Chapter 7, Section 7.2.1

and the participants would respond to their doctors' questions, for example, identifying the area where they were experiencing pain. After gathering this information, their clinical team would make a decision as to what treatment was in their best interests. Subsequently, their doctors would communicate this to their parents and parental consent would be obtained. In some instances, the participant would be present for these discussions. Typically, the doctor would then inform them about what treatment they were *going* to have.²⁹ Daniel, Julie, Jonathan and Chris (group 4) confirmed a similar pattern to all their consultations,³⁰ implying that the past-paediatric patient's experiences were not unusual.

The empirical data from all the participants, including the health care professionals, shows that telling children and their parents what is going to happen and expecting their compliance is a common method used by doctors. All the past-paediatric patients shared numerous examples of being 'directed' and 'told what to do' with little or no opportunity to formulate an opinion or enter a dialogue with their doctors.³¹ For example, the doctors would phone the participants' parents informing them that their child was being admitted into hospital for IV antibiotics.³² Doctors would hand the participant a scan slip or blood form, expecting their compliance.³³ Using Hart's ladder of participation, I deduce that this form of participation is tokenistic.³⁴ Although the process of informing the child appears to involve the child, their participation has little or no influence over the decision-making process, thus is considered by Hart as low-level, tokenistic participation.³⁵ William (group 3) explained that he felt like an "object of medical interest" and that he was only told what was going to

²⁹ See Chapter 7, Section 7.2

³⁰ Ibid.

³¹ See Chapter 7, Section 7.2.2

³² Ibid.

³³ Ibid.

³⁴ Hart, 'Children's Participation: From Tokenism to Citizenship' (n 1).

³⁵ Ibid.

happen because they required his compliance.³⁶ Similar, asking the patient to tell their narrative and explain why they have come to visit the doctor appears to be incorporating the child into the decision-making process when in fact, they have little or no influence over the decision-making process. Nevertheless, asking the child to explain their symptoms and concerns in their words is vital to give the child a sense that they are being listened to and to help doctors get an accurate description of the child's symptoms. Emily (group 1) was the only participant to influence the decision-making process by telling her doctor her symptoms (without any associated assent or consent). Emily's symptom reports determined the dosage and frequency of her IV infusions thus, influenced the treatment that she received.³⁷

Aside from Abigail, Liam and Logan (group 2), the participants were not satisfied with being told what was going to happen to them.³⁸ They shared that they would have liked to have adapted their treatment plans to ensure it met their own concerns and priorities.³⁹ For example, Zoe (group 1) desired to delay her routine treatment by a week so she could sit her GCSE examinations. However, Zoe stated that this was not possible as she had no opportunity to discuss her concerns with her doctors.⁴⁰ It is possible that Zoe's doctors would have agreed to move her routine medical treatment to after her examinations if Zoe had asked. However, like many participants in this study, Zoe and her parents felt unable to ask for this adjustment.⁴¹ Zoe explained this was because there was no opportunity within the conversation for her to ask questions or raise concerns. The doctors would phone her parents, informing them that she needed to be admitted into hospital before ending the conversation with "looking forward to seeing

³⁶ See Chapter 7 Section 7.2.1.

³⁷ Ibid.

³⁸ See Chapter 7, Section 7.2.2.

³⁹ Ibid.

⁴⁰ Ibid.

⁴¹ Ibid.

you next week”. Zoe felt a lingering unease that her request may have been possible if she had had more agency.⁴²

As discussed in Chapter 7, Section 7.2.3, participants in this study were hesitant to communicate with their doctors in part, because they were intimidated by their authority and status. Lee (group 2) stated that he felt unable to ask questions or suggest ideas because he was not knowledgeable enough and felt inferior to his doctor.⁴³ As such, even when there was an opportunity to discuss his concerns, he felt unable to do so because he was intimidated by his doctor’s status. In Chapter 7, participants showed the following behaviours: holding back concerns against their better judgment, complying with treatment that they are not content with; staying silent when they were concerned and not asking for what they desire. Berry et al. term these behaviours in a clinical setting “hostage bargaining syndrome”.⁴⁴ “hostage bargaining syndrome” is where in the presence of clinicians, patients and their families feel unable to ask questions, express their concerns and often remain silent.⁴⁵ This is because they are negotiating from a position of fear and confusion, for their health.⁴⁶

Many of the participants in this study had rare and complicated medical conditions.⁴⁷ Berry explains that as “clinical conditions deteriorate and the stakes of health decisions rise”,⁴⁸ the patient becomes more dependent on doctors to make them better which perpetuates their “hostage negotiating

⁴² *ibid*

⁴³ See Chapter 7, Section 7.2.3.

⁴⁴ Berry, L.L, Danaher, T.S, Beckham, D, Awdish, R.L.A & Mate, K.S, ‘When Patients and Their Families Feel Like Hostages to Health Care’ (2017) 92(9) *Mayo Clinic Proceedings*, 1373 at 1373.

⁴⁵ *Ibid*.

⁴⁶ *Ibid*.

⁴⁷ See Chapter 5, Section 5.3.

⁴⁸ Berry et al. (n 44) at 1374.

behaviours”,⁴⁹ such as, compliance. This is because the power dynamics tip in favour of the health care professionals and patients become more anxious about their health. Equally, when things are going well, patients will show less signs of compliance.⁵⁰

I argue that the clinical environment has a role to play in enabling the development of a power dynamic in favour of health care professionals and perpetuating ‘hostage negotiating behaviours’. The empirical evidence in Chapter 6, Section 6.2 documents that typically, in a clinical environment doctors wear smart and formal clothes to distinguish themselves from other members of staff. Any communication with doctors is in a formal setting. Outpatient clinics are in a doctor’s office where participants describe sitting opposite the doctor. Where the participants were an inpatient, their doctor would enter the patient’s bed space, a private and personal space, often without warning or permission and accompanied by junior doctors, nurses and where necessary, therapy staff. Participants described how their doctors would talk towards their team instead of engaging with them. Moreover, during a time-pressured ward round there is typically little opportunity for patients to ask questions.⁵¹

Health care professionals confirmed that these behaviours are a normal element of the clinical environment.⁵² However, I suggest that the actions of doctors communicate to patients that the doctor has a high status within the hospital. Moreover, for patients, these practices and environment are new and unfamiliar thus creating feelings of uncertainty and anxiety. I argue that these factors tip the power balance in favour of the clinicians perpetuating the ‘hostage negotiating behaviours’ that Berry et al.⁵³ refer to. This may explain why the participants with chronic health

⁴⁹ *ibid*

⁵⁰ *Ibid.*

⁵¹ See Chapter 6, Section 6.2.

⁵² *Ibid.*

⁵³ Berry et al. (n 44) at 1374.

conditions became more confident to express themselves as they got older and more comfortable in the clinical environment.⁵⁴

Moreover, doctors may impact the power dynamic by not talking directly to the child or providing opportunities for the child to ask questions. Where the participants in this study experienced this, they felt disempowered and out of control.⁵⁵ Where a participant did communicate their concerns to their doctors, they rarely received feedback as to how their concerns were addressed, leading them to the assumption that they were not.⁵⁶ This reinforces the presumption that all decisions are for the doctors to make, discouraging participants from attempting to communicate with their doctors.

Telling patient's what will happen to them, reinforces the notion that doctors are the 'experts' from whom advice is sought and with whom patients are expected to comply. This is a form of paternalism which Szasz and Hollender term guidance co-operation.⁵⁷ Guidance co-operation describes a circumstance where a conscious and aware patient is seeking guidance from the 'expert', the doctor, in search of a cure, treatment or advice. The patient is expected to comply with the expert's guidance without challenge.⁵⁸ The data suggests that the participants' doctors took a guidance co-operation approach, directing the treatment and expecting compliance from the child without providing them an opportunity for consultation or assent. Whilst it is justifiable to use doctor paternalism in certain settings such as emergency medicine - where there is no opportunity or time to involve the child – paternalism cannot be justified

⁵⁴ See Chapter 7, Section 7.2.

⁵⁵ Ibid at Section 7.2.1.

⁵⁶ Ibid.

⁵⁷ Szasz, T.S & Hollender, M.H, 'A Contribution to the Philosophy of Medicine: The Basic Models of the Doctor – Patient Relationship' (1956) 97(5) *AMA Arch Intern Med* 585 at 587.

⁵⁸ Ibid.

outside of these parameters.⁵⁹ This is because, paternalism tips the power balance in favour of the doctors, reducing the patient's autonomy to decide what will happen to their body.⁶⁰

The displays of authority and status by doctors could explain why the participants felt a disconnect between their doctors and often preferred to communicate with their wider health care team.⁶¹ Emily discussed how talking to her physiotherapist with whom she had developed a strong rapport, felt more natural than talking to her doctor who Emily described as impersonal and formal.⁶² Liam recalled how his nurses were the ones that provided care and compassion and who he felt able to talk to.

Unfortunately, the evidence suggests that not all the participants had access to specialist nurses and therapists.⁶³ For these participants, they had no one outside of their family who they could confide in. This is a concern for participants such as Abigail and Lee who were acutely aware of the impact that their medical condition was having on their family and therefore, kept their concerns bottled up.⁶⁴

The participants also felt unable to approach their doctors because they desired to be considered a good, not demanding patient, and were sensitive to the knowledge that their doctors had limited time to spend with each patient.⁶⁵ Berry argues that behaviours of compliance and not speaking out are perpetuated by an "assumed hierarchy and the fear of

⁵⁹ Coynea, I, Amorya, A, Kiernanb, G, & Gibsonc, F, 'Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences' (2014) 18(3) *European Journal of Oncology Nursing*, 273.

⁶⁰ Beauchamp, T & Childress, J, *Principles of Biomedical Ethics* (7th ed Oxford University Press 2013) at 106-107.

⁶¹ See Chapter 6, Section 6.3.1.

⁶² *Ibid.*

⁶³ *Ibid.*

⁶⁴ See Chapter 6, Section 6.4.

⁶⁵ See Chapter 7, Section 7.2.3.

jeopardising the important doctor patient relationship”.⁶⁶ Furthermore, not all participants were aware that they could challenge a health care professionals’ decision, believing that the treatment given was “up to the doctors”.⁶⁷ These feelings of powerlessness reported by participants were further exacerbated by the child’s age and the associated lack of social status and agency which informs children that adults are the decision-makers.⁶⁸ This was particularly notable in the case of Susan whose cultural background and upbringing prohibited challenging an elder.⁶⁹ This prevented Susan for disclosing information to her doctors that could have been vital to her health care.⁷⁰

Health care professionals are expected to talk directly to the child, respect the child’s views, involve the child in discussions about their care, provide information and create opportunities for children to ask questions.⁷¹ The NHS is committed to a child centred model which respects the child’s existing and emerging autonomy.⁷² I suggest that informing a child of what is going to happen and failing to create opportunities for children to ask questions, creates a power imbalance in favour of the doctor. Moreover, doctors are missing out on valuable information from children who are

⁶⁶ Berry et al. (n 44) at 1374.

⁶⁷ Chapter 7, Section 7.4.6.

⁶⁸ Oswell, D *The Agency of Children: From Family to Global Human Rights* (Goldsmiths University of London 2013) at 3; Baraldi, C and Cockburn, T, *Theorising Childhood: Citizenship, Rights and Participation* (Palgrave Macmillan 2018).

⁶⁹ Chapter 6, Section 6.4.2.

⁷⁰ *Ibid.*

⁷¹ GMC, ‘GMC, ‘Introduction, 0-18 years: guidance for all doctors’ <<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/introduction>> accessed 16 June 2019 at para 3.

⁷² NHS, ‘NHS Five Year Forward View’ (*NHS*, 22 October 2014) <<https://www.england.nhs.uk/five-year-forward-view/>> accessed 19 February 2019.

experts in their own conditions and can provide a unique insight.⁷³ Sinclair argues this facilitates better decision-making.⁷⁴

The empirical data found that the communication between doctors and the participants was poor. It found that the participants were hesitant to engage with their doctors due to intimation caused by their doctors' authority and doctor paternalism. As a result, the participants exhibited what Berry would argue are "hostage negotiation behaviours", such as, compliance, silence and not speaking out despite one's better judgment.⁷⁵ Berry argues that "hostage syndrome" or "white cloak silence" impacts the relationships between doctors and patients, leading to a reduction in effective communication, the breakdown of doctor patient relationships and has the effect of making patients feel unable to participate in their health care.⁷⁶ The findings from this study confirm Berry et al. conclusions. However, I argue, that poor communication, lack of opportunities to engage with doctors, doctor paternalism and authority *does* contribute towards a child participating in a low level and tokenistic manner. However, where the child is participating in this manner, but is capable of more and desires more, Hart would argue,⁷⁷ that they are not meaningfully participating in their health care.

8.2.3. Parental Paternalism

Past-paediatric patients and health care professionals highly praised the role of parents.⁷⁸ In Chapter 6, Section 6.4.1., it was explained that parents act as their child's primary carer, communicator, translator, expert in their

⁷³ Chapter 7, Section 7.2.1.

⁷⁴ Sinclair, R, 'Participation in Practice: Making it meaningful, effective and sustainable' (2004) 18 *Children and Society*, 108 at 107.

⁷⁵ Berry et al. (n 44) at 1374 – 1378.

⁷⁶ *ibid*

⁷⁷ Hart, 'Children's Participation: From Tokenism to Citizenship' (n 1).

⁷⁸ See Chapter 6, Section 6.4.

child's condition and decision maker, offering practical and emotional support. This is in line with findings from previous research.

A recent review highlighted that parents of children with chronic health conditions typically assume primary responsibility for management of the condition, which can often include medication adherence, specialized diets, allied health interventions and services, and vigilance to risk behaviours that could exacerbate the condition.⁷⁹

As the child matures, it is anticipated that parents stop being the 'decision-maker' and engage in shared decision-making with their child in preparation for their child's transition to adult services.⁸⁰ Despite this expectation, this study found that 15 of the 18 participants' parents remained the decision-maker throughout their child's paediatric health care journey, discontinuing when they became an adult because doctors required their adult child's consent.⁸¹ This is unsurprising given the expectations of parents to stay with their child whilst in hospital and take on caring responsibilities.⁸² Participants reasoned that their parents remained the 'decision-maker' in part because health care professionals would seek parental consent. However, they also identified that their

⁷⁹ Zelman, J & Ferro, M, 'The Parental Stress Scale: Psychometric Properties in Families of Children With Chronic Health Conditions' (2018) 67 *Family Relations*, 240 at 241; Morawska, A, Calam, R, & Fraser, J, 'Parenting interventions for childhood chronic illness: A review and recommendations for intervention design and delivery' (2015) 19 *Journal of Child Health Care*, 5 at 5-17

⁸⁰ Coynea & others (n 59) at 273-280.

⁸¹ See Chapter 6, Section 6.4.1 and Chapter 7, Section 7.5.

⁸² Platt, H, 'The Welfare of Children in Hospital: Report of the Committee' (Ministry Of Health Central Health Services Council, 1959)
<<https://ia800201.us.archive.org/8/items/op1266065-1001/op1266065-1001.pdf>>
accessed 12 February 2018 at chapter 11.

parents' anxiety was a contributing factor to their desire to take an active role in their child's health care.⁸³

It is well documented that parents with children who have chronic health conditions suffer symptoms of depression and anxiety.⁸⁴ Pinquart's recent study analysed the findings of 12 empirical studies that had interviewed parents.⁸⁵ They found that parents of children with chronic health conditions "showed small to moderate elevations of depressive symptoms compared with parents of healthy/nondisabled children".⁸⁶ The highest elevations of depression symptoms were found among parents of children with cerebral palsy, neuromuscular disorders and cancer.⁸⁷ It is, therefore, noteworthy that the participants in this study with life-threatening, limiting and progressive conditions emphasised their parents' anxiety in contrast to participants without these conditions who acknowledged their parents' anxiety in passing, rather than a stand-alone topic.⁸⁸ All the participants in this study, with both chronic and acute medical conditions, reported changes in their parents' mental health after their diagnosis.⁸⁹

Because of their anxiety, parents struggled to share the decision-making role with their child as they matured. For many participants, such as Lee and Zoe, their mothers' involvement in their health care prevented them

⁸³ See Chapter 6, Section 6.4.

⁸⁴ Pinquart, M 'Featured Article: Depressive Symptoms in Parents of Children With Chronic Health Conditions: A Meta-Analysis' (2019) 44(2) *Journal of Pediatric Psychology*, 139; Miodrag, N Burke, M, Tanner-Smith, E & Hodapp, R.M, 'Adverse health in parents of children with disabilities and chronic health conditions: a meta-analysis using the Parenting Stress Index's Health Sub-domain' (2015) 59(3) *Journal of Intellectual Disability Research* at 257.

⁸⁵ *ibid*

⁸⁶ Pinquart, M 'Featured Article: Depressive Symptoms in Parents of Children With Chronic Health Conditions: A Meta-Analysis' (2019) 44(2) *Journal of Pediatric Psychology*, 139.

⁸⁷ *Ibid.*

⁸⁸ See Chapter 6, Section 6.4.

⁸⁹ *ibid*

from formulating, voicing and having their opinions heard.⁹⁰ I argue that in these circumstances, the parents' well-meaning role as decision-maker limited the child's role to tokenistic non-participation. Although, the desire of parents to take an active role in their child's care is understandable, health care professionals expressed their concern that parental involvement when children were capable of participating in their health care, prevents children from learning the skills required to make decisions in adult services.⁹¹ Emily, James and Megan were the only participants to describe their parents encouraging their increasing participation in their health care.⁹² Their parents did so because they sought to equip them for adult services. However, it is important to note that their parents worked in health care. Emily and James mothers were nurses and Megan's parents were carers.⁹³

Nevertheless, parents taking a leading and active role in their child's consultations is not necessarily an indicator of no participation. Those participants that enjoyed a strong parent-child relationship, describe talking to their parents prior to every consultation about what they hope to achieve, their concerns and worries about their treatment and medical condition. They would disclose bullying experienced as a result of their disability, inform their parents of any new symptoms and openly talk about their mental health, specifically any distress caused by their symptoms. They would share intimate details that would be reciprocated. The participants had a deep understanding of the impact that their condition had on their parents. They detailed their anxiety, the effect on siblings and the wider family including financial, mental health and relationship difficulties.⁹⁴ Consequently, their parents would enter a consultation

⁹⁰ *ibid*

⁹¹ *Ibid* and Chapter 7, Section 7.5.

⁹² See Chapter 6, Section 6.4.

⁹³ See Chapter 5, Section 5.3.

⁹⁴ See Chapter 6, Section 6.4.

equipped with the concerns of their child, and a list of what their child would like to be articulated to the doctor.⁹⁵ Chapter 6 establishes that, in many instances, parents would be a translator, acting as a conduit for their child's voice.⁹⁶ This was beneficial to participants who felt unable to effectively communicate with their health care team due to doctor paternalism or who, because to their medical condition, were unable to communicate with their clinician, for example, the study participant James (group 2).⁹⁷ Parental input in this circumstance can aid, rather than hinder, a child's participation.

In contrast, a challenging parent-child relationship is a barrier to meaningful participation. For example, in Chapter 6, Section 6.4.2, Susan (group 1) explains that due to her cultural background she was taught not to speak to adults without invitation. Consequently, during outpatient consultations, Susan was prevented from speaking openly in front of her health care team. Susan's doctors were unaware of the severity of her symptoms and did not provide the appropriate treatment until she reached 16 years of age, at which point she was able to see a doctor without her parent's presence.⁹⁸ In complex dynamic like that described by Susan, Daniel (group 4) explains how the child's voice can become lost in the sea of adult opinions.⁹⁹ The family dynamic and well-being of parents is crucial to enabling and facilitating participation.

8.2.2. Information

The GMC cites the exchange of information between doctor and patient as "central to good decision making".¹⁰⁰ In law, to protect against a tort of

⁹⁵ Chapter 6, Section 6.4.1.

⁹⁶ *ibid*

⁹⁷ Chapter 6, Section 6.4

⁹⁸ See Chapter 6, Section 6.4.2.

⁹⁹ Chapter 6, Section 6.4.3

¹⁰⁰ GMC, 'Consent: Patients and Doctors Making Decisions Together, Part 2: Making Decisions about Investigations and Treatment' (GMC, 2 June 2008) <<https://www.gmc->

trespass, the doctor must inform the patient “what he intends to do, and its implications, in the way a careful and responsible doctor in similar circumstances would have done”.¹⁰¹ To protect against a tort of negligence, the doctor must inform the patient of the material risks. A material risk is a risk that “a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor was or should reasonably be aware that the particular patient would be likely to attach significance to it”.¹⁰² The extent of disclosure depends on the patient’s individual characteristics, including their capability to understand. The GMC states that “children and young people usually want or need to know about their illnesses and what is likely to happen to them in the future”.¹⁰³ Academic research found that to inform and involve avoids “confusion, frustration, distress and anger”,¹⁰⁴ and despite being initially upset about a diagnosis or prognosis, most children appear to appreciate this information.¹⁰⁵

Throughout the interviews, the participants described (i) an absence of information; (ii) desiring more information; and (iii) feeling satisfied with the information. Whilst one participant, Emily, always felt fully informed,¹⁰⁶ the remaining participants disclosed numerous examples of where they experienced a complete absence of information¹⁰⁷ or selective

uk.org/ethical-guidance/ethical-guidance-for-doctors/consent> accessed 17 January 2018 para 28.

¹⁰¹ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582, *Chatterton v Gerson* [1981] 1 ALL ER 257 at 443

¹⁰² *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 at paras 39-87.

¹⁰³ GMC, ‘Introduction, 0-18 years: guidance for all doctors’ < <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/introduction>> accessed 16 June 2019 at para 17.

¹⁰⁴ Aldridge, J, Shimmon, K, Miller, M et al, ‘I can’t tell my child they are dying. Helping parents have conversations with their child’, (2017) 102 *Achieves of Disease in Childhood Education and Practice*, 182 at 182.

¹⁰⁵ *ibid*

¹⁰⁶ See Chapter 7, Section 7.3.3.

¹⁰⁷ See Chapter 7, Section 7.3.2.

information.¹⁰⁸ Most concerning were the instances described by Bethany and Anjali where there was a complete absence of information and their medical procedures were conducted without their knowledge.¹⁰⁹

8.2.2.1. Absence of information

An absence of information is a barrier to a child's meaningful participation. In Chapter 7, five participants documented instances during their paediatric health care where they had a complete absence of information.¹¹⁰ Abigail recalls being unaware of the name of her condition until the age of 18.¹¹¹ Susan and Emily describe being uninformed about their scan results and treatment plans.¹¹² For Bethany and Anjali, this absence of information extended to a medical procedure.¹¹³ In Chapter 7, Section 7.3.2. Bethany recalls her first blood test at eight years of age. Accompanied by her mother, Bethany met a "very kind" phlebotomist who acknowledged Bethany but did not explain that she was going to have a blood test nor what this involved. Similarly, at 15 years of age, and during what was expected to be a routine appointment to discuss further treatment options for her ongoing eye condition, Anjali had a procedure under local anaesthetic. Neither Anjali nor her mother were aware that she would be undergoing this procedure.¹¹⁴

Bethany and Anjali report that they had no time to prepare for the procedure.¹¹⁵ The importance of preparation time before a medical

¹⁰⁸ See Chapter 7, Section 7.3.3.

¹⁰⁹ See Chapter 7, Section 7.3.2.

¹¹⁰ See Chapter 7, Section 7.3.2.

¹¹¹ See Chapter 7, Section 7.5.

¹¹² See Chapter 7, Section 7.3.

¹¹³ See Chapter 7, Section 7.3.2.

¹¹⁴ *ibid*

¹¹⁵ See Chapter 7, Section 7.3.3.

procedure is well documented.¹¹⁶ Liddle explains that it is necessary to prepare patients well in advance for surgery to ensure that there is plenty of opportunity for the patient to ask questions and to fully understand the procedure.¹¹⁷ Moreover, for a parent, a *Gillick* competent child or a 16-17 year old to consent to medical treatment,¹¹⁸ valid consent requires that a patient is sufficiently informed of the nature of the procedure.¹¹⁹ A sudden procedure where the patient is unprepared and unable to ask questions undermines the validity of consent. Unlike Bethany, where her mother provided the consent for the blood test, in the case of Anjali her parents were uninformed¹²⁰ and therefore, it is questionable whether valid consent was obtained. The impact of an absence of information on the participants was an increase in anxiety, causing unnecessary worry and concern.¹²¹ Unlike Bethany and Anjali who were uninformed before a procedure, Emily, Susan and Abigail felt anxious but did not feel as though their bodily integrity had been violated by the lack of information.¹²² The participants who noted feeling a violation of bodily integrity had all undergone a medical procedure.¹²³ There appears to be a connection between being uninformed and something unexpected happening to your body which triggers feelings of violation.

Liddle explains that preparation time reduces anxiety.¹²⁴ Research establishes that anxiety is extremely common amongst patients

¹¹⁶ Liddle, C, 'Preparing patients to undergo surgery' (2012) *Nursing Times*, 108 at 48, 12-13.

¹¹⁷ *Ibid.*

¹¹⁸ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] A.C. 112; [1985] 3 W.L.R. 830.

¹¹⁹ *Chatterton v Gerson* (n 107) at 443; *Montgomery v Lanarkshire Health Board* (n 102).

¹²⁰ See Chapter 7, Section 7.3.3.

¹²¹ *ibid*

¹²² *ibid*

¹²³ Lee, Bethany, Anjali, William, Rachel, Megan.

¹²⁴ Liddle, C, 'Preparing patients to undergo surgery' (2012) *Nursing Times*, at 48, 12-13.

undergoing any form of medical procedure.¹²⁵ Anxiety is alleviated or reduced by the patient being informed and feeling prepared. In Anjali's case, her past medical history was a cause for anxiety. At the age of 12 she underwent lifesaving brain surgery followed by a long and challenging recovery.¹²⁶ At 15 she suffered severe and unanticipated side effects from the general anaesthetic administered during Botox injection surgery for her eyes.¹²⁷ As such, Anjali was concerned about the anaesthetic, the outcomes of the procedure and concerns about what would happen next if this did not work. Anjali recalls not being given an opportunity to ask those questions and, as such, was extremely anxious when told she would be having the procedure without prior information and consultation. Anjali lost trust in her medical team, a lack of trust that extends to all health care professionals.¹²⁸

For Bethany, who was a "smart" and "engaged child" with an interest in how things worked and a desire and curiosity for information, this lack of explanation and preparation time led to a feeling of violation of her bodily integrity leading to symptoms of trauma.¹²⁹ Bethany identifies this event as the cause of her life-long needle phobia.¹³⁰ Trauma is defined as "the unique individual experience of an event or enduring conditions in which the individual's ability to integrate his/her emotional experience is overwhelmed and the individual experiences (either objectively or subjectively) a threat to his/her life, bodily integrity, or that of a caregiver or family".¹³¹ Trauma is often caused by "an exceptional experience in which powerful and dangerous stimuli overwhelm the child's capacity to

¹²⁵ *ibid*

¹²⁶ See Chapter 5, Section 5.3.

¹²⁷ *Ibid.*

¹²⁸ Chapter 7, Section 7.3.2.

¹²⁹ *ibid*

¹³⁰ *ibid*

¹³¹ Saakvitne, K.W, Gamble, S.J, Pearlman, L.A, & Lev, B.T. *Risking connection: A training curriculum for working with survivors of childhood abuse.* (Lutherville, MD: Sidran 2000).

regulate emotions”.¹³² Research has found that children with medical conditions are significantly more likely to experience symptoms of trauma in contrast to their counterparts without medical conditions.¹³³ One explanation for this is the “potentially recurring nature of these traumas, and repeated exposures to medical settings”.¹³⁴ This finding was reflected in this research project. However, in this instance, Bethany was an exception as it was her first exposure to needles that prompted a phobia and symptoms of trauma. Needle phobias in children and adolescents have been widely documented.¹³⁵ They present an ongoing issue in clinical practice and are a consequence of biology, conditioning, and life events.¹³⁶ Orenius argues that an important element to reducing phobia is the “suitable preparation before injection procedures”¹³⁷ where nurses can involve children in coping strategies. However, absence of information meant that the coping strategies could not be implemented in the cases documented in this study. An absence of information is a barrier to children participating at any level in their health care. Information is necessary in unlocking participation.

8.2.2.2. Desiring more Information

Ten of 18 participants were dissatisfied with the information that they received as children.¹³⁸ Primarily this was because they received selective

¹³² UCFS, The Early Trauma Treatment Network (2016) <<https://globalprojects.ucsf.edu/project/early-trauma-treatment-network-0>> accessed 1 April 2018.

¹³³ Wilcox, H.C, Rains, M, Belcher, H, et al., ‘Behavioral Problems and Service Utilization in Children with Chronic Illnesses Referred for Trauma-Related Mental Health Services’ (2016) 37(1) *Journal of Developmental and Behavioral Pediatrics*, 62 at 69.

¹³⁴ Ibid.

¹³⁵ Orenius, T, Säilä, H, Mikola, K & Ristolainen, L, ‘Fear of Injections and Needle Phobia Among Children and Adolescents: An Overview of Psychological, Behavioral, and Contextual Factors’ (2018) 4 *Open Nursing*, 1, at 1-8.

¹³⁶ Ibid.

¹³⁷ Orenius, T, Säilä, H, Mikola, K & Ristolainen, L (n 135).

¹³⁸ See Chapter 7, Section 7.3.3.

information. Chapter 7, Section 7.3.3 reports that participants receive information from parents, doctors, the health care team and independent research. It is of note that the most common source of information is the child's parents.¹³⁹ This suggests children do not receive a sufficient amount of information from their health care team to satisfy their desire for information. In part, this may be because children are often excluded from conversations.¹⁴⁰ Therefore, it is understandable that children will turn to their parents for this information. The doctors in this study regularly stated that they desired patients to be accurately informed to prevent unnecessary worry and concern.¹⁴¹ Yet, with parents being the main source of information, there are no assurances that children are receiving accurate information.

Four participants routinely received information in conversations with their doctors and health care team.¹⁴² Doctors describe giving patients information that they believed satisfied the balance between overload and sufficient information.¹⁴³ Asked what information doctors typically give children prior to a medical procedure, the health care professionals interviewed in this study stated that it was necessary to include:

- (i) A brief overview of the procedure, if necessary, using illustrations to assist understanding
- (ii) The reasons why they required the operation and the benefits they will reap
- (iii) The most common risks¹⁴⁴

Whilst past patients were keen to receive this information, the participants desired more specific and detailed information:

¹³⁹ *ibid*

¹⁴⁰ See Chapter 7, Section 7.2.

¹⁴¹ See Chapter 7, Section 7.3.1.

¹⁴² Emily, Lee, Maddison and James.

¹⁴³ See Chapter 7, Section 7.3.1.

¹⁴⁴ *Ibid*.

- (i) What the procedure will entail?
- (ii) The risks and benefits of the procedure, even if the risks are unlikely
- (iii) Alternative treatment options
- (iv) Who will be conducting the procedure and who will be present in the operating theatre?
- (v) Where will they wake up?
- (vi) The expected length of the operation
- (vii) Details of the recovery process, for example, length of time, names of the physiotherapist who will be involved and what the therapy will entail
- (viii) Length of inpatient admission¹⁴⁵

In comparing these two lists, it is clear that the desires of patients do not align with the doctors' assumption of the information necessary to be sufficiently informed. This misalignment is further illustrated by Daniel (group 4) in Chapter 6, Section 6.3, where he assumes that children primarily desire a positive personal relationship with their doctor above knowledge, whilst their parents desire accuracy of information above doctor-parent rapport.¹⁴⁶ Although, the participants did desire a positive relationship with their doctor and in many instances, experienced it, they also desired information about what was going to happen to their bodies. They desire both information and a rapport, not solely a rapport without information as Daniel suggests. All participants reported the same frustrations such as not enough information, irrespective of whether they had a positive or negative health care experience.¹⁴⁷ In the main, the participants did not feel satisfied with the information that they received, arguing that it was selective and controlled by their doctors.¹⁴⁸

¹⁴⁵ See Chapter 7, Section 7.3.3.

¹⁴⁶ See Chapter 6, Section 6.3

¹⁴⁷ Ibid.

¹⁴⁸ See Chapter 7, Section 7.3.3.

Selective information seeks to protect children from overloading and unnecessary worry.¹⁴⁹ However, this study found that participants who received partial or no information would worry more as a result of the unknown.¹⁵⁰ Liddle¹⁵¹ states that to be prepared for a procedure requires being fully informed as to the nature of the procedure, to understand the sequence of events, the side effects and being able to ask any questions. The participants in this study, although told about the procedure, did not have the resources described by Liddle to adequately prepare and thereby, reduce anxiety, stress and trauma.¹⁵²

In the main, the participants state that they were provided with an overview of the procedure, the common risks and the reasons for the procedure.¹⁵³ This information was argued by health care professionals to be information that a reasonable patient would desire.¹⁵⁴ Therefore, unless the participants gave a doctor reason to believe that more specific information was desired, such as the length of the operation or who is conducting the procedure, *Montgomery and Bolam v Friern Hospital Management Committee* that the doctor should only be expected to provide information that is valued by the objectively reasonable patient. Otherwise, the standard established in *Montgomery and Bolam v Friern Hospital Management Committee* has been met.

Nevertheless, there is a misalignment between what a doctor believes is necessary to disclose and what the patient desires. Thus, it could be argued that *Montgomery and Bolam v Friern Hospital Management Committee* does not go far enough. A better standard may be that a doctor should be under a duty to provide a patient with information that meets their

¹⁴⁹ See Chapter 7, Section 7.3.1.

¹⁵⁰ See section 7, Section 7.3.3

¹⁵¹ Liddle (n 124) at 12-13.

¹⁵² *ibid.*

¹⁵³ See section 7, Section 7.3.3

¹⁵⁴ See Chapter 7, Section 7.3.1.

expectations. However, as discussed in Chapter 2, this is an unfair obligation to place on health care professionals who would struggle to meet this standard. It is unreasonable to expect a doctor to identify all the subjective desires of an individual patient. Moreover, it is impractical to do so due to the time constraints doctors experience.¹⁵⁵ Whilst the health care professionals in this study agreed that, ideally, full information ought to be given to the patient, in Chapter 7, Section 7.3.2, Chris describes the huge time pressure facing doctors. In a typical ward round of 50 patients, the doctor has one or two minutes with each patient. In this time, it is expected that the doctor sufficiently informs the patient of the procedure, including the risks and benefits, answers the patient's questions, assesses the patient's competency and obtains their consent. Ideally, patients ought to be fully informed but in practice, this is rarely the case.

If the participants had spoken with their doctors and asked for more information, it is possible that they would have received this additional information. For example, Emily describes continuing to ask her doctors for information until she received it, "we would get there in the end" Emily explained.¹⁵⁶ However, the reason why most of the participants did not approach their doctor and ask for additional information is because of their doctors' authority and status, their desire to be a "good patient" who is compliant and not challenging nor demanding, and the dearth of resources such as time that means doctors inform a child before quickly moving on to the next patient giving limited or no opportunity for the child to ask for further information.¹⁵⁷

Although, a complete absence of information is rare, the health care professionals explained that receiving selective information is not uncommon, nor limited to paediatric health care.¹⁵⁸ Thus, although

¹⁵⁵ See Chapter 7, Section 7.3.3.

¹⁵⁶ Ibid.

¹⁵⁷ See Chapter 8, Section 8.2.2.

¹⁵⁸ See Chapter 7, Section 7.3.2 and Section 7.3.3.

selective information is not ideal, provided the information given to the child meets the legal standards, selective information is unlikely to prevent meaningful participation unless coupled with the inability to use this information to effect change. However, it is not unreasonable to suggest that health care professionals should check with their patients that they have provided all the information that their patient desires rather than assume that their assessment of what information is valuable is accurate.

8.2.2.3. Satisfied with the Information

Four participants reported feeling satisfied with the information that they received as a child because they felt “sufficiently informed”.¹⁵⁹ However, on close examination of the information these participants received, they do not disclose any additional information than the other participants who reported receiving selective and limited information. Like the ten participants who were dissatisfied with the information that they received, these participants were unaware of the risks of the procedure, the length of the operation and recovery time.¹⁶⁰ In addition, when talking about their experiences, they reported the same frustrations as the other participants.¹⁶¹ In a 2010 research project about patients’ perception of being informed, Sepucha et al. found that there was no relationship between the perception of being informed and the patients’ knowledge scores.¹⁶² Therefore, a child may be uninformed but be satisfied with the information that they received.

Nevertheless, even where a child is fully informed, and receives information meeting the legal standard, information alone is not enough for meaningful participation. Arnstein argues that there is an essential

¹⁵⁹ See Chapter 7, Section 7.3.3.

¹⁶⁰ Ibid.

¹⁶¹ Ibid.

¹⁶² Sepucha, K.R, Fagerlin, A, Couper, M.P, et al ‘How Does Feeling Informed Relate to Being Informed? The Decisions Survey’ (2010) 30(5) Medical Decision Making at 77-84.

difference between “going through the empty ritual of participation and having the real power needed to affect the outcome of the process”.¹⁶³ In this study, although participants had been fully or selectively informed, participants did not have any real power to affect the outcome of the medical decisions. Only a minority of participants were able to go on to assent to a medical procedure. The participants that did assent to a medical procedure during the paediatric experience, state that in the majority of instances where they underwent a medical procedure, they were not provided the opportunity to assent or consent to medical treatment.¹⁶⁴

I argue that the results of this study suggest that participants did not have any power or control over the decision-making process, including an opportunity to have their concerns heard and acted upon. Providing children with information creates an illusion of meaningful participation, however, there remains no opportunity to consult, provide assent or dissent. This was further compounded by feelings of intimidation due to the health care professional’s authority. Montgomery and Alderson explain that participation is more than informing someone of the basic facts.¹⁶⁵ Whilst information is extremely important to unlocking higher levels of participation such as assent and consent to medical treatment, information is not in itself participation if the patient does not have any influence over the decision.

“Participation” ranges in meaning from having minimal information to having quite a full share in decision-making. Sometimes this rather grand term is used to express virtually nothing, such as when a child is told, “You are going to have chemotherapy, do you want

¹⁶³ Arnstein, S.R, 'A Ladder Of Citizen Participation' (1969) 35(4) *Journal of the American Planning Association*, 216.

¹⁶⁴ See Chapter 7, Section 7.4.6.

¹⁶⁵ Montgomery, J, & Alderson, P, *Health care choices: making decisions with children* (IPPR, 1996) at 27.

to have a drip in your left or right hand?” Participation can be worse than useless when used as a pretence of consultation, or to disguise the fact that no real choice is being given.¹⁶⁶

If meaningful participation is designed solely from an objective perspective which considers whether the child can inflict change on the decision-making process, it can be argued that the participants in this study were participating at most, on a tokenistic level.

Hart argues that for participation to not be meaningful a child must (i) be capable of acting at a higher participatory level and (ii) desiring to do so.¹⁶⁷ A child who is not capable of acting at a higher participatory level or is capable but does not desire to participate at this level is acting meaningfully from a subjective perspective. Equally, if a child is capable of acting at higher participatory level and desires to do so they are not participating meaningfully from a subjective perspective.¹⁶⁸

In this study, all participants had a desire for information, from as early as they can remember. Moreover, the findings suggested that above the age of 10 most of the children did have the capacity to act at a higher level of participation.¹⁶⁹ Indeed, many participants were informed by their doctors that if it were not for the law, they would be capable of higher forms of participation.¹⁷⁰ Therefore, I argue that the lack of opportunity to use the information they had received to engage in assent, consent or shared decision-making meant that participants were not acting meaningfully from a subjective and objective perspective.

As Chapter 7 states, from around the age of ten, and eight for Hannah and Maddison (group 3), all participants desired to participate in the decision-

¹⁶⁶ Ibid.

¹⁶⁷ Hart, 'Children's Participation: From Tokenism to Citizenship' (n 1) at 24.

¹⁶⁸ Ibid.

¹⁶⁹ See Chapter 7, Section 7.4.3. and 7.4.4.

¹⁷⁰ Chapter 7, Section 7.4.4.-7.4.7

making process.¹⁷¹ Therefore, prior to this stage, where the participants did not have the desire or perhaps the capabilities to participate at a higher level, being informed is subjectively meaningful participation. However, I argue that this stage has been reached, where the participants desired to participate at a higher level and were capable of doing so, the inability to use this information to influence the decision-making process is non-meaningful participation.

Participants were dissatisfied when their doctors did not consider their concerns or desires, for example, where doctors recommended surgical treatment options despite the patient's stated preference for non-surgical options.¹⁷² If doctors gave weight to the concerns of patients and adapted proposed treatment plans accordingly where possible, the child would have used their knowledge to impact the outcome of the decision-making process and thus participated meaningfully from an objective and subjective perspective. The child patient would be directly involved in devising the treatment options, irrespective of whether consent was taken by the parents or the child. It could be argued that it is an unrealistic expectation to require doctors to tailor their recommendations to the desires and needs of each child, especially in the current clinical environment starved of resources, including time. Nevertheless, if the NHS is serious about offering a patient/child-centred service with collaboration between doctor and patient, in line with the legal and policy rhetoric outlined above, the tailoring of treatment options would be a reasonable expectation in instances where such tailoring would be subjectively and objectively meaningful for the child.

Person-centred care supports people to develop the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own health and care. It is coordinated and tailored to the needs of the individual, and

¹⁷¹ See Chapter 7, Section 7.4.7.

¹⁷² See Chapter 7, Section 7.4.5.

healthcare professionals work collaboratively with people who use the services.¹⁷³

Providing greater flexibility will assist the NHS in moving towards the patient-centred service they committed to in their “five-year forward view”¹⁷⁴.

8.2.3. Decision-Maker

It is presumed that between the ages of 16 and 17 children are competent to consent to therapeutic medical treatment¹⁷⁵ although, parental consent is concurrent.¹⁷⁶ In contrast, children under 16 are presumed to lack competency to consent.¹⁷⁷ Where a young person is deemed to have the “sufficient maturity and intelligence”¹⁷⁸ to understand the proposed treatments including the risks and benefits, they may consent to therapeutic medical treatment without parental involvement as they are said to be *Gillick* competent¹⁷⁹. For those children who are not *Gillick* competent, the Children Act¹⁸⁰ requires those with parental responsibility to act as a surrogate decision maker, consenting to medical treatment on behalf of the child.

Where a child is not capable to consent to medical treatment, a child may provide their assent to medical treatment. As discussed in Chapter 1, assent refers to a positive and voluntary agreement by a child who is not *Gillick* competent and may not be in possession of a sufficient amount of information to provide a legally valid consent.¹⁸¹ Levesque laid down the

¹⁷³ NHS, ‘Involving people in their own care’ (*NHS*)

<<https://www.england.nhs.uk/ourwork/patient-participation/>> accessed 5 March 2019.

¹⁷⁴ NHS, ‘NHS Five Year Forward View’ (n 601).

¹⁷⁵ Family Law Reform Act 1969 c.46.

¹⁷⁶ *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11.

¹⁷⁷ Family Law Reform Act (n 174).

¹⁷⁸ *Gillick* (n 118) at 189 per Lord Scarman.

¹⁷⁹ *ibid*

¹⁸⁰ Children Act 1969 c.51 at section 2 and 3.

¹⁸¹ The Research Ethics Guidebook: a resource for social scientists (n 54).

four requirements for assent: (i) the child has awareness of their situation that is developmentally appropriate for them, (ii) as much as possible, the child is aware of “what they can expect during and after the procedures”,¹⁸² (iii) the health care professionals are aware of the child’s understanding of their situation and (iv) the child is willing to act; their action is voluntary. Assent encourages the child to participate in the decision-making process, according them the opportunity to make their opinions known without giving the non-*Gillick* competent child too much control where they may make a life-threatening or self-destructive decision.

The purpose of an assent process is not to provide a second consent but to allow the child to have an appropriate level of involvement in the decision-making process about something that affects him.¹⁸³

In this form, a child’s assent could be considered to be participating at rung four of Hart’s ladder, ‘assigned but informed’, where the child understands the intentions behind their treatment, knows who made the treatment decisions and why, has a meaningful, not decorative, role in the treatment and volunteers or assents to the treatment suggested by the health care professionals. Where the child is consulted about the treatment options rather than merely assenting to what is proposed, the child could be participating at rung five, ‘consulted and informed’. Finally, if the child is consulted about every step in the process, their assent could fall into rung six, ‘adult-initiated shared decision-making’. For the non-*Gillick* competent child, assent provides an opportunity for the child to express their voice. Where parents are uncertain as to whether to consent to a medical procedure, their child’s assent may provide parents with the reassurance

¹⁸² Levesque, R, ‘Informed Consent and Assent’ (2018) (Encyclopaedia of Adolescence, 28 February 2018) < https://0-doi-org.pugwash.lib.warwick.ac.uk/10.1007/978-3-319-33228-4_440 > accessed 18 August 2019 at section ‘Adolescents, Consent, and Assent’.

¹⁸³ Sibley, A Sheehan, M & Pollard, A, ‘Assent is not Consent’ (2012) 38(1) *Journal of Medical Ethics* 3) at 3.

that they are not only acting in their child's best interests but that their child agrees with this course of action. In this instance, the child is influential in the decision-making process. However, the power of a child's assent is limited. Their decision is not legally binding thus does not have to be followed. Moreover, if a child did not provide their assent, parental consent would be sought - and often obtained for a procedure suggested and supported by the health care team. The presence of a child's assent rarely changes the outcome of the decision-making process that normally results in parental consent to medical treatment. Therefore, the child's assent is not influential, rather tokenistic, appearing to provide power when the child's decision has little or no impact on the parents' final decision. Subjectively, however, the child may value this level of participation.

Where a non-*Gillick* competent child does not provide their assent to the proposed medical treatment, their power over the decision-making process is dependent on the adults around them. In Chapter 7, Section 7.2, six out of ten participants that had an experience of assenting to medical treatment stated that if they dissented, their parents would override their decision and consent to the medical treatment. Leikin argues that overriding a child's dissent "breaks his or her trust with those involved; thus compromising future relationships with health care professionals".¹⁸⁴ Although, Leikin's article is on children's participation in research, their argument is relevant to children's participation in their health care. These six participants did not trust their parents to respect their decision, felt disempowered and out of control. Hannah and Anjali reported a breakdown in their relationship with their doctors as a result of feeling pressured to undergo a medical procedure. Thus, had a child's dissent been overruled, it is plausible that their relationships between their parents and doctors would be affected.

¹⁸⁴ Leikin, S, 'Minors' Assent, Consent, or Dissent to Medical Research', (1993) 15 (2) Ethics and Human Research, 1 at 5.

The remaining four participants were confident that their parents would stand by their dissent.¹⁸⁵ Megan uses the example of where she did not wish to have scoliosis spinal surgery, thus did not assent to therapeutic medical treatment. Her parents, respecting their daughter's wishes and concerns, refused to consent to the surgical procedure.¹⁸⁶ Although these participants have examples of where their parents have agreed with their dissents, they have no examples of instances where the treatment they are refusing is lifesaving. It is unknown whether their parents would continue to respect their child's decision in these instances. Through collaborating with their parents, these four participants engaged in shared decision-making.¹⁸⁷ However, where parents are consenting or refusing medical treatment on the basis of their child's decision, it begs the questions, who is consenting to medical treatment, is parental consent an autonomous decision and is the consent valid if parents are following the instructions from their non-*Gillick* competent child?

Six participants believed that their parents would override their dissent to medical treatment.¹⁸⁸ They did not feel as though they had any control over their medical treatment and felt disempowered. It is argued that assent "seek[s] to empower adolescents to be involved in decision-making to the extent of their capacity to do so".¹⁸⁹ Throughout this empirical study, health care professionals argued that assent is beneficial to the child in recognising their evolving competencies, autonomy and encouraging their meaningful participation within their health care. Assent is empowering when it is at the edge of the child's ability and the child would not desire more. However, where the child is capable of and does desire a higher level of participation, assent is not empowering. Participants describe feeling

¹⁸⁵ See Chapter 7, Section 7.5.

¹⁸⁶ *ibid*

¹⁸⁷ *ibid*

¹⁸⁸ *ibid*

¹⁸⁹ *ibid*; Sibley, Sheehan, Pollard (n 183) at 3.

disempowered and shared frustrations at their assent having limited impact on the outcome of their treatment.¹⁹⁰ Unlike the parents that supported their child's refusal of medical treatment, these participants describe how their parents' consent was always the determining factor, that their assent/dissent became irrelevant. Where a child dissents, or disagrees, their opinion is only heard or upheld if their parents respect their decision. The impact of their decision is dependent on their parents' desire to respect their child's views and in doing so, put aside their desire to act in accordance with their child's doctors. Health care professionals should be alert to the capacity of their child patient and if consent rather than assent is the appropriate level of participation. The data from this project suggests that not to not enable the capable child to perform to their capacity may result in feelings of disempowerment.

Asking for a child's assent appears to accord children choice, however, in practice, the outcome of any decision is dependent on the adults around them. Thus, the child has no more influence over the decision than when they were unable to assent to medical treatment. The UNCRC states that all children regardless of their age have the right to "full and meaningful participation"¹⁹¹, to be "actively involved in decision-making at all levels"¹⁹², and for adults to "listen to children and ensure their participation"¹⁹³. For a non-*Gillick* competent child, assent can result in their meaningful participation in the decision-making process. In particular where their parents give weight to their child's views for example, where a parent is hesitant to consent without their child's assent or the parent refuses or adapts the child's treatment plan to address their child's concerns. However, where a child's assent has no impact on the parent's

¹⁹⁰ See Chapter 7, Section 7.4.4.

¹⁹¹ UNCRC 1969.

¹⁹² *ibid*

¹⁹³ *ibid*

decision-making, I argue that their assent is tokenistic thus, not meaningful participation.

Where a child is *Gillick* competent or 16 and 17 years old, I suggest that their assent is not meaningful because they are able to access a higher level of participation but do not have the opportunity to do so. During the interviews, all the participants in this study reported that whilst under the age of 16 they did not consent to therapeutic medical treatment. Although all participants who received medical treatment after the *Gillick* judgment desired to be the decision-maker after the age of ten. In Chapter 7 participants describe being informed by their doctors that no child under 16 can legally consent to medical treatment. Whilst it cannot be ascertained that all the participants were *Gillick* competent, the participants were informed that irrespective of their maturity and competency the law prevents any child under 16 consenting to medical treatment.¹⁹⁴ Moreover, the majority of the participants who were invited to assent were informed by their doctors that they were mature, competent and capable to make a decision.¹⁹⁵ Participants recalled how their doctors were impressed at the level of maturity they showed as a child.¹⁹⁶ Consequently, this interpretation of the law in practice, would appear to prevent *Gillick* competent children or 16 and 17 year olds from accessing the higher levels of participation and developing their autonomy and competency through the process of decision-making.

Denying children the rights of freedom and autonomy would pose an ethical problem if they were denied solely on the basis of their chronological age, with no corresponding association to some other quality.¹⁹⁷

¹⁹⁴ See Chapter 7, Section 7.4.4.

¹⁹⁵ Ibid.

¹⁹⁶ Ibid.

¹⁹⁷ Sibley, A, 'Developing a new justification for assent' (2016) 17(2) BMC Med Ethics.

The purpose of *Gillick* competency and the FLRA¹⁹⁸ is to recognise a child's emerging autonomy. However, this lack of participation prevents such emerging autonomy being developed or respected. Montgomery and Alderson state that there is a danger to participation rights that it is used to:

deny the greater status of autonomous individuality, even where young people are capable of exercising choice and wish to do so. Due respect for the autonomy of competent children entails their right to choose, not simply permission to do so on certain conditions set by the adults around them.¹⁹⁹

The health care professionals in this study explain that doctors assume, often without an assessment, that all children under 16 years are not competent. They explain that in their careers, it is rare to meet a child capable of refusing medical treatment although, it is increasingly more common to meet children capable of consenting to medical treatment.²⁰⁰ Julie, a GP, explained that in her practice more children between the ages of 13-16 are seeking to attend appointments alone, taking responsibility for their health care and showing the maturity and capability associated with a child capable of consenting to their medical treatment. Despite this, no participant in this study reported consenting to medical treatment. Therefore, where a child is *Gillick* competent and denied the opportunity to consent to medical treatment if they desired, their assent is not meaningful even if this has influence and impact over the decision-making process.

8.2.3.1. Competency

The research findings suggest that the legal ambiguities associated with competency have an impact on clinical practice creating uncertainty among doctors which in turn, limits the rights of children to participate in their

¹⁹⁸ Family Law Reform Act 1969 C.46.

¹⁹⁹ Montgomery & Alderson (n 165) at 27.

²⁰⁰ See Chapter 7, Section 7.4.1.

health care, inhibiting their autonomy. In the “Medical Practitioners, Adolescents and Informed Consent project”, Cave and her colleagues conducted focus groups with health care professionals where similar findings were ascertained.²⁰¹

This study found that health care professionals are apprehensive around the application of *Gillick* competency in clinical practice.²⁰² Although, the GMC and BMA provide guidance, the doctors interviewed in this study found it unhelpful because the guidance was working with an ambiguous law, thus had elements of ambiguity itself.²⁰³ When seeking to define competency, the doctors interviewed for this study recited the Fraser guidelines.²⁰⁴ However, seeking to understand how doctors define competency in clinical practice, I probed further. The doctors struggled to explain how they assess for each of the elements of competency. They were unable to provide examples of how they assessed competency, stating it was a feeling and instinct rather than a careful assessment of the child, as may be anticipated. Competency is typically composed of four main elements, however, how these elements are understood or applied are often subjective. The health care professionals in this study acknowledged that their interpretations of competency were subjective.²⁰⁵ They describe how doctors are inconsistent in their competency assessments explaining that their colleagues use different approaches to themselves.²⁰⁶ This was illustrated by the four doctors who each had a different assessment method, most relying on instinct rather than a comprehensive framework.²⁰⁷ In the main, they shared the same

²⁰¹ Emma, C & Stavrinides, Z, ‘Medical Practitioners, Adolescents and Informed Consent project’ (2013) Final report University of Leeds.

²⁰² See Chapter 7, Section 7.4.1. and Section 7.4.4.

²⁰³ *ibid*

²⁰⁴ *Ibid.*

²⁰⁵ *Ibid.*

²⁰⁶ *Ibid.*

²⁰⁷ *Ibid.*

frustrations as to what competency means and how to assess it. Moreover, because *Gillick* competency is context specific a child may need to be regularly assessed. They may be considered competent to consent to medical treatment but not necessarily if they refuse their consent or refuse all medical treatment. As a result, doctors are cautious of deeming a child *Gillick* competent.

As illustrated in Chapter 7, doctors do not receive regular or appropriate training on how to assess a child's competency. Julie, who conducts training alongside her role as a GP, explains that training in this area is often optional and limited. It is potentially because of this that doctors misunderstand the law. In Chapter 7, Section 7.4.6, the past-paediatric patients state that their doctors told them they could not consent to medical treatment prior to the age of 16, even if they are competent to do so. The participants in this study expressed confusion as to the application of the law in clinical practice.²⁰⁸ Despite being informed that they are mature and capable, doctors told them that they were unable to consent to medical treatment. The doctors used age as the determining factor, unsupported with other factors such as the child's competency.²⁰⁹

The doctors express that in part, the difficulty in assessing competency stems from the ambiguity within the law.²¹⁰ Because there is no general consensus on the definition of competency in the medical profession, including how it ought to be applied, there is a lack of clear guidance for health care professionals to adopt. As such, an assessment of competency is left to the subjectivity of individual doctors. Thus, there is an inconsistent application across the health care profession. Julie explains that although she is very conscientious and seeks to conduct a formal assessment of her patient's competency, many of her colleagues rely on instinct.²¹¹ In Chapter

²⁰⁸ Ibid.

²⁰⁹ Ibid.

²¹⁰ Ibid.

²¹¹ Ibid.

7, Section 7.4.1, Jonathan described using a computer system which assists GPs in some practices with the assessment of competency by providing a checklist. He explained it was useful and clear, however, that its application is only available in some areas of the country and there is limited training on how to use it.

A further factor preventing doctors from assessing a child under the age of 16 as *Gillick* competent is the fear of litigation. The doctors describe being hesitant to assess a child as *Gillick* competent, lacking confidence in assessing competency due to the law's ambiguity.²¹² When a doctor assesses a child as competent, potentially allowing them to refuse medical treatment, they must be able to justify their decision in a court of law. Due to the ambiguity and lack of clarity, doctors are hesitant to do so. They do not feel secure that their decision will be supported by other health care professionals. Therefore, seeking to avoid the risk, doctors seek assent, not consent, from the child. I suggest that doctors may inform patients that they are unable to consent to medical treatment prior to the age of 16, not because they have a genuine lack of understanding of the law, but because they are seeking to avoid the risk of litigation.

Naturally, where a child's competency is not being assessed, the autonomy of a *Gillick* competent child is being inhibited. Consequently, children may feel disempowered and out of control of their own medical care. What happens to their body is determined by the adults around them. The consequence of this lack of experience in making decisions was found in Chapter 7, Section 7.5, where participants stated feeling unprepared, out of control and overwhelmed during their transition to adult care. All the participants who transitioned to adult care, struggled with the transition to adult services, including the participants who had met with their new medical team prior to the transition.²¹³ This is concerning as it suggests that paediatric services have inadequately equipped children for their

²¹² Ibid.

²¹³ See Chapter 7, Section 7.5.

decision-making responsibilities in adult care. Consequently, despite being in adult services, the participants reported being unable to make a decision without parental support. For example, Anjali, Lee and Liam explain how they still heavily rely on parental advice despite having transitioned to adult services five years ago.²¹⁴ Their heavy reliance on parental advice leads us to question the extent to which the participant is making a truly autonomous decision as an adult. It was an interesting finding that the participants' participation as a child impacted their ability to meaningfully participate in decisions about their treatment as an adult.

8.3. Conclusion

Half of the participants in this study reported a positive experience as a paediatric patient. However, irrespective of whether a participant had a positive or negative overall health care experience, all participants shared the same frustrations with regards to their participation in their health care. The participants who reported a positive experience did so in reference to their sound rapport with their doctors. Whilst Section 8.2.1 establishes the importance of a strong doctor-child rapport, the section also emphasises the need to address the frustrations experienced by the participants as they sought to meaningfully participate in their health care as a child.

Although a shift towards patient-centred health care has been reported in the literature, the findings in this study argue that there remains an element of doctor paternalism within health care. Participants describe being told what treatment they would undergo with an expectation of compliance and parental consent. Doctors would talk directly to the child's parents during the decision-making process, the child being aware but excluded from engaging in their health care. Indeed, direction and expectation of compliance are illustrative of tokenistic participation. Subjectively, the child's tokenistic participation is not meaningful where

²¹⁴ Chapter 7, Section 7.5.

the child is capable of and desires engagement at a higher level of participation. Where this is not the case, for example, where the child is seriously ill and does not desire – or is unable- to participate in their health care, their tokenistic participation is meaningful. Moreover, the presence of parental paternalism, where parents understandably take the lead in their child's health care can also be a barrier to meaningful participation such as 'adult-initiated shared decision-making'. In these instances, children's voices are often lost within the complex discussions about them.

Overall, the findings from this study suggests that doctors are cautious and rely on assent until age of 16. As such, there remains a misalignment between the information children expect and desire to receive from their doctor, and the information they do receive in clinical practice. Providing more information to children will not be without its problems, especially in light of the time pressures under which most doctors operate. However, the results of this study do conclude that participants felt that this lack of information impacted their ability to make decisions about their health care. Due to the notable impact on children as documented in Chapter 7, the disclosure of information needs to be readdressed to find alternatives where patients can have access to more in-depth information if required.

Nevertheless, information alone is not enough to establish meaningful participation. The information must be coupled with the opportunity to use this information to influence the decision-making process, via assent, consent or shared decision-making. In the majority of instances described by the participants, assent, consent and shared decision-making was not an option thus, resulting in their tokenistic participation. Where children are capable of higher levels of participation and desire to act at this level, tokenistic participation is not meaningful.

Assent was occasionally an option for ten participants, albeit a rarity. Where participants assented to medical treatment, these participants had the opportunity to engage in the decision-making process even if their assent held no real influence over the treatment that they received. For a

non-*Gillick* competent child, an assent or dissent is meaningful where the decision-making adults gave weight to their voice and used this within their decision-making process. However, where their dissent was not recognised, subjectively and objectively this is a form of tokenistic non-meaningful participation. For a *Gillick* competent child capable of consenting to medical treatment and desiring such participation, assent was not a meaningful form of participation. All the participants above the age of ten desired to consent to their medical treatment. Moreover, the findings were suggestive that most of these participants had the capacity to do so although this claim remains speculative. In this study no participant had the opportunity to consent to medical treatment in part, due to their doctors' interpretation of the law and hesitancy in assessing a child's competency.

This study argues the presence of doctor paternalism, parental paternalism, a lack of communication, 'direction', poor understanding and assessment of the law and an absence of information are barriers in clinical practice that prevent children's meaningful participation in their health care. In addition, it claims that the ambiguity of the law and the lack of guidance accompanying the legislation leave doctors hesitant to assess a patient's competency. There is a systemic difficulty in understanding the law and how to apply it which causes misinterpretation within the medical profession. *Gillick* competency is inconsistently applied creating instances where some patients have access to higher levels of participation than others because of the doctor they visit. The challenges to the law discussed in Chapters 2 and 3 filter down into the medical profession. This impacts how doctors interpret and apply the law, in turn, affecting the extent to which children participate in their health care.

This is a concern as not all children experience the right to participate created by international and national frameworks. The findings from this study suggest that non-meaningful participation prevents the recognition of a child's emerging autonomy and inadequately equips them to make

decisions as an adult. Children experience increased anxiety and feelings of disempowerment. Children lack confidence and do not develop the skills required to be a decision maker in adult services. Children develop a mistrust of health care professionals leading to a lifelong breakdown in the doctor patient relationship. Thus, both law and practice have created barriers that prevent children consistently meaningfully participating in their health care.

9. CONCLUSION

9.1. Introduction

This investigation into the participation of children in their NHS health care has been premised on the fact that international and national Law accords all children the right to have the opportunity to participate in their healthcare.¹ With this in mind, I sought to determine whether these commitments are translating into children meaningfully participating in their health care and, if not, the reasons why children may not be consistently engaging in meaningful participation in their health care. The findings of these study only apply to the lived experiences of the participants interviewed, however, are of significance due to the research area being in its infancy.

Throughout this study, I have documented how children participate in their health care. Whilst the interviewees did participate in their health care, this study found that they had little or no influence in the decision-making processes thus I claim that their participation was objectively tokenistic. Where tokenistic participation was at the edge of the child's ability and the child did not desire to participate at a higher level, their participation was subjectively meaningful, using Hart's ladder of participation. However, the majority of the participants in this study did desire to participate at a higher level than tokenism and the data suggested that it was likely that they had the capabilities to do so. Thus, I argue that their participation was not always subjectively meaningful.

This study identified legal and practical barriers to meaningful participation. The law's ambiguity, and the lack of guidance accompanying it is a barrier to meaningful participation. However, there are other reasons why children do not always meaningfully participate in their health care,

¹ UNCRC 1968 at Article 12; Children Act 1969 C.51; *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] A.C. 112; [1985] 3 W.L.R. 830 and Family Law Reform Act 1969 C.46.

either objectively or subjectively, as outlined above, and therefore, I conclude these results suggest that reform of law and practice is needed to enable and facilitate children's meaningful participation in their health care.

This thesis began with my starting hypothesis in Chapter 1: that due to the ambiguities of the law, children are not meaningfully participating in their health care. Through an in-depth analysis of the interviews with past-paediatric patients and health care professionals, this thesis sought to test this starting proposition and provide a holistic and comprehensive appreciation for children's participation in clinical practice. This thesis sought to address one main research question and five secondary research questions.

Main Research Question:

- (i) Is law and practice successful in enabling and facilitating children's participation in all aspects of their health care from the lived experiences of patients?

Secondary Research Questions:

- (ii) How do children participate in clinical practice?
- (iii) Does an examination of lived experiences reveal that the participants in this study *meaningfully* participated in their health care as children?
- (iv) Does an examination of lived experiences expose any barriers or enabling factors to meaningful participation?
- (v) What is the long- and short-term impact of the participation on the participants in this study?
- (vi) Have the lived experiences of children evolved in accordance with the introduction of law valuing participation in clinical practice?

Questions two, five and six were addressed in Chapters 5 to 7. Chapter 8 addressed questions one, three and four. I seek to bring these findings together in Section 9.2 where I will provide a summary of my findings, and

consider, how and where the research questions have been addressed. Finally, in Section 9.3 I recommend that future research is conducted to seek to develop practical and legal methods of facilitating and enabling children's meaningful participation in their health care.

Before summarising my research findings, it is necessary to refer back to Chapter 4, Section 4.3.3 and once again acknowledge the limitations of this data. The following conclusions are drawn primarily from the empirical research findings and thus, the limitations of the data are likely to have impacted the findings.²

9.2. Summary of my Findings

In Chapter 2, I claimed that law and policy has evolved to value the right of every child to participate in their health care. Through a review of academic literature that has contributed to the discourse of childhood, I illustrated how law and policy has incrementally evolved to hold this value. Furthermore, Chapter 2 established the three theoretical foundations that this thesis has been based on: (i) that every child has a right to meaningfully participate in their health care, (ii) that children ought to have a right to meaningful participation and (iii) that some children are capable of making independent health care decisions.

Chapter 3 critically analysed the law. I argued that the law, despite its noble intentions to uphold a child's right to participate in their health care, does not consistently do so. A critical analysis of the law, and a review of the academic literature, suggests that children may not be meaningfully participating in their health care. Academic literature argues that this is primarily because of the ambiguities within the UNCRC,³ the Children Act,⁴

² See Chapter 4, Section 4.13 and Chapter 5, Section 5.5 for an in-depth discussion of the limitations of the research data.

³ UNCRC (n 1) at Article 12. Family Law Reform Act (n 1).

⁴ Children Act (n 1);

*Gillick v West Norfolk and Wisbech Area Health*⁵ and the lack of guidance accompanying the law to assist health care professionals and judges on how to apply the law, in particular for the everyday cases of participation that children experience in clinical practice.

Chapter 3, begins to answer the main research question, arguing that the law's wording and application, in addition, to the lack of accompanying guidance, unsuccessfully facilitates and enables the meaningful participation of children in their health care. However, absent from the literature was empirical evidence to support the academics' assumption that children are not meaningfully participating in clinical practice. Thus, these chapters justified the empirical research study I conducted.

Taking the lead from the research questions that were developed from the literature review, I outlined the methodology and method for this empirical study in Chapter 4. I chose to use IPA as the methodology due to its value in documenting the 'lived experience' of participants, including the meaning that the participants attribute to their experience. In addition, IPA facilitates an analysis that moves from the specific to the general, enabling the formulation of recommendations for reform to help others in a similar situation.⁶ Semi-structured interviews were justified as a method for gathering data due to the opportunity to explore a participant's 'lived experiences' in depth, and to enable discussions to be directed by the participant to topics deemed of importance to them. I detailed how I selected and recruited potential participants, designed the interview questions and conducted the interviews. I evaluated my position as a researcher, identified the ethical considerations relevant to this project and considered the limitations of this research project. Chapters 5-7 presented the empirical evidence using a thematic approach which assisted in answering the second, fourth, fifth and sixth research question. To answer

⁵ *Gillick* (n 1).

⁶ Smith, J.A, 'Interpretative Phenomenological Analysis: Getting at Lived Experience' (2017) 12(3) *The Journal of Positive Psychology* 303-304.

these questions, it was necessary to answer the second research question, 'how do children participate in clinical practice?'

9.2.1. How Do Children Participate in their Health Care?

The interviewees in this study participated in their health care in a variety of ways. The participants would engage in informal niceties with their health care teams, discussing their hobbies, interests, family and schooling. The participants would inform their doctors of any recent changes in their health including new symptoms. Sometimes this would occur verbally and at other times visually, for example, showing their doctor a symptom chart. However, communication during the decision-making process was primarily between the participants' parents and their doctor. This was often in the presence of the participant, although, they felt excluded from the conversation. It was notable that the participants in this study felt unable and uncomfortable to communicate with their doctors outside of these parameters. They would not confidently raise concerns that they were having, ask for adaptations to their treatment plans or seek alternative treatment options. As past paediatric patients, Anjali and Emily, got older, they became more confident and capable of raising issues with their doctor. However, the remaining participants never felt able to do so. In the case of Kate, this led to her non-compliance with home medical treatment. The reasons behind the participants' hesitance to initiate a conversation with their doctors was the authority of their doctors, the desire to be a 'good patient' and comply with their medical treatment, and the lack of time or opportunity during a consultation to raise their concerns which were often led by doctors under a strict time pressure. The lack of communication about treatment decisions between the doctor and child was a striking and concerning finding.

In the main, the participants received medical information from their doctors that appeared to meet the legal standards. As illustrated in Chapter 8.2.1. there were some instances where the participants received a complete absence of information. However, this was rare. Where their

doctors and wider health care teams shared information with the child, they used scan results, letters and leaflets as aids. Despite this, the main source of information for participants was predominantly their parents.

Some of the participants who had a sound parent-child relationship engaged in shared decision-making. Prior to a consultation, these participants would talk to their parents, sharing information which would then be passed on to their doctors. Their parents would act as translators during consultations, acting as a conduit for their child. These parents discussed the treatment options with their child and sought their child's assent prior to providing their parental consent. These participants expressed confidence that their parents would not consent to any procedure without their assent, refusing the specific treatment if they dissented. Shared decision-making such as this was initiated by the parents. However, participants that had a poor parent-child relationship did not have access to shared decision-making and were often excluded from the decision-making process.

All the participants assented to minor medical interventions, such as blood tests and scans. Half of the participants assented to a moderate to major medical procedures, such as, an operation. However, participants reported that their assent was inconsistently sought and was dependent on the health care professionals treating them. No child under the age of 16 consented to therapeutic medical treatment. Four participants consented to medical treatment after the age of 16. However, for the majority of participants who received treatment after the age of 16, their parents continued to provide consent on their behalf. No child refused therapeutic medical treatment but some parents did. For all of these participants, their parents refused medical treatment at their request.

Overall, these findings suggest that children do participate in their health care although, their participation rarely goes beyond assent to medical treatment. How a child participates in their health care was found to be dependent on the members of their health care team, and the

relationships between the participant, their doctor and their parents. Other factors impacting how the interviewees participated in their health care included the participants desire to operate at a higher level of participation, their ability to participate - not being so unwell that they are unable to participate - their competency, maturity and having the opportunity to participate.

9.2.2. Have the 'Lived Experiences' of Children Evolved in Accordance with the Introduction of the Law Which Values Children's Participation in their Health Care?

The past-paediatric patients were divided into three groups: (i) participants aged 18-25 and (ii) participants aged 26 -35 and (iii) 35 years and above. The second and third group were divided into participants who received medical treatment before and after the *Gillick* judgment. The purpose of these divisions was to seek to identify if there were any measurable differences in how the interviewees participated in their health care and to identify whether the 'lived experiences' of paediatric patients have changed in accordance with the evolving law that increasingly values the child's right to participate in their health care.

Participants aged 36 and above described a different clinical environment to the other participants. Parents were unable to stay with their child during their children's inpatient admissions and there was no separation between younger and older children on paediatric wards and outpatient clinics. The health care professionals explained that children today are willing to attend a GP appointment alone prior to the age of 16. Two decades ago, it was unusual for a child under 16 to be unaccompanied by an adult. This suggests that society now supports children's desire to take more control over their health care. However, this finding was said to be unique to GPs. Where a child attends a hospital outpatient clinic rather than their GP, children are most commonly accompanied by an adult.

Aside from these differences, there does not appear to be any other identifiable variations between the groups experiences. There were no differences in how they participated in their health care and the extent of this participation. The findings between the three groups were comparable throughout. This suggests that the 'lived experiences' of paediatric patients has not evolved in accordance with legal reforms and policy introductions. However, I make this suggestion tentatively and with caution. It is necessary to acknowledge the limitations of the data gathered in this study. The sample size for each group was dependent on those who self-selected to be interviewed. Thus, due to the unequal and small sample size it was not possible to draw conclusive findings from this data. Consequently, this research question cannot be as satisfactorily answered as the other research questions. Nevertheless, the data does provide an argument for further research which would specifically investigate whether the 'lived experiences' of paediatric patients has evolved in accordance with the introduction of law valuing children's participation in their health care.

9.2.3. Does an Examination of the Participant's 'Lived Experiences' Reveal that the Participants in this Study Meaningfully Participated in their Health Care as Children?

After identifying how the participants participated in their health care, I then turned to Hart's ladder of participation as an objective assessment of whether the participants were engaging in objectively meaningful participation.

It is important to distinguish between participation and meaningful participation. Meaningful participation empowers children, equips them with the skills to be independent decision makers, protects and develops their emerging autonomy and their fundamental human rights to have their voices heard, respected, given 'due weight' and where the child is

competent, the right to consent to medical treatment.⁷ As such, I argue that there is important to scrutinize the participation of children in health care to encourage and facilitate meaningful participation and thus, uphold the law's rhetoric.

With regards to the communication between the participants and their doctors, the participation was primarily tokenistic and from an objective perspective lacked meaning because the child had no influence over the decision-making process. The child was expected to comply and predominantly, did so.

Nevertheless, the empirical evidence found that the rapport between doctor and patient was incredibly meaningful to the participants. In fact, those participants who had a sound rapport with their doctor reported a positive overall paediatric health care experience. This was irrespective of the extent to which they participated in their health care. However, a positive rapport did not equate to a participant meaningfully participating in their health care. Rather, all the participants expressed the same frustrations at having limited participation in decisions about their health care. Nevertheless, the participants that had a poor rapport with their doctors did desire a better relationship. Moreover, all the participants desired greater communication with their doctors, particularly with regards to decision-making. Thus, where the participants were capable of more communication and desired it, their participation was not subjectively meaningful. For a child's participation to be subjectively meaningful, Hart argues that the child must have the opportunity to participate at the highest level of participation that they are capable of.⁸

It was concluded that the participants received information from their doctors that met the legal standards (aside from the participants that

⁷ Hart, R, *Children's Participation: From Tokenism to Citizenship* (UNICEF International Child Development Centre, 1992) <https://www.unicef-irc.org/publications/pdf/childrens_participation.pdf> accessed 5 March 2019.

⁸ Ibid.

experienced a complete absence of information).⁹ Despite this finding, ten participants expressed dissatisfaction with the information that they received. When asking all the participants what information they desired, it was found that there was a misalignment between what information they desired and what they actually received. Whilst this is not a legal concern or a challenge to the integrity of health care professionals, it is still an important concern that needs to be addressed.

Where the information given to the participant was not coupled with shared decision-making, assent or consent, the child's participation was at most, tokenistic from an objective perspective. Whilst information gives the impression of participation, in reality, the participant had little or no opportunity to influence their treatment decisions. Where a child is capable of participating at a higher level and desired to do so, information without the opportunity to engage in the decision-making process is subjectively not meaningful. All the participants stated that after the age of ten (eight in the case of Hannah), they desired to participate at a higher level. Prior to this age, information alone was meaningful to the participants in this study.

Assent is a halfway point between no involvement in the decision-making process and consenting to medical treatment for a non-*Gillick* competent child. Assent can empower these children and assist them in engaging in the decision-making process, where they learn the skills necessary for making independent decisions. Here their evolving autonomy is developed. Thus, from a subjective perspective, where a non-*Gillick* competent child is participating at the highest level of their capabilities their participation is meaningful. Although a child's assent is not legally binding, doctors and parents are under a duty to accord 'due weight' to their child's views. However, there is no guidance on how to define or assess 'due weight'. Thus, how much weight a child's opinion is given was found to be

⁹ *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 at paras 39-87.

determined by the adults making the decisions. Consequently, the participants had little to no independent power over the decision-making process. Therefore, their participation was objectively not meaningful.

For a *Gillick* competent child, or 16 or 17-year-old, where they desire to consent to medical treatment, their assent was not meaningful either objectively or subjectively. Chapter 7 found that no participants under the age of 16 had the opportunity to consent to medical treatment, despite desiring to do so, and, as far as it is possible to ascertain, being capable of doing so. Thus, a child's assent is meaningful when it is at the edge of the child's ability and the child does not desire more. However, where the child is capable of and does desire a higher level of participation, assent is not a form of meaningful participation.

As these findings were consistent across all the groups including the health care professionals who collaborated the participants findings, the study suggests that in current clinical practice not all children will be meaningfully participating in their health care. This is a concerning finding, especially due to the long- and short-term impacts experienced by the participants in this study where they did not engage in meaningful participation.

9.2.4. What is the Long- and Short-term Impacts on the Participants in this Study?

Where the participants did not have the opportunity to participate at the level that corresponded to their competency the participants reported positive mental health. However, where a participant was dissatisfied with the information that they received, or received a complete absence of information, they felt inadequately prepared for the medical procedure. The participants experienced anxiety, depression, phobia's and symptoms of trauma. For example, Bethany has a life-long needle phobia and has been diagnosed with Post Traumatic Stress Disorder as a result of a complete absence of information prior to a blood test as a child. Hannah experiences on-going anxiety and flashbacks from waking from surgery

with unanticipated and unknown side-effects. Lee continues to experience anxiety around hospitals and continues to struggle to consent to therapeutic medical treatment as an adult. All the participants were emotional when talking about their experiences. They disclosed to me that they continue to struggle with lifelong mental health symptoms that they believe originated from being unprepared prior to a procedure, receiving selective information and being unable to engage in and have influence over the decision-making process. The impact on their mental health has gone on to affect their treatment and relationships with health care professionals as adults.

Where the participants emerging or existing autonomy was not respected by an opportunity to engage in shared decision-making, assent or consent, participants described a lack of control over their medical treatment that left them feeling disempowered. Where participants felt no control over the treatment that they receive and pressured into a specific treatment, participants lost trust in their health care teams and, in some cases, their parents. This in turn, caused a breakdown in the doctor-patient relationships that for some participants has been life-long.

Most participants described trusting only their specialists and were hesitant to visit another doctor. This lack of trust of other health care professionals was fuelled in part by the specialists themselves. Participants reported that their doctors would express a lack of trust in non-specialist doctors encouraging them to go straight to a specialist hospital rather than a general accident and emergency department where they were concerned about their health. The findings from the interviews with health care professionals collaborated this report. During the interviews the doctors sought to distinguish themselves from non-specialists who often have little experience of working with children and therefore, do not routinely involve the child in their health care as much as the specialist doctors seek to do.

Where doctor-patient relationships broke down, some participants parents sought second opinions and moved between hospitals in search of a

specialist. All the participants with chronic medical conditions continue to do this as adults. Whether a participant has a positive or negative doctor-patient relationship, they would transition to adult care anticipating a similar experience.

A severe and worrying consequence of a breakdown in doctor-patient relationships is a child's non-compliance with treatment. Whilst the lack of compliance did not seriously impact the health of the participants in this study, it is possible that in other cases, non-compliance could leave a child without any effective treatment threatening their health in the short and long term.

One of the most unanticipated impacts of not having the opportunity to consistently engage in shared decision-making, assent or consent, identified by this study, was the child's difficulty when making independent decisions as an adult. Chapter 7, Section 7.5. reported that all the participants had struggled with the transition to adult services. In particular, the need to make their own decisions and consent to medical treatment. During their first experience of an adult consultation they felt highly anxious, overwhelmed and overloaded with information and burdened with responsibility of being the decision-maker. In contrast to their paediatric health care, they were suddenly receiving more information directly from their doctor. Anjali reported that she did not know enough about her paediatric medical history to make an informed decision as an adult. The lack of parental presence and support during consultations left participants feeling vulnerable, isolated and under pressure to make the right decision. The majority of participants continue to seek their parent's advice and reassurance before consenting to medical treatment. These findings suggest that the participants experience as a child inhibited the evolution and growth of their competency and autonomy. The participants describe remaining 'child-like', unable to take on responsibility because they had no experience of being a decision-maker. As such, rather than incrementally developing and facilitating their

emerging autonomy, the participants growth was limited by their lack of meaningful participation in the decision-making process in paediatric health care.

9.2.5. Does an examination of Participant's 'Lived Experiences' Expose Any Barriers to Meaningful Participation?

With these findings in mind, I then explored the reasons *why* the participants did not consistently meaningfully participate in their health care. To achieve this, I analysed the data gathered in Chapters 5-7 using Hart's ladder of participation and academic literature identified in Chapters 2 and 3. I identified legal and practical barriers to participation.

Although the NHS has made great strides towards a child centred health care system, and away from physician paternalism, this study suggests that there is still a way to go. The participants described doctors informing them about the treatment that they were going to have, expecting their compliance, rather than proposing treatments and seeking the child's assent or consent. Chris, a paediatrician stated, 'I would propose a treatment and then the challenge is getting the parents and child to agree to it'. This could be argued to be against the spirit of GMC guidelines which require doctors to collaborate with their patients, listen to and act on their concerns and create opportunities for them to ask questions.

The data from participants also suggested poor communication between doctor and child. The communication appeared one sided, with the doctors informing the child and their families rather than a two-way dialogue where a child and their parent could share ideas. The participants stated that both they and their parents felt hesitant to approach their doctors and ask questions. This was caused by the participants desire to be a good, undemanding patient and their awareness and sensitivity towards the NHS's scarce resources which restricted doctors' time. Furthermore, due to doctors' authority and status within the medical profession and society more generally, participants felt intimidated and detached from them on a personal level. Although many participants had a positive doctor-patient

relationship, the relationship was formal and not one in which the participant could disclose how they were feeling. As such, where it was possible to do so, participants turned to their wider medical team who were more approachable and offered support and comfort. The interviews with the health care professionals suggested that the participants' doctors may have been willing to adapt their treatment plans if they had been aware of the concerns of their patients. However, due to the participants' unwillingness and inability to communicate with their doctors, the participants were unable to influence how their medical treatment was administered.

The participants' parents played a crucial role in the extent to which the participants participated in their health care. Where participants had a sound relationship with their parents, they received emotional and practical support, which often enabled their participation in their health care. This support was notably absent from the narratives of participants who had a poor parent-child relationship. Some participants with sound parent-child relationships describe their parents as desiring to be the decision-maker, in part, due to their anxieties associated with having a child with a medical condition. In these instances, the participants struggled to have their voice heard and believed that their parents would act in what they determined to be their best interests, irrespective of whether the participant would assent or dissent to their medical treatment. These participants did not have the opportunity to participate in the decision-making process in a meaningful way because their parents took the lead in their child's medical treatment. Where children had a challenging relationship with their parents or their parents continued to be the sole decision-maker until the child transitioned to adult services, the participants' emerging autonomy was inhibited as they were unable to develop the skills required to be an independent decision-maker. The participants who did engage in shared decision-making had parents who sought to incrementally involve their child in the decision-making process

as they matured. These parents often worked in the health care profession so perhaps were aware of the importance of children's increasing participation in their health care. Nevertheless, although the transitioned to adult services was challenging, these participants fared better than their counterparts who had not engaged in shared decision-making.

Although most participants were informed, the participants felt that selective information was a barrier to their meaningful participation. Aside from Emily, all the participants reported a misalignment between the information that they were given and the information that they desired. Overall, participants desired more specific information about the recovery process, who would be conducting their operation and what symptoms to expect in the days following their surgery. The participants felt that the information selected by their doctors was not enough to adequately prepare them for a procedure, to understand and appreciate what they were to undergo. Thus, without this information they did not feel able to make a decision as to what medical treatment was best for them.

The most common barrier to participation was a lack of opportunity to participate in shared decision-making, assent or consent. This lack of opportunity was found to stem from doctors' apprehension of litigation and confusion as to the law. The doctors interviewed for this study found the law ambiguous and noted a need for a more comprehensive framework that is flexible to various medical contexts.

The data suggests that this ambiguity causes the law to be misinterpreted in practice, supporting the argument of Cave that there are subtle differences in how the law is applied in court compared to clinical practice.¹⁰

For example, participants reported that they did not have the opportunity to consent to their medical treatment despite being told that they were

¹⁰ Cave, E 'Goodbye Gillick? Identifying and resolving problems with the concept of child competence' (2014) 34(1) *Legal Studies* at 103.

mature and capable to make decisions by their doctors, suggesting that doctors might be failing to engage with the law surrounding *Gillick* competency and instead give a blanket pronouncement that children cannot consent to treatment under the age of 16.

The participants who experienced the opportunity to assent to their medical treatment were all treated by specialist children hospitals and paediatricians. Where a participant was treated by a non-specialist doctor, they did not have the opportunity to assent or engage in shared decision-making. The doctors interviewed in this study explained that non-specialist children's doctors are less confident with child anatomy and childhood disorders, being less used to treating children, receiving less paediatric training on children's participation and having only limited access to services such as play therapists who assist this process. This lack of confidence would be perhaps exacerbated where non-specialist doctors were treating participants that had rare and genetic medical conditions. In these instances, from the accounts of the participants, it might be concluded that children treated by less confident doctors are less likely to be participating in their health care in a meaningful manner and will experience inconsistencies in their care.

9.2.6. Is law and practice successful in enabling and facilitating children's participation in all aspects of their health care from the lived experiences of patients?

Chapter 2 and 3 discussed the complexity surrounding the law of consent for children. In particular, the ambiguity surrounding the terms 'due weight' and *Gillick* competency, the lack of guidance accompanying the law, the distinction between consent and refusals, whether *Gillick* applies to refusals of therapeutic medical treatment, and the use of inherent jurisdiction. Interviews with health care professionals confirmed that doctors struggle to understand and apply both international and national law in clinical practice.

One of the biggest concerns facing health care professionals is assessing whether a child is *Gillick* competent. As illustrated in Chapter 3, the definition of competency is a source of academic debate and a contentious issue. Whilst academics and the law agree that there are four main elements for competency, there is no guidance as to how each element is to be understood and assessed. Thus, whether a child is competent is in part, dependent on the subjective assessment by a doctor. Consequently, the health care professionals acknowledged that the law is applied differently from doctor to doctor as illustrated in the interviews with past-paediatric patients.

Doctors acknowledged being hesitant in assessing a child as *Gillick* competent because of this ambiguity. They expressed concern that another doctor may disagree with their competency assessment because *Gillick* competency is context- and decision-specific. In addition, a child may need routine assessment throughout their treatment. Out of fear of litigation, doctors are extremely cautious in terms of who they deem to be *Gillick* competent. It transpired that doctors were hesitant to provide children with the opportunity to consent, in part because they were not confident in applying the *Gillick* competency test. As such, participants were not afforded the opportunity to engage in the decision-making process thus inhibiting the child's emerging and existing autonomy and failing to comply with the child's right to participate in their health care.

At a legal level, as Cave has advised, clarification of the law of consent is needed.¹¹ What does "due weight" mean? How is "due weight" measured and assessed? How is *Gillick* competency assessed in clinical practice? Is a *Gillick* competent child's refusal to be respected? Cave and McFarlane¹² have suggested the removal of *Gillick* competency in favour of 'one test for

¹¹ Ibid.

¹² McFarlane, A 'Mental capacity: one standard for all ages' [2011] 41 Fam Law 479, at 484.

all' as the "test has led to minors being labelled incompetent when they are capable of making an autonomous decision and competent when they lack the functional capacity to decide." She suggests introducing the Mental Capacity Act which is more developed and comprehensive than *Gillick*. However, there are limitations including preventing doctor, parents and judges overriding a competent child's decision thus, allowing a child to make a decision that may cause serious harm. As such, a test case is needed to establish the values of the law. Does the law desire to continue protecting competent children from the harm caused by their decisions thereby arguably undermining a child's autonomy or does the law seek to protect a competent child's autonomy similarly as it does with adults and in doing so accept the potential for harm. Without a clear decision as to the values of the law, child consent and refusals will continue to be ambiguous.

In addition to legal reform, the findings from this study suggest that doctors receive limited training on the law of consent. As such, there is a need for more extensive and compulsory training for doctors on what the law is and how it ought to be applied to increase the likelihood that the law is applied consistently. Moreover, there are no formal guidelines on how to assess a patient's consent to medical treatment.

Jonathan (group 4), a GP, described how his GP surgery use the "*Gillick* template": an electronic form that accompanies a child's medical notes and must be completed during and after every consultation with a child. It details the four elements of competency and asks the doctor to tick when assessed and provide their reasoning behind their assessment. Although beneficial, Jonathan expressed difficulty in knowing how to assess a child. He stated that it would be helpful to have mock questions that a doctor could use as a prompt alongside each element of competency.

In a 2008 article, Appelbaum produced guidance to assist the understanding of the four elements of competency.¹³ He inserted questions that may be asked such as “please tell me in your own words what your doctor [or I] told you about the problem with your health now?”; “Do you believe that you will need some kind of treatment?”; “What is treatment likely to do for you?”; “What makes [chosen option] better than [alternative option]?”¹⁴ Alongside the ‘*Gillick* template’, these questions would act as guidance and reassurance according doctors greater confidence to deem a child *Gillick* or not *Gillick* competent. If used throughout the NHS, there would be greater consistency in the assessment of *Gillick* competency.

Whilst the law acts as a barrier for meaningful participation, the findings of this study suggest the reasons why children do not meaningfully participate in their health care run deeper than a lack of guidance provided by the law.

The poor communication between doctor and child was a concerning finding with several possible causes: patients feeling rushed and sensitive to their doctors’ limited time, and a hesitancy on the part of patients and their parents to ask questions and raise concerns due to feelings of intimidation. In a recent article Dalgo develops a patient medical chart similar to social media which includes a continued narrative about the child.¹⁵ Dalgo recommends the child taking ownership of their online chart, adding pictures and stories about their life and health. He recommends that doctors use this chart to ask (i) in what way can they use the information about the child to assist the clinical interaction and (ii) how

¹³ Appelbaum, A.P, ‘Assessment of Patients’ Competence to Consent to Treatment’ (2008) 357(18) *New England Journal of Medicine* 1834.

¹⁴ *ibid* at 1836.

¹⁵ Dalgo, A.L, ‘Early Integration of Pediatric Participation in Health Care as Preventive Ethics’ (2018) 18(3) *Early Integration of Pediatric Participation in Health Care as Preventive Ethics*, *The American Journal of Bioethics*, 22 at 23

have the child's family, life experiences and development evolved since I last saw them in clinic?¹⁶

The first question presumes the child's involvement and asks what the best strategy is for communicating uniquely with the child. The second question presumes a relationship of continuity and a familiarity with the child's life story and considers the ever-changing dynamism of relating to children.¹⁷

Although this may assist the doctor in the decisions of 'who ought to decide', the process is time consuming. The doctors interviewed in this study emphasised the lack of time stating that no recommendations for reform must involve a system that is too time consuming. As doctors already conduct patient questionnaires and must record their conversation after speaking to each patient, a 'traffic light form system' could be adopted. Before (green), during (amber) and after (red) their medical treatment, the child is provided with the coloured form to complete either independently or with the assistance of their play therapist or parents. The online form asks the child for information about themselves, the symptoms they have, their concerns. Questions directed to the patient could be: do they know what condition you have been diagnosed with; how do you feel about this; what do you know about your proposed treatment; what would you like to know about your treatment; would you like to have the proposed treatment; do you have any concerns; are there any questions you would like to ask your doctor.

This form would provide the child with an opportunity to write down their answers away from the hospital, and directly communicate with their doctors in a different manner than talking during a consultation which they may find intimidating. The form gives the child permission to ask questions so the child does not feel like they are being a "challenging patient" and it

¹⁶ *ibid*

¹⁷ *ibid*

assists doctors during consultations to keep the focus on the child. Using the form in consultation meetings provides the child a voice, ensures communication between doctor and patient and can also be used as an additional method for assessing the child's competency. Moreover, because the child attends with the form and the doctor reads and engages with it during the consultation, this should not put too much pressure on the limited time they have to see each patient.

Such a form also seeks to help the child gain all the information that they desire. Whilst the participants received information that may well met the standard of *Montgomery*, many felt they did not receive the knowledge that they desired. The traffic light form would give doctors insight into the information a child truly desires so that they can respond to the child's concerns and show them they are being listened to.

A further simple measure to assist communication could be for doctors to ask patients whether they are giving too much or too little information. There is a need for the doctor to burden this responsibility because of the difficulty that patients have approaching doctors due to their authority, status, desire to be a 'good patients' and opportunity to ask questions in light of limited resources including time. Doctors should be encouraged to probe as patients may be unwilling to readily admit a lack of understanding.

Peer-to-peer support may also assist patients to access meaningful information. As doctors may lack information that child desire, children could be supported to turn to a child of a similar age, with a similar condition to facilitate peer support of each other, providing the information that a doctor would not give or may not know such as, how it has impacted their school work or what it felt like after the surgery, how it felt being housebound for a number of months during rehabilitation and what items they should bring into hospital with them.

Thus, the barriers to meaningful participation were both legal and practical. Both law and practice were not always successful in enabling and facilitating meaningful participation, and consequently, there is strong evidence for reforms and recommendations for change.

9.3. Future Research

This study suggested that children participate in their health care in an inconsistent manner. In many instances, this participation is low level, tokenistic and not objectively or subjectively meaningful. Moving forward, it would be necessary to engage more deeply with the recommendations for reforms to identify systems that would work in paediatric medicine and reduce the barriers to participation.

Due to the limitations of this study, further research ought to be conducted to account for the variable factors such as age, gender, whether the child was treated by a specialist or a non-specialist or had a chronic or acute condition. More research ought to be conducted to established whether the 'lived experiences' of patients has evolved in accordance with the law and to consider the perspective of parents and health care professionals.

9.3. Conclusion

This thesis has sought to ascertain whether law and practice are successful in enabling and facilitating children's meaningful participation in their health care. To do achieve this, I conducted a qualitative empirical research project interviewing 18 past-paediatric patients and four health care professionals. The empirical findings suggest that children do participate in their health care. However, their participation is often low level, tokenistic and in the main, not subjectively meaningful. This is a significant concern most especially, as the right to participate is accorded to children in national and international law.

In the study, I identified numerous barriers to meaningful participation including a breakdown in communication, parental paternalism, doctor paternalism, a misalignment between the information desired and the

information received and an ambiguous law. In identifying these barriers, this study suggests that there is need for both legal and practical reforms. I have tentatively and briefly suggested some recommendations for reform, however, a further research project would be beneficial to take each recommendation in turn, assess its applicability and suitability and test it in paediatric health care to measure its success. If law and practice are to meet its obligations to enable every child to have the opportunity to participate at their potential, there is a need for reforms in both law and practice. The intentional and national frameworks can only take us so far, and a multifactorial, holistic and comprehensive response is needed to ensure that all children can meaningfully participate in their health care.

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Appendix 1: University Sponsorship Approval Letter (Health Care Professionals)– SC.87/16-17



Dr Jane Bryan
School of Law
University of Warwick
Coventry
CV4 7AL
United Kingdom

3 November 2017

Project Title: An Investigation into the Issues Surrounding Competent Paediatric Patients and Refusals of Therapeutic Medical Treatment
Chief Investigator: Dr Jane Bryan
PhD Student: Rebecca Limb
Our Ref: SC.87/16-17

Dear Dr Bryan,

I confirm that the University of Warwick will act as research sponsor for the above project, in accordance with the Department of Health's Research Governance Framework for Health and Social Care (2005), and, where appropriate, UK Statutory Instrument Number 1031, that implements the Medicines for Human Use (Clinical Trials) Directive 2004 and subsequent amendments; effective from 3 November 2017.

I confirm that the University holds Public and Products Liability Insurance, and, where appropriate, Clinical Trial Insurance, which will provide cover for this study.

Any researcher involved in the project is required at all times to comply with the University of Warwick's Research Codes of Practice and Policies, available on the Research and Impact Services website via the following link:

http://www2.warwick.ac.uk/services/ris/research_integrity/code_of_practice_and_policies/

Researchers are also required to comply with all relevant requirements of Standard Operating Procedures (SOPs), which are applicable to all University of Warwick sponsored studies and are available via the following link:

<http://www2.warwick.ac.uk/fac/med/research/hscience/ctu/conducting/planning/sop/>

In particular, please ensure that you are familiar with the relevant safety and reporting requirements applicable to your study, as set out in SOP 17 'Safety Reporting' and SOP 31 'Deviations, Violations, Misconduct and Serious Breaches of GCP and/or Trial Protocol'.

As research sponsor the University of Warwick is committed to ensuring that studies carried out under its auspices are delivered to the highest standards, in order to ensure the safety of participants, the integrity of the study and compliance with applicable legislation, regulations and guidance. As part of this commitment, the University has established a programme of



institutional quality assurance to ensure appropriate oversight of University sponsored studies. You will be contacted by the Research Governance and Quality Assurance Manager in Research and Impact Services with further information regarding this should your study be selected for review.

Please notify the Research Governance Team via email to sponsorship@warwick.ac.uk of any key changes to your University sponsored study throughout its lifecycle, in particular if your study requires amendment, changes status, closes, is completed or if there are any changes to the proposed or anticipated closure date. Please also copy the above email address into any Annual Progress Reports or End of Study Notifications sent to the Health Research Authority (HRA) or Research Ethics Committee (REC), where appropriate

If you have any queries regarding these responsibilities or research sponsorship more generally, please contact the Research Governance Team via email at: sponsorship@warwick.ac.uk

Kind regards,

Professor Aileen Clarke
Chair of Sponsorship Committee

The University of Warwick
Coventry
CV4 7AL
E: sponsorship@warwick.ac.uk
T: + 44 (0) 24 761 50189

Appendix 2: University Sponsorship Approval Letter (Past-Paediatric Patients) – SC. 22/17-18



Dr Jane Bryan
School of Law
University of Warwick
Coventry
CV4 7AL
United Kingdom

21 March 2018

Project Title: An Investigation into the Issues Surrounding Competent Paediatric Patients, Their Consent and Refusals of Therapeutic Medical Treatment
Chief Investigator: Dr Jane Bryan
PhD Student: Rebecca Limb
Our Ref: SC.22/17-18

Dear Dr Bryan,

I confirm that the University of Warwick will act as research sponsor for the above project, in accordance with the Department of Health's Research Governance Framework for Health and Social Care (2005), and, where appropriate, UK Statutory Instrument Number 1031, that implements the Medicines for Human Use (Clinical Trials) Directive 2004 and subsequent amendments; effective from 14 March 2018.

I confirm that the University holds Public and Products Liability Insurance, and, where appropriate, Clinical Trial Insurance, which will provide cover for this study.

Any researcher involved in the project is required at all times to comply with the University of Warwick's Research Codes of Practice and Policies, available on the Research and Impact Services website via the following link:

http://www2.warwick.ac.uk/services/ris/research_integrity/code_of_practice_and_policies/

Researchers are also required to comply with all relevant requirements of Standard Operating Procedures (SOPs), which are applicable to all University of Warwick sponsored studies and are available via the following link:

<https://warwick.ac.uk/fac/med/research/ctu/conducting/planning/sop2016>

In particular, please ensure that you are familiar with the relevant safety and reporting requirements applicable to your study, as set out in SOP 17 'Safety Reporting' and SOP 31 'Deviations, Violations, Misconduct and Serious Breaches of GCP and/or Trial Protocol'.

As research sponsor the University of Warwick is committed to ensuring that studies carried out under its auspices are delivered to the highest standards, in order to ensure the safety of participants, the integrity of the study and compliance with applicable legislation, regulations and guidance. As part of this commitment, the University has established a programme of



institutional quality assurance to ensure appropriate oversight of University sponsored studies. You will be contacted by the Research Governance and Quality Assurance Manager in Research and Impact Services with further information regarding this should your study be selected for review.

Please notify the Research Governance Team via email to sponsorship@warwick.ac.uk of any key changes to your University sponsored study throughout its lifecycle, in particular if your study requires amendment, changes status, closes, is completed or if there are any changes to the proposed or anticipated closure date. Please also copy the above email address into any Annual Progress Reports or End of Study Notifications sent to the Health Research Authority (HRA) or Research Ethics Committee (REC), where appropriate

If you have any queries regarding these responsibilities or research sponsorship more generally, please contact the Research Governance Team via email at: sponsorship@warwick.ac.uk

Kind regards,

Dr Catherine Cochrane
Director of Research and Impact Services

The University of Warwick
Coventry
CV4 7AL
E: sponsorship@warwick.ac.uk

Appendix 3: Provisional REC Approval Letter IRAS ID: 23883



Health Research Authority South West - Cornwall & Plymouth Research Ethics Committee

Level 3
Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

22 January 2018

Dr Jane Bryan
School of Law
University of Warwick
Coventry
CV4 7AL

Dear Dr Bryan

Study Title: An Investigation into the Issues Surrounding Competent Paediatric Patients and Refusals of Therapeutic Medical Treatment.
REC reference: 18/SW/0007
Protocol number: SC.87/16-17
IRAS project ID: 238834

The Research Ethics Committee reviewed the above application at the meeting held on 16 January 2018. Thank you for attending to discuss the application.

Provisional opinion

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

Clarification requested

1. Explain whether patients and parents not fluent in English would be eligible for to take part in the study.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Documents reviewed

The documents reviewed at the meeting were:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|---|----------------|-------------------|
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance] | 1 | 24 July 2017 |
| Interview schedules or topic guides for participants [Interview Schedule] | 2 | 26 September 2017 |
| IRAS Application Form [IRAS_Form_15122017] | | 15 December 2017 |
| IRAS Application Form XML file [IRAS_Form_15122017] | | 15 December 2017 |
| IRAS Checklist XML [Checklist_15122017] | | 15 December 2017 |
| Letter from sponsor [Sponsor Letter] | 1 | 03 November 2017 |
| Participant consent form [Interview Consent Form] | 2 | 26 September 2017 |
| Participant consent form [Recording Consultations Consent Form 8+] | 2 | 26 September 2017 |
| Participant consent form [Recording Consultations 13+ and Parents Consent Form] | 2 | 26 September 2017 |
| Participant consent form [Recording Consultation Consent Form Consultants] | 2 | 26 September 2017 |
| Participant information sheet (PIS) [Interview Participation Information Sheet] | 2 | 26 September 2017 |
| Participant information sheet (PIS) [Recording your consultations Participant Information Sheet 8+] | 2 | 26 September 2017 |
| Participant information sheet (PIS) [Recording your consultations participant information sheets 13+ and parents] | 2 | 26 September 2017 |
| Participant information sheet (PIS) [Recording your consultations participant information sheets consultants] | 2 | 26 September 2017 |
| Research protocol or project proposal [Project Proposal] | 2 | 24 August 2017 |
| Summary CV for Chief Investigator (CI) [Jane Bryan CV RL] | 1 | 01 December 2017 |
| Summary CV for student [Rebecca Limb CV 1] | 1 | 29 November 2017 |
| Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flow Diagram - What will happen during the study] | 2 | 26 September 2017 |

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet

None

Statement of compliance

A Research Ethics Committee established by the Health Research Authority

The Committee asked whether the reference to refusal of treatment in the study title might pre-empt or influence the findings of the study.

Miss Limb explained that the study title referred to refusal of rather than consent to treatment because the law regarding refusal is different, but added that she could amend the title if the Committee requested it.

The Committee suggested including both consent and refusal of treatment in the study title.

Miss Limb agreed to do so.

The Committee asked Miss Limb to revise the participant information sheets to make them more accessible and age appropriate. It suggested including some images in the information sheet for participants over the age of eight.

Miss Limb agreed to do so, and asked for further feedback on how to improve this document.

The Committee suggested asking adults who work with children, and eight year olds, to review the document and provide feedback.

The Committee noted that choosing not to participate in the study would have no negative impact on patients' care or staff members' employment. The Committee asked Miss Limb to clarify this in the information sheet for staff.

Miss Limb agreed to do so.

The Committee noted a number of inconsistencies and omissions in the information sheets and consent and assent forms, which it decided to raise in its opinion letter.

Other general comments

The Committee noted that occasionally cases in which an underage patient wishes to refuse treatment result in publicity or litigation. It asked what would be the status of research data would be under such circumstances.

Miss Limb replied that her observations and recordings would not be suitable as proof or evidence for the purposes of litigation.

The Committee asked that the participant information sheets make it clear that individual transcripts of research interviews would be available to participants, and that a summary of the results could be provided. (IRAS)

Miss Limb agreed to do so.

Miss Limb was thanked for being available via telephone, and the call was ended.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

| | |
|-------------------|---|
| 18/SW/0007 | Please quote this number on all correspondence |
|-------------------|---|

Yours sincerely

pp. *L Roberts.*

**Canon Ian Ainsworth-Smith
Chair**

Email: nrescommittee.southwest-cornwall-plymouth@nhs.net

Copy to: *Mrs Jane Prewett
Theresa Morton, Birmingham Children's Hospital NHS Trust*

South West - Cornwall & Plymouth Research Ethics Committee

Attendance at Committee meeting on 16 January 2018

Committee Members:

| <i>Name</i> | <i>Profession</i> | <i>Present</i> | <i>Notes</i> |
|---------------------------|---|----------------|--------------|
| Miss Clare Adams | Consultant Colorectal and General Surgeon | Yes | |
| Canon Ian Ainsworth-Smith | Retired Hospital Chaplain | Yes | |
| Dr Rachel Clarke | Clinical Psychologist | Yes | |
| Dr Stephen Coles | Director and Owner | Yes | |
| Dr Kass Gibson | Lecturer | Yes | |
| Miss Helen Moore | Support Pharmacist | Yes | |
| Miss Lucy Roberts | REC Manager | No | |
| Mrs Caroline Theyer | Solicitor | Yes | |
| Mr Duncan Trotter | Retired | Yes | |
| Mr Robert Wosley | Deputy Service Line Cluster Manager | Yes | |

Also in attendance:

| <i>Name</i> | <i>Position (or reason for attending)</i> |
|----------------|---|
| Ms Helen Sivey | REC Manager |

A Research Ethics Committee established by the Health Research Authority

Appendix 4: Final HRA and REC Approval IRAS ID: 238834



Health Research Authority

Dr Jane Bryan
School of Law
University of Warwick
Coventry
CV4 7AL

Email: hra.approval@nhs.net

25 January 2018

Dear Dr Bryan

Letter of HRA Approval

| | |
|-------------------------|--|
| Study title: | An Investigation into the Issues Surrounding Competent Paediatric Patients, Their Consent and Refusals of Therapeutic Medical Treatment'. |
| IRAS project ID: | 238834 |
| Protocol number: | SC.87/16-17 |
| REC reference: | 18/SW/0007 |
| Sponsor | University of Warwick |

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the [HRA website](#).

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through [IRAS](#).

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

| | |
|-----------------|--------|
| IRAS project ID | 238834 |
|-----------------|--------|

procedure. If you wish to make your views known please use the feedback form available on the [HRA website](#).

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the [HRA website](#).

Your IRAS project ID is **238834**. Please quote this on all correspondence.

Yours sincerely

Catherine Adams
Senior Assessor
Email: hra.approval@nhs.net

Copy to: *Mrs Jane Prewett, Sponsor's Representative
Theresa Morton, Birmingham Children's Hospital NHS Trust*

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|---|----------------|-------------------|
| Contract/Study Agreement template [HRA Schedule of Events] | 1 | 10 January 2018 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance] | 1 | 24 July 2017 |
| HRA Statement of Activities [HRA Statement of Activities] | 1 | 10 January 2018 |
| Interview schedules or topic guides for participants [Interview Schedule] | 2 | 26 September 2017 |
| IRAS Application Form [IRAS_Form_23012018] | | 23 January 2018 |
| Letter from sponsor [Sponsor Letter] | 1 | 03 November 2017 |
| Other [Cover Letter] | 1 | 23 January 2018 |
| Other [Project Proposal] | 3 | 22 January 2018 |
| Participant consent form [Interview Consent Form] | 3 | 22 January 2018 |
| Participant consent form [Recording Consultations Consent Form 8+] | 3 | 22 January 2018 |
| Participant consent form [Recording Consultations 13+ and Parents Consent Form] | 3 | 22 January 2018 |
| Participant consent form [Recording Consultation Consent Form Consultants] | 3 | 22 January 2018 |
| Participant consent form [Recording Consultations 13+ and Parents Consent Form] | 2 | 26 September 2017 |
| Participant information sheet (PIS) [Interview Participation Information Sheet] | 3 | 22 January 2018 |
| Participant information sheet (PIS) [Interviews- Participation Information Sheet (Tracked)] | 3 | 23 January 2018 |
| Participant information sheet (PIS) [Recording your consultations Participant Information Sheet 8+] | 3 | 22 January 2018 |
| Participant information sheet (PIS) [Recording your consultations Participant Information Sheet 8+ (Tracked)] | 3 | 22 January 2018 |
| Participant information sheet (PIS) [Recording your consultations participant information sheets 13+ and parents] | 3 | 22 January 2018 |
| Participant information sheet (PIS) [Recording your consultations participant information sheets 13+ and parents (Tracked)] | 3 | 22 January 2018 |
| Participant information sheet (PIS) [Recording your consultations participant information sheets consultants] | 3 | 22 January 2018 |
| Participant information sheet (PIS) [Recording your consultations participant information sheets consultants (Tracked)] | 3 | 22 January 2018 |
| Research protocol or project proposal [Project Proposal] | 3 | 22 January 2018 |
| Summary CV for Chief Investigator (CI) [Jane Bryan CV RL] | 1 | 01 December 2017 |
| Summary CV for student [Rebecca Limb CV 1] | 1 | 29 November 2017 |
| Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flow Diagram - What will happen during the study] | 2 | 26 September 2017 |

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Mrs Jane Prewett
E-mail sponsorship@warwick.ac.uk
Telephone 024 765 22746

HRA assessment criteria

| Section | HRA Assessment Criteria | Compliant with Standards? | Comments |
|---------|---|---------------------------|---|
| 1.1 | IRAS application completed correctly | Yes | No comments |
| 2.1 | Participant information/consent documents and consent process | Yes | No comments |
| 3.1 | Protocol assessment | Yes | No comments |
| 4.1 | Allocation of responsibilities and rights are agreed and documented | Yes | A statement of activities will act as agreement of an NHS organisation to participate. The sponsor is not requesting and does not expect any other site agreement. |
| 4.2 | Insurance/indemnity arrangements assessed | Yes | Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this |

| Section | HRA Assessment Criteria | Compliant with Standards? | Comments |
|---------|--|---------------------------|--|
| | | | research study |
| 4.3 | Financial arrangements assessed | Yes | No funding is to be provided as detailed in the statement of activities. |
| | | | |
| 5.1 | Compliance with the Data Protection Act and data security issues assessed | Yes | No comments |
| 5.2 | CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed | Not Applicable | No comments |
| 5.3 | Compliance with any applicable laws or regulations | Yes | No comments |
| | | | |
| 6.1 | NHS Research Ethics Committee favourable opinion received for applicable studies | Yes | No comments |
| 6.2 | CTIMPS – Clinical Trials Authorisation (CTA) letter received | Not Applicable | No comments |
| 6.3 | Devices – MHRA notice of no objection received | Not Applicable | No comments |
| 6.4 | Other regulatory approvals and authorisations received | Not Applicable | No comments |

Participating NHS Organisations in England

| |
|---|
| <i>This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.</i> |
| <p>There is one participating organisation and therefore there is only one 'site-type'.</p> <p>The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.</p> <p>If Chief Investigators, sponsors or Principal Investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the Chief Investigator, sponsor or Principal Investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision</p> |

Confirmation of Capacity and Capability

| |
|--|
| <i>This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.</i> |
| <p>Participating NHS organisations in England will be expected to formally confirm their capacity and capability to host this research.</p> <ul style="list-style-type: none"> • Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the <i>Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)</i> section of this appendix. • The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability. |

Principal Investigator Suitability

| |
|---|
| <i>This confirms whether the sponsor's position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England, and the minimum expectations for education, training and experience that PIs should meet (where applicable).</i> |
| <p>A Principal Investigator is required at the participating organisation and has been identified.</p> <p>GCP training is <u>not</u> a generic training expectation, in line with the HRA/MHRA statement on training expectations</p> |

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken.

Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking the staff interviews would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking consultation observations would be expected to obtain a Letter of Access based on enhanced DBS checks excluding barred list check and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England in study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 5: Final REC Approval Letter IRAS ID: 242598



North West - Preston Research Ethics Committee

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8019

17 May 2018

Dr Jane Bryan
University of Warwick
School of Law
Coventry
CV4 7AL

Dear Dr Bryan

Study title: An Investigation into the Issues Surrounding Competent Paediatric Patients, Their Consent and Refusals of Therapeutic Medical Treatment.
REC reference: 18/NW/0339
Protocol number: SC.22/17-18
IRAS project ID: 242598

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals)

A Research Ethics Committee established by the Health Research Authority

from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

A Research Ethics Committee established by the Health Research Authority

The final list of documents reviewed and approved by the Committee is as follows:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|---|----------------|------------------|
| Copies of advertisement materials for research participants [Recruitment Email] | 1 | 15 December 2017 |
| Covering letter on headed paper [Cover Letter] | 1 | 15 May 2018 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance] | 1 | 22 July 2017 |
| Interview schedules or topic guides for participants [Interview Schedule] | 1 | 15 December 2017 |
| IRAS Checklist XML [Checklist_15052018] | | 15 May 2018 |
| Letter from sponsor [SC.22 17-18 Sponsorship Approval Letter] | 1 | 21 March 2018 |
| Letters of invitation to participant [Recruitment Email] | 1 | 15 December 2017 |
| Participant consent form [Consent Form] | 2 | 15 May 2018 |
| Participant consent form [Consent Form] | 2 | 15 May 2018 |
| Participant information sheet (PIS) [Participant Information Sheet] | 2 | 15 May 2018 |
| Participant information sheet (PIS) [Participant Information Sheet] | 2 | 15 May 2018 |
| REC Application Form [REC_Form_15052018] | | 15 May 2018 |
| Research protocol or project proposal [Research Protocol] | 1 | 15 December 2017 |
| Summary CV for Chief Investigator (CI) [Jane Bryan CV] | 1 | 01 December 2017 |
| Summary CV for student [Summary CV Rebecca Limb] | 1 | 22 March 2018 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

18/NW/0339

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



**PP: Professor Carol Haigh
Chair**

Email: nrescommittee.northwest-preston@nhs.net

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: *Mrs Jane Prewett*



Health Research Authority

South West - Cornwall & Plymouth Research Ethics Committee

Level 3
Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

27 July 2018

Miss Rebecca Limb
School of Law
University of Warwick
Coventry
CV4 7AL

Dear Miss Limb

Study title: An Investigation into the Issues Surrounding Competent Paediatric Patients, Their Consent and Refusals of Therapeutic Medical Treatment'.
REC reference: 18/SW/0007
Protocol number: SC.87/16-17
Amendment number: 1
Amendment date: 09 July 2018
IRAS project ID: 238834

Thank you for your letter of 09 July 2018, notifying the Committee of the above amendment.

Summary of Amendment

This amendment sought to notify of an addition of a study site. In order to widen the recruitment pool, the study sought to interview health care professionals at Warwick Medical School - a Non-NHS site. The protocol, participant information sheet and consent forms had been updated to include this new site.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

| Document | Version | Date |
|---|---------|--------------|
| Copies of advertisement materials for research participants [Recruitment Message] | 1.0 | 03 July 2018 |
| Notice of Non Substantial Amendment | 1 | 09 July 2018 |
| Other [A. Certificate GCP] | | |

| | | |
|---|-----|--------------|
| Other [eGCP (Primary Care) Oct 2017_ Introduction to GCP eLearning CERTIFICATE] | | |
| Participant consent form | 4.0 | 02 July 2018 |
| Participant information sheet (PIS) [Interviews- PIS] | 4.0 | 02 July 2018 |
| Research protocol or project proposal [Protocol] | 4.0 | 02 July 2018 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

| | |
|--------------------|---|
| 18/SW/0007: | Please quote this number on all correspondence |
|--------------------|---|

Yours sincerely



Lidia Gonzalez
REC Assistant

Email: nrescommittee.southwest-cornwall-plymouth@nhs.net

Copy to:

Theresa Morton, Birmingham Children's Hospital NHS Trust
Miss Rebecca Limb

Appendix 7: Amendments Approval Letter IRAS ID: 242598



North West - Preston Research Ethics Committee

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

16 August 2018

Dr Jane Bryan
University of Warwick
School of Law
Coventry
CV4 7AL

Dear Dr Bryan

Study title: An Investigation into the Issues Surrounding Competent Paediatric Patients, Their Consent and Refusals of Therapeutic Medical Treatment.
REC reference: 18/NW/0339
Protocol number: SC.22/17-18
Amendment number: 1
Amendment date: 27 July 2018
IRAS project ID: 242598

- In addition to emails that are GDPR compliant and word of mouth recruitment, this study is seeking to recruit participants via a volunteering page called 'insite' run by University of Warwick Communications Team which advertises ongoing research projects looking for participants, and through departmental and society newsletters.

Thank you for submitting the above amendment, which was received on 14 August 2018. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

Documents received

The documents to be reviewed are as follows:

| Document | Version | Date |
|--|---------|--------------|
| Notice of Substantial Amendment (non-CTIMP) [Amendment Form] | 1 | 27 July 2018 |
| Research protocol or project proposal [Protocol] | 2 | 21 July 2018 |

Notification of the Committee's decision

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

We are pleased to welcome researchers and R & D staff at our Research Ethics Service Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

18/NW/0339:**Please quote this number on all correspondence**

Yours sincerely



Nafeesa Khanam
REC Assistant

Email: nrescommittee.northwest-preston@nhs.net

Copy to: N/A



CONSENT FORM
Interviews

version 4, 02/07/18 IRAS Project ID: 238834

Participant Number:

Title of Project: An Investigation into the Issues Surrounding Competent Paediatric Patients, Their Consent and Refusals of Therapeutic Medical Treatment.

Name of researcher(s): Miss Rebecca Limb (Student Researcher), Dr Jane Bryan (Academic Supervisor).

Please initial box

1. I confirm that I have read and understood the information sheet (*version 4, 02/07/18*) provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my *legal rights or employment* being affected.

3. I consent to the interview being audio recorded, transcribed and the use of anonymized verbatim quotations.

4. I understand that my audio data will be securely stored for the duration of the project, and that the transcription data will be securely stored for a minimum of 10 years, in line with the University of Warwick's Research Data Management Policy.

5. I agree to take part in the above study.

Name of Participant

Date

Signature



Name of Researcher

Date

Signature

Appendix 9: Consent Form Past-Paediatric Patients



CONSENT FORM Interviews

version 2, 15/05/18, IRAS Number: 242598

Participant Number:

Title of Project: An Investigation into the Issues Surrounding Competent Pediatric Patients, Their Consent And Refusals Of Therapeutic Medical Treatment.

Name of researcher(s): Miss Rebecca Limb (Student Researcher) and Dr Jane Bryan (Chief Investigator and Academic Supervisor)

Please initial box

1. I confirm that I have read and understood the information sheet (*version 2, 15/05/18*) provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without consequence. My legal rights will not be affected.
3. I consent to the interview being audio recorded, transcribed and the use of anonymised verbatim quotations being used in the publication of this study.
4. I understand that my audio data will be securely stored for the duration of the project, and that the transcription data will be securely stored in line with the University of Warwick's Research Data Management Policy.
5. I understand that I may withdraw from the study up to a month after the interview, after which I am considered to have given permission for my data to be used in the publication of this study.
6. I agree to take part in the above study.



Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix 10: Participation Information Sheet Health Care Professionals

Participant Information Sheet

Interviews

version 4, 02/07/18 IRAS Project ID: 238834

Study Title: An Investigation Into The Issues Surrounding Competent Paediatric Patients, Their Consent and Refusals of Therapeutic Medical Treatment.

Investigator: Miss Rebecca Limb (Student Researcher), Dr Jane Bryan (Academic Supervisor)

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

This study seeks to gain valuable insight into the process of consents to and refusals of therapeutic medical treatment by a paediatric patient in medical practice.

Why have I been asked to take part?

You have been invited to take part in this study because you work at Warwick Medical School.

If you are a health care professional with at least one year's experience in paediatric medicine we are interested to hear your experiences and thoughts about consent and refusals of therapeutic medical treatment by paediatric patients in medical practice.

Do I have to take part?

It is entirely up to you to decide. We will describe the study and go through this information sheet, which we will give you to keep. If you choose to participate, we will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw at any time without giving a reason and this will not affect you, your legal rights or career in any way.

What will happen to me if I take part?

Once you have agreed to take part I will contact you through your preferred means of communication (usually Warwick University email or number) to arrange a time and place at

the University of Warwick to meet for the study. Before the study begins we will go through this information sheet where you can ask any questions that you may have. I will ask you to sign a consent form to confirm that you have agreed to take part. I will ask questions about your experiences. It is a narrative study so I am interested in listening to your perspective. I will record our conversation with an audio recorder so that I can listen to our conversation again. An anonymised transcription will be created from this recording. Identifiable details will not be used in the report. After our conversation, I will provide you with my contact details so that you can contact me if you have any questions or concerns.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

Time commitment: all interviews will be conducted at a time and date that suits the participant. The length of the study will aim to stay within one hour (or two half hour sessions). If a longer interview is needed then another interview can be arranged. If the participant is fatigued or uncomfortable in any way the interview can be stopped or postponed and re-arranged.

Confidentiality: you may be concerned with any professional consequences of speaking with me however, everything that is discussed is anonymised and accurately transcribed and reported. Only myself and my supervisor will have access to personal details and the audio recordings. You can withdraw from the study at any point and your data will be destroyed in line with the University of Warwick data protection guidelines.

Safeguarding Concerns: If during the interviews, any safeguarding concerns are identified, these will be reported to the Principal Investigator.

What are the possible benefits of taking part in this study?

It is unlikely that there will be a direct benefit to taking part. However, the purpose of the data collection is to add knowledge to the existing academic debate. Therefore, there is a potential future benefit to others and the opportunity to have your experiences listened to. This study wishes to gain valuable insight into the process of consent to and refusals of therapeutic medical treatment by paediatric patients in medical practice.

Expenses and payments

No expenses or payments will be made.

What will happen when the study ends?

After the study, the audio recording will be transcribed. The data will be analysed and presented in the final report/thesis and published. A summary of the results will be provided if you wish to receive it.

Will my taking part be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

This study is conducted as part of an application for a PhD in Law. This study is unfunded.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw.

Choosing not to participate in the study or deciding to stop the interview at any point, will not be detrimental to your employment.

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance

Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Will my taking part be kept confidential?

Yes. The data will be collected through an audio recording during the interview. The interview will be recorded on an encrypted Dictaphone. The electronic audio data and electronic transcriptions will be stored in the encrypted MyFiles. The hard copies of consent forms and transcriptions will be stored in a locked filing cabinet at the University of Warwick in line with the University's data protection policy.

The audio recording will then be transcribed. At this point the data will be anonymised. Your name will be substituted for a number and the date and time of the interview. Rather than use your specific job title a general title will be used (i.e. doctor, nurse) and your speciality will not be included. The transcribed data will be used and published. However, only myself and my supervisor will have access to the audio recordings. The electronic audio recordings and transcription logs will be stored using the University of Warwick's encrypted personal storage system. Hard copies of personal contact details and consent forms will be stored in a locked filing cabinet at the University of Warwick and destroyed at the end of the study.

Data Protection Privacy Notice

The data controller for this project will be the University of Warwick. The Information and Data Compliance Team at Warwick will provide oversight of activities involving the processing of personal data, and can be contacted via gdpr@warwick.ac.uk. The Data Protection Officer for the University of Warwick is Anjali Bajaj. Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data is Article 6(1e) a task in the public interest.

In addition to the legal basis for processing personal data, the University of Warwick must meet a further basis when processing special category data, including: racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data, data concerning health, data concerning a natural person's sex life or sexual orientation. The basis for processing your special category personal data is Article 9(2j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

What will happen to the results of the study?

After the interview, the data will be transcribed. You will receive a summary of results. The anonymised data collected in this study will be used in an application for a PhD in Law and later published.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by (TO BE COMPLETED ONCE APPROVALS HAVE BEEN OBTAINED)

What if I want more information about the study?

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact:

To contact the Principal Investigator email or call [name] at

Rebecca Limb (Student Researcher) – R.L.A.Limb@warwick.ac.uk

Jane Bryan (Academic Supervisor) – J.M.Bryan@warwick.ac.uk

Thank you for taking the time to read this Participant Information Sheet.

Appendix 11: Participant Information Sheet Past-Paediatric Patients

Participant Information Sheet

Interview

version 2, 15/05/18 IRAS Number: 242598

Study Title: An investigation into the issues surrounding competent paediatric patients and refusals of medical treatment.

Investigator: Miss Rebecca Limb (Student Researcher) and Dr Jane Bryan (Chief Investigator and Academic Supervisor)

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

This study seeks to gain valuable insight into the experiences of consenting to and refusing medical treatment as a paediatric patient.

Why have I been asked to take part?

You have been invited to take part in this study because you have self-identified as an adult with experience as a paediatric patient during your childhood, where you received treatment in England and Wales. We are interested to hear your experiences and thoughts about consents and refusals of therapeutic medical treatment by paediatric patients in medical practice.

Do I have to take part?

It is entirely up to you to decide. We will describe the study and go through this information sheet, which we will give you to keep. If you choose to participate, we will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw without consequence at any time without giving a reason, your legal rights will not be affected in any way.

What will happen to me if I take part?

Once you have agreed to take part I will contact you through your preferred means of communication to arrange a time and place to meet for the study. Before the study begins we will go through this information sheet where you can ask any questions that you may

have. I will ask you to sign a consent form to confirm that you have agreed to take part. I will ask questions about your experiences. It is a narrative study, so I am interested in listening to your perspective. I will record our conversation with an audio recorder so that I can listen to our conversation again. An anonymised transcription will be created from this recording. Identifiable details will not be used in the report. After our conversation, I will provide you with my contact details so that you can contact me if you have any questions or concerns.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

Time commitment: all interviews will be conducted at a time and date that suits you. The length of the study will aim to stay within one hour (or two half hour sessions). If a longer interview is needed then another interview can be arranged. If you are fatigued or uncomfortable in any way the interview can be stopped or postponed and re-arranged.

Confidentiality: you may be concerned with sharing personal information however, everything that is discussed is anonymised and accurately transcribed and reported. Only myself and my supervisor will have access to personal details and the audio recordings. Moreover, you will receive a copy of the transcription. You can withdraw from the study at any point and your data will be destroyed in line with the University of Warwick data protection guidelines.

What are the possible benefits of taking part in this study?

It is unlikely that there will be a direct benefit to taking part. However, the purpose of the data collection is to add knowledge to the existing academic debate. Therefore, there is a potential future benefit to others and the opportunity to have your experiences listened to.

Expenses and payments

No expenses or payments will be made.

What will happen when the study ends?

After the study, the audio recording will be transcribed. The data will be analysed and presented in the final report/thesis and published. A summary of the results will be sent to you, if you wish to receive it.

Will my taking part be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

This study is conducted as part of an application for a PhD in Law. This study is unfunded.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw.

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance

Research & Impact Services

University House

University of Warwick

Coventry

CV4 8UW

Email: researchgovernance@warwick.ac.uk

Tel: 024 76 522746

Will my taking part be kept confidential?

Yes. The data will be collected through an audio recording during the interview. The interview will be recorded on a Dictaphone. The electronic audio data and electronic transcriptions will be stored in the encrypted file on the University of Warwick's server. The hard copies of consent forms will be stored in a locked filing cabinet at the University of Warwick in line with the University's data protection policy.

The audio recording will then be transcribed. At this point the data will be anonymised. Your name will be substituted for a reference number and the date and time of the interview. The transcribed data will be used and published. Only the Student Researcher and

Academic Supervisor will have access to the audio recordings. The electronic audio recordings and transcription logs will be stored using the University of Warwick's encrypted personal storage system. The audio recordings and personal contact details will be destroyed at the end of the study (publication of PhD work).

What will happen to the results of the study?

After the study, the audio recording will be transcribed. The data will be analysed and presented in an application for a PhD in Law and later published in an academic journal. A summary of the results will be provided if you wish to receive it.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by North West – Preston NHS REC.

What if I want more information about the study?

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact:

Miss Rebecca Limb (Student Researcher) – R.L.A.Limb@warwick.ac.uk

Dr Jane Bryan (Academic Supervisor) – J.M.Bryan@warwick.ac.uk

Thank you for taking the time to read this Participant Information Sheet.

Appendix 12: Recruitment Email/Insite Health Care Professionals

version 1, 03/07/18 IRAS Project ID: 238834

Emails/Newsletters:

My name is Rebecca Limb and I am a PhD student at the University of Warwick. I am undertaking research into consent to and refusals of medical treatment by paediatric patients in England and Wales, which has full ethical approval. This study seeks to do interviews health care professionals who have at least one year working with paediatric patients in England and Wales about their experiences working with paediatric patients. I am interested in your stories and opinions. The interviews can be conducted in person at the University of Warwick at a time and location suitable to you.

This study has been approved by South West - Cornwall & Plymouth Research Ethics Committee

If you were a health care professional, who has at least one years' experience working with paediatric patients in England and Wales and are interested in this study, please see attached a participant information sheet for more information about the study. If you would like to participate in this study, please contact me via email (R.L.A.Limb@warwick.ac.uk).

Thank you for your interest and time.

Best wishes,

Rebecca

Appendix 13: Recruitment Email/Insite Past-Paediatric Patients

version 2, 21/07/18, IRAS Number: 242598

Insite Page Recruitment: https://warwick.ac.uk/insite/staff_forums/volunteering

Title:

Call for participants: Did you receive medical treatment or spend time in hospital as a child?'

Main text:

We are seeking to recruit participants who as children received medical treatment such as physiotherapy, occupational therapy, surgery, procedures, investigations, IV infusion or scan in England and Wales.

This study aims to document your valuable experiences through interviews. I am interested in your stories, opinions and feelings. The interviews can be conducted in person, in a public place suitable to you, or via skype.

This study has been approved by North West – Preston NHS REC.

If you are interested in this study, please see attached a participant information sheet for more information about the study. If you would like to participate in this study, please contact me via email (R.L.A.Limb@warwick.ac.uk).

Thank you for your interest and time.

Best wishes,

Rebecca

Email and newsletters:

Hi,

My name is Rebecca Limb and I am a doctorate student at the University of Warwick. I am undertaking research into consent to and refusals of medical treatment by paediatric patients in England and Wales, which has full ethical approval. This study was designed in response to the lack of research documenting the valuable experiences of paediatric patients and their involvement in consenting to and refusing medical treatment. This study seeks to document such experiences through interviews with adults who, during their childhood were a paediatric patient in England and Wales. This includes physiotherapy,

occupational therapy, surgery, infusions and scans. I am interested in your stories and opinions. The interviews can be conducted in person, in a public place suitable to you, or via skype.

This study has been approved by North West – Preston NHS REC.

If you were a paediatric patient in England and Wales and are interested in this study, please see attached a participant information sheet for more information about the study. If you would like to participate in this study, please contact me via email (R.L.A.Limb@warwick.ac.uk).

Thank you for your interest and time.

Best wishes,

Rebecca Limb

Appendix 14: Interview Schedule Health Care Professionals

(I) Introduction

Explain the research to the participant using the participant information sheet and the consent form covering the purpose of the project, voluntary participation, the collection, transcription, analysis and publication of their data, confidentiality, data security, future use of data and agreement to take part in the study. Build rapport with the participant. Obtain participants consent to be involved in the study.

(II) Participant Information

Start the audio recording

(III) Topic 1: Medical Treatment

In as much detail as you feel comfortable, can you explain the treatment that you had as a child?

(iv) Topic 2: Participation

How would you describe your participation in your health care?

(Probes) Did you participate in your health care? How did you participate? How did you feel about this?

(v) Topic 3: Consent and refusals

What does consent/refusals mean to you?

Can you recall an experience where you consented to/refused medical treatment as a child?

(Probes) If I had been there what would I have observed? How did you feel about this? What do you think about children consenting to medical treatment?

(vi) Topic 4: Issues and concerns

How would you describe your experience of having medical treatment as a child? How do you feel about your experience?

What barriers did you face to participation? What factors enabled you to participate?

Would you recommend any changes? What changes would you recommend?

(Probes) Could your experience be improved? How could your experiences you had as a child be improved?

(vii) Topic 5: Questions

- Is there anything else you would like to add? Have I missed anything?
- Do you have any questions for me?

Thank the participant for their time. End audio recording

Appendix 15: Interview Schedule Past-Paediatric Patients

(I) Introduction

Explain the research to the participant using the participant information sheet and the consent form covering the purpose of the project, voluntary participation, the collection, transcription, analysis and publication of their data, confidentiality, data security, future use of data and agreement to take part in the study. Build rapport with the participant. Obtain participants consent to be involved in the study.

(II) Participant Information

Start the audio recording

(III) Topic 1: Experience in paediatric medicine

In as much detail as you feel comfortable, can you explain your role as a health care professional working with children?

(IV) Topic 2: Participation

How would you describe children's participation in their health care?

(Probes) How do children participate in their health care? Recent examples? How do you feel about this? What are the role of parents? Are there other actors?

(V) Topic 3: Consent and refusals

Can you recall the last time a child consented to/ refused therapeutic medical treatment? What would I have observed?

(Probes) How did you feel about this? Is this reflective of the 'norm'? If not, what is the 'norm'? What are the role of parents? Are there other actors? Have you experienced exceptions?

(VI) Topic 4: Issues and concerns

How would you describe your experience as a health care professional working with children?

(Probes) Do you face any challenges as a health care professional working with children? What do you think about children participating in their health care, consenting to and refusing medical treatment? Would you make any changes/recommendations, if so, what changes? Could your experience be improved?

(VII) Topic 5: Questions

- Is there anything you would like to add? Have I missed anything?
- Do you have any questions for me?

Thank the participant for their time. End audio recording.