Resuscitation decisions:
An exploration of the problems with the "Do Not Attempt Cardiopulmonary Resuscitation" form and the development and evaluation of a new approach.

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Acknowledgments

Firstly, many thanks to the staff and patients who participated in focus groups, interviews, and contributed time and thought to the development of the UFTO as well as to its evaluation.

Dr. Jonathan Fuld encouraged me to pursue this research, and walked a perfect line between supervision and collaboration throughout, allowing me to find my own feet, but providing advice when needed. Anne Marie Slowther and Frances Griffiths have provided further excellent support and supervision in submitting the combined works as a thesis. I am grateful for the mentorship provided by all three, and continue to be inspired by them.

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Submission declaration

I declare that the submitted material as a whole is not substantially the same as published or unpublished material that I have previously submitted, or am currently submitting, for a degree, diploma, or similar qualification at any university or similar institution. No parts of the works submitted have been submitted previously for any aforementioned qualification.

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Table of publications submitted for consideration for the degree of Doctor of Philosophy by Published Work

Statements of the candidate's contribution to the published work

Paper	*Authorship*
Paper I: **Ethical issues surrounding do not attempt resuscitation orders: decisions, discussions and deleterious effects.** *J Med Ethics. 2010 Oct;36(10):593-7* Zoe Fritz conceived the idea for the paper, and conducted the literature search. She took the lead role in writing the paper in liaison with co-author Dr. Fuld and responded to reviewers as the corresponding author.	*Fritz Z,* *Fuld J*
Paper II: **Interpretation and intent: a study of the (mis)understanding of DNAR orders in a teaching hospital.** *Resuscitation. 2010 Sep;81(9):1138-41* Zoe Fritz conceived the idea for the study, and designed and distributed the questionnaire. She contributed to data analysis which was led by Chris Palmer. She took the lead role in writing the paper in liaison with her co-authors and she responded to reviewers as the corresponding author.	*Fritz Z,* *Fuld J,* *Haydock S,* *Palmer C.*
Paper III: **Characteristics and outcome of patients with DNACPR orders in an acute hospital; an observational study.** *Resuscitation. 2014 Jan;85(1):104-8* Zoe Fritz conceived the idea for the study, and contributed to data collection and analysis. She took a lead role in writing the paper in liaison with Dr. Heywood and the contribution of other co-authors and responded to reviewers as the corresponding author.	*Fritz ZB*,* *Heywood RM*,* *Moffat SC,* *Bradshaw LE,* *Fuld JP*
Paper IV: Do Not Attempt Cardiopulmonary Resuscitation orders in acute medical settings: a qualitative study. *QJM 2013 Feb;106(2):165-77* Zoe Fritz conceived the idea for the study, wrote the protocol and obtained ethics and other approvals. She supervised and contributed to data collection and contributed to data analysis. With Dr. Simon Cohn, she took a lead role in writing the paper.	*Cohn S*,* *Fritz ZB*,* *Frankau JM,* *Laroche CM,* *Fuld JP*

Paper V: Documentation of resuscitation decision-making: a survey of practice in the United Kingdom. *Resuscitation. 2014 May;85(5):606-11* Zoe Fritz conceived the idea for the study. She supervised data collection, and contributed to data analysis and the writing of the paper along with her coauthors.	*Clements M, Fuld J, Fritz Z*
Paper VI: Development of the Universal Form of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a cross-disciplinary approach. *J Eval Clin Pract. 2015 Feb;21(1):109-17.* Zoe Fritz conceived the idea for the study, wrote the protocol and obtained ethics and other approvals. She led the data collection and analysis. She took the lead role in writing the paper in liaison with her co-author Jonathan Fuld and she responded to reviewers as the corresponding author.	*Fritz Z, Fuld JP*
Paper VII: The Universal Form of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a mixed methods evaluation of the effects on clinical practice and patient care. *PLoS One. 2013 Sep 4;8(9):e70977. doi: 10.1371/journal.pone.0070977.* Zoe Fritz conceived the idea for the study, wrote the protocol and obtained ethics and other approvals. She led the data collection and analysis. She took the lead role in writing the paper in liaison with her co-authors and she responded to reviewers as the corresponding author.	*Fritz Z, Malyon A, Frankau JM, Parker RA, Cohn S, Laroche CM, Palmer CR, Fuld JP*
Copies of these statements of contribution, signed by all coauthors can be found in Appendix A. * denotes joint first authors	

List of additional papers submitted as supplementary material

These papers can be found in Appendix C

Do not attempt cardiopulmonary resuscitation (DNACPR) orders: a systematic review of the barriers and facilitators of decision-making and implementation.
Mockford C, Fritz Z, George R, Court R, Grove A, Clarke B, Field R, Perkins GD. Resuscitation. 2015 Mar;88:99-113

Systematic review of interventions to improve appropriate use and outcomes associated with do-not-attempt-cardiopulmonary-resuscitation decisions.
Field RA, Fritz Z, Baker A, Grove A, Perkins GD. Resuscitation. 2014 Nov;85(11):1418-31.

DNACPR decisions: challenging and changing practice in the wake of the Tracey judgment.
Fritz Z, Cork N, Dodd A, Malyon A.Clin Med (Lond). 2014 Dec;14(6):571-6.

Patients' resuscitation preferences in context: lessons from POLST.
Fritz ZB, Barclay SI. Resuscitation. 2014 Apr;85(4):444-5

Does resuscitation status affect decision making in a deteriorating patient? Results from a randomised vignette study.
Moffat S, Skinner J, Fritz Z J Eval Clin Pract. 2016 May 30. doi: 10.1111/jep.12559. [Epub ahead of print]

Summary

Background

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms exist to provide immediacy and clarity of instruction in the event of a cardiorespiratory arrest; they are written either at a patient's request, or because a clinical decision has been made that a patient would be unlikely to survive attempted cardiopulmonary resuscitation. They are extremely common, with around 92% of patients who die in hospital dying with a DNACPR decision in place.[1]

While working as a physician in the acute care setting and in intensive care, I became concerned about ethical problems with the use, interpretation and unintended consequences of DNACPR decisions: they were considered in an *ad hoc* manner; often documented without discussion with patients; and appeared to act as an unofficial triage marker, with patients with DNACPR forms being treated differently from those without them.

A review of the literature revealed empirical research which supported my concerns, but a lack of contemporary evidence in the UK about the use or understanding of DNACPR decisions and forms. Supported by my colleague, Dr. Jonathan Fuld, I successfully applied for an NIHR Research for Patient Benefit Grant to conduct research to further assess these problems in the UK setting and to develop and evaluate an alternative approach.

Research Questions

1. How are resuscitation decisions commonly decided upon, discussed and documented in the UK?
2. What are the ethical problems associated with the current practice surrounding resuscitation decisions?
3. Would an alternative approach help resolve these ethical problems?

Aims and Objectives

1. To explore current UK practice associated with Do Not Attempt Cardiopulmonary Resuscitation decisions, and to identify inconsistencies, inequities and ethical problems associated with current practice
    a. To explore how DNACPR decisions are understood by doctors and nurses
    b. To explore the characteristics and outcomes of those patients who have DNACPR decisions
    c. To observe the behaviours around the use of DNACPR decisions among nursing and medical staff
    d. To identify any national variation in recording DNACPR decisions.
    e. To examine potential ethical concerns with the current approach to Do Not Attempt Cardiopulmonary Resuscitation decisions

2. To develop an alternative approach to resuscitation decisions to address any problems substantiated in the first part of the project
    a. To explore clinicians' views on what an alternative system should include
    b. To develop an alternative approach with doctors, nurses and the public and test for usability with clinicians
    c. To pilot the approach in a clinical setting

3. To evaluate the new approach using clinician and patient related outcomes

Methods

1. A mixed methods approach was used to achieve the first aim. Methods included:

a. An analysis of the existing literature on Do Not attempt Cardiopulmonary resuscitation orders, identifying ethical problems with the current practice *(Paper I)*[2]

b. A questionnaire of doctors and nurses at a teaching hospital using McNemar and Fishers tests to assess differences between what clinicians thought 'should' take place for those patients with DNACPR decisions, and what they thought did in practice take place. (*Paper II)*[3]

c. A retrospective case note analysis of 541 patients from an acute hospital (*Paper III)*[4]

d. A six-month multi-source qualitative study, primarily using direct observation and semi-structured interviews on two acute wards in a middle sized NHS hospital *(Paper IV)*[5]

e. A survey questionnaire of all acute trusts in the UK *(Paper V)*[6]

2. An Adapted Delphi technique was used to develop an alternative approach (Aim 2) including:

a. Interviews with twenty senior clinicians from a broad range of specialties about problems with the current approach and what changes they thought might address these problems.
b. Six focus groups with clinicians and lay individuals

c. Testing for usability using simulations with junior doctors
d. Piloting on two wards

(Paper VI)[7]

3. A prospective mixed-methods before-and-after study was carried out in a 480 bed hospital on two wards over nine months (Aim 3). This included observation and face to face semi-structured interviews with consultants, nurses, and junior doctors. Quantitative data was collected on all patients in whom a decision not to attempt CPR was made during the study period. Data was also collected contemporaneously on two case control groups in both periods.
Outcomes measured included:

a. Behavioral change in nursing and medical staff when the new approach was introduced
b. Change in characteristics (age, comorbidity, acuity of illness) of patients in whom a decision not to attempt CPR was made
c. Objective 'harms' using the Institute for Health Care Improvement (IHI) Global Trigger Tool (GTT) to assess rate, severity and preventability of harms.
d. Change in number of resuscitation attempts per ward
e. Identification of patients who would benefit from a palliative approach.

(Paper VII)[8]

Results

Problems with current UK practice identified in papers I-V

- DNACPR forms were completed on an *ad hoc* basis with wide variation amongst clinicians and institutions.
- Patients remained inappropriately for resuscitation and some patients had unwanted and futile resuscitation attempts
- Doctors did not like talking about CPR decisions, and patients rarely initiated discussions: documentation of discussions only occurred in about 50% of decisions
- DNACPR decisions were often interpreted by nurses and doctors to mean that other care should not be given
- Patients with DNACPR forms sometimes received fewer appropriate interventions and treatments than patients without them.

Development of an alternative approach (paper VI)

- The Universal Form of Treatment Options (UFTO), a new approach to resuscitation decisions was iteratively developed with doctors, nurses and lay representatives to gain consensus approval.
- UFTO contextualized the resuscitation decision within overall goals of care and was completed universally.
- Accompanying process recommendations included patient involvement in decision-making wherever possible, and early completion to make the process routine.
- A patient information leaflet was developed to support patient involvement and understanding.

Evaluation of the UFTO (paper VII)

- The introduction of the UFTO and the standardization of considering a resuscitation decision did not change the threshold (in terms of patient characteristics) for patients in whom a decision not to attempt CPR was made.

- The introduction of the UFTO was associated with reduced objective harms (as measured by the Global Trigger Tool)[9] in those patients in whom a decision not to resuscitate was made: Rate difference per 1000 patient-days was 12.9 (95% CI: 2.6–23.2, p-value = 0.01).
- There was a reduction in the proportion of harms contributing to patient death during the period when the UFTO was used compared to the period when a DNACPR form was used. (23/71 in the DNACPR period to 4/44 in the UFTO period (95% CI 7.8–36.1, p-value = 0.006). Significant differences were maintained after adjustment for known confounders; no significant change was seen on contemporaneous case control wards.

- Interviews with clinicians and observation of ward practice revealed the UFTO helped provide clarity of goals of care and reduced negative associations with resuscitation decisions for clinicians. Reporting at nurse handover changed from referring to the patient in terms of the resuscitation decision to talking about the patient's condition and overall goals of care.

Conclusions, impact, and future work

The previous method of documenting DNACPR decisions had substantive ethical and logistical problems.

Implementation of an alternative approach (the UFTO), developed with patients and the public to address these problems, was associated with a change in attitude and practice of health care professionals and a reduction in objective harms to a group of vulnerable patients when assessed on two wards in one hospital. This approach needs to be further developed and assessed in order for it to be able to cross care boundaries (and be applicable to primary care) and to ensure that its positive effects are applicable outside East Anglia, where this work was conducted.

My research is beginning to have impact on health policy in the UK. I presented the research findings to the Health Select Committee Inquiry into end of life care; their recommendation 16 was: *"We recommend that the Government review the use of*

DNACPR orders in acute care settings, including whether resuscitation decisions should be considered in the context of overall treatment plans. This Committee believes there is a case for standardising the recording mechanisms for the NHS in England."[10]

I was invited to sit on the working group, led by the Resuscitation council UK and the Royal College of Nursing, to develop an approach, using evidence from my research amongst others, to develop a national form. The resulting form (the 'Recommended Summary Plan for Emergency Care and Treatment' - ReSPECT) has been through public consultation and usability testing; we are hoping to make it available for any Trust that wishes to use it nationally by the end of 2016.[11] I am a co applicant on a grant led by Professor Gavin Perkins to evaluate its use in five sites over the next three years.

List of abbreviations and acronyms

Acronym	Meaning	Explanation (where necessary)
BP	Blood Pressure	
CCU	Coronary Care Unit	
CPR	Cardio Pulmonary Resuscitation	
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation	
DNAR	Do Not Attempt Resuscitation	
DNR	Do Not Resuscitate	
GGT	Global Trigger Tool	A tool developed by the IHI to measure objective harms, and to be used to assess the impact of interventions designed to improve patient safety
HDU	High Dependency Unit	A unit with increased monitoring and nursing support. Some non invasive organ support can also be offered such as non-invasive ventilation.
ICU	Intensive Care Unit	A unit where organ support such as invasive ventilation, cardiac support with drugs (inotropes) and/ or emergency dialysis can be provided, alongside intensive medical and nursing monitoring.
The Joint Statement		The 2007 'Joint Statement on Decisions relating to Cardiopulmonary Resuscitation' from the Resuscitation Council (UK), the Royal College of Nurses and the British Medical Association
IHI	Institute of Healthcare Improvement	
MEWS	Modified Early Warning Score	A combined score of acute physiological illness, calculated using physiological parameters

Acronym	Meaning	Explanation (where necessary)
NCEPOD	National Confidential Enquiry into Patient Outcomes and Death	NCEPOD's stated purpose is: "to assist in maintaining and improving standards of care for adults and children for the benefit of the public by reviewing the management of patients, by undertaking confidential surveys and research, by maintaining and improving the quality of patient care and by publishing and generally making available the results of such activities".[12] NCEPOD published a report in 2012 called 'time to intervene' which investigated the process and highlighted concerns and the need for improvement over the process of care for patients aged 16 and over who received cardiopulmonary resuscitation in an in-hospital setting
POLST	Physician order for Life Sustaining Treatment	POLST Paradigm[13] is an approach to end-of-life planning that emphasizes patients' wishes about the care they receive. It is intended for seriously ill or frail patients, and is now widespread in the United states.
ReSPECT	Recommended Summary Plan of Emergency Care and Treatment	An alternative to resuscitation decisions, building on the UFTO work undertaken by the author, and that of others. It contextualizes resuscitation decisions within overall goals of treatments, and is designed to cross care boundaries.[11]
SpR	Specialist Registrar	A junior doctor, who is undertaking training in their chosen specialty. Typically a doctor will be an SpR after several years of core general training, and will work and train as an SpR for about five years before becoming a consultant
TEP	Treatment Escalation Plan	A form used in Devon to delineate 'ceilings of care' such as whether ward-based care, non invasive ventilation on a high dependency unit or or invasive ventilation on an intensive care unit should be considered, alongside the resuscitation decision.
UFTO	Universal Form of Treatment Options	An alternative to resuscitation decisions developed in Cambridge with patients, doctors and nurses, which contextualizes resuscitation in overall goals of treatment, and is intended for hospital use

Background

History of the development of the Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form

Cardiopulmonary Resuscitation (CPR) was first introduced in the 1960s[14] and was initially used on anaesthetized patients during surgery - as such, it had a high success rate. It was rapidly acknowledged that this success on physiologically well patients did not translate to those who had terminal disease or who were very frail. The authors of the initial paper subsequently wrote:

"*Not all dying patients should have CPR attempted. Some evaluation should be made before proceeding. The cardiac arrest should be sudden and unexpected. The patient should not be in the terminal stages of a malignant or other chronic disease and there should be some possibility of a return to a functional existence.*"[15]

In 1991 clarification on guidance regarding the documentation of resuscitation decisions was called for by the UK Parliamentary Ombudsman following a complaint.[16] From 1993 'Do Not Resuscitate' (DNR) forms became a common feature in the medical records: often red, often at the front of the notes, they provided a clear instruction to clinical teams. From the beginning however, there were concerns. It became apparent that the public thought that there was a much higher rate of success for resuscitation attempts than was actually the case: the public believed it was around 60% (in line with TV portrayals)[17, 18] in contrast with the 15% clinical success rate.[19] A 'DNR' was therefore perceived by some as giving up on a patient who might otherwise have a good chance of survival. To convey that having CPR started was not the same as having a successful resuscitation an 'A' for 'attempt' was added to the acronym: Do not *Attempt* Resuscitation. But 'DNAR' also had problems, this time with the clinical teams. 'Resuscitation' is to revive someone who has lost consciousness – from whatever means, and not necessarily through their heart stopping. There is also 'fluid resuscitation' which is to bring someone's blood pressure up with intravenous fluids, often when they are sick from

an overwhelming bacterial infection, or having lost fluid by other means. The intention of 'DNAR' was not to attempt *Cardiopulmonary* Resuscitation in the event of the patient's heart stopping, but staff were interpreting it to mean that other treatments should be withheld.[20, 21] The acronym was thus further lengthened in the UK to provide a more specific instruction: DNACPR or Do Not Attempt Cardiopulmonary Resuscitation. In this commentary I shall use this longer acronym throughout for consistency, unless referring to a specific article or quote where another form was used.

Another note on terminology: The DNACPR decision is documented on a form; the process of considering the resuscitation decision, documenting and filing it is referred to as 'DNACPR' colloquially rather than 'DNACPR form' (and the colloquial pleural is ' DNACPRs'). 'DNACPR order' was used in the literature (including in our publications) but it was emphasised in a Court of Appeal judgement[22] in 2014 that this was misleading as the documentation was a recommendation rather than legally binding. I will therefore use the colloquial 'DNACPR' with both the 'form' and the 'recommendation' implied rather than explicitly written in this commentary.

Clinical context of DNACPRs nationally and internationally

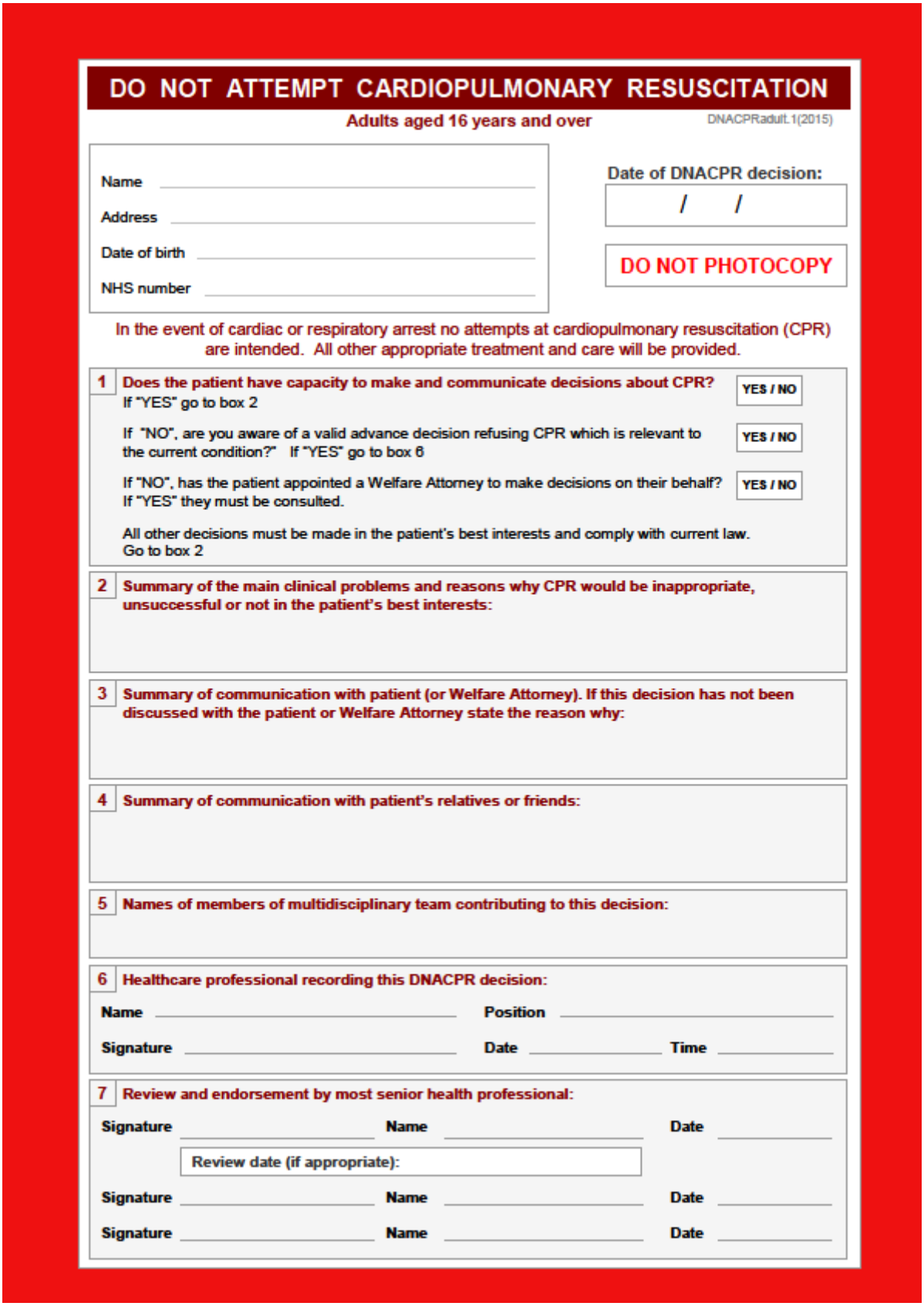
In the UK, there are on average 285,000 hospital deaths annually.[23] The National Cardiac Arrest Audit[24] indicates that around 92% of patients who die in hospital have a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form in place.[1]

DNACPRs (Figure 1) exist to provide immediacy and clarity of instruction in the event of a cardiorespiratory arrest and are made in three circumstances:

A. When a patient with capacity refuses CPR (or a patient currently without capacity has recorded their refusal of CPR in a valid and applicable advance decision).
B. When CPR is judged very unlikely to be effective because the patient is dying from an irreversible condition.

C. When a decision has been reached that the potential burdens of CPR outweigh the likelihood of benefit. (At the time of the research commencing, this was sometimes but not always done in discussion with a patient with capacity or with those close to the patient if the patient lacked capacity).

DNACPR does not mean that the patient is expected to die and anecdotally many patients with DNACPRs are discharged from hospital, although the precise proportion was not known at the outset of the research. The decision not to attempt CPR should be distinct from decisions to initiate palliative care or to withhold other treatments. The 2007 'Joint Statement on Decisions relating to Cardiopulmonary Resuscitation' from the Resuscitation Council (UK), the Royal College of Nurses and the British Medical Association (hereafter referred to as 'The Joint Statement')[25] explicitly states: *"DNAR decisions apply only to CPR and not to any other aspects of treatment."*



DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Adults aged 16 years and over

DNACPRadult.1(2015)

Name _____

Address _____

Date of birth _____

NHS number _____

Date of DNACPR decision: / /

DO NOT PHOTOCOPY

In the event of cardiac or respiratory arrest no attempts at cardiopulmonary resuscitation (CPR) are intended. All other appropriate treatment and care will be provided.

1 **Does the patient have capacity to make and communicate decisions about CPR?** YES / NO
If "YES" go to box 2

If "NO", are you aware of a valid advance decision refusing CPR which is relevant to the current condition?" If "YES" go to box 6 YES / NO

If "NO", has the patient appointed a Welfare Attorney to make decisions on their behalf? YES / NO
If "YES" they must be consulted.

All other decisions must be made in the patient's best interests and comply with current law.
Go to box 2

2 **Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests:**

3 **Summary of communication with patient (or Welfare Attorney). If this decision has not been discussed with the patient or Welfare Attorney state the reason why:**

4 **Summary of communication with patient's relatives or friends:**

5 **Names of members of multidisciplinary team contributing to this decision:**

6 **Healthcare professional recording this DNACPR decision:**

Name _____ **Position** _____

Signature _____ **Date** _____ **Time** _____

7 **Review and endorsement by most senior health professional:**

Signature _____ **Name** _____ **Date** _____

Review date (if appropriate):

Signature _____ **Name** _____ **Date** _____

Signature _____ **Name** _____ **Date** _____

Figure 1: DNACPR model form (adult) from the Resuscitation Council (UK)
Taken from: https://www.resus.org.uk/dnacpr/do-not-attempt-cpr-model-forms/

A preliminary review of the literature revealed there were problems with DNACPR:

1. Cardiopulmonary resuscitation decision-making was conducted in an 'ad hoc' manner in the UK with no consistency in approach or documentation

Myint et al[26] had, in a questionnaire survey, previously exposed variability in making decisions relating to CPR "*SpRs [Specialist Registrars] are being tossed around in a sea of uncertainty. There is considerable inconsistency in opinion and practice in the DNAR decision-making process among these SpRs, and many do not find the available guidelines to be particularly helpful*"

There was no national policy on when or on whom a resuscitation decision should be recorded. There was anecdotal evidence to suggest it varied not only among institutions but among clinical settings within the same hospital and even among individual clinicians; however no quantitative or qualitative studies had been published to substantiate this claim.

The Joint Statement in 2007[25] included a sample DNACPR document that hospitals could modify and adopt. Many hospitals, however, had already invested time in developing their own forms and policies and were content to continue with them. No information existed on what degree of variability there was in documentation across the country.

2. Futile or 'Inappropriate' CPR attempts were carried out on patients.

Studies from the UK and US reported that clinicians described having attended CPR attempts where it was apparent that the deceased patient had little or no chance of survival.[27] In a survey of seventy junior doctors from the UK 71% said that they had participated in inappropriate CPR; 88% of those attributed this to the failure of a senior doctor in documenting CPR status".[28]

3. DNACPR decisions were discussed infrequently or inadequately

There was growing legal and public concern[29] about the manner in which DNACPR decisions were approached, with decisions often not discussed or communicated effectively to patients or their relatives. Legally, physicians' obligations in relation to discussing treatments decisions with their patients arise from different branches of the law - medical, human rights and criminal - and from judgments and statutes such as the Mental Capacity Act 2005. At the time of this research commencing, physicians were obliged to obtain consent to give a treatment, but not to withhold one.[30, 31] Patients had the right to refuse a treatment but not to demand one.[32] The Mental Capacity Act required that physicians make 'best interests' decisions on behalf of those patients lacking capacity, and that to do so one must (where it is '*practicable')* take into account the views of those close to the patient.[33] In practice these were interpreted by most clinicians that, while discussion and consent needed to be obtained to give a treatment, the withholding of a treatments – such as CPR - did not routinely need to be discussed, although it was considered good practice to do so. The 2007 joint guidance stated: "*When a clinical decision is made that CPR should not be attempted, because it will not be successful, and the patient has not expressed a wish to discuss CPR, it is not necessary or appropriate to initiate discussion with the patient to explore their wishes regarding CPR.*"[25] The law continued to evolve during the course of the research (and is discussed further in the commentary).

Despite common practice, there was evidence that patients do wish to have discussions about resuscitation. Morgan *et al*[34] interviewed 100 elderly patients and those close to them after an acute illness necessitating their admission to hospital; 89 patients and 88 relatives thought that CPR decisions should be discussed with them. Nicolasora *et al*[35] randomized 297 patients into being given information about CPR and mechanical ventilation or not. Of the 136 patients offered information, 98% discussed it willingly and 82% said they found it useful. Even accounting for considerable selection bias towards patients who want to discuss such matters consenting to participate in the research, the findings were so

consistent across studies that collectively they suggested patients want to be involved in such decisions. The GMC's 'Duties of a Doctor'[36] emphasises that doctors should *"work in partnership with patients"* and *"...respect patients' right to reach decisions with you about their treatment and care"*. Despite this, doctors frequently do not discuss resuscitation decisions with patients, or feel uncomfortable doing so[37] and in practice few patients seek information about DNAR.[38]

Research exploring how discussions with patients and those close to them may be encouraged have considered a wide range of interventions: providing patient leaflets did not change the number of discussions which occurred.[39] Implementing routine discussion of CPR with inpatients made house staff more comfortable discussing end of life issues[40] but the patient perspective was not evaluated. Rosenfeld's[41] interviews of 21 elderly patients suggested that altering the focus of discussion from specific treatment options to acceptable health states and valued life activities would be more acceptable, but this change has not been evaluated.

4. DNACPRs can be misinterpreted by doctors and nurses leading to other treatments being inappropriately withheld.

In 1984 a questionnaire survey showed that the intention and interpretation of DNAR forms by physicians varied among 31 resident physicians.[42] Similarly, a prospective study in 1988 of the intentions of resident physicians showed that many physicians believed a wide range of treatments, including antiarrhythmic (56%) antibiotics (32%) and surgery (75%), should be withheld for patients who were not for resuscitation.[43] Similar findings have been reported with nurses by McAdam *et al*.[44]

In the UK it has been acknowledged anecdotally that such misapprehensions are common, but no studies had been published on UK practice or understanding of DNACPR.

Within a hospital setting, three early studies suggest that mortality is higher in patients with DNRs, independent of other variables. In 1995 a retrospective study was carried out on 12,821 patients (all over 65).[45] After adjusting for sickness at admission, pre-admission nursing home residence, patient and hospital characteristics, state and period, patients with DNRs were significantly more likely to die than those without them (40% vs. 9% p<0.001). Given the variability in DNRs being written, Shepardson *et al* used a propensity score for DNR decisions, and retrospectively analyzed 13,337 consecutive stroke admissions to 30 hospitals.[46] They found that the odds of death were substantially higher [33.9 (95% CI, 27.4-42.0)] in those with DNRs, having adjusted both for the propensity score and severity of illness. Mortality rates were, higher (p<0.001) in patients with DNRs across all propensity strata. Examining matched patients with intracerebral haemmorhage, Hemphill *et al*[47] looked at the case notes of a total of 8233 patients from 234 hospitals: 68% of patients who had a DNR died, whereas only 26% of patients without them died. A DNR was thus associated with an increased risk of mortality of the order of 2.6 times (p<0.001).

The above studies were carried out retrospectively with what information could be obtained from patient records. Differences in care received when a DNR was present could thus be attributed to a number of reasons: the patient might want less aggressive treatment generally; a DNR may act as a surrogate marker for other, unmeasured variables, or the very presence of a DNR may affect patient care.

In order to address these shortcomings, Beach *et al*[20] used patient scenarios to eliminate all variables other than the DNR in a questionnaire survey of attending physicians. Findings showed that patients with DNRs were significantly less likely to be transferred to an intensive care unit, or to be intubated. The presence of a DNR was also associated with a decreased willingness to take blood cultures (91% vs. 98%, P =.038), put in a central line (68% vs. 80%, P =.030), or give a blood transfusion (75% vs. 87%, P =.015). Hennemen *et al*[21] carried out a similar study

with scenarios for nursing staff. Nurses were significantly less likely to report that they would perform a variety of monitoring and interventions for patients with a DNR than for those without. These two studies strengthen the hypothesis that the DNR is likely to have an independent impact on clinical decision-making.

More recent studies have shown that DN(A)Rs continue to affect both basic and intensive treatments. Chen *et al*[48] carried out an observational study on 4537 patients admitted to 11 hospitals with acute heart failure, and found that patients with DNRs were less likely to have had their left ventricular function assessed ($p<0.001$) receive renin-angiotensin system blockade ($p<0.001$) anticoagulation ($p<0.001$), or non-pharmacologic interventions ($p<0.001$) as compared to patients without DNRs. Cohen *et al*[49] studied internal referrals to a medical intensive care unit (MICU). Out of 179 patients, DNARs were the only factor significantly associated with a decision to refuse a patient to the MICU (odds ratio, 0.25; 95% CI, 0.09-0.71, $p < .006$).

Previous attempts to create an alternative approach to making and recording CPR decisions

Prior to my research there had been previous attempts in the UK, Canada, and the US to address some of the problems associated with DNACPRs by developing alternative approaches.

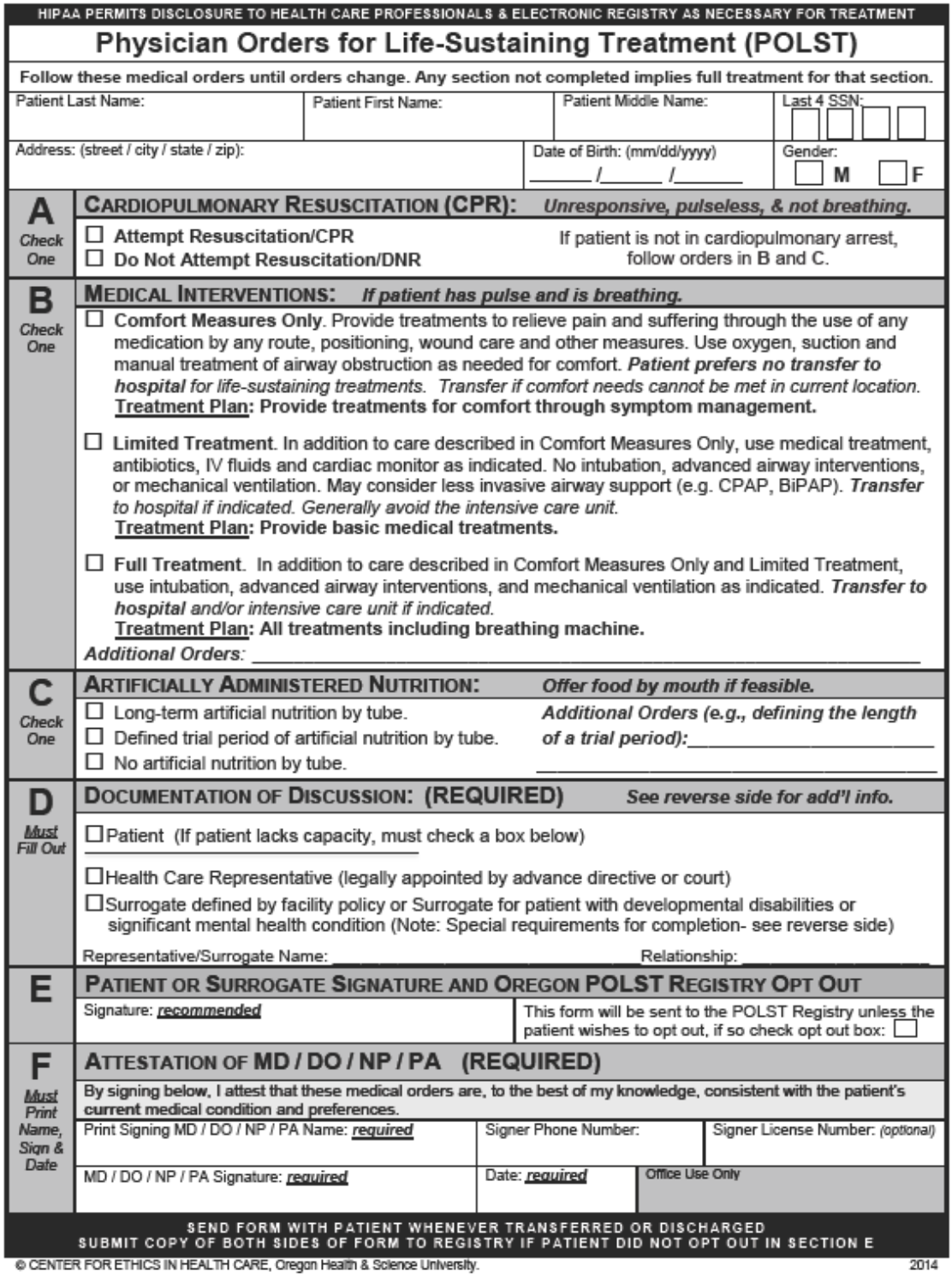
Several groups had developed forms which contained not only a 'Do Not Attempt CPR' but additional 'ceiling of care' decisions such as whether a patient should be admitted to the intensive care unit. In the 1980s Davila *et al* created a 'patient care category' (PCC) policy.[50] Their system assigned each patient into a category on admission: 'Full Support including CPR'; 'Full support, excluding CPR' and 'modified support, excluding CPR'. They retrospectively examined patients over 7 years. Compared with DNR years, during the PCC years mortality (8%), CPR (-53%), and

ventilatory support (42%) per 1000 admissions and CPR per 100 deaths (46%) decreased.[51] The PCC therefore reduced inappropriate resuscitation attempts, but the team did not assess whether care for those who were not for CPR was affected.

O'Toole *et al*[52] introduced a Specific Treatment-Limiting Order page (STOP). It was assessed using a prospective cohort study over two years, with 2733 patients. Rates of death and DNRs did not change, but among DNR patients there was an increased frequency of orders limiting 12 other treatments (e.g. mechanical ventilation was explicitly prohibited in 2% of DNR patients, compared with 66% after the STOP policy, $p< 0.001$). Using questionnaires, nurses and doctors reported improved communication (60%). However, while the STOP form may have improved communication about what treatments to withhold, it did not emphasise those treatments which were to be given, and did not address the negative stigma associated with DNR decisions.

Alternative forms e.g. the Treatment Escalation Plan (TEP)[53, 54] in Devon have been developed and introduced in other hospitals; they have been well received by those working with them.

The Physician order for Life Sustaining Treatment (POLST- Figure 2) has been adopted widely in the the US.[55]



HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Physician Orders for Life-Sustaining Treatment (POLST)

Follow these medical orders until orders change. Any section not completed implies full treatment for that section.

Patient Last Name:	Patient First Name:	Patient Middle Name:	Last 4 SSN: ☐☐☐☐
Address: (street / city / state / zip):		Date of Birth: (mm/dd/yyyy) _____/_____/_____	Gender: ☐ M ☐ F

A *Check One*

CARDIOPULMONARY RESUSCITATION (CPR): ***Unresponsive, pulseless, & not breathing.***

☐ **Attempt Resuscitation/CPR**
☐ **Do Not Attempt Resuscitation/DNR**

If patient is not in cardiopulmonary arrest, follow orders in B and C.

B *Check One*

MEDICAL INTERVENTIONS: ***If patient has pulse and is breathing.***

☐ **Comfort Measures Only**. Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. ***Patient prefers no transfer to hospital*** *for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.*
Treatment Plan: Provide treatments for comfort through symptom management.

☐ **Limited Treatment**. In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). ***Transfer*** *to hospital if indicated. Generally avoid the intensive care unit.*
Treatment Plan: Provide basic medical treatments.

☐ **Full Treatment**. In addition to care described in Comfort Measures Only and Limited Treatment, use intubation, advanced airway interventions, and mechanical ventilation as indicated. ***Transfer to hospital*** *and/or intensive care unit if indicated.*
Treatment Plan: All treatments including breathing machine.

Additional Orders: _____

C *Check One*

ARTIFICIALLY ADMINISTERED NUTRITION: ***Offer food by mouth if feasible.***

☐ Long-term artificial nutrition by tube.
☐ Defined trial period of artificial nutrition by tube.
☐ No artificial nutrition by tube.

Additional Orders (e.g., defining the length of a trial period): _____

D *Must Fill Out*

DOCUMENTATION OF DISCUSSION: (REQUIRED) ***See reverse side for add'l info.***

☐ Patient (If patient lacks capacity, must check a box below)

☐ Health Care Representative (legally appointed by advance directive or court)
☐ Surrogate defined by facility policy or Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion- see reverse side)

Representative/Surrogate Name: _____ Relationship: _____

E

PATIENT OR SURROGATE SIGNATURE AND OREGON POLST REGISTRY OPT OUT

Signature: ***recommended***	This form will be sent to the POLST Registry unless the patient wishes to opt out, if so check opt out box: ☐

F *Must Print Name, Sign & Date*

ATTESTATION OF MD / DO / NP / PA (REQUIRED)

By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's current medical condition and preferences.

Print Signing MD / DO / NP / PA Name: ***required***	Signer Phone Number:	Signer License Number: *(optional)*
MD / DO / NP / PA Signature: ***required***	Date: ***required***	Office Use Only

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED
SUBMIT COPY OF BOTH SIDES OF FORM TO REGISTRY IF PATIENT DID NOT OPT OUT IN SECTION E

Figure 2: Oregon's Physician Orders for Life Sustaining Treatment (POLST)
Taken from: http://www.polst.org/wp-content/uploads/2014/10/2014.10.02-Oregon-POLST-Form-FINAL.pdf

POLST was first developed in Oregon to ensure that patients' preferences for end of life care (including whether or not they wanted attempted CPR) were honoured;[56] it is intended for those who are seriously ill or frail.[13] Early studies focused on assessing the uptake of POLST and whether the orders were respected by clinicians;[57, 58] it will be discussed further in the commentary.

While these approaches tried to address issues of misinterpretation, no previous approach had been developed with patients, nursing staff and doctors, nor had the impact of alternative approaches been assessed in terms of diminishing the negative effects associated with DNACPRs; my research aimed to first identify the problems with DNACPRs in the UK, then to develop an alternative approach with patients and providers to address the problems identified, and finally to evaluate whether the new approach diminished the negative effects associated with DNACPRs.

Commentary linking publications and other national and international work

NIHR Research for Patient Benefit Grant

With the support of Dr.Jonathan Fuld, I successfully applied for an NIHR Research for Patient Benefit grant as Chief Investigator to carry out research into the problems associated with DNACPRs and the development and evaluation of an alternative approach. Our application included strands of quantitative, qualitative and health services research methodology; our team therefore included statisticians and qualitative researchers. I led the work throughout, writing the grant, the ethics and research and development approvals, and responding to methodological challenges in collaboration with my colleagues. Several streams of the work were conducted in parallel, with publications being staggered over four years. Because of this, the chronology of the studies and the publications are not consistent; I describe them below alongside a national report in the order which provides a logical narrative.

Ethical implications of DNACPRs

Although papers had previously been written on the ethics of 'CPR'[59] "*Ethical issues surrounding do not attempt resuscitation orders: decisions, discussions and deleterious effects.' (Paper I)* was the first paper to bring together disparate pieces of empirical evidence revealing problems with specific elements of *DNA*CPR, and highlighting the ethical implications of these problems.

In doing so, we identified gaps where further empirical and analytical work was required. We also revealed a particular ethical dilemma many physicians faced daily: If physicians did not discuss resuscitation with a patient, and left them (by default) 'for CPR' then the physician would potentially be subjecting the patient to futile CPR - or partial recovery with associated physical and/or mental disabilities. If, however, the physician did write a 'DNACPR' they may inadvertently worsen the

care the patient would receive, perhaps increasing the chances of them suffering a cardiac arrest.

This tension may have contributed to the infrequency of DNACPR decisions and discussions: since many clinicians believed that writing a DNACPR would lead to worse care for their patients they would find it difficult to involve an autonomous patient in this kind of decision and still have the patient maintain trust in his or her care.

This first paper (cited 27 times since its publication) therefore acted both as a way of synthesising the current problems and as a call to action for empirical research to address the issues with existing practice.

(Mis)understanding of DNACPRs in the UK

Although previous studies[20, 21] had revealed that clinicians often misinterpreted DNACPRs to mean that other treatments should be withheld, these studies were carried out in the US and were not recent. Since then, the acronym had been lengthened to emphasise that only CPR should be withheld, and the Joint Statement had been published reiterating this.[25] In order to establish whether misunderstandings were common in the UK despite these changes, a convenience sample questionnaire was conducted of 50 doctors and 35 nurses asking what treatments they thought patients with DNACPRs *should* receive, and what treatments patients with DNACPRs received *in practice*. The results of this questionnaire were published in *Interpretation and intent: a study of the (mis)understanding of DNAR orders in a teaching hospital. (Paper II)*

Firstly we found that misunderstandings were still prevalent: around 40% of nurses and doctors thought that an out-of-hours medical team should be contacted less frequently if a patient had a DNACPR; this result was cited in the National Confidential Enquiry into Patient Outcomes and Deaths report[60] (further discussed below). Secondly, there were significant differences ($p < 0.0001$) in what doctors

believed 'should' take place and what they perceived took place 'in practice'. Most doctors believed that nursing observations, contacting outreach, and contacting a medical team were reduced when a patient had a DNACPR; the unspoken concern that when a DNACPR was written it would affect patient care was widespread, but the reasons for this – or how to address this problem – were unknown.

Characteristics and outcomes of patients with DNACPRs

A plausible explanation for why patients with DNACPRs were getting fewer interventions than those without them was that DNACPR was being conflated with a label that patients were 'about to die' and therefore not in need of (for example) being seen by the doctor out of hours. A move in the USA to change from DNACPR to 'Allow Natural Death' (AND)[61] may have contributed to this misunderstanding. Although it was known that most patients who died in hospital died with DNACPRs in place[62] it was not known how many patients with DNACPRs were discharged from hospital. Anecdotally we believed that this was the case for many patients but most studies only examined those DNACPRs which had been identified at the time of death or cardiac arrest. We identified only one paper that looked at all patients with DNACPRs: a paper from Holland in 1998 which analysed the medical records of 470 patients admitted over a five-month period.[63] 58 patients were identified with DNACPRs; 50% of them were discharged home, 29% went to a nursing home and 21% died in hospital.

In '*Characteristics and outcome of patients with DNACPR orders in an acute hospital; an observational study.' (Paper III),* the characteristics of all patients who died in 2009 in one District General Hospital were analysed, along with all of those who had a carbon copy DNACPR filed in 2009, and a sample of age-matched patients without known DNACPRs. This latter step was undertaken to estimate the return rate of DNACPR carbon copies, and ensure that there was no difference in the characteristics of those whose carbon copies were not returned. Consistent with the Dutch study, we found that around half of the 541 sampled patients were

discharged home and 17% were still alive at one year. This evidence counteracted the idea that patients with DNACPRs were 'about to die'.

DNACPR in practice

As clinicians, our own experience and observation of the use and effects of DNACPRs was through the prism of the practitioner. One of the strengths of the NIHR grant was that it allowed us to collaborate with medical anthropologists who provided a more objective (and critical) perspective. Few ethnographic studies existed in this field, and those that did focused on the decision-making around DNACPR rather than the documentation or impact of the CPR decision. An ethnographic study of current DNACPR practice and interviews with clinicians was therefore one of the first strands of the research funded by the grant, and the findings were published in *Do Not Attempt Cardiopulmonary Resuscitation orders in acute medical settings: a qualitative study (Paper IV).*

The specific aims were twofold: first to observe how the DNACPR form was used in practice. Secondly, given the evidence that those with DNACPRs appeared to get different care, we were interested in establishing if and how this simple form might produce unintended effects. Over a six-month period, nursing and medical behaviours were observed; 13 doctors and 14 nurses were interviewed using a semi- structured interview guide and 100 sets of notes of patients with DNACPR decisions were read to understand the context and documentation of the DNACPR decision, as well as what happened after the decision was documented.

The resulting qualitative data contributed to understanding possible mechanisms for the problems identified in the literature, and therefore which elements were important to change in an alternative approach. However, during observation of practice, no specific changes in care were observed which would be amenable to quantifiable assessment.

Development of the Universal Form of Treatment Options (UFTO)

The development of an alternative approach to DNACPR began with the identification, in papers I,II, and V of the problems that needed to be addressed, and continued with the questionnaire on 'interpretation and intent' (paper II) when physicians and nurses were asked as an open question how DNACPR could be improved. 10 of the 17 doctors who responded included comments about the need for more 'options' to be included alongside the CPR decision, for example decisions about intensive care admission. In *The Development of the Universal Form of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a cross-disciplinary approach* (Paper VI), the methodology used in development of the UFTO (a name established in a patient focus group) is outlined. From the outset, the significant change from any current approach was that the resuscitation decision should be considered universally; those who were 'for' attempted resuscitation would have an UFTO too, so that the form stopped acting as a potential unofficial 'stop' sign as had been seen with the DNACPR forms.

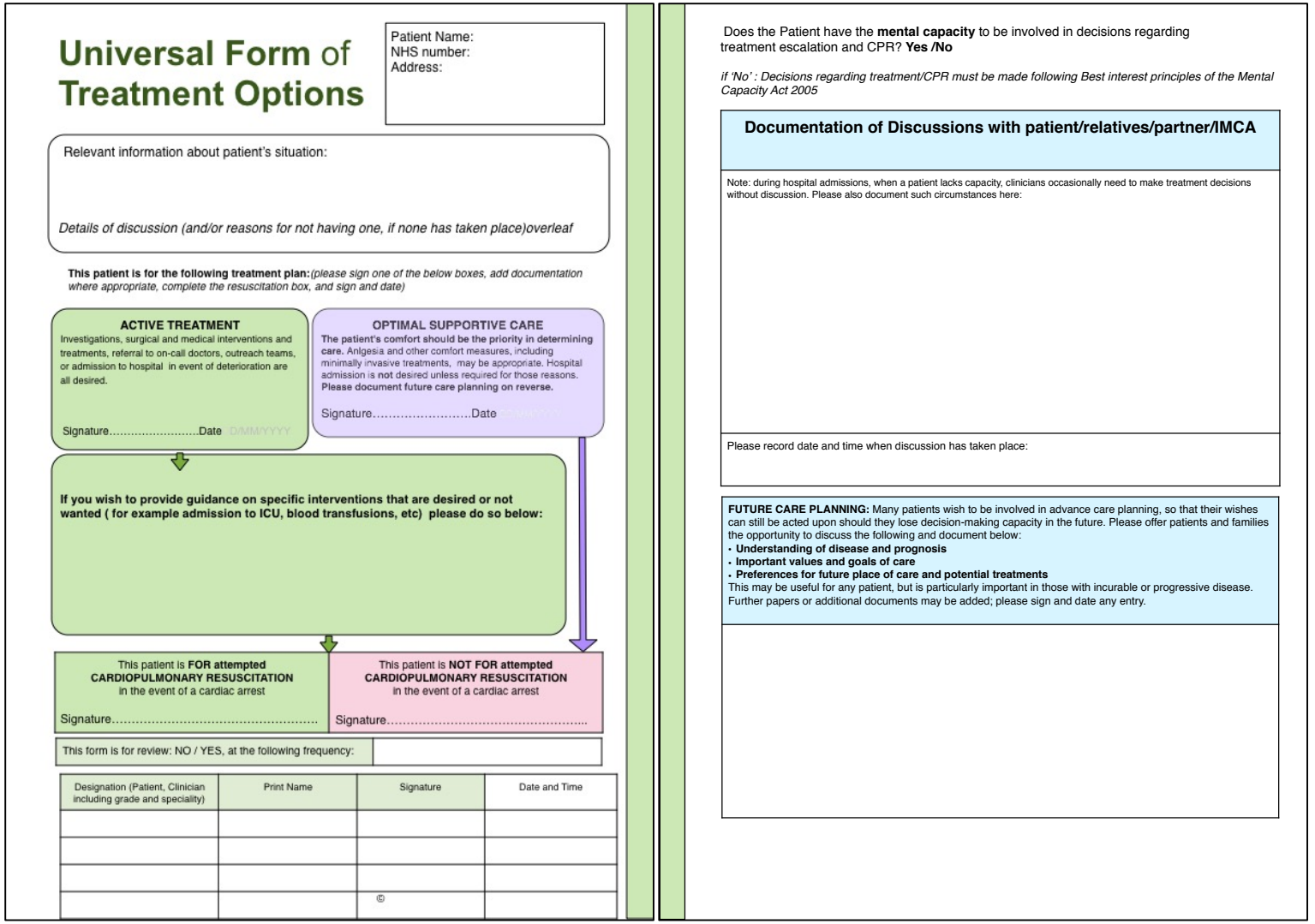
Substantial changes were made from initial proformas over 23 significant iterations; most important of these was the transition from a tick box approach with a 'menu' of treatment decisions to a more open approach with a dichotomous choice between goals of care ('active treatment' or 'optimal supportive care') and a free space box in which more specific instructions could be written. (Figure 3: UFTO 10 and 18 comparators). This was a major departure from most of the other international approaches to resuscitation decisions (e.g. POLST, TEP) and came from behavioural economics literature,[64, 65] and focus groups with clinicians.

We conducted a randomized vignette study (unpublished) among 150 doctors; a third had the vignette with a completed DNACPR, a third with an UFTO 10 (a tick box option) and the final third with UFTO 18 (an open layout). Our hypothetical

patient was significantly more likely (p<0,03) to have documentation of limitation of care on the tick box UFTO 10 than on the open UFTO 18.

Adding further credence to this approach, Rosenfeld had published interviews with elderly patients[41] and concluded that *"physician-patient discussions that focus on acceptable health states and valued life activities may be better suited to patients' end-of-life care goals than those that focus on specific medical interventions, such as cardiopulmonary resuscitation."*

The resulting UFTO (figure 4) was thus different from all other ceiling of care approaches internationally in that it was Universal, without tick boxes and a positive decision was always being documented about which treatments were desired rather than recording which ones were to be withheld.



Universal Form of Treatment Options

Patient Name:
NHS number:
Address:

Relevant information about patient's situation:

Details of discussion (and/or reasons for not having one, if none has taken place)overleaf

This patient is for the following treatment plan: *(please sign one of the below boxes, add documentation where appropriate, complete the resuscitation box, and sign and date)*

ACTIVE TREATMENT
Investigations, surgical and medical interventions and treatments, referral to on-call doctors, outreach teams, or admission to hospital in event of deterioration are all desired.

Signature……Date DD/MM/YYYY

OPTIMAL SUPPORTIVE CARE
The patient's comfort should be the priority in determining care. Anlgesia and other comfort measures, including minimally invasive treatments, may be appropriate. Hospital admission is not desired unless required for those reasons. **Please document future care planning on reverse.**

Signature……Date DD/MM/YYYY

If you wish to provide guidance on specific interventions that are desired or not wanted (for example admission to ICU, blood transfusions, etc) please do so below:

This patient is **FOR attempted CARDIOPULMONARY RESUSCITATION** in the event of a cardiac arrest

Signature……

This patient is **NOT FOR attempted CARDIOPULMONARY RESUSCITATION** in the event of a cardiac arrest

Signature……

This form is for review: NO / YES, at the following frequency:

Designation (Patient, Clinician including grade and speciality)	Print Name	Signature	Date and Time
		©	

Does the Patient have the **mental capacity** to be involved in decisions regarding treatment escalation and CPR? **Yes /No**

if 'No' : Decisions regarding treatment/CPR must be made following Best interest principles of the Mental Capacity Act 2005

Documentation of Discussions with patient/relatives/partner/IMCA

Note: during hospital admissions, when a patient lacks capacity, clinicians occasionally need to make treatment decisions without discussion. Please also document such circumstances here:

Please record date and time when discussion has taken place:

FUTURE CARE PLANNING: Many patients wish to be involved in advance care planning, so that their wishes can still be acted upon should they lose decision-making capacity in the future. Please offer patients and families the opportunity to discuss the following and document below:

- **Understanding of disease and prognosis**
- **Important values and goals of care**
- **Preferences for future place of care and potential treatments**

This may be useful for any patient, but is particularly important in those with incurable or progressive disease. Further papers or additional documents may be added; please sign and date any entry.

Figure 4: UFTO version 21 front and reverse sides.

Evaluation of the UFTO

The final element of this research was the evaluation of the UFTO: In *The Universal Form of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a mixed methods evaluation of the effects on clinical practice and patient care (Paper VII)* we sought to comprehensively evaluate the impact of the UFTO in relation to clinical decision-making, patient safety and ward-based practice.

The study was a before-and-after design on two wards, with contemporaneous controls. See Figure 5 for the time line of the study periods.

Timeline for Universal Form of Treatment Option Study	May -10	Jun -10	Jul-10	Aug -10	Sep -10	Oct-10	Nov -10	Dec -10	Jan -11	longer time frame		
Observation of DNACPR practice on intervention wards												
Prospective identification of eligible patients for quantitative data collection												
Education of UFTO materials												
Bedding in of UFTO practice												
Observation of UFTO practice on intervention wards												
Prospective identification of eligible patients for quantitative data collection												
Periods of data collection from control wards where UFTO not introduced												
Data collected and anonymised from all wards and both periods by primary reviewer for GTT (Global Trigger Tool)												
GTT analysis of randomised data												
Statistical analysis of GTT data												

Figure 5: Timeline of UFTO data collection

No differences in characteristics of patients in the two periods were observed, suggesting that the threshold for writing a DNACPR had not changed. Consistent with Sivakumar's previous work[38] the number of documented discussions did not go up despite the provision of a patients information leaflet. The clinicians we interviewed reported that the nature of the conversations that did take place had changed: they felt more comfortable, and believed that the patients had less anxiety.

The most important element of the research was assessing whether documenting the resuscitation decision on the UFTO changed the negative impact of the DNACPR form. Since no single aspect of care had been identified as being impacted in previous studies or our observation it was difficult to measure an improvement in care. We looked instead at a reduction in harms, using the Global Trigger Tool;[9] the methodology and results are fully explained in the paper.

The introduction of the UFTO was associated with a significant reduction in the objective harms to those patients in whom a decision not to attempt CPR had been made ($p= 0.01$). The reduction was even greater when we looked only at the most significant harms - those thought to contribute to a patient's death ($p=0.006$).

When a sample of patients on other wards was looked at over the same time period, no such change was observed, suggesting that the change was attributable to the introduction of UFTO rather than hospital-wide changes.

In parallel with the quantitative analysis, our observation and interviews (the first half of which were presented in paper IV), continued. A change in practice was observed: nursing handover, for example, changed from talking about resuscitation status, to first describing the medical problems of the patients and then the overall goals for the patient and finally the resuscitation status. Nursing staff reported having more 'power' when calling the junior doctors to see a patient who had deteriorated: 'they are for active treatment' could be emphasized, instead of the

previous 'they are not for resuscitation'. Doctors, similarly, reported a change in the way they were able to communicate about patients, and found it particularly useful when coming to see a patient out of hours. Although clinicians recognised that it took some investment of time at the point of admission, they unanimously asked to continue using the UFTO after the end of the trial period: the approach was extended to the whole hospital, and a (renamed) further iteration is still being used.

The NCEPOD report 2012

In 2012 the National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD) report 'Time to intervene'[66] provided the first comprehensive evidence on resuscitation decision making and outcomes in the UK.[67] The team of researchers assessed the medical notes of all adult patients who had a cardiac arrest triggering a call to the resuscitation team that led to delivery of chest compressions or defibrillation during a 14-day study period in 2011 throughout NHS hospitals in England, Wales and Northern Ireland. They found that a decision about CPR status was recorded in only 22% of the patients who had died following attempted resuscitation; despite the majority of people dying with DNACPRs in place, a significant minority of very sick people do not have them considered.

Further assessment of these notes led the researchers to conclude that 138 patients (37% of those assessed) had resuscitation attempted on them 'inappropriately'. This was determined by independent medical advisors reviewing the anonymised notes and determining a low chance of success from attempted CPR; advisors had the opportunity to discuss cases with colleagues in a multidisciplinary forum if they had any uncertainty. The report identified that inappropriate CPR attempts took place because DNACPRs were not routinely completed even in dying patients (30% of patients whose deaths were expected did not have DNACPR forms in place). The misunderstandings associated with DNACPRs already discussed contributed to this; the report noted that a common reason given for not completing a DNACPR was that the patient remained for 'active treatment'.

The NCEPOD report made three recommendations about 'resuscitation status' which were:

1. *An effective system for recording all decisions and discussions relating to CPR/DNACPR must be established, allowing all people who may care for the patient to be aware of this information.*
2. *Health care professionals as a whole must understand that patients can remain for active treatment but that in the event of a cardiac arrest CPR attempts may be futile. Providing active treatment is not a reason not to consider and document what should happen in the event of a cardiac arrest.*
3. *The use of 'ceilings of care' documentation would facilitate decision making and clarity of intent. There is need for a national project to lead this work.*

Variability of recording of DNACPR nationally

Although the NCEPOD report provided a national picture of how DNACPRs were being used, there was still no information on the variability in the forms used, or how many of them followed Resuscitation Council (UK)'s guidance on what should be included on such forms, and when DNACPR should be considered.

A survey was thus undertaken of all UK trusts about their current practice and drivers for change. In *Documentation of resuscitation decision-making: a survey of practice in the United Kingdom*. (Paper V) we reported wide variability in approach with several regions having multiple approaches within the same geographical boundary, leading to patients needing to have more than one form. Drivers for change included the NCEPOD guidance that 'ceiling of care' forms should be considered, and the desire to have a unified approach. Subsequent work by Freeman *et al*[68] showed similar variation in hospital policies.

Limitations

Although the limitations of each methodology are discussed in individual papers, a limitation of the research overall is that it was conducted in one geographical region. While many different users - nurses and doctors of different seniorities and specialties, resuscitation officers, and lay and expert patients - contributed to the development of the UFTO – they all came from the same three hospitals, and therefore all approached the problem through a shared set of experiences. East Anglia is a relatively prosperous part of the UK, with higher than average English literacy levels; the ability of patients to read an information leaflet was therefore not questioned, and the engagement of patients in decision-making is generally high. Both of these factors will have contributed to the development of the UFTO and associated materials, and both would need to be considered in the development of an approach which could be adopted in areas with lower English literacy levels.

The evaluation was a single-center before-and-after study; to more rigorously evaluate the UFTO a step wedge, cluster randomized control trial was needed. We were unsuccessful in an application for funding for this study. This was in part due to the increasing recognition that change to DNACPR was needed urgently and that alternative approaches were being adopted by many Trusts. In this context of rapidly changing practice a five-year evaluation would have been difficult.

A relevant secondary outcome in the final paper was that the introduction of the UFTO was associated with earlier recognition that some patients would benefit from palliative care. The number of patients was very small, however, and they were on general wards. We therefore did a further retrospective case note analysis before and after the UFTO was introduced to specialist respiratory and oncology wards, and found no difference in early recognition of palliative care needs, although there was both an increase in advance care planning discussions and in CPR decision-making on the oncology wards (Malyon et al, in press).

Related changes to the law that occurred after our research period

In 2014 the UK Court of Appeal considered a case (Re Tracey)[22] where a DNACPR form was written without a patient's knowledge, to be in breach of article eight of the European convention on Human Rights, since it would deprive the patient of an opportunity to ask for a second opinion or to ask the clinician questions about why the decision had been made. It therefore became law that DNACPR decisions must be discussed with patients, unless doing so would cause '*physical or psychological harm*'. Fear of a patient finding the topic 'distressing' should not be a reason to omit a discussion.

A more recent case,[69] has clarified the requirement for doctors to contact the relatives of those patients without capacity when it is 'practicably possible' if a decision about CPR needs to be made; waiting until the morning to call a relative is no longer considered defensible.

What was surprising was not the content of these judgments, but the time it took for cases to be brought to court. In paper IV we commented: *"…although we do not have supportive evidence to justify, one could anticipate that the gulf between widespread lay perception of use of DNACPRs* [that they are always discussed] *and reality* [that they are only discussed about 50% of the time, and there is no obligation to do so] *is wider than the public would imagine or tolerate."*

Following these judgments, there has been anecdotal evidence of a reduction in the number of DNACPRs written. The national cardiac arrest outcome data is due to be published on the 20th Oct 2016, and we will know then if there was a resulting increase in the number of inappropriate CPR attempts.

Related research that occurred after our research period

Further evidence on the unintended negative effects of DNACPRs,

Building the evidence base that a change in approach was needed Kazuare *et al* showed DNR status remained an independent predictor of mortality (odds ratio, 2.2; 95% confidence interval, 1.8-2.8) after risk adjustment in surgical patients;[70] and Mc Neil et al showed increased mortality and length of stay in those with 'Not For Resuscitation' forms in Australia and New Zealand, after propensity matching of the controls for age and co-morbidity (14% vs. 5%, P<0.005).[71]

Further development and use of POLST

In the USA, POLST was iteratively developed in 26 states, with accompanying evaluations.[57, 72-78] In the context of a health system where patients and relatives have the right to request treatments, and where one in five deaths occur in intensive care[79] the purpose of POLST (figure 2) is to help patients avoid aggressive unwanted treatments; it is intended for those who have significant illness or frailty. As such POLST has a different set of drivers and a different function than the UFTO, but lessons can be learnt from its continued evaluations.[80]

CPR survival prognosticator tool

Ebell et al have developed a helpful prognosticator to aid in resuscitation decision making: the "GO FAR" (Good Outcome following Attempted Resuscitation) scoring system is the first objective tool which can be used to help identify which patients have a low likelihood of survival to discharge.[81] The authors have designed a web based tool to facilitate its use.[82] In the future the Go FAR score could allow more informed decision making for patients and clinicians, and could be integrated into a discussion about CPR.

DNACPR evidence synthesis

Professor Gavin Perkins and colleagues in Warwick were awarded an NIHR HS&DR grant to conduct an evidence synthesis on use of DNACPRs. I was invited to join their team and was second author on two systematic reviews of the literature looking at a) barriers and facilitators of DNACPRs[83] and b) interventions to improve use and outcomes associated with DNACPR decisions.[84] The strongest evidence internationally for an intervention to improve outcomes was the UFTO (the strength of evidence was determined by independent authors). The results of these reviews, along with a review of Trust policies and guidelines,[68] and a review of complaints from multiple sources (including NHS Trusts, the National Reporting and Learning System, the Parliamentary and Health Service Ombudsman, and the Office of the Chief Coroner) emphasized themes already identified above: there were problems in considering, discussing and documenting resuscitation decisions.

In addition, focus groups were held with different groups of clinicians. Analysis of the data identified several themes but a consistent theme across all groups was concern about the unintended negative consequences of DNACPRs.

The need for a new national approach to resuscitation decisions (drawing on evidence from the work presented here as well as that of others) was agreed upon at the project's dissemination event.(1)

Vignette study comparing UFTO and DNACPR

The vignette studies of Beach[20] and Henneman[21] were adapted to assess whether the UFTO counteracted the effect of the DNACPR on reported nursing behavior. We presenting a developing case scenario to 231 nurses: a third with No form, a third with a DNACPR and a third with an UFTO completed with 'for active treatment but not for attempted CPR'.[85] Echoing the previous studies, the nurses in the DNACPR group were less likely to initiate intense nursing interventions than no-form groups ($P<0.001$). This was not the case when comparing the UFTO and no-form groups ($P = 0.795$), suggesting that the UFTO did indeed accurately

communicate that patients should remain for active treatments, even when a decision not to resuscitate had been documented.

Future research

Adapting the UFTO approach for primary care

The UFTO was developed and evaluated for the acute setting – and the majority of the work looking at DNACPR decisions also came from hospital based settings.

It is unknown how common DNACPR forms are in the community, although anecdotally their incidence is rising. In England in 2013 the Emergency Medical Services (EMS) attempted to resuscitate approximately 28,000 people; the figures for the number of deaths they attended where CPR was not commenced is estimated to be around 30,000.[23] However, the possibility of community DNACPRs having unintended consequences equivalent to those observed in hospital has been considered: in Zweig et al's 2004 study patients with a DNACPR were less likely to be admitted to hospital than those matched patients without them.[86]

Although there may be recognition among some that resuscitation and other decisions should be considered early, this is contrasted with a continued stigma associated with talking about death and a fear that any attempt to do so is a covert step towards being 'written off'. When the south east senate attempted to introduce routine discussions the hyperbolic media response was*: "Over 75? Sign here if you're ready for death: GPs to ask ALL older patients if they'll agree to a 'do not resuscitate' order"*[87] The distress caused by the misuse of the Liverpool care pathway culminating in the Neuberger report "More care, less pathway"[88] emphasised the problems both with the public's discomfort with withdrawal of treatments and the dangers of standardised proformas with tick boxes.

Work is therefore needed to explore the current use of DNACPRs in primary care. Examining patient preferences for when (and with whom) discussions about resuscitation and other decisions should take place, and what triggers might be appropriate for such discussions is important. Finally, qualitative work with patients and GPS is needed to understand how an alternative (UFTO based) approach might be adapted for primary care.

The interface of UFTO with Advance Care Planning

Advance Care Planning (which has its own significant literature beyond the scope of this commentary) has been shown to have many strengths. These include allowing patients to discuss important issues about their treatment or care before they lose capacity to do so through dementia or serious illness[89, 90] and ensuring that their future wishes will be respected.[91] However very few people write advance care plans or Advance Decisions to Refuse Treatment in the UK: Compassion in Dying's statistics suggest 4% of the population have an ADRT. [10]

A DNACPR has traditionally been seen as separate to advance care plans – historically it did not represent what a patient wanted but rather what a clinician felt was futile. If, however, the resuscitation decision was contextualised within overall goals of care and combined with discussions about what treatments (or outcomes) a patient did or did not want then the boundaries between this and ACP might be harder to define. If an UFTO-like approach was introduced to primary care, then studies (both qualitative and quantitative) would be needed to assess the impact of this on Advance Care Planning: it is possible that a resuscitation-in-context discussion would act as a springboard to a wider set of conversations and documented preferences or decisions. Alternatively, it might inhibit people from comprehensively undertaking ACP.

Policy implications

Development of a unified national approach: the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

A group of stakeholders from all four nations and all specialties convened to develop a new national approach to resuscitation decisions following the recommendation of the Health Select Committee and the HS& DR dissemination event. The resulting 'ReSPECT Process' (Figure 6) draws on the UFTO research presented here.

The ReSPECT process encourages active engagement with the individual whose form it is, including understanding what their priorities of care are,[41, 92, 93] rather than asking them to focus on particular treatments. Guided by this where possible, a clinical recommendation is then documented.

Given the importance of the positive labelling that we observed in the UFTO study, the ReSPECT process asks clinicians to choose whether the primary focus should be on 'life sustaining treatment' or 'symptom control' and then allows details of specific treatment recommendations to be written in a free text box, before documenting the resuscitation recommendation. This approach has been to public consultation and usability testing. A final version is due to be made nationally available in November, and a grant has been secured to evaluate its use in five early adopter sites.

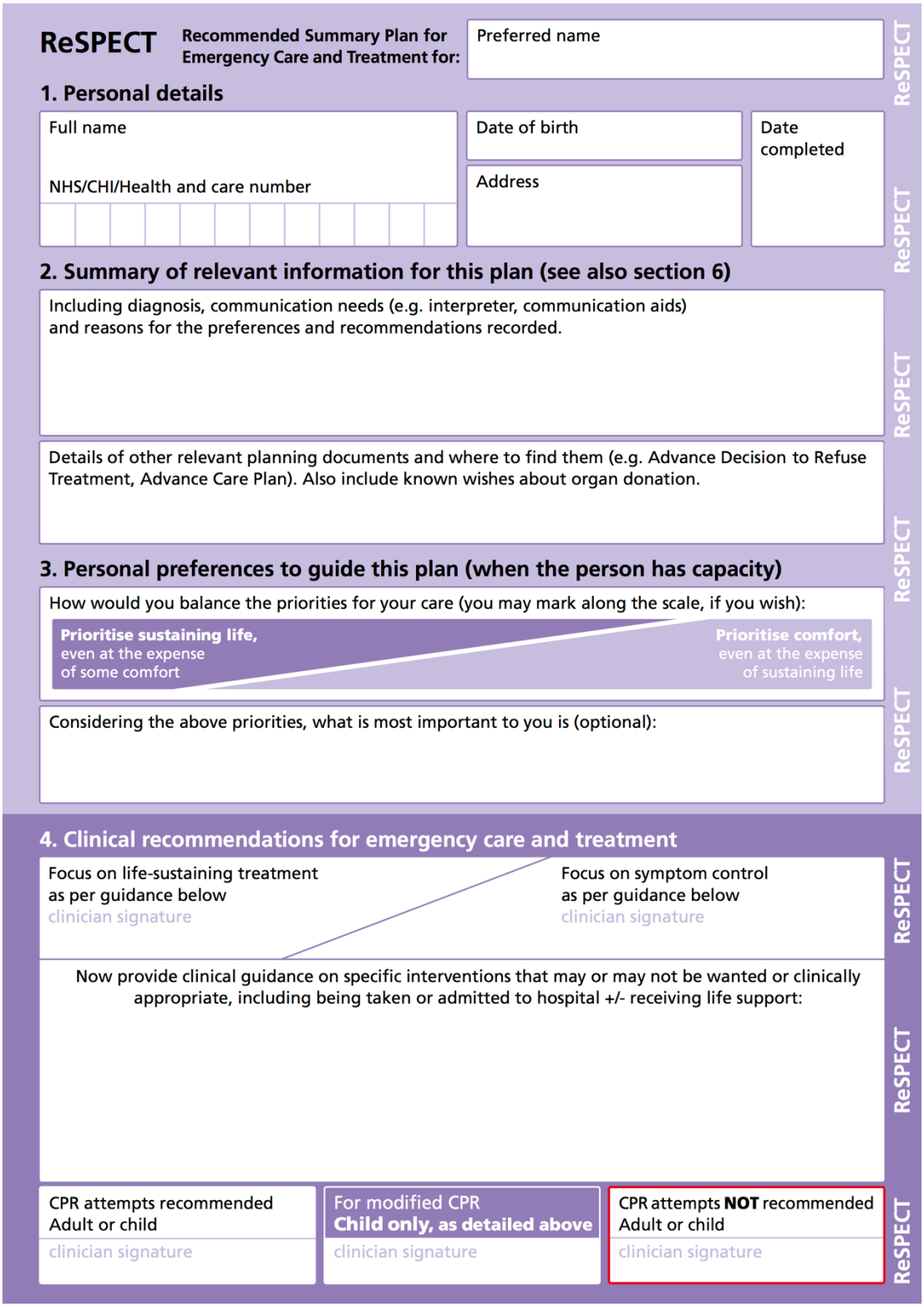


Figure 6A: Current draft (38) of front side of ReSPECT form

5. Capacity and representation at time of completion

Does the person have sufficient capacity to participate in making the recommendations on this plan? **Yes / No**

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? **Yes / No / Unknown**
If so, document details in emergency contact section below

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that these recommendations have (circle at least one):

- **A** been recorded after discussion involving this person, who has sufficient mental capacity to participate in making relevant decisions
- **B** where appropriate, been discussed with a person holding parental responsibility
- **C** in the case of a person who does not have sufficient mental capacity to participate in relevant decision-making, been made in accordance with capacity law
- **D** been made without involving the patient (or best interests/overall benefit meeting if the patient lacks capacity)

If **D** has been circled, state valid reasons here. Document full explanation in the clinical record.

Date, names and roles of those involved in discussion, and where records of discussions can be found:

7. Clinicians' signatures

Designation (grade/speciality)	Clinician name	GMC/NMC/ HCPC Number	Signature	Date & time
Senior responsible clinician				

8. Emergency contacts

Role	Name	Telephone	Other details
Legal proxy/parent			
Family/friend			
GP			
Lead Consultant			
Other			

9. Confirmation of validity (e.g. for change of condition)

Review date	Designation (grade/speciality)	Clinician name	GMC/NMC/ HCPC number	Signature

Figure 6B: Current draft (38) of back side of ReSPECT form

Conclusions

This programme of research has shown the value of examining ethical and behavioural issues in clinical practice.

Problems in considering, discussing and documenting resuscitation decisions were identified, and evidence of the unintended effects of such orders was brought together.

In response to these problems an alternative approach was developed with patients and users. It contextualised resuscitation decisions within overall goals of care and focused on treatments to be given rather than those being withheld. This alternative was found, in a hospital setting, to be associated with a behavior change among staff and a reduction in harms to those patients for whom a resuscitation decision had been made. This approach can be applied more broadly; further development and evaluation will be needed to ensure it is suited to those in different care settings and with different health needs.

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Appendix A: Statements of contribution signed by all co-authors

Appendix B: Publications included in the thesis

Appendix C: Additional related publications submitted as supplementary material

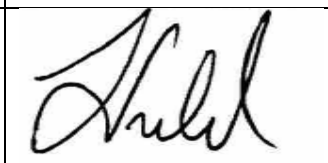
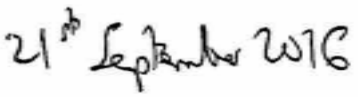
Paper I:
Ethical issues surrounding do not attempt resuscitation orders: decisions, discussions and deleterious effects.
Fritz Z, Fuld J J Med Ethics. 2010 Oct;36(10):593-7

Zoe Fritz conceived the idea for the paper, and conducted the literature search. She took the lead role in writing the paper in liaison with co-author Dr. Fuld and responded to reviewers as the corresponding author.

I agree that Zoë Fritz made the aforementioned contribution to this paper		
Name	Signature	Date
Jonathan P. Fuld		15 Sept 16

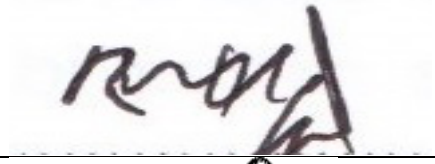
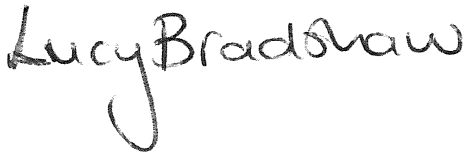
Paper II:
Interpretation and intent: a study of the (mis)understanding of DNAR orders in a teaching hospital.
Fritz Z, Fuld J, Haydock S, Palmer C. Resuscitation. 2010 Sep;81(9):1138-41

Zoe Fritz conceived the idea for the study, and designed and distributed the questionnaire. She contributed to data analysis which was led by Chris Palmer. She took the lead role in writing the paper in liaison with her co-authors and she responded to reviewers as the corresponding author.

I agree that Zoë Fritz made the aforementioned contribution to this paper		
Name	Signature	Date
Jonathan P. Fuld		
Stephen Haydock		26th September 2016
Chris R Palmer		

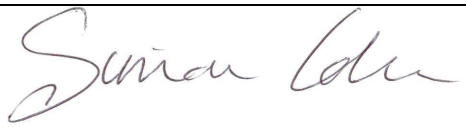
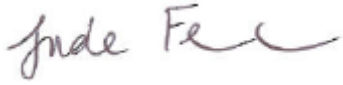
Paper III:
Characteristics and outcome of patients with DNACPR orders in an acute hospital; an observational study.
Fritz ZB, Heywood RM, Moffat SC, Bradshaw LE, Fuld JP. Resuscitation. 2014 Jan;85(1):104-8

Zoe Fritz conceived the idea for the study, and contributed to data collection and analysis. She took a lead role in writing the paper in liaison with Dr. Heywood and the contribution of other co-authors and responded to reviewers as the corresponding author.

I agree that Zoë Fritz made the aforementioned contribution to this paper		
Name	Signature	Date
Richard M Heywood		26th Sept, 2016
Suzanne C Moffat		7th Sept
Lucy E Bradshaw		5th Sept 2016
Jonathan P. Fuld		15 Sept 16

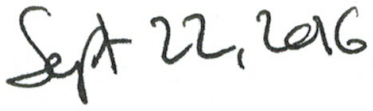
Paper IV:
Do Not Attempt Cardiopulmonary Resuscitation orders in acute medical settings: a qualitative study.
Cohn S, Fritz ZB, Frankau JM, Laroche CM, Fuld JP.QJM 2013 Feb;106(2):165-77

Zoe Fritz conceived the idea for the study, wrote the protocol and obtained ethics and other approvals. She supervised and contributed to data collection and contributed to data analysis. With Dr. Simon Cohn, she took a lead role in writing the paper.

I agree that Zoë Fritz made the aforementioned contribution to this paper		
Name	Signature	Date
Simon Cohn		02- Sept- 2016
Jude Frankau		02-Sep-2016
Clare Laroche		08-Sept-2016
Jonathan P. Fuld		15 Sept 16

Paper V:
Documentation of resuscitation decision-making: a survey of practice in the United Kingdom.
Clements M, Fuld J, Fritz Z. Resuscitation. 2014 May;85(5):606-11

Zoe Fritz conceived the idea for the study. She supervised data collection, and contributed to data analysis and the writing of the paper along with her coauthors.

I agree that Zoë Fritz made the aforementioned contribution to this paper		
Name	Signature	Date
Meredith Clements		
Jonathan P. Fuld		

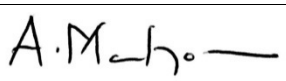
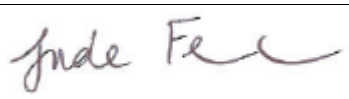
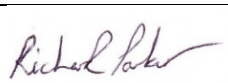
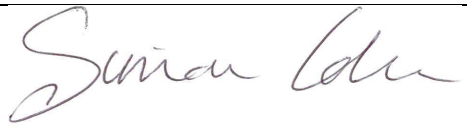
Paper VI:
Development of the Universal Form Of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a cross-disciplinary approach.
Fritz Z, Fuld JP . J Eval Clin Pract. 2015 Feb;21(1):109-17.

Zoe Fritz conceived the idea for the study, wrote the protocol and obtained ethics and other approvals. She led the data collection and analysis. She took the lead role in writing the paper in liaison with her co-author Jonathan Fuld and she responded to reviewers as the corresponding author.

I agree that Zoë Fritz made the aforementioned contribution to this paper		
Name	Signature	Date
Jonathan P. Fuld		15 Sept 16

Paper VII:
The Universal Form of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a mixed methods evaluation of the effects on clinical practice and patient care.
Fritz Z, Malyon A, Frankau JM, Parker RA, Cohn S, Laroche CM, Palmer CR, Fuld JP. PLoS One. 2013 Sep 4;8(9):e70977. doi: 10.1371/journal.pone.0070977.

Zoe Fritz conceived the idea for the study, wrote the protocol and obtained ethics and other approvals. She led the data collection and analysis. She took the lead role in writing the paper in liaison with her co-authors and she responded to reviewers as the corresponding author.

I agree that Zoë Fritz made the aforementioned contribution to this paper		
Name	Signature	Date
Alexandra Malyon		02-Sep-2016
Jude Frankau		02-Sep-2016
Richard A Parker		06-Sep-2016
Simon Cohn		02- Sept- 2016
Clare Laroche		08-Sept-2016
Chris Palmer		21st September 2016
Jonathan P. Fuld		15 Sept 16

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PLOS ONE

The Universal Form of Treatment Options (UFTO) as an Alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders: A Mixed Methods Evaluation of the Effects on Clinical Practice and Patient Care

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Abstract

Aims: To determine whether the introduction of the Universal Form of Treatment Options (the UFTO), as an alternative approach to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders, reduces harms in patients in whom a decision not to attempt cardiopulmonary resuscitation (CPR) was made, and to understand the mechanism for any observed change.

Methods: A mixed-methods before-and-after study with contemporaneous case controls was conducted in an acute hospital. We examined DNACPR (103 patients with DNACPR orders in 530 admissions) and UFTO (118 decisions not to attempt resuscitation in 560 admissions) practice. The Global Trigger Tool was used to quantify harms. Qualitative interviews and observations were used to understand mechanisms and effects.

Results: Rate of harms in patients for whom there was a documented decision not to attempt CPR was reduced: Rate difference per 1000 patient-days was 12.9 (95% CI: 2.6–23.2, p-value = 0.01). There was a difference in the proportion of harms contributing to patient death in the two period (23/71 in the DNACPR period to 4/44 in the UFTO period (95% CI 7.8–36.1, p-value = 0.006). Significant differences were maintained after adjustment for known confounders. No significant change was seen on contemporaneous case control wards. Interviews with clinicians and observation of ward practice revealed the UFTO helped provide clarity of goals of care and reduced negative associations with resuscitation decisions.

Conclusions: Introducing the UFTO was associated with a significant reduction in harmful events in patients in whom a decision not to attempt CPR had been made. Coupled with supportive qualitative evidence, this indicates the UFTO improved care for this vulnerable group.

Trial Registration: Controlled-Trials.com ISRCTN85474986 UK Comprehensive Research Network Portfolio 7932

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Introduction

In the UK, there are on average 160,000 hospital deaths annually [1]. Of those, 80% die with a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place [2,3]. DNACPR orders exist to provide immediacy and clarity of instruction in the event of a cardiorespiratory arrest; they are written either at a patient's request, or because a clinical decision has been made that a patient would be unlikely to survive attempted cardiopulmonary resuscitation.

The decision not to attempt CPR should not be conflated with decisions to initiate palliation or withhold other treatments; around 50% of patients with DNACPR orders are discharged from hospital [unpublished data].

All NHS Trusts use some kind of *proforma* to record a DNACPR decision. While practice varies, most follow the Resuscitation

Council UK's guidance, and a model DNACPR form was published in 2009. Documentation is placed at the front of the notes, with red demarcation common for rapid identification in an emergency [4].

Several problems exist with the current practice:

Firstly, there is evidence that DNACPR orders are often misinterpreted by doctors and nurses [5], leading to other treatments being inappropriately withheld [6–9] including echocardiograms for patients with heart failure [10] or admission of patients to ICU [11]. In-hospital mortality is higher in patients with DNACPR orders than for those with similar comorbidities and severity of illness without such orders in place [12–15].

Secondly, the recent UK National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD) report [16] highlighted the current ad hoc nature of resuscitation decision-making, revealing that many patients have resuscitation attempted on them inappropriately, because DNACPR orders are not completed when they should be. In many cases the reason given for not completing a DNACPR order was that the patient remained for 'active treatment'. However, providing active treatment is not a reason not to consider and document what should happen in the event of a cardiac arrest.

Finally, there is growing legal and ethical concern [17] about the manner in which DNACPR decisions are approached, with decisions often not discussed or communicated effectively to patients or their relatives.

With the aim of improving communication about what care was desired and appropriate, we developed an alternative approach: The Universal Form of Treatment Options contextualizes the CPR decision within overall treatment plans, and is completed on every medical in-patient (UFTO - Figure 1). While alternative approaches have previously been developed, [18,19] they have not been applied universally, nor their impact on patient care assessed.

Using a mixed-methods approach we sought to comprehensively evaluate the impact of the UFTO: in relation to clinical decision-making, patient safety and ward-based practice.

Methods

Summary

The protocol for this trial and supporting STROBE checklist are available as supporting information along with the appendix which contains details of the amendments; see Checklist S1, Protocol S1, and Appendix S1.

The trial was registered with ISRCTN- registration number 85474986 and the UK Comprehensive Research Network Portfolio- registration number 7932.

Ethics approval was obtained from the Norfolk Research Ethics Committee. The intervention was the introduction of a new approach to resuscitation decisions at ward level, and the ethics committee agreed that individual patient consent was not required for the introduction of the UFTO. Written patient consent was obtained for participating in interviews.

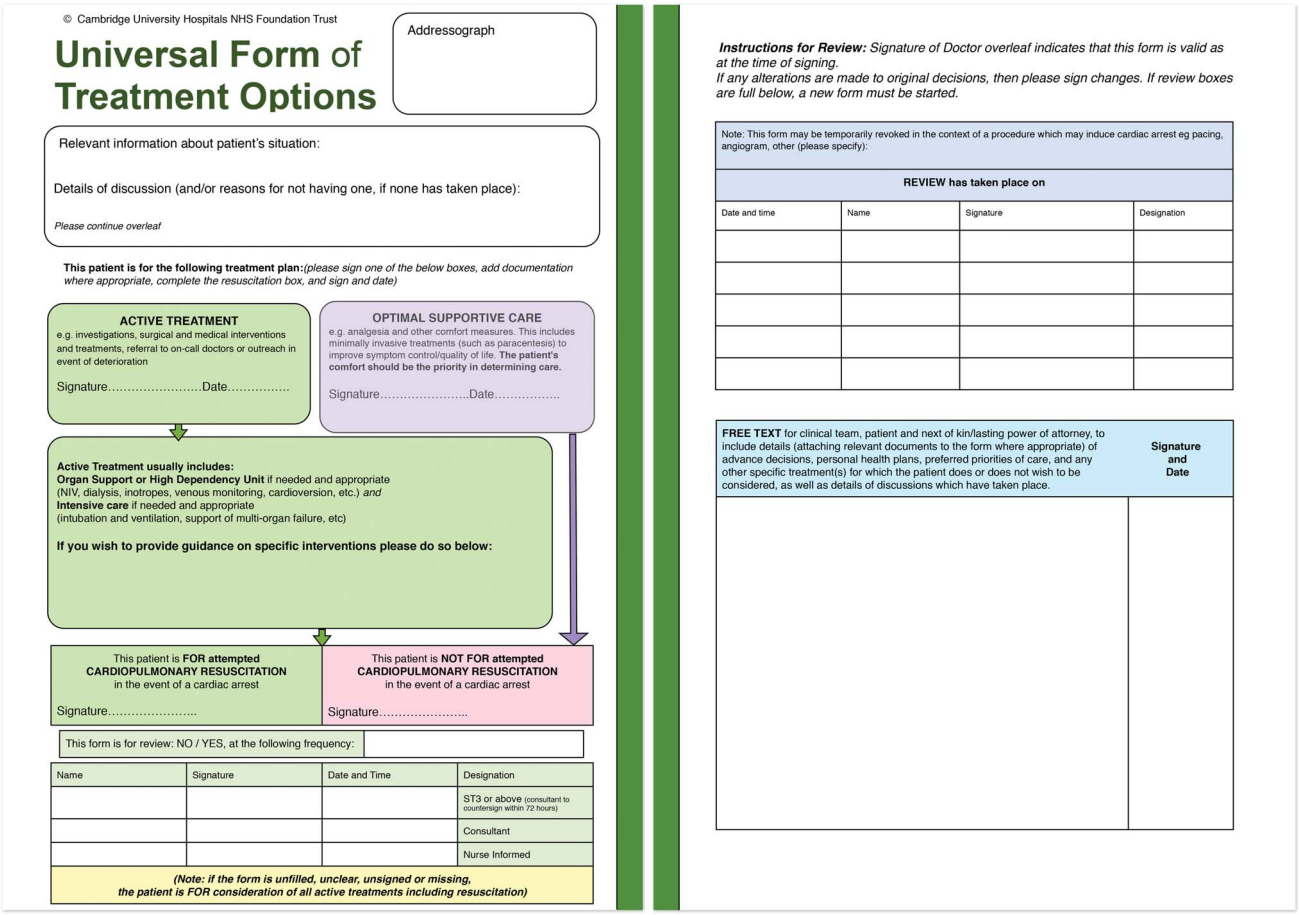

Figure 1. The Universal Form of Treatment Options (UFTO) version 21.
doi:10.1371/journal.pone.0070977.g001

Table 1. Exclusions from dataset on study wards during DNACPR and UFTO periods.

	DNACPR period	UFTO period
Total included admissions	513	520
Missing notes	1	2
Excluded because length of stay <24 hrs	9	13
Excluded because age <18 yrs	2	3
Other Exclusions	1	3
Total non-palliative care exclusions	13	21
Palliative/Optimal Supportive Care initially excluded, reincluded in subsequent analysis	5	21

Abbreviations: DNACPR: Do Not Attempt Cardiopulmonary Resuscitation.
UFTO: Universal Form of Treatment Options.
doi:10.1371/journal.pone.0070977.t001

The UFTO was developed iteratively in collaboration with patients, doctors, nurses and resuscitation officers. The process included 20 semi-structured interviews, 6 focus groups with senior and junior nurses, senior and junior doctors from different clinical settings, and patients, and behavioral economist advice. Specific features of the form include completion of resuscitation status for all patients (in contrast with the often ad hoc DNACPR decision-making), and a focus on treatments to be given rather than withheld: in particular there was a distinction drawn between whether active treatment (with the emphasis on attempted cure) or supportive care (with the emphasis on symptom relief) was in the patient's best interest. An accompanying patient information leaflet was also developed (Appendix S1).

A prospective mixed methods before-and-after study was carried out in a 480 bed acute hospital on two wards. Three months (May-July 2010) of qualitative and quantitative baseline data was collected on current (DNACPR) practice. The DNACPR form was completed whenever a physician thought it appropriate, or at a patient's request. A month-long UFTO education period (further details of implementation policy and associated training materials can be found at ufto.org) was followed by two months of

IHI Global Trigger Tool (UK version)

Category E: contributed to or resulted in temporary harm to the patient & required intervention
Category F: contributed to or resulted in temporary harm to patients& required initial or prolonged hospitalisation
Category G: contributed to or resulted in permanent patient harm
Category H: required intervention to sustain life
Category I: contributed to the patient's death

Trigger		+	Event Description and Severity E-I
	General care module		
G 1	Lack of early warning score or early warning score requiring response		
G 2	Any patient fall		
G 3	Decubiti		
G 4	Readmission to hospital within 30 days		
G 5	Shock or cardiac arrest		
G 6	DVT/PE following admission evidenced by imaging +/or D dimmers		
G7	Complication of procedure or treatment		
G8	Transfer to higher level of care		
	Surgical care module		
S 1	Return to theatre		
S 2	Change in planned procedure		
S3	Removal/Injury or repair of organ		
	Intensive care module		
I 1	Readmission to ICU or HDU		
I 2	Unplanned transfer to ICU or HDU		
	Patient identifier		
	Total events		
	Total length of stay		

Trigger		+	Event Description and Severity E-I
	Medication module		
M 1	Vitamin K		
M 2	Naloxone		
M 3	Flumazenil		
M 4	Glucagon or 50% glucose		
M5	Abrupt medication stop		
	Lab test module		
	Haematology		
L1	High INR (>5)		
L 2	Transfusion		
L3	**Abrupt drop in Hb or Hct (>25%)**		
	Biochemistry		
L4	Rising urea or creatinine (>2x baseline)		
L5 L6	Electrolyte abnormalities Na^+ <120 or >160 K^+ <2.5 or >6.5		
L7	Hypoglycaemia (<3mmol/l)		
L8	Raised Troponin (>1.5 ng/ml)		
	Microbiology		
:L9	MRSA bacteraemia		
L10	C. difficile		
L11	VRE		
L12	Wound infection		
L13	Nosocomial pneumonia		
L14	Positive blood culture		

Figure 2. The United Kingdom Version of the Institute for Healthcare Improvement Global Trigger Tool (GTT).
doi:10.1371/journal.pone.0070977.g002

Table 2. Comparison of characteristics of patients in whom a decision not to resuscitate was made in both groups.

	Group		
	DNACPR (n = 103)	**UFTO (n = 118)**	**p–value**
Age	Mean 82.5 (SD 9.39)	Mean 82.1 (SD 9.11)	0.77
Female gender	47 (46%)	53 (45%)	1.00
Respiratory Ward	60 (58%)	73 (62%)	0.68
Length of hospital stay (days)	Median 12.0 (IQR 22.0)	Median 12.0 (IQR 16.25)	0.86
Charlson comorbidity score	Median 2.0 (IQR 3.0)	Median 2.5 (IQR 3.0)	0.61
MEWS score	Median 2.0 (IQR 3.0)	Median 2.0 (IQR 3.0)	0.97

doi:10.1371/journal.pone.0070977.t002

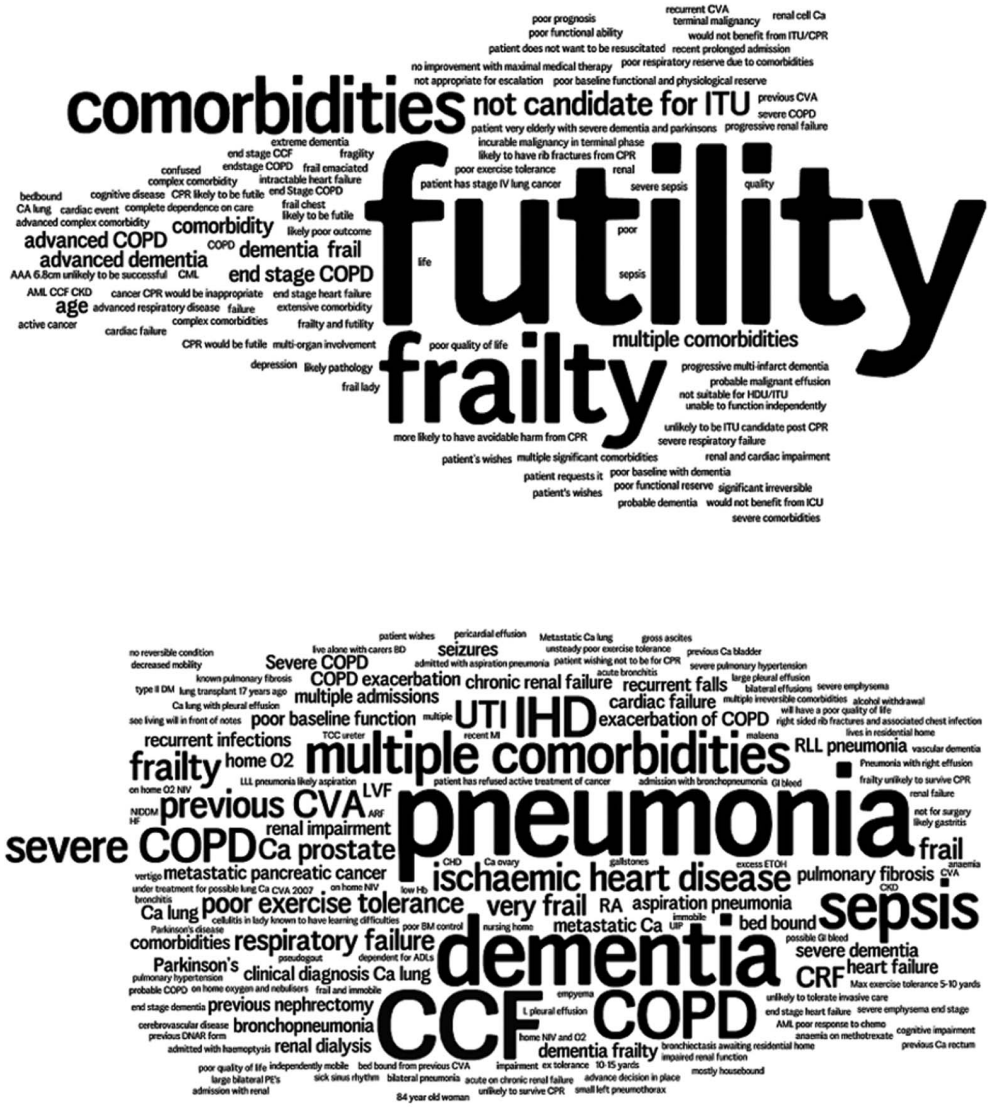

Figure 3. 'Word Clouds' generated from summary text on forms of all patients not for cardiopulmonary resuscitation. 3a. Text taken from Do Not Attempt Cardiopulmonary Resuscitation orders. 3b. Text taken from Universal Form of Treatment Options.
doi:10.1371/journal.pone.0070977.g003

Table 3. Non-GTT variables measured.

	DNACPR period A (May–July 2010)	UFTO period B (Nov 2010–Jan 2011)	Between group difference (95% CI)	P–value[§]
Discussion rate in those in whom a decision not to resuscitate was made (DNAR group n = 103; UFTO group n = 118)	42/103 (41%)	41/118 (35%)	**6.0% (–6.7% to 18.6%)**	**0.40**
Early Warning Score (EWS) response in those in whom a decision not to resuscitate was made (DNAR group n = 103; UFTO group n = 118)	24/102 (24%)	19/117 (16%)	**7.3% (–3.3% to 18.0%)**	**0.23**
Length of hospital stay for those not for resuscitation (DNAR group n = 103; UFTO group n = 118)	Median 12.0 (IQR 20.5)	Median 12.0 (IQR 15.75)	Median difference0.0 (–3.0 to 3.0)	0.86
Whole ward mortality	58/530 (11%)	71/560 (13%)	–1.7% (–5.6% to 2.1%)	0.40

doi:10.1371/journal.pone.0070977.t003

bedding-in, then three months data collection on UFTO practice (Nov 2010–Jan 2011).

Contemporaneously, a sample of patients with DNACPR orders from non-intervention wards was assessed.

Qualitative data collection. Face-to-face semi-structured interviews took place with all consultants and a purposive selection of nurses and junior doctors. Direct observation was undertaken on the participating wards both before and after use of the UFTO became routine practice to contextualize the interview data. Transcribed interviews together with field-notes were coded descriptively and thematically, providing the basis for a framework approach to analysis [20,21].

Quantitative data collection. All patients in whom a decision not to attempt cardiopulmonary resuscitation was made during the study period (May-July 2010 and Nov 2010–Jan 2011) were eligible for inclusion. Those <18 years old or with an admission of <24 hours were excluded. Those who were determined to be for palliative care only within 72 hours of admission were initially excluded (Table 1), but were re-included in subsequent analysis to address possible confounding.

Data were also collected contemporaneously on two case control groups: 1) patients remaining for resuscitation (every 7th admission on the study wards); 2) patients from non-study wards, which had an electronically recorded DNACPR decision.

We collected baseline demographic and hospital data, along with a modified early warning score (MEWS) [22–24] on admission and Charlson co-morbidity scores [25].

The Institute for Healthcare Improvement Global Trigger Tool (GTT- Figure 2) [26,27] was used to as a validated method of assessing rate, severity, and preventability of harms. Patient case notes were reviewed in a standardized way and in a random order, to identify predefined 'triggers' such as a hospital acquired pneumonia or an early warning score requiring action, which may be an indication that harm has occurred.

Using preselected modules of GTT, the presence of any of the 29 triggers was recorded; no assessment was made at this stage of association with harm. A short paragraph describing each trigger event was inputted into a database. Multiple triggers could be recorded for an individual patient.

Blinded physician reviewers independently reviewed the information on the GTT triggers making a determination of presence, severity and preventability of harm. Severity was classified using the index of the National Coordinating Council for Medication Error Reporting and Prevention (NCC MERP): category E: temporary harms requiring intervention; category F: temporary harms requiring initial or prolonged hospitalization; category G: permanent harms; category H:life- threatening harms; and category I: harms causing or contributing to death. Preventability of harm was rated using a Likert scale with scores from 1 = definitely not preventable to 4 = definitely preventable.

Where reviewers did not agree about whether an event constituted a harm, the case was discussed and agreement reached. Although the GTT was initially intended as a quality improvement tool, the methodology for using it remains the same in the context of evaluating an intervention with contemporaneous case controls.

Statistics

Sample size. The primary endpoint was timely (within 4 hours) referrals of patients with an Early Warning Score (EWS) of

Table 4. Global Trigger Tool Analysis on those patients in whom a decision not to attempt resuscitation was made (DNACPR group n = 103; UFTO group n = 118).

	DNACPR period A (May–July 2010)	UFTO period B (Nov 2010–Jan 2011)	Between group difference (95% CI)	P–value[§]
Harm rate per 100 admissions	68.9	37.3	31.6 (12.2 to 51.1)	0.001
Harm rate per 1000 patient days	34.7	21.8	12.9 (2.6 to 23.2)	0.01
Harms contributing to patient death (categories H and I)	23/71 (32%)	4/44 (9.1%)	23.3% (7.8% to 36.1%)	0.006
Harms preventable on any level (categories 2–4)	66/71 (93%)	43/44 (98%)	–4.8% (–13.4% to 5.6%)	0.40

doi:10.1371/journal.pone.0070977.t004

Table 5. Rating of Severity of Harms using the NCC MERP Index in DNACPR and UFTO groups.

	Group		Total
Severity	**DNACPR**	**UFTO**	
E	17	15	32
F	30	25	55
G	1	0	1
H	1	0	1
I	22	4	26
Total	71	44	115

Legend: NCC MERP Index.
Category E: Temporary harm to the patient and required interventionCategory F: Temporary harm to the patient and required initial or prolonged hospitalisation.
Category G: Permanent patient harm.
Category H: Intervention required to sustain life.
Category I: Patient death.
doi:10.1371/journal.pone.0070977.t005

greater than 3. The power calculation was constructed assuming a two-sided Fisher's exact test would be performed at the 5% significance level, on a EWS outcome representing the proportion of patients inappropriately managed. A sample size of 108 individuals with 'Not for CPR' orders per group was considered to provide 80% power to detect an absolute difference of 20% between the UFTO and DNACPR groups in the proportion of patients inappropriately managed (as defined by the EWS). It was anticipated, using preliminary data, that this number of patients would be admitted onto the study wards in a 3 month period.

The results we report here refer primarily to the secondary outcome measure of harms sustained by patients, as measured by the GTT. We have therefore applied a higher statistical stringency of 2% for significance.

Analysis

Qualitative data. A preliminary set of codes from a sample was agreed upon to ensure that they were sufficiently reliable and unambiguous. During analysis further refinement allowed for the identification and inclusion of emergent themes as well as those drawn from relevant literature. These codes were subsequently used for mapping and interpretation of the key comparative themes between the DNACPR and UFTO phases including recognition of atypical cases. Discussion between clinical and anthropological authors ensured that clinical experience could inform the contextualization and interpretation of results.

Quantitative data. UFTO and DNACPR groups were compared by calculating the absolute rate difference of GTT harms between them. Patient characteristics were compared between groups using Fisher's Exact test for all categorical variables and the Mann-Whitney test for all continuous variables except age, for which an independent samples t-test was used.

The frequency distribution of the type of harms, and the severity and preventability of harms was also tabulated for each group. The tables had low expected counts so the analysis focused on comparing proportions of serious harms and proportions of preventable harms using Fisher's Exact test.

A Poisson regression model was fitted to the number of harms data to evaluate the effect of group (UFTO or DNACPR) on number of harms after adjusting for possible confounders.

Table 6. The frequency of each type of harm for trigger categories within UFTO and DNACPR groups.

	Frequencies of harms per group	
Trigger	**DNACPR**	**UFTO**
L13 (Nosocomial pneumonia)	15 (21%)	10 (23%)
G1 (EWS requiring response)	10 (14%)	4 (9%)
G4 (Readmission within 30 days)	9 (13%)	6 (14%)
G3 (Decubiti)	6 (8%)	6 (14%)
M5 (Abrupt medication stop)	5 (7%)	1 (2%)
G7 (Complication of treatment)	4 (6%)	1 (2%)
G6 (DVT/PE)	4 (6%)	0
G2 (Fall)	3 (4%)	6 (14%)
M4 (Glucagon or 50% Dextrose)	3 (4%)	5 (11%)
L5 (Abnormal Na+)	3 (4%)	0
L3 (>25% drop in Hb)	2 (3%)	1 (2%)
L4 (Rising Urea or creatinine)	2 (3%)	1 (2%)
L6 (Abnormal K+)	2 (3%)	0
M2 (Naloxone administered)	1 (1%)	0
L1 (High INR)	1 (1%)	0
L8 (Raised Troponin)	1 (1%)	0
L7 (Hypoglycaemia)	0	2 (5%)
L2 (Transfusion)	0	1 (2%)
Total harms	71	44

doi:10.1371/journal.pone.0070977.t006

As a sensitivity analysis, negative-binomial regression models were also fitted to account for any over-dispersion in the data. A log-transformed offset term was included for hospital length of stay, to adjust for differences in periods of observation across patients.

To address a known confounding factor, the effect of including palliative care patients in the analysis was tested using the same statistical methods by re-including them into the dataset.

Additional assessments, using the same analysis, were conducted on the two contemporaneous case control groups.

R software [28] and SPSS version 18 [29] were used for analyses. A 2% significance level was used for the GTT because of multiplicity of outcomes; 5% significance levels were used elsewhere.

Results

There were 530 admissions (with 13 exclusions) during the DNACPR period and 560 (with 21 exclusions) in the UFTO period.

Patient Data

Table 2 shows a comparison of patient characteristics for patients in whom a decision not to attempt CPR was made. There were no significant differences at the 5% level.

Completion of Form

The completion rate of the UFTO was 82%. The decision not to attempt CPR was documented in 108/517 patients (20.9%) in the DNACPR period and 139/539 (25.8%) in the UFTO period (Fisher's Exact p-value = 0.07). 'Word Clouds' in which the size of the word represents the frequency of its use [30,31] were

Table 7. Balancing measures of GTT in those patients for resuscitation (n = 60 in period A, n = 58 in period B) and on patients in whom a decision not to resuscitate was made on non–study wards in the same periods (n = 25 in period A, n = 25 in period B).

	DNACPR period A (May–July 2010)	UFTO period B (Nov 2010–Jan 2011)	Between group difference (95% CI)	P–value
Harms rate per 1000 patient days in those for resuscitation	7.1	7.3	–0.2 (–9.6 to 9.3)	0.97
DNAR harms rate per 1000 patient days in non–study wards	18	32	–14.2 (–32.4 to 4.1)	0.13

doi:10.1371/journal.pone.0070977.t007

generated from the summary texts written on both forms of patients in whom a decision not to resuscitate had been made (Figure 3). There was an increase in the number of patients who were recognized and documented as being for palliative or optimal supportive care within 72 hours of admission: 5/517 (1.0%) in the DNACPR group and 21/539 (3.9%) in the UFTO group (Fisher's Exact p-value = 0.002).

Frequency of Referrals when Early Warning Scores >3

The frequency of EWS greater than 3 did not occur at the same rate as in the preliminary data, and there was no statistically significant difference in these results (Table 3).

Rate of Harms - Global Trigger Tool (GTT)

Secondary reviewers had a concordance rate of 93.7% in establishing whether a documented GTT event constituted harm. There were 71 harms among 103 patients over 2048 patient-days in the DNACPR group, equating to 68.9 harms per 100 patient admissions (95% CI: 54.6 to 87.0), or 34.7 per 1000 patient days (Table 4). In comparison, there were 44 harms among 118 patients over 2021 patient-days for those not for attempted CPR (NFAR) in the UFTO group (hereafter referred to as UFTO/NFAR), equating to 37.3 harms per 100 patient admissions (95% CI: 27.7 to 50.1), or 21.8 per 1000 patient days. The rate difference per 100 patient admissions (DNACPR - UFTO/NFAR) was 31.6 harms (95% CI 12.2 to 51.1, p-value 0.001). The rate difference in harms per 1000 patient days (DNACPR - UFTO/NFAR) was 12.9 per 1000 patient-days (95% CI: 2.6 to 23.2, p-value 0.01).

The Poisson regression and negative binomial models show a significant difference in rate of harm between the groups at the 5% level after adjusting for ward, age, gender, MEWS score and Charlson co-morbidity score.

Severity, Type, and Preventability of Harms

There was a difference in the proportion of harms contributing to patient death in the two periods (p = 0.006) (Tables 4 and 5).

The frequency of each type of harm can be seen in Table 6. The categories which were most frequently associated with harms were 'nosocomial pneumonia' (determined by radiological changes) and 'lack of Early Warning Score (EWS) or EWS requiring a response'. There was no significant difference in the preventability of harms (p = 0.40).

Inclusion of Palliative Care Patients

Because our intervention changed the number of patients excluded, we collected data on those patients identified as being for palliative care. When these patients were analyzed, the rate difference per 100 patient admissions (DNACPR - UFTO/NFR) was calculated to be 32.6 harms (95% CI: 14.4 to 50.8; p-value <0.001), or per 1000 patient-days the rate difference was 14.7 harms (95% CI: 5.0 to 24.4; p-value 0.003).

Contemporaneous case Control Studies

In patients with DNACPR orders, taken from wards where the UFTO was not introduced, there was no significant change in rate of harms: 52 harms/100 admissions or 18 harms/1000 patient days in May–July 2010 versus 68 harms/100 admissions or 32 harms/1000 patient days in Nov 2010–Jan 2011 (95% CI: −26.9 to 58.9; p-value 0.47 and 95% CI: −4.1 to 32.4; p-value 0.13 respectively). Multivariate regression on these groups showed no significant difference in rate of harm between the UFTO and DNACPR periods at the 5% level, even after adjustment for ward, age, gender, MEWS score, and Charlson co-morbidity score.

There was no significant change in harms observed in a sample of patients remaining for resuscitation from the study wards in the same period (Table 7).

Secondary End Points

There were no significant differences seen with discussion rates, mortality, or length of stay (Table 3).

Interviews and Observation

Forty-seven interviews were conducted with nurses and physicians, the results of which were integrated with field-notes from prolonged periods of situated observation. The key themes derived from our adapted framework analysis comparing DNACPR and UFTO are summarized in Table 8 with illustrative quotations. We identified three main domains of care in which it was possible to compare the use and understanding of the original DNACPR with those of the UFTO. These were: Interdisciplinary communication; clarity and consistency; patient dignity and respect. In each one, interviewees contrasted use of the original DNACPR form with the UFTO, highlighting a range of advantages they associated with the new form.

Prior to the introduction of the UFTO, completing DNACPR forms was not routine; they were initiated at *ad hoc* times and sometimes based on unsystematic criteria. One major concern raised about the introduction of the new form was the likely increase in workload. This referred not only to UFTO completion, but also that there might be an exponential rise in the number of discussions with patients and their relatives. Once the UFTO was embedded, however, clinicians reported there was a reduction in negative associations for patients who were not for CPR because of the routine and universal application of the UFTO. Staff commented that use of the UFTO both initiated and recorded forward planning, giving them a much better "sense of direction" about the care of the patient. Increased clarity of goals resulted in

Table 8. Key comparative themes emerging from interview accounts.

Domains of Care	DNACPR	UFTO (with illustrative quotation)	
Interdisciplinary communication, clarity and consistency	Unequivocal, 'STOP' sign	Sense of direction/ forward planning	"basically made us question where we were going with the patient from the beginning." (SPR) "It gives a plan; it makes the doctors do a plan for the patients so that you're completely in the picture… as to who's for resus, how far we're going to go for active treatment, for escalation to ITU, that type of thing. And who isn't for resus but they're still for active treatment and are going to escalate, how far are we going to escalate" (Nurse)
Interdisciplinary communication, clarity and consistency	Arbitrary, ad hoc, only at crisis point	Systematic	"everyone has to have one, so it is thought about at the time of admission… before it was if someone suddenly becomes poorly and then you think 'Oh, were they for resus?' and then you realise they are and then there's all a bit of a hoo–ha about trying to change that quite quickly" (Nurse)
Interdisciplinary communication, clarity and consistency	Marking out, 'special case'	Habitual, universal, routine	"with the UFTO because everybody gets one you kind of get into the habit of constantly thinking about it for everyone" (Junior Doctor)
Interdisciplinary communication, clarity and consistency	Unofficial triage	General clinical summary	"If you've got all the information in one place rather than flicking through four weeks of admission… you know, that can only be a good thing for a patient." (SPR)
Interdisciplinary communication, clarity and consistency	Insidious	Open	"it has been a long time now since somebody has asked me about somebody who wasn't for resuscitation whether we should be actively treating them. Because it quite clearly says" (Consultant)
Patient dignity and respect	Potentially negative associations for patients/relatives	Normalising for patients/relatives	"If you say everyone gets one it makes them feel better that it's sort of part and parcel of coming in, and it's not that we think they're going to die" (Junior Doctor)
Patient dignity and respect	Negative associations for clinicians	Normalising for clinicians	"now I think because everyone has the UFTO it's more like they're for treatment whether or not for resus" (Junior Doctor)
Patient dignity and respect	Precipitates evaluations of futility	Encourages evaluations of appropriate actions	"you know that there's been a thought process, it's not just some sort of arbitrary decision based upon the initial assessment of the patients' chances" (Nurse)
Patient dignity and respect	Clinical discomfort with decision	Clinical comfort with decision	"I do find it more comfortable that I can say for ward level of care, antibiotics and things, but not for CPR…" (Consultant)
Patient dignity and respect	Stigma of form discourages conversations with patients and relatives	Makes clinicians more comfortable in their discussions with patients and relatives	"once you've explained it and you've shown them the form, they [a patient's relatives] do feel happier." (Junior Doctor)
Pragmatic details	Recognisable in an emergency	Recognisable in an emergency	"it's something that, the same as DNACPRs, it's somewhere that's easily accessible, you can find it… you can see things quite easily and quickly" (Registrar)
Pragmatic details	Straightforward to complete – not demanding on time	Straightforward to complete – takes a little time but saves more time later on	"you're putting the effort in filling them in; so's everybody else which makes your on–calls easier. Then, you know, that's the kind of culture that perpetuates itself… it is more hard work filling in the forms, but it's appropriate hard work. It's not like it's creating work, we should be considering DNACPR on all patients but it's just not done." (Registrar)
Pragmatic details	Permanent record of a single clinical decision	Permanent record of a range of clinical decisions	"it's also good because DNARs, yeh that's fine it kind of says 'if this person's heart stops beating we're not, you know, going to resuscitate them' but it doesn't give any other sort of advice about 'if this patient deteriorates massively what's our ceiling of care?' … Especially when you're on call and you don't necessarily know what has been happening with the patient and the limits of treatment are. So if you've got something like that to be able to say "right, ok, they wouldn't go to ITU", that's helpful. " (Junior Doctor)

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better communication between clinicians, particularly out of hours.

These qualitative insights corroborate the quantitative findings; the introduction of the UFTO was perceived to make a positive global difference to how staff delivered care to many patients. Frequently this was described in general terms instead of ways in which it influenced specific treatment decisions or interventions. Rather than being able to link observations and interview data to particular instances or types of harm reduction, the qualitative findings suggest that the UFTO shifted ward practices in range of inter-related ways.

Discussion

Clinical Impact

Reduction in harm. Use of the UFTO was associated with an appreciable decrease in both frequency and severity of harms in patients for whom a decision not to attempt CPR was made. The characteristics of the patients studied, in terms of age, co-

morbidities, and sickness at admission were similar, and the reduction in rates of harm was maintained after palliative care patients were re-included in the analysis. There was no such reduction in harms in patients with DNACPR orders on other wards during the same time-period, or for patients remaining for CPR, suggesting that the change we observed was due to the use of the UFTO, and not seasonal variation or hospital-wide safety improvements. Accepting that we were looking at a group of patients who have worse outcomes than the standard hospital population, it is worth noting that no previous study of any initiative aimed at improving patient safety (as measured with the GTT) has shown such a profound effect, and that while alternative approaches to recording DNACPR decisions have previously been developed they have not been rigorously assessed for impact upon patient care [18,19].

The mechanism for this quantifiable reduction in harm can be partly understood from existing literature which demonstrates that standard DNACPR orders are often misinterpreted, leading to treatments being withheld [5–11], and by drawing on the qualitative findings. Nurses and doctors explicitly reported that they felt they were able to provide better care with the UFTO: clinicians' attitudes towards patients were re-orientated by focusing on the primary decision between active or supportive treatment, and treatments to be given, rather than a treatment to be withheld; the removal of the stigmatizing, negative effect of the red DNACPR order [32] led to less distinction between patients who were for and not for CPR. Nurses and doctors unanimously requested to continue using the form despite their recognition that it added to the workload on admission.

Use of the UFTO. Use of the UFTO rapidly became habitual, with over 80% completion. Doctors and nurses incorporated the UFTO into their handovers, and found it useful when reviewing a patient out-of-hours. Word clouds (Figure 3) demonstrate the changed nature of what was written about patients. From a predominant use of the word "futility" on the DNACPR forms, there was a shift to document diagnoses on the UFTO. Interviews and observations suggested that the new form at the front of the notes acted as a summary of the patient's condition and which treatments would be appropriate, while continuing to document CPR status. Use of the UFTO led to a significant increase in the number of patients identified early as requiring palliative or optimal supportive care, with no change in mortality. It is possible that this early recognition allowed better palliative care to be delivered. Several tools exist [33] to alert doctors to when a shift in goals of care might be appropriate, but the benefit of the UFTO is that it will do so universally.

Perhaps surprisingly, given the universal nature of the UFTO, there was no significant difference in the proportion of patients in whom a decision was made not to attempt CPR. There was also no significant change in other patient characteristics (age, co-morbidity, sickness on admission), suggesting that the UFTO did not affect the threshold of the CPR decision. Physicians reported that they felt more comfortable 'making' a patient 'not for resuscitation', while simultaneously documenting that a patient was for 'active treatment'. The benefit of mandating decision-making about CPR is that there are likely to be fewer "inappropriate" resuscitation attempts, in particular when patients might not want such an attempt.

Discussions. The number of documented discussions with patients did not increase, despite all patients being given a leaflet encouraging them to discuss treatment options with their physicians. This finding is consistent with a previous study [34]. Although several studies have suggested that patients want to have discussions about CPR, they have significant selection bias [35,36]. Doctors using the UFTO reported that conversations with patients were 'easier' but it is hard to quantify this, or know whether this benefits patients. Further work is needed to investigate whether patients would like to be actively involved in UFTO completion, and if patient capacity should be included in the UFTO.

Limitations. Although we have addressed several limitations, this remains a 'before and after' study with contemporaneous case controls. We tried to minimize the Hawthorne effect by interviewing clinicians in both arms of the study, and having a two-month 'bedding in' period before assessing the UFTO. We did not conduct a DNACPR education package before the DNACPR period, because we wanted to compare the UFTO with standard practice, but recognize that the effect we saw might in part relate to education provided with the introduction of the UFTO. The intervention may have changed the population we were studying, by increasing the proportion of patients who were identified as being for optimal supportive care. However, we have re-analyzed our data with the palliative patients included, with consistent results. We were not powered to determine whether the intervention affected mortality or length of stay, but these are two outcomes which would be interesting to assess in a larger study. Finally, we were unable to interview patients in this study. Our ethics approval was to interview patients with whom resuscitation decisions had been discussed; the frequency of these discussions was low, and even when they had been documented, patients often did not remember having such discussions. Further research is therefore needed to understand the patient and family perspective.

Conclusion

The decision not to attempt cardiopulmonary resuscitation is often a reasonable and ethically sound one, either because of patient choice, or because attempting resuscitation would deprive a patient of dignity in their death or risk causing more harm than benefit. Unfortunately there is mounting evidence that those with DNACPR orders also receive inadequate treatment.

By changing the approach to resuscitation decisions – contextualizing resuscitation amongst other treatments and ensuring that documentation is universal - a major shift was seen in the behavior of nursing and medical staff. This work indicates that an alternative approach, delivered by a simple form, has the ability to improve care for this group of vulnerable patients.

Supporting Information

Protocol S1 Trial Protocol.
(DOCX)

Checklist S1 STROBE Checklist.
(DOC)

Appendix S1 Online appendix including details of Standard Operating Procedures, protocol amendments, Patient Information leaflet "Talking with your doctor" and detailed breakdown of quantitative and qualitative data.
(DOCX)

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Author Contributions

Conceived and designed the experiments: ZF JPF AM JMF SC CRP CML. Performed the experiments: ZF JMF AM CML. Analyzed the data: ZF JPF SC RAP CRP. Contributed reagents/materials/analysis tools: ZF JPF SC JMF. Wrote the paper: ZF JPF AM JMF RAP SC CML CRP.

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