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Hidden Work and the Challenges of Scalability and Sustainability in Ambulatory Assisted Living

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Assisted living technologies may help people live independently while also—potentially—reducing health and care costs. But they are notoriously difficult to implement at scale and many devices are abandoned following initial adoption. We report findings from a study of global positioning system (GPS) tracking devices intended to support the independent living of people with cognitive impairment. Our aims were threefold: to understand (through ethnography) such individuals’ lived experience of GPS tracking; to facilitate (through action research) the customization and adaptation of technologies and care services to provide effective, ongoing support; and to explore the possibilities for a co-production methodology that would enable people with cognitive impairment and their families to work with professionals and technical designers to shape these devices and services to meet their particular needs in a sustainable way. We found that the articulation work needed for maintaining the GPS technology in “working order” was extensive and ongoing. This articulation work does not merely supplement formal procedures, a lot of it is needed to get round them, but it is also often invisible and thus its importance goes largely unrecognized. If GPS technologies are to be implemented at scale and sustainably, methods must be found to capitalize on the skills and tacit knowledge held within the care network (professional and lay) to resolve problems, improve device design, devise new service solutions, and foster organizational learning.

CCS Concepts: • Human-centered computing → Computer supported cooperative work; Ethnographic studies; Empirical studies in collaborative and social computing;

Additional Key Words and Phrases: Articulation work, assisted living, ageing in place, co-production, collaboration, telecare, telehealth, GPS, cognitive impairment

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1 INTRODUCTION

Assisted living solutions, which include telecare (remote delivery of support services via devices such as alarms or fall detectors to enable vulnerable people to live independently at home) and telehealth (remote clinical monitoring, consultation, and treatment of people in their homes), are increasingly seen by health and social care policy makers as a solution to the inter-related trends of an ageing population; rising rates of chronic illness and disability; cutbacks in health system capacity and budgets; and shifting social roles and expectations. However, while such policy interventions may be well-motivated, in practice there is a substantial gap between the vision and the realities of assisted living technologies and services adoption (Greenhalgh et al. 2012). Recent UK studies suggest that potential users—i.e., dementia sufferers (clients) and their carers of assisted living technologies are often reluctant to adopt them and/or abandon or disable them after their initial experiences (Sanders et al. 2012; Clark et al. 2011; Bentley et al. 2014; Cook et al. 2016). Such outcomes must cast doubt on whether the policy ambitions of delivering assisted living solutions at scale and sustainably are achievable (Greenhalgh et al. 2015; Agbakoba et al. 2016; Merkel and Enste 2016).

Our previous research showed that one important reason for this gap between vision and practice is that many people are assessed for, and fitted with, an assisted living service solution that interferes with rather than facilitates daily living (Greenhalgh et al. 2013, 2015). Older people have a highly individual set of technological and support needs because no two people have the same combination of illnesses, the same set of family, social and cultural circumstances, the same attitudes to, or ability to use, the technologies—and even within a single individual these characteristics may vary over time. For these reasons, assisted living solutions can never be “plug and play”: they need to be “grown” as part of a wider care system for any given individual and this demands a socio-technical systems approach, shifting the focus from “designing technologies” to “creating personalized care solutions,” asking what needs to happen across the system, including interactions between people at the microlevel, and across organizations and sectors at a more macrolevel (Greenhalgh et al. 2016). Successful assisted living solutions are socially and collaboratively accomplished—“co-produced”—on a day-to-day basis by the efforts of clients, and their professional and lay networks of carers (Procter et al. 2014).

In this article, through a series of action research case studies, we report findings from a project focusing on the use of GPS (Global Positioning System) tracking devices and their associated care services intended to support independent living by people with cognitive impairment. Various studies and trials of GPS in this context have been conducted over the past 10 years (e.g., Robinson et al. 2007, 2009; Landau et al. 2010; White et al. 2010); recent trials have concluded (despite often also reporting high attrition rates among participants) that levels of acceptance are high by both people with cognitive impairment and their carers (Pot et al. 2012; Liu et al. 2017). In the United Kingdom, GPS enabled tracking services are now routinely offered to assisted living service clients and their carers but, elsewhere, evidence of acceptability is mixed. As with telecare more generally (Greenhalgh et al. 2013), resolving GPS tracking adoption issues requires a socio-technical perspective. Like Wan et al. (2014) in their prototyping of a monitoring tool for GPS tracking, we have taken a multistakeholder approach in order to take into account issues beyond those that would typically be addressed by a focus on design alone. As Wan et al. (2014) observe, “The business model of such a product needs careful thought since service before-, at- and after-sale are at least as important as the technology itself.” (p. 3995). Hence, the focus in this article is on the work needed to configure, deploy and make GPS tracking services usable and useful in real-world service settings, where healthcare professionals must attempt to find a match between technologies and the needs of their clients, and clients, their carers and telecare call center staff must then discover if—and how—it is possible to make them work effectively in practice.
The aims of our study are the following threefold: to understand (through ethnography) clients’ lived experience of GPS tracking; to facilitate (through action research) the customization and adaptation of the technical and organizational subsystems of care services to provide effective, ongoing support; and to explore the possibilities for a co-production methodology that would enable people with cognitive impairment and their families to work with health and social care professionals and technical designers to shape these devices and services to meet their particular needs. We focus in particular on what we may learn from the various types of articulation work we observed being performed by different actors involved in configuration, deployment, and day-to-day support of GPS tracking services. Such work, much of which is often hidden, contributes significantly to ensuring that effective, ongoing support is feasible, and an understanding of it is key to supporting co-production in ways that are both scalable and sustainable.

2 RELATED WORK

A number of studies have revealed how ageing in place is socially and collaboratively accomplished by the efforts of both professional (e.g., health and social care departments, telecare call center workers, sheltered housing staff) and lay (e.g., family, friends, neighbors) networks of care and that both the technologies and services (the technology’s “soft periphery” (Denis et al. 2002)) must be adaptable if they are to meet the needs of the client, though this does not always occur in practice (Pols and Willems 2011; Milligan et al. 2011; Roberts et al. 2012; Bratteteig and Wagner 2013; Greenhalgh et al. 2013; Procter et al. 2014; Sugarhood et al. 2014; Wherton et al. 2015a, 2015b; Procter et al. 2016; Schorch et al. 2016). Collectively, these studies highlight four key issues that need to be acknowledged and managed if the benefits of technology-supported, assisted living services are to be realized fully.

First, assisted living technologies and services necessarily become interwoven with existing social networks and hands-on care, shaping the meaning of care and the role of support workers (Pols and Willems 2011; Milligan et al. 2011; Roberts et al. 2012; Pols 2012). For example, call takers in telecare call centers undertake a variety of complex tasks in their efforts to ensure their clients benefit: they utilize their knowledge of individual clients to mediate between their perceptions, requests, and demands, and their knowledge of how such requests must be framed for the organization to respond adequately; they must also be able to join up information from diverse sources when a situation is unclear; they are often called upon to perform “emotional labour” (Roberts et al. 2012), providing social contact to people who are lonely and reassurance to those in crisis until help arrives.

Second, support workers rely to a significant extent on tacit knowledge based on personal and shared experiences of what to do in order to “get the job done.” For example, while standard procedures are important, they cannot accommodate the variety of possibilities and situations telecare center call takers encounter day-by-day. It is this tacit knowledge that allows, for example, the call operators to take the initiative; to work around problems and align the service with the needs of the client; to identify, assemble and coordinate a set of resources, both technical and social, through a series of situated, practical actions; and to work around rather than with the technical system (Procter et al. 2016). This may involve using the technical system in ways that were neither intended by designers nor laid down in standard operating procedures (Alberdi et al. 2005; Anderson et al. 2008; Voss et al. 2000).

Third, working effectively across the organizational and professional boundaries that are a feature in assisted living services deployment and delivery can be difficult, especially when carers are under pressure to make decisions quickly, e.g., about how to respond to an alert. For example, Procter et al. (2014) and Schorch et al. (2016) have examined the difficulties professional and lay carers face when trying to work together and have suggested how technology might be used
to overcome some of the barriers they currently experience in sharing information, either by repurposing existing socially-oriented platforms such as Facebook (Procter et al. 2014) or by creating more bespoke solutions (Schorch et al. 2016).

Fourth, successful use of assisted living devices often depends on “bricolage” (pragmatic customization, combining new with legacy devices) by members of clients’ lay care networks (Greenhalgh et al. 2013). This has led us to argue for the adoption of a “co-production” approach, a participatory methodology that aims to ensure assisted living technologies and the services in which they are embedded are assessed and co-evolve in ways that are grounded in the lived experience of clients (Procter et al. 2014; Wherton et al. 2015). Unfortunately, neither assisted living device design, nor the ways that care services are typically configured, adequately acknowledge this critical dependency, making the efforts of lay carers undervalued, “largely invisible to professionals, managers and designers” (Moreira 2008, p. 102), and, consequently, of limited effectiveness.

In this study, our aim was to examine these four issues through the lens of “articulation work.” Articulation work refers to ways that people engaged in collaborative activities act to maintain mutual understanding and ensure their activities “mesh” across divisions of labor, time, and distance (Strauss 1985; Corbin and Strauss 1993) and has become a recurrent theme of workplace studies (e.g., Schmidt 1994; Heath et al. 2000; Suchman 1996). In applying the concept to the workplace, Star and Strauss (1999) distinguished between four different types of articulation work: visible, routine articulation work, as is embodied in standard operating procedures within an organization and often made visible through actions such as form-filling (Hampson and Junor 2005); visible, non-routine articulation work, i.e., deviations from standard operating procedures necessary to deal with unanticipated contingencies (Hampson and Junor 2005); hidden or invisible, routine articulation work, i.e., work necessary for dealing with anticipated contingencies—“normal, natural troubles”—but which is not documented (Grant et al. 2015); and invisible, non-routine articulation work, which includes ad-hoc, unplanned responses to contingencies (Allen 2014) or work that is external to the organization (Hampson and Junor 2005).

Postma et al. (2015) have shown that invisibility in articulation work may arise from a number of different circumstances: it is not recognized in formal job descriptions (e.g., “emotional labor”) and so is undocumented in official records; it reflects the use of tacit understandings that resist definitions; and it is spatially and temporally bounded such that it is not readily available to other actors. They also distinguish between intra-professional, inter-professional, and lay articulation, all of which may be needed to make a technology “work” in “the wild.” The roles of these different forms of articulation work in “getting the work done” may have an important bearing on how to improve organizational work practices (Star and Strauss 1999), which is likely to be a significant issue when addressing scalability and sustainability of technological and service innovations.

The remainder of this article is structured as follows. First, we briefly describe the project from which our ethnographic data is derived. Next, we describe the affordances and socio-material properties of the particular assisted living technologies and services relevant to our study. We outline our methodology and analytic approach, and the sites where the ethnographic observation took place. We set out key descriptive findings with illustrative excerpts from our fieldwork, before offering a more analytic synthesis. Finally, we discuss our findings with reference to the wider literature and propose some principles for assisted living service practices, and, in particular, for taking the co-production agenda forward in this domain in a scalable and sustainable way.

3 THE PROJECT

The project focused on the delivery of mobile telecare with GPS tracking for adults with cognitive impairment who were at risk of wandering or getting lost outdoors. The 18-month study, entitled “Co-producing socio-technical solutions for people living with complex multi-morbidity,” was
funded by the National Institute for Health Research and conducted in partnership with a National Health Service (NHS) trust and local authority in East London. The aim was to explore the feasibility of implementing a co-production approach to the delivery of telecare solutions. Co-production is a participatory design approach that focuses on user-centered design-in-use of both the technology and ways of working with it, through continually feeding back users’ experiences and practices into ongoing design and development process (Hartswood et al. 2000, 2002, 2003b, 2008).

The Inner City Borough (ICB) Adult Social Care service provides assisted living equipment, home adaptations and telecare to clients in East London. There had been increasing demand for GPS tracking technology in the borough, due to high prevalence of people with cognitive impairment becoming lost in the community. However, implementation and use of such technology was difficult, due to the complex and changing needs of the clients and resources needed to manage the solution. For example, clients must remember to wear the device; it must be charged daily; and a “responder” must be available to find the wearer in the event of an alert. In addition, it requires a greater degree of configuration than home-based telecare, including geographical and temporal parameters that enable sufficient freedom while also providing a degree of safety and reassurance. We were initially approached by ICB commissioners to help them establish how such solutions can be effectively personalized to meet the complex needs of the clients and their carers.

4 METHODOLOGY

We used ethnography and action research to both explore and extend the capacity of the organization to support co-production. Over the course of 18 months, we held informal discussions and meetings with key staff (e.g., management, commissioning, telecare coordinators, and care professionals). Data were collected to map people and processes—both formal and ad hoc—involving in the delivery and use of GPS devices, which covers activity across Adult Social Care (telecare coordinators, telecare review panels, commissioners), NHS practitioners (occupational therapists (OTs)) and monitoring centers (call operators, managers), and technology suppliers (engineers, sales managers). The fieldworker (JW) took notes of work practices and discussions with staff were recorded and subsequently transcribed.

GPS tracking services cases were identified by the OTs involved in the assessment and provision of assisted living technology, including GPS tracking. The sample consisted of seven participants (index cases) with complex multi-morbidity (all had both cognitive and physical impairment). Participants presented different levels of severity of cognitive impairment and different physical co-morbidities; they were also diverse in terms of their ethnicity, family settings, and wider social networks. An overview of the five cases reported on here is presented in Table 1.

Each participant was then visited in their home initially by the fieldworker and a care professional, where the purpose of the study was explained to the client and family members. The fieldworker then conducted multiple subsequent home visits with each participant over the period of the study, using ethnographic techniques developed through a previous study (Greenhalgh et al. 2013) in order to build a rich picture of lives and experiences of the clients and their families with GPS tracking technology and services. This included capturing the everyday reality of using the technology; discovering how needs changed over time; and identifying opportunities to adapt and reconfigure the solution. The techniques used included narrative interviews (e.g. stories of a ‘wandering’ event, problems with the technology), ‘go along’ interviews (participants show the fieldworker indoor and outdoor spaces that are important to them) and ‘cultural probes’ (Gaver et al. 1999) adapted for use in this setting (Crabtree et al. 2003; Wherton et al. 2012). From an initial pilot of a number of different cultural probe ‘tools’, we found that participants and their carers where most comfortable with using a simple A4 sheet of blank card as a ‘Wish List’ on which they could record their comments on the devices and services provided. Participants were asked
Table 1. Overview of Cases (Anonymized)

<table>
<thead>
<tr>
<th></th>
<th>Michael</th>
<th>Patrick</th>
<th>Rahim</th>
<th>Arthur</th>
<th>James</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td>85</td>
<td>87</td>
<td>79</td>
<td>73</td>
<td>89</td>
</tr>
<tr>
<td>Sex:</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>M</td>
</tr>
<tr>
<td>Ethnicity:</td>
<td>White British</td>
<td>White British</td>
<td>Asian Pakistani</td>
<td>Black Caribbean</td>
<td>Black Caribbean</td>
</tr>
<tr>
<td>Language:</td>
<td>English</td>
<td>English</td>
<td>Punjabi</td>
<td>English</td>
<td>English</td>
</tr>
<tr>
<td>Main diagnoses</td>
<td>Vascular Dementia; Oedema; Stroke; Heart failure</td>
<td>Alzheimer’s Type dementia; Asthma, High blood pressure</td>
<td>Mixed-type dementia; Impaired hearing; Urinary tract infection</td>
<td>Alzheimer’s Type dementia; Depression; Dizziness</td>
<td>Mixed-type dementia; Diabetes; Back pain</td>
</tr>
<tr>
<td>Home:</td>
<td>Terraced house; Owner-occupied</td>
<td>Terraced house; Owner-occupied</td>
<td>Terraced house; Owner-occupied</td>
<td>Terraced house; Owner-occupied</td>
<td>Terraced house; Owner-occupied</td>
</tr>
<tr>
<td>Lives with:</td>
<td>Alone</td>
<td>Son and daughter</td>
<td>Wife, son, daughter-in-law, granddaughters</td>
<td>Wife and son</td>
<td>Wife</td>
</tr>
<tr>
<td>GPS devices</td>
<td>Genie Clip</td>
<td>Genie</td>
<td>Genie Clip</td>
<td>Genie Clip</td>
<td>Dorado Watch &amp; WatchMe</td>
</tr>
</tbody>
</table>

to write down ideas and wishes related to the technology, which could be discussed during the subsequent visit. The findings from each case study were written up as a longitudinal case narrative to show how they and their families adapt—and adapt to—the technology and service in use. Each case was unique, with great diversity in terms of how the technology and service supported them. However, the cases consistently demonstrated how the service could successfully involve service users in the development of personalized solutions so that they can make significant changes to their lives. By focusing on a small sample of cases, we aimed to highlight the complex social and organizational challenges to be addressed in order to embed the co-production approach within routine practice and take these findings forward to inform service development.

One use of the case narratives was to provide a context for discussions between the fieldworker and service staff aimed at identifying opportunities to change social and technical processes. In particular, it was hoped they would enable insights into how the technology could better meet clients’ needs, motivate its review and adaptation over time, and help explore opportunities to improve and resolve problems. These might include subtle, but important, configurations of the technology (e.g., changing safe-zone parameters to reduce false alerts) or of materials at hand (e.g., attaching device to house keys to reduce the risk of forgetting it). Resolution of more complex problems might draw on the technical, clinical, and personal knowledge across professional and lay support networks (e.g., clients refusing to wear the tracking device or taking it off and forgetting to put it back on) and highlight the importance of maintaining dialogue with clients and their carers, creating communication channels between call operators and social care staff, and providing resources for training and hands-on support. In this way, the fieldworker would
be in a position to bring together key stakeholders from within the service (and collaborating organizations) in order to establish the inter- and intra-organizational changes needed to support the co-production of personalized GPS solutions, and to evaluate and inform these changes as a part of an iterative service development process.

The case narratives, cultural probe records, transcribed interview data, and fieldwork notes were analyzed to identify recurrent themes, which were then refined in an iterative and inductive way (Strauss and Corbin 1990). The names of public and industry sector organizations, products, staff, and clients that appear in the extracts below have been anonymized to preserve confidentiality.

5 GPS TECHNOLOGY

GPS tagging devices allow the tracking of the location of the wearer and raise alerts when they exit a predefined “safe zone.” At the start of the study, ICB Adult Social Care provided two types of GPS devices, “Genie” and Dorado Watch, which present different functionalities and design features (e.g., fall detection, lockable strap, and two-way communication) and thus potentially allow for the service to be more tailored to the needs of individual clients. Two other GPS tracking devices, the “Ranger” mobile and “WatchMe,” were under consideration for adoption at the time the fieldwork was conducted.

There are two Genie devices. The “old” style Genie has GPS tracking, fall detection (accelerometer), SOS functionality (two buttons on the side to be pressed simultaneously), and velocity sensor (to detect travelling in vehicle). The Genie “Clip” is an updated version. Functionality is similar to the old Genie, but has additional features, including speaker and microphone (for two-way communication) and a wristband with fall detection (worn inside and outside the home). However, it does not have any velocity detection. It has a charging hub, which is designed to communicate wirelessly to detect when the device is at home (within 20 feet). The Genie Clip also operates with a different online portal that allows carers/service providers to adapt and configure parameters and settings. During the study, the company decided to stop production of the old Genie, despite a lot of feedback that many older people prefer it over the new one. Initially they decided to continue it for this reason, but then made a business decision to focus on supply of the new model.

The Dorado Watch is a GPS device designed to have the appearance of a watch. It also has a stationary charging hub, which detects whether the device is in the house and disables the GPS to save battery power. It does not have fall detection, but it does have the two-way communication and SOS functionality. The strap can be locked. The Dorado Watch was often recommended when a client did not wish to carry an additional device or was considered to be at risk of losing or forgetting to carry it. However, it was not considered suitable if clients would be uncomfortable wearing large items on their wrist or if they already owned a watch and would not want it to be replaced.

The Ranger is a basic mobile phone, with four speed dial buttons, SOS button, and GPS tracking. It includes the geo-fence functionality and can be provided stand-alone or through a monitoring center. The Ranger was recommended if the client had mild cognitive impairment and was familiar with using a mobile phone and keeping it on their person when leaving the house. However, it was not considered suitable if the client was unfamiliar with using and carrying a mobile phone, or if the family were concerned they may lose it or press buttons and inadvertently trigger calls or alerts. Finally, the Information and Equipment Demonstration Area (see below) decided to also take on one more device, the WatchMe. This is similar to the old style Genie, but with the option of reduced functionality, having no SOS button or fall detection capability. Due to the reduced functionality, there are no buttons, it is slightly smaller and lighter than the other devices and designed to fit on a key ring. The WatchMe was recommended if the family members were not concerned about the risk of falling and believed the client could be relied upon to remember to carry their house keys.
The current generation of devices can be set up to connect with 24-hour call centers, family members – or some combination of these – if the wearer crosses a geo-fence (predefined area where the client should not go). A carer or call operator (or anyone else with access details) can view the location of the device using an online portal with a virtual map. Call center staff triage alerts and typically have an arrangement with responders as to who will be called, under what circumstances and what actions will be taken when an alarm is triggered. Clients may be living in sheltered accommodation, where their care is the responsibility of yet another professional team or they may be living at home; in either case, family members are generally involved as responders, even though they may live some distance away, making false alerts a real concern.

6 THE SETTING

We begin by describing the intra- and inter-organizational structures in place within the Trust to support the provision of GPS tracking services to its clients. We then present a series of vignettes consisting of anonymized extracts from field notes from the individual cases of GPS tracking services in our study. These vignettes have been selected to illustrate recurrent themes (Sharrock and Randall 2004; Crabtree et al. 2013) that emerged from our analysis of the fieldwork data: case management; matching GPS devices with the preferences of clients and their families; domesticating devices; patterns of use and non-use; the organization of care by family members; making sense of and responding to alerts. The names of public and industry sector organizations, products, staff and clients, and their family members have been anonymized to preserve confidentiality.

6.1 Intra- and Inter-Organizational Structures and Relationships

6.1.1 Inner City Borough Adult Social Care Service. ICB Adult Social Care service consists of two main units; the Adult and Social Care commissioning team, and the Assisted Living Requirements Center (ALRC). The former makes the ultimate decision on which technology supplier and monitoring service will be contracted to support the individual client, but rely heavily on the latter team’s knowledge when making these decisions. The ALRC team, which consists of two staff, Lucy and Nicolle, review and coordinate clients’ telecare, and assistive technologies. In effect, they act as the interface between the dementia care team, which supports the client, the technology suppliers and the monitoring services and the knowledge gained in this intermediating role gives them a powerful influence over these decisions.

The decision-making process follows set procedures, with forms, emails, and an online database to support and document them. Once the dementia team completes the assessment, they submit a “Telecare Assessment Form” to the ALRC team for review. Lucy and Nicolle do not have a clinical or technical background, but have developed good knowledge of technology options and processes within ICB, and experience of when a device might or might not work: “I don’t know how it works, but I know what it does” [Lucy] and they know the internal processes (what clients can or can’t have, implications for personal budgets, how to get things approved). Lucy and Nicolle also intermediate between the overly optimistic/modernist vision of the suppliers and the reality/messiness presented by frontline staff. They are open and welcoming to new technologies (they invite suppliers to come and give talks/presentations, and try things out), but also conscious that the technology does not always live up to expectations. There is a relaxed, informal, and casual feel to the center, which gives a sense of being connected with and accessible to the local community and this environment supports their role as a point of call for practitioners, as well as service users.

Lucy and Nicolle have pretty much free rein on what devices can be put forward to meet a client’s need—as long as it can be justified that this cannot be met by the default devices. Consequently, as the service engaged with more clients over the course of the study, the range of device options provided gradually increased in order to help devise practical solutions to the very
complex and diverse support needs and requirements. This is fine for standalone devices (not requiring a call center), but involvement of a backend service is more complex, as it would then depend on agreements/contracts for monitoring. They also need to understand and trust the technology and so will test it out thoroughly over evenings and weekends. Lucy and Nicolle only interact with service users by phone or on occasions in which users come to the ALRC. They will never meet (in-person) the majority of service clients and their carers, particularly those with dementia who interact more with the local NHS Trust dementia care team.

6.1.2 Dementia Care Team. The dementia care team consists of two OTs and two assistant OTs. The team is led by the senior OT (Kathy), who reports to the mental health community service manager (Moira). The team is responsible for assessing care package needs for clients diagnosed with dementia. They play an active role on the implementation side; liaising with clients and their families to assess what is needed and how it might work (e.g., what GPS tracker would be most appropriate, who would act as the responders), introducing and explaining the technology to clients and their carers, as well reviewing (within 6 weeks) whether the client should, and wishes, to continue with the technology. If their initial assessment presents a role for technology (such as GPS) then they will complete and submit their recommendation (using the Telecare Assessment Form) for review and agreement by an ICB panel (conducted by Lucy and Nicolle). The form covers client personal details, summary of their situation/support needs, recommended technology, and a pricing of the technology/equipment requested.

Whereas ALRC have a lot of contact with relevant suppliers/services, the dementia care team is the main contact point for service users—it is standard practice for them to visit the client at home for care package assessments, introduction to devices, reviews of the intervention. However, organizational processes and pressures dictate that there is a finite period in which they are supposed to work with a client and they are under a lot of pressure to “open” and “close” cases quickly. Once a case has been closed, that is it; the problem has been officially solved and the person’s care package has been put in place. To re-engage, they need to open it again, requiring additional paperwork, which the team are struggling to keep on top of—“constantly chasing your tail”—and so try to avoid this. Furthermore, if the case runs beyond 28 days, then it must involve a “care-coordinator,” leading to further paperwork and communications with other healthcare departments and professionals. Most of this activity and paperwork—visible, routine, inter-professional articulation work—is seen as unrelated to actually supporting the client—tick-boxes, general health data gathering (e.g., lifestyle questionnaires, along with consent forms to use this data) and data entry for the client records system (due partly to lack of data integration with other healthcare databases). The paperwork for each client includes 21 forms and documents—nine for when meeting the client (e.g., client details, lifestyle questionnaires physical health assessment form, carer assessment, “permissions to share” form), a further six for care-coordination (care plan, care plan authorizations, meeting reports) and, finally, another six at discharge (such as discharge letter, discharge plan, dementia medication follow-up).

Despite these challenges, the dementia care team has a good relationship with ALRC and they will talk on the phone/email 2–3 times during the week about a case or some technology: “We can have calls backwards and forwards where we’re checking something or arranging to do something, or an email... We can even pop in as well. It’s so handy that it’s quite close, you know, on the way in.” [Laura, community OT].

6.2 Client Participants

6.2.1 Rahim. Rahim who is 79 and from Pakistan, does not speak English, is hard of hearing and has mixed-type dementia. He lives at home with his wife, son, daughter-in-law, and two
granddaughters. At least one of the granddaughters is always present in the house during the day. Rahim is physically mobile, and spends all day, every day walking around his local area. He enjoys exploring, with no set routine or plan—“I don’t know where I will go, I can go anywhere”. He goes out after breakfast, comes back for lunch, before going out again. Rahim has a history of falls (two known occasions)—both occasions while walking outside. The family also reported that while Rahim is out, he collects things (e.g., carrier bags, tissues, elastic bands, and other small items). His daughter in law is his main carer during the day and stays at home with Rahim, while the rest of the family members are in and out of the house going to work or college. However, there are times when she is busy elsewhere in the house.

At his last OT assessment, he had become lost on three occasions in the space of three weeks. On each occasion it was because he continued past his usual route and was found several hours later about 3 miles away. In response, Rahim was given the Genie Clip. This was considered the most suitable device because it included fall detection and his family members were confident that he would keep it on his person (in his shirt pocket) when they gave it to him every morning. Tara, his daughter-in-law, says it still works and he always remembers to carry it on him. However, they have had some problems tracking him down and they have noticed a delay between the signal (where he is located on the GPS map) and Rahim’s actual location.

Rahim’s “geo-fence” covers a local park and surrounding roads, as his family are confident that he knows those areas. If he crosses the geo-fence boundary, the monitoring center will call his daughter on her mobile, who will then call the granddaughter staying at the house that day. From that point on, the granddaughter will check his location on the virtual map, and collect him if necessary. But this sequence rarely triggers an actual response with regard to finding and retrieving Rahim. Instead, his granddaughters will keep check of his location beyond the geo-fence, only taking action if he continues to walk further away from his usual routes or toward more hazardous roads.

"Like if he has gone to the corner shop, they [call operator] will say he is out of his boundary, but we know he comes back. But if he doesn’t come back within ten minutes, we will look where he is… About three times a week [they get a call], and twice out of that three we know where he is. And then once we don’t know. If they say three roads away or further, we know he is not familiar with the area. Someone will pick him up… Usually we get someone like my sister, auntie, someone who drives, and they will be on the phone. And she will call us and ask, and we say ‘Kings Road’. And if they can’t find him we look again and say, “He is on Duke Lane now.”

6.2.2 Arthur. Arthur lives in his own home and has a large and well-connected social support network, with all six of his children acting as potential responders to alerts. One son, Malcolm, is the primary contact and so will be the first person to receive an alert from the call center. He also receives numerous text messages (e.g. “battery low,” “wristband out of range”). It appears Arthur becomes frustrated at not being able to do what he wants and dislikes being told what to do. He has gone missing during the day and the family has had to drive around the local area to find him. On one occasion the family followed him to a train station. He showed no awareness of the traffic, which had to stop to allow him to cross the road and the family are concerned for his safety, as well as risk of becoming lost.

He has been given the Genie Clip, as his family were concerned about accidents and his risk of falling when outside. However, he does not wear it all the time and tends not to take the device with him when he goes out. He is unpredictable as to when he leaves the house and is often in a state of distress. The Genie Clip is attached to his keys and kept on the docking station, but he
Malcolm explains that there is a lot of co-ordination and communication required among the family to deal with alerts that do not require any responding to. Family members will often take Arthur out (beyond the geo-fence). This will trigger an alert to all other siblings, who will then contact each other to find out what is going on. This has been somewhat facilitated through the WhatsApp network established among the family—e.g., if someone gets an alert they will send out a WhatsApp message—which another sibling may respond to in order explain that he/she has taken Arthur for a trip. More routinely, alerts are triggered by Arthur’s twice-weekly visits to the community center and memory clinic. All siblings are very busy with work and family, and so such alerts can potentially be disruptive, despite their efforts to coordinate and communicate with each other by phone and messaging. Malcolm asked whether these alerts could be configured to minimize such alerts. He would like the system to be aware of Arthur’s routine trips to the day and community centers. In addition, he would like the family to have the option to continually configure when alerts should be raised (e.g., disable if being taken out to see relatives) and who should get the alerts (e.g., if Malcolm or his sister are away on holiday or at work). In addition to this degree of configuration, Malcolm proposed an additional level of monitoring within the system.

There is always at least one person home, or within close proximity who can respond quickly to an alert. As it is the family home, they all know the area well and would not find any problem locating the appropriate street. The difficulty lies in the time delay. Malcolm thinks that there is about 15 minutes delay between the reading on their GPS map and Arthur’s location in real time, and so Arthur is likely to be gone before a family member reaches the location. With this delay in mind, Malcolm has considered whether a different GPS tracking system might be more appropriate. Malcolm is a professional fitness trainer and is aware of various fitness monitoring devices that include GPS functionality. He believes that many sports watches provide a more accurate and reliable reading of the wear’s location than the Genie Clip. He acknowledges that the Genie Clip has other features (e.g., SOS alert, geo-fence), but wonders if the they might be an option, or possibly used in conjunction with the Genie Clip. He would also like to have some way of sharing the GPS map with others in the house, so that the family could cooperate more effectively in tracking Arthur down: “If there could be a large screen in the living room or the kitchen with the map showing. We could all then look together and work out where he is.” This would be particularly useful for his mother—who does not currently have a facility to view the maps and would also allow one person to monitor the screen, while giving instructions to the person on foot via mobile phone. The difficulty with using just the phone is that one cannot view the map and talk on the phone [to an operator] at the same time.

6.2.3 James. James (aged 89) lives at home with his wife Annette. He has vascular dementia, diabetes, and arthritis. He goes out daily to the main high street and can be gone for hours. Annette says people locally know who he is, which provides her with some reassurance when he goes out. She has, however, had to request that the bank blocks his access to the bank account because he has taken out and spent lots of money, but does not know (or say) where this money has gone. This has placed additional stress on Annette who now must take responsibility for their domestic finances and bills.

James has been provided with the Dorado Watch but has not yet worn it. This was initially considered to be a suitable device for James, as he liked the idea of wearing a new watch and wanted the tracking device to be discreet and unnoticeable to others. Annette says she will wait
until James is in a “good mood” before trying to get him to wear it. She goes on to say that he is being difficult about it—that he has told her “Now you want to tag me like a dog.” The fieldworker mentioned that if the Dorado watch is not working for them, then there may be other options, such as the WatchMe device; explaining that it looks a bit like a key ring and may be more acceptable for James. Annette is surprised to hear of the other option and shows slightly more interest in that prospect over continuing with Dorado Watch.

When visiting ALRC, the fieldworker met with Lucy and Nicolle to talk about the issues experienced by James and his wife. Lucy had noticed the lack of activity on the device [on the online portal]—although she saw it was being charged. She called the Social Worker—who reported that James’ wife informed her that the device was working well and “closed the case.” Lucy is annoyed, as she feels the Social Worker did not really look into the issue in sufficient detail. She also sensed from the Social Worker that the “assessment” was rather superficial “It is like she just said there is this watch with GPS and that was it. She didn’t explain all the options.” Nicolle suggested that both she and Lucy should visit James. This is not something they usually do—but are coming around to realize that it is something they should do more often. Nicolle wants to meet James (only Annette has been to ALRC) and see what their setup is like at home, but most importantly, explain the technology to James in a way that he will understand and accept. The comment of being “tagged like a dog” suggests that it has not been presented in a way that fits with his sense of pride and independence.

Afterwards, Lucy and Nicolle tell me about their visit to James. Initially he would not come downstairs to meet them. He told his wife to say he was out—which she refused. But when he came downstairs he was full of life and they immediately formed a good rapport. He went into detail about the problems with the Dorado watch—that it is too big (he can’t cover it with his sleeve) and it keeps catching on his trousers when he puts his hands in his pockets. “Ooh yes that was terrible. It was also over my wrist, it was big and heavy and it was difficult to put my hands in my pockets”. They said he loved the WatchMe—and wanted to keep the demonstration model presented to him.

6.2.4 Michael. Michael is 85, has moderate vascular dementia and had a stroke about six years ago. He is a widower and lives alone in a terraced house in an estate near to an airport. He has regular visits from carers (three times a day) and one of his daughters (Sally and Rachael) in the evening. Sally is the main contact person with regard to Michael’s care package and the deployment of the Genie Clip. This device was chosen because Michael had experienced a number of falls inside and outside the home, and his daughters believed it would be easier and more comfortable for him to wear around his neck as lanyard, as opposed to wearing the Dorado Watch on his wrist (the only other device available at the time). Sally and Rachael both live about an hour’s drive away from Michael. Both work full-time and so alternate their evening visits to Michael. Michael has a history of falls and has been provided with a personal alarm (worn as a pendant) and an automatic falls detector (also worn as a pendant). They received the Genie device in addition to his existing telecare package about three weeks ago, following an incident in which Michael went missing and the police were called to help find him. They will trial the device for a total of six weeks before deciding whether to keep it.

They are using the Genie Clip (the main device with the GPS SIM), the Genie “wristband” (which is worn on the wrist to detect falls) and the docking station (which is used to charge the Genie Clip and wristband). Sally knows that the Genie Clip does not need to be worn inside the house, but she believes that the wristband needs to be worn at all times indoors. However, she is still confused as to how the two pieces of kit interact—is the wristband standalone? Does it communicate with the clip or the hub, or both? “I don’t know how the two… I just know he has to wear that [Genie
wristband], and when he goes out, put that [Genie Clip] in his pocket or around his neck.” Sally says his dementia has progressed a lot since he first had the telecare pendant alarms. At one time, he would have known to press the button if he had a fall, but not now.

Michael often walks around the local estate; he knows the neighbors and sometimes knocks on the next-door neighbor’s door. Beyond the estate is a busy highway and roundabout, with a lot of airport traffic. Sally believes that Michael becomes lost and disorientated in this area and so the Genie “safe zone” is restricted to the residential area—about half a mile around his house. If he goes outside that zone (with the device) then it alerts Sally (via her mobile), as primary contact, and her sister (Rachael) as secondary contact. As of yet, Sally and her sister have not got round to establishing this strategy/routine despite having the technology for nearly a month.

Despite it not being used, Sally recalls about 30–40 (false) alerts since the device was installed. However, it is unclear how many of these were “out of zone” calls, as it soon becomes apparent that some of these were text messages (automated) indicating other alerts, such as “battery low” and “wristband out of range.” To illustrate this problem, Sally starts scrolling through her phone. It is clear that Sally struggles to interpret and explain what these messages mean, and is adding stress, and confusion to her life. Sally lives over one hour’s drive away, so these false alerts have caused a great amount of disruption. A few times she has come down to the house, and Michael has been indoors. This has even occurred when Sally is with Michael in the house, so she knows it is an error. To avoid unnecessary journeys, Sally now calls the house landline whenever an alert is raised. If Michael answers, she knows he is at home.

Following one alert, Sally tried to speak to the operator about this issue while he was on the phone, but with little progress in resolving it. The operator simply explained that they were “duty bound” to call her when an alert is raised. There was no suggestion or reasoning around how this might be resolved. They did not grasp the geographical aspect of where she lived and where they were suggesting Michael had gone.

It did seem a bit impersonal, to be honest. He [the operator] didn’t sort of understand that I’m [one hour drive away] and that dad is here. And if it was a false alarm, I have got to come all the way over here to find out what, if anything, is wrong, or nothing. He didn’t grasp that. And it’s not his fault. But I thought ‘Huh?’ The people who phone me, they said “We’re really sorry, there is nothing we can do. We just get a message on the screen and we have to call you.” There is not a lot of…there is someone down there in Southampton. I’m someone sitting in London. They don’t know anything about round here…

In relation to the false alerts, Lucy is surprised to hear Sally’s account of the high volume of “out of zone” calls. She opens up the Genie portal—an online platform used to setup users’ systems (set geo-fences, client details, etc.) and tries to find the log data for Michael’s device. The portal lists indicate the state of the device at various times. (e.g., battery level at certain times, whether the device is in the “safe zone,” etc.) She can also view various locations where the device has been over the last few weeks. However, it does not give an account of when the monitoring center made contact with the responder. Lucy decides to call Charles (her contact at Genie HQ) for the call center logs. She gives Charles the client name and address. Charles explains that he does not have direct access to this data, but will get in touch with the monitoring center and tells Lucy he will send it to her tomorrow.

6.2.5 Patrick. Patrick is 87 and has Alzheimer’s type dementia. He lives with his son, Steve (aged 60) and has done so for the last 12 years. They live in a terraced house, which has been the family home for 52 years. They are 10 minutes’ walk from the nearest tube station and 2 minutes'
walk from the main road. On the main road is the grocery store, betting shop, pub and post office. Patrick goes down this road to the betting shop daily. Steve is at home most of the day and only goes out for short periods of a time (e.g., to do the shopping, provide a “taxi service” for his daughter). Steve plays an active role in supporting Patrick’s social engagement. For example, he drives Patrick and his friends to a pub once a week. For a number of years, Patrick has independently been frequenting his local betting shop and pub near his home. This appears to be a perfect set up for Patrick—it is a short walk around the corner to these places, both in close proximity.

In the past two months, Patrick has become lost three times. On two occasions a member of the public spotted him and helped walk him back to the local area. On the third occasion, the police were involved, so he was assessed for a GPS tracking device and it was decided that the old style Genie was the most suitable because this has a velocity sensor (it detects if a person is traveling at speed—such as on a bus), which the new Genie does not have. The old style Genie also has an SOS alert feature (which the user manually presses), but Steve does not think his father will use this.

Steve was getting multiple alerts day and night despite Patrick (and the device) remaining in the house. This was just about manageable during the day as they could check Patrick’s whereabouts or make an informed judgment about when to respond.

I did have one to say he was on foreign shores. She [the operator] said she knew it was a false alarm but she had to ring me. There was one more local one, but I didn’t think it was right. I spoke to [the operator] and took his number to go and check, but I was sure it was wrong. So I went down and he was in the betting shop. So I rang him back… There was another one, where they said he was up by the Thames River, and I said ‘No he wouldn’t be going up there’. Because I knew he only left the house two minutes prior. But when it happens at silly o’clock in the morning, and we’re asleep in bed... I was lying there and got a phone call at 4:20am to say Patrick has moved out of the area. And I said, ‘I doubt it, he’s still in bed’. And all they do, they say ‘ok no problem’. There wasn’t like, no argument, disagreement [in terms of whether or not he was outside the zone]. It was like ‘ok no problem must have been a glitch…

During this home visit, Steve suggested that the device be disabled at night, as his father has not presented any problems of wandering at night. He suggested disabling it from between 8pm (when Patrick usually goes to bed) to 8am.

Following this home visit, the fieldworker discussed the occurrence of the night-time alerts and Steve’s proposed solution with the ALRC team. Subsequent to this, the ALRC team contacted the supplier and requested changes be implemented by the monitoring center. In addition to this, the supplier produced a “beacon” plug—which sends a signal to the GPS device to override the GPS signal whenever it is in the house. This particular device was intended for tracing convicted criminals on probation, but had been “hacked” by one of the engineers to communicate with Patrick’s device.

7 ARTICULATION WORK IN CONFIGURING AND IMPLEMENTING GPS TRACKING SERVICES

The fieldwork extracts above exemplify a number of common themes related to configuring and implementing usable and effective GPS tracking services for people with cognitive impairment. A recurring feature of these themes was the importance of articulation work in helping to ensure that actions carried out by professional and lay carers mesh sufficiently well. In this section, we will examine in some detail the role of articulation work. We focus, in particular, on the following:
case management; matching technology options with clients’ needs; locating and tracking as a collaborative activity; and dealing with false alerts and wandering.

7.1 Case Management

Much to the dementia care team’s frustration, their work is dictated by the case management process. They are overwhelmed by paperwork that documents this process and which they feel draws them away from focusing on working with clients. Their time on each case is dominated by the completion and inputting of multiple assessment forms, health surveys/questionnaires and permission letters—much of which has little or no connection to the problem they seek to resolve. Their day-to-day work practices are driven by perceived risks of increasing their paperwork, distracting them from what they see to be their actual role as OTs:

Oh, it’s sort of these boxes you’ve got to tick. Like you’ve got to record the smoking, like do they smoke, do they drink, physical health and all that kind of thing. You’ve got to look at their medication and sort of a lot of quite general stuff... Even if that’s not what you’re being referred for, if it’s not a concern to them, we still have to ask these questions, the set questions. Even though there’s no history, say, of them hallucinating, or any present hallucinations, we still have to ask that question because it’s on one of the set forms. So we kind of say, ‘Well we ask this of everybody, hope you don’t mind... ’... I wouldn’t want to be asked that... They can refuse and we can just say ‘declined‘ or whatever. I think the managers here, our immediate managers, can see the frustration and they’re frustrated. [Laura, Occupational Therapist, Dementia Care Team]

Overstretched and understaffed, they seek to avoid crossing the 28-day deadline and to keep their workload to a just about manageable level. The GPS technology is particularly problematic in this regard, due to the lengthy and unpredictable aspects involved—such as establishing an appropriate solution in discussion with the client and carers, waiting for the equipment to arrive (especially if it is new or one-off purchase), setup and installation, resolving issues, or trying alternative solutions. This is further drawn out by challenges of engaging and meeting with clients and carers, many of whom are stressed and lacking the motivation or capacity to invest time and energy into learning about and supporting the technology. The dementia care team have tried to make the case with other teams and members of the organization for a more flexible approach to understanding clients’ requirements, stressing that prescribing technological solutions cannot, in their experience, be treated in a standardized way:

So we are a bit annoying in that sense because the care coordinators just want to sort of get rid of that person; everything’s working well, that’s fine... We try and say, well consider it like it’s medication being trialed... You have to give it so many weeks, don’t you, to be realistic and see whether that’s working or whether you need to tweak things or change things. [Kathy, Occupational Therapist, Dementia Care Team]

The dementia care team sometimes feel compelled to work around the standard procedures in order to “make the system work” for the client, keeping a case “open” for some time, which goes against organizational pressures to close cases as quickly as possible.

I don’t think anybody knows I still have this case open, they expect it to be closed. But I have been waiting for the Ranger to arrive, and so been keeping it going for that. [Laura, Occupational Therapist, dementia care team]
However, only the “care coordinated” cases are recognized on the commissioning side, and so there is a tension between the practitioners’ goal to avoid paperwork against the managers’ incentives to increase the number of such cases.

And a lot of stuff we do, if they’re not coordinated, not getting recognized from up above, because unless somebody’s on a CPA—so, being care planned, or care coordinated, rather—a healthcare professional doesn’t count on the figures, financially. The trust isn’t getting paid whatever money, although a lot of that should get recognized and we could have them being care coordinated. But then it’s the paperwork and that awful thing we’re thinking, well, we know we’re helping them, but yes, we’re not getting recognized. Or you’re going to get recognized and then you’re struggling to try and help someone. It doesn’t really work well together. It’s the one thing everyone says about paperwork; there’s more and more. Every few months there seems to be another sheet to fill in. [Kathy, Occupational Therapist, Dementia Care Team]

Once the case has been “closed,” formal engagement with the client ceases. The dementia care team invites clients to contact them if problems arise, but they do not actively seek to monitor or evaluate any aspect of the care package. The level of support they provide must be minimal (as it is not recognized as an open case and the service is not paid), although they acknowledge that helping the client with the little things can help prevent a more serious incident that brings them back onto their case load.

So we’re kind of reliant on the carers, the family, to let us know if there’s a problem after discharge, or if there’s a change in their presentation. The doctor might ring back and then we’d find out, but we wouldn’t normally. So that person would keep that piece of kit because, at the time of our assessment and end of our work, that would be it. But it is interesting because we know dementia does progress and something might work for so long but it doesn’t mean it’s going to work for ever. [Kathy, Occupational Therapist and Dementia Care Team]

We see in these extracts how management and front line service staff are at odds in their attitudes toward the organization’s standard procedures. The hidden work they undertake enables the technology to work despite the formal procedures. It is not that the hidden work merely supplements these procedures, a lot of it is only needed to get round them. For ICB Adult Social Care, what is most important is bringing closure to the process of dealing with a case and that means meeting deadlines and having an auditable paper trail that provides evidence of due process having been followed, a classic example of visible, routine articulation work whose aim is to track and make staff accountable for meeting organizational norms. In contrast, the dementia care team appreciate that matching GPS devices to individuals’ needs is a difficult and unpredictable task; however, because missing the 28-day closure deadline means even more paperwork, more often than not they are forced to make the work look like it fits management dictats. This, in turn, makes them reliant on informal interactions with users—extra-professional articulation work that is routine yet invisible to management—to maintain their workload within manageable levels.

7.2 Matching Technology Options with Clients’ Needs

The frontline care practitioners (social workers, dementia care team) take on the primary role of assessing and recommending GPS interventions. This includes their clinical reasoning (suitability, how it might work, risk) and required configurations (e.g., geo-fence, alert contacts). This is achieved through a home visit assessment with clients and their carer(s), guided by the Assistive
Technology Assessment, which was devised by the ALRC telecare team in order to help review the recommendation. This assessment form is emailed to the ALRC team and reviewed as part of the weekly Telecare Review Panel meetings. If the recommendation is agreed by the panel, they will inform the practitioner and arrange for the GPS solution to be set up (i.e., ordered from supplier, submit the client profile and configurations). Once the system has been set up, the practitioner will usually re-visit the client to present the device and explain how it works.

This process helps manage and document the GPS tracking interventions in place. However, it is the visible, non-routine, inter-professional articulation work manifest in the ongoing interactions among the ALRC team and care practitioners that really drives the consideration and exploration of personalized solutions. Discussions take place between the dementia care team and ALRC team (usually by phone or email, but in person when opportunities arise) to talk about specific challenges or requests regarding a particular case. This is an informal and ad hoc dialogue, in which practitioners have to make time to talk. But it is facilitated by the personal relationships established between the practitioners and ALRC team members, as well as ALRC team’s deliberate efforts to represent themselves as an open and accessible resource for such discussion.

We can have calls backwards and forwards where we’re checking something or arranging to do something, or an email… We can even pop in as well. It’s so handy that it’s quite close, you know, to go in. [Laura, Occupational Therapist, Dementia Care Team]

There are resources - catalogues for practitioners - but it’s not the same [as talking]. Even though you have a catalogue and it tells you what the thing does. There is nothing there to tell you what to connect it to, how or why something can be. It doesn’t say ‘well if you want to put it this way…’, all that sort of stuff. It tells you it monitors movement and that’s it. It’s usually practitioners who come to us, coming all the time. They don’t know what to do. They describe something, what they think they need, but don’t have the level of detail, or how it all fits together. Sometime the technology doesn’t do what they want it to do. (ALRC telecare coordinator)

We see in these extracts the importance of visible, non-routine articulation work for working up a common understanding between ALRC and the dementia care team of clients’ needs and how this contrasts with the form-filling driven, visible, routine articulation work that dominates the dementia care team’s relationship with Adult Social Care. Each GPS tracking intervention has distinct features that resist standard solutions. Solutions are developed through ongoing dialogue via phone and emails between the OTs and ALRC staff that, as visible but non-routine articulation work, make feasible the collaborative working up of bespoke GPS tracking solutions for clients.

7.3 Locating and Tracking as a Collaborative Activity

An essential requirement for the GPS tracking intervention to work is the existence of at least one “responder”—a lay carer (usually a family member) who is able to physically find and assist the client once an alert has been raised. The client case studies reveal examples of the various ways in which clients’ families have devised solutions to the challenges of coordinating care. Each one highlights how effective use relies on carers’ ability to coordinate their actions and to use their local knowledge of domestic habits and situations in order to interpret the meaning of alerts and overcome the limitations of both devices and alert monitoring systems.

In Arthur’s case, his family often takes him out beyond the geo-fence, so they rely on their own WhatsApp group to check among themselves if a response is actually necessary. However,
Arthur’s case also illustrates how the configuration of alerts may fail to mesh with the routines of the client and family and makes a case for the alerts systems to be more configurable to the needs of the individual client and family.

When an alert is determined to be genuine, responders need to be made aware of the location of the family member. In Rahim’s case, we saw how his family members have access to the virtual map (via granddaughters’ smartphones) in order to determine his location. In other cases, however, carers may not have access to this information, and so are dependent on the skill and willingness of monitoring center staff to assist. One problem is that road names may often be meaningless to the operator in one of the monitoring centers; we found that staff have devised a way to overcome this problem. This is embodied in a tacit reconfiguration or elaboration of standard procedures and technical systems through the use of a widely used geo-mapping tool.

The monitoring operator [Tina] tells me how they have developed strategies to help guide and direct responders as to the whereabouts of the user. The GPS tracking portal links directly into Google Maps, but it can often be difficult to describe the location based on road names indicated within the map. Carers are often unfamiliar with many of the actual road names (even in their local areas). Tina shows me how she can quickly switch to Google Street View, which they find easier to relay over the phone to describe the wearer’s location in relation to landmarks as a point of reference, for example: “he is just by Cafe Nero” or “going down a small alleyway opposite what looks like the church car park.” [Monitoring Center A]

The ALRC team received contrasting feedback on clients’ experiences of the monitoring services depending on the tacit knowledge, interpersonal qualities, and initiative on the part of the monitoring staff member. This illuminates the different approaches by the organizations involved and how this shapes the monitoring staff interactions with responders on the ground:

We have had positive feedback from client carers about [monitoring center A]. The operator doesn’t close the call until the person was found, so that makes the difference. The family was in constant contact and the operator was actually willing to call the person and say, “Okay, well this person has now moved from here to there...” With the other one [monitoring center B], they weren’t very helpful - just said oh, he’s at [road name] and that was it. Obviously he’s not going to stay there. There was no ‘Okay, I’ll stay on the phone or I’ll call you back in another ten minutes’. Because remember, they’ve got to go and retrieve their relative. So, by the time they get there, they [relative] could be somewhere else. And when they phone back, they had to go through the whole process again. They called the center and it was a different person who answered the call, and they had to go through a whole thing again. There was no continuity. The person was already agitated because they don’t know where the person is. It’s like, you know, it’s your problem. [Lucy, ALRC Telecare Coordinator]

These examples suggest that this invisible, routine articulation work by monitoring staff is an important contribution to making the GPS intervention work effectively. Staff in monitoring center A demonstrate a willingness to prioritize the needs and concerns of carers above following the standard procedure that appears to dictate the approach of staff in monitoring center B to the task. We also see, that rather than saving monitoring center B staff work, how following standard protocols may lead to additional work, as well as stress for the carers.
7.4 Dealing with False Alerts and Wandering

Our findings suggest that a major part of supporting GPS trackers by both lay and professional carers is taken up in dealing with false alerts. A wearer’s location is inferred through the triangulation calculation of three satellites, which can be affected by various uncontrollable and unpredictable factors, such as atmospheric conditions, building structures, terrain. Erroneous readings trigger a false alert if it places the wearer beyond their geo-fence.

The case studies show that many carers learn to manage and tolerate these false alerts—again through coordinating their efforts and sharing knowledge of the individual, the system and local geography (e.g., checking the wearer’s home or other “local haunts” before actually attending to the GPS location). However, there are also occasions in which the false alerts are unsustainable (e.g., multiple alerts at night) and some lay carers struggle to understand their significance, as Michael’s case illustrates. It also shows how monitoring center operators lack of local knowledge—and thus their inability to resolve the alert themselves, coupled with their reluctance to deviate from standard procedures—can make the lives of lay carers more difficult. Monitoring staff require lay carers to “contextualize” every alert as if “for the very first time” and no matter how many times it has happened before. This problem is compounded by monitoring staff’s lack of attention to the personal circumstances of responders—i.e., to undertake articulation work in the form of “emotional labor.”

When faced with recurrent false alerts at night (which are, again, compounded by monitoring staff’s lack of local knowledge), Patrick’s family propose to disable the tracking device during this period as a way to “repair” the problem. However, their status in the social care system makes them unable to implement these changes themselves, either through requests to the call center or through a system portal. As the service provider, the telecare coordinators want control over such changes. They consider it their responsibility to ensure system integrity, and so act as the gatekeeper for any proposed system modifications. This is a mediating role that the ALRC telecare coordinators decided to take on themselves so that they can be sure clients or their lay carers do not make erroneous or unintended reconfigurations (e.g., disabling an alert feature). It illustrates how invisible, routine articulation work has become established to maintain reliability and safety of the technology in use:

Because of the level of access they [carers] have on the system, they can only request for certain changes or information. So, they could ask where the person was, but they couldn’t adjust a safe zone. They wouldn’t just do it. They can make the request to [supplier name] but the supplier will request for us to confirm if it’s okay. [Laura, ALRC telecare coordinator]

8 DISCUSSION

For policy makers, assisted living service innovations offer a solution to the pressures of an ageing population with rising rates of disability at a time of cutbacks in health and social care budgets (e.g., Department for Business, Innovation and Skills 2013; National Information Board 2014; Deloitte 2015). If policy makers’ plans are to come to fruition, then assisted living service innovations must be scalable and sustainable (Greenhalgh et al. 2017), which means that they must not only deliver their promised benefits, but do so in ways that are cost effective (van Limburg et al. 2011). However, the optimism that has accompanied various initiatives designed to promote the scaling up of assisted living services pilots and demonstrate their sustainability has not been justified by results (Sanders et. 2012; Bentley et al. 2014; Cook et al. 2016; Merkel and Enste 2016; Greenhalgh et al. 2017).
Scalability implies that services may be rolled out at multiple sites with minimal adaptation to local settings and service user needs, with “plug and play” representing the ideal scenario (Greenhalgh et al. 2016); sustainability implies that costs of running and maintaining the service over time is consistent with the resources available. However, scalability and sustainability goals may be in conflict (Agbakoba et al. 2016): keeping roll out costs down by not paying sufficient attention to local settings and service users’ needs may negatively impact on sustainability as users may then find themselves facing demands that are difficult to meet, which could then lead to limited use or even complete abandonment. Evidence for this can be found in the fact that of the seven participants, four had stopped using the devices by the end of our study (Greenhalgh et al. submitted). Numerous studies (Kinder 2010; McLoughlin et al. 2012; Tinker et al. 2013; Procter et al. 2014; Greenhalgh et al. 2015; Wherton et al. 2015; Greenhalgh et al. 2016) have emphasized the importance of engaging much more closely with service users and, in particular, of taking a co-production approach to assisted living, and health and social care services generally (van Limberg et al. 2011).

We set out to gain a better understanding of the challenges to achieving scalable and sustainable assisted living service innovations by looking in detail at the processes involved in the configuration, deployment and day-to-day support of GPS tracking services for people with cognitive impairment and their families. Drawing on a number of frameworks (Star and Strauss 1999; Hampson and Junor 2005; Postma et al. 2015), we have focused on the roles of different types of articulation work undertaken by health and social care professionals. Previous studies of articulation work have emphasized its importance for the successful conduct of collaborative work: “…the continuous efforts required in order to bring together discontinuous elements – of organizations, of professional practices, of technologies – into working configurations.” (Suchman 1996, p. 407). In our study, we observed the role of articulation work in the following: coordinating activities; devising work arounds for standard procedures; helping manage relationships with clients and their families; providing ad-hoc solutions when standard solutions do not exist. We also observed the contribution of articulation work undertaken by clients’ families as they attempt to “domesticate” (Williams et al. 2000) the technology and discharge their duties as responders in a manageable way. What do these different forms of articulation work reveal about the challenges for the scalability and sustainability of GPS tracking services and how could their configuration, deployment and support be adapted to address them?

The processes involved in configuring and deploying a GPS tracking service are managed through a combination of various forms of articulation work: form filling, records of meetings and visits with the individual, email, telephone calls, and conversations that, collectively, serve to manage the trajectory of this “arc of work” (Strauss 1985) as it crosses intra- and inter-organizational boundaries (Grant et al. 2015). However, the dementia care team regards the form filling they are obliged to complete in order to demonstrate compliance with official procedures as a distraction from what they see as the more important task of ensuring the client’s needs are met and they then find themselves having to undertake additional work in order to bypass strict deadlines on how long a case can remain open. Such mismatches between formal procedures and what is actually necessary in practice to “get the job done” may compromise the scalability of the service at the organizational level, stressing the importance of having mechanisms in place to support organizational learning for adapting procedures as experience accumulates of the challenges of delivering it effectively and efficiently, and hence at scale. For example, the progressive nature of dementia means that clients’ needs are likely to require regular re-assessment. In this study, the fieldworker’s continued engagement with service users, beyond the “closing” of a case, and the subsequent involvement of the ICB team to resolve problems or adapt solutions brought the
organization’s attention to the need to routinely initiate contact with service users, at least by telephone phone, during the periods between the “annual review.”

Post-deployment, adaptations of the service are shaped by tacit knowledge of the client’s habits and routines, so sustaining it increasingly relies on various forms of articulation work undertaken by lay carers in order to deal with false alerts; and adapt devices and service support to meet the client’s (changing) needs. Lay carers came up with various coping strategies for the problem of false alerts. Often, however, these were not sufficient to make false alerts manageable. Among solutions suggested (and in some cases actively pursued) by lay carers are the following: more configurability of the alerts (e.g., being able to disable them at night); design improvements to the devices; and repurposing GPS devices marketed for fitness training. Such “repair” work would normally remain invisible to health and social care professionals, with the consequence that opportunities to put in place better solutions and to learn how to avoid problems in the future would be lost. However, by assuming an intermediating role between the individual, their lay carers, and the network of health and social care professionals, the fieldworker was able to recover the “hidden work” undertaken by the former and make it accessible to the latter. In turn, this set in motion efforts by the latter to deal with these problems: replacing a tracker with one that did not duplicate the functionality of a fall pendant; re-purposing (hacking) a device designed for a rather different scenario; a home visit by staff, which enabled them to get a more detailed insight into issues with the GPS tracker and, crucially, allowed the client and their family to build trust in the people “behind the technology.”

This role entitled repeated visits to study participants’ homes to discuss their experiences with the GPS tracker, with the cultural probe “Wish List” serving as a memory aid that facilitated dialogue between the fieldworker and participants about their experiences. It was found that the comments recorded focused almost exclusively on the occurrence of “false” alerts (in one case recording the exact time and frequency of each alert) and the fieldworker was subsequently able to use this material to help communicate to the ICB team and monitoring centers issues not routinely captured by existing reporting systems (while alerts and call logs were monitored at the call center, the frequency and impact of “false” alerts were not routinely captured) and to draw attention to their impact on participants’ everyday lives and help them prioritize efforts to develop systems capable of monitoring and responding more effectively to “wandering” of GPS alerts.

Though piecemeal and small scale, these interventions by the fieldworker reveal the benefits of recovering this “hidden” work. These interventions created, however crudely, opportunities for, on the one hand, organizational learning about how to address operational issues, some of which (such as false alerts) are commonplace and burdensome and, on the other, for lay carers to become more actively involved in co-producing useful and usable solutions.

Facilitating both organizational learning and co-production is essential for scalability and sustainability of assisted living services (Greenhalgh et al. 2017). From the perspective of health and social care professionals, this requires creating the right intra- and inter-organizational processes, for example, scalability would benefit from enabling staff to evolve standard procedures (e.g., relaxing rules about how long a case may remain “open”) in ways that make them better matched to meeting clients’ initial needs; sustainability would benefit from allowing health and social care professionals flexibility when managing relationships with people and their families (e.g., enabling them to identify and respond to changes in clients’ conditions and needs) and promote a co-production approach. Co-production exemplifies the potential for tension between scalability and sustainability and may seem difficult to justify at a time of cutbacks in health and social care budgets. Part of the solution might be to revise organizational procedures so that health and social care professionals devote less time to routine articulation work (paperwork), thereby freeing them for more home visits. We would also argue that when considering how to resolve this tension, it
is important to bear in mind that scalability has limited or no benefit services then deliver limited benefits or are abandoned.

9 CONCLUSIONS

In this article, we have examined in detail the ways in which professional and lay carers perform various kinds of articulation work in order to help ensure a GPS tracking service meets the needs of people with cognitive impairment. That articulation work is important in this context is not, in itself, surprising; articulation work is a well-documented feature of organizational work (Strauss 1985; Schmidt 1994; Suchman 1996; Star and Strauss 1999; Heath et al. 2000).

Our findings are, however, distinctive in three ways. First, by following the “arc of work” of GPS tracking solutions from initial configuration through to deployment and use, and by distinguishing between different types of articulation work, we have been able to reveal how, for example, standard organizational procedures, instantiated through various kinds of articulation work (e.g., form filling) during the configuration phase, inevitably lead to lay carers having to perform articulation work in the subsequent deployment phase. Exposing such relationships is an important step for making the case for adapting organizational procedures, while also helping to avoid adaptations based on formal models of work—rather than how the work is actually done in practice—which could make the organization less effective (Hampson and Junor 2005). Second, and following one from the first, our study emphasizes the importance in new models of healthcare services of articulation work by non-organizational actors who are key to successful adoption. Third, our study reveals that new models of healthcare and social care that are exemplified by assisted living services—where, for example, knowledge codified in monitoring center procedures displaces local knowledge—mean that the burden of undoing “‘Tayloristic’ notions of labor division and managerial control that were introduced in public services in the last decades” (Postma et al. 2015, p. 62)—and whose limitations this study clearly exposes—falls not only on health and social care professionals but also on lay carers, who are often ill-equipped to carry them.

Drawing on these three points leads us to conclude that the hidden nature of much of the articulation work performed by professional and lay carers alike to keep GPS tracking services in “working order” has significant implications for their scalability and sustainability and for assisted living services more generally, and we have suggested how changes in organizational processes would help to address this. Adopting more user-centered approaches for the design of GPS devices and monitoring systems (Wan et al. 2016) has also an important role to play, as has the introduction of systems to help support articulation work (e.g., Crabtree et al. 2006). Regarding the latter, a secure, digital collaborative space—an assisted living “dashboard”—could facilitate new ways for health and social care professionals and lay carers to communicate and share information, log use of and collaboratively manage the customization, integration, and configuration of devices, and provide richer mechanisms for feeding back experiences of using both devices and services (Procter et al. 2014). As van Limberg et al. (2017) concluded in their studies of the development of eHealth technologies, “… it is imperative stakeholders all stay involved and interested in supporting and further developing the technology.” (p. 4)

However, any attempt to introduce new technological resources into what is already a technically rich and (for many users) complex setting should be undertaken with caution, making it would be prudent to consider to what extent existing platforms that enjoy widespread adoption and familiarity might be re-purposed. We saw, for example, how one family had created its own WhatsApp group to help coordinate their responses to alerts, suggesting that tools like this could also provide a way of overcoming current challenges of communication and of sharing information among health and social care professionals (e.g., Iversen et al. 2013) and between health and social care professionals and lay carers. Subject to satisfying security requirements, social media
platforms such as Facebook might also find a role, especially as they are designed around a rich model of shared information.

Finally, personal technologies, such as GPS tracking devices, are themselves a tool for doing articulation work in that they provide accounts—albeit very “thin” and decontextualized—to remote carers (both professional and lay) of people’s activities. This makes it important to reflect on how such technologies may evolve in the future and, in particular, whether these accounts might become “thicker” and more strongly contextualized, and thus more useful and usable for professional and lay carers alike. The Internet of Things (IoT) is the generic name given to an emerging set of technologies and devices that feature network connectivity, often coupled with remote sensing and/or control capabilities. Hence, it would not be surprising if IoT solutions that have been developed for other market segments (e.g., smart homes) migrate into the assisted living device and service market place. This prospect raises a number of interesting opportunities and challenges for the future of assisted living services. One potential benefit is that IoT may promote standards for interoperability that will make bespoke assisted living solutions more easily achievable. A second and perhaps more important benefit lies in the fact that IoT enables the collection of vast amounts of data about people’s behavior and their environments that can be analyzed using machine learning techniques. It is therefore tempting to imagine that for assisted living services, this combination of IoT and machine learning offers the promise of making possible the real-time, remote monitoring of people in ways that would improve on the crude capabilities of the current generation of fall devices, pendant alarms, GPS trackers, and so on, creating opportunities for new and more effective, technologically supported articulation work (Chen 2012). However, such optimism may be misplaced: others argue that making sense of such data itself poses challenges that require human articulation work to resolve them (Tolmie et al. 2016). Finally, IoT faces major challenges in addressing privacy, security, and safety, which will need to be addressed if it is to meet the requirements of health and social care providers.

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