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# User and Desk-based Research on Improving Home Care for Older Adults



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Link to trello project page

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## Part I Executive Summary

This Local Digital Fund (LDF) research has the goal of producing a principled approach to improving care of older adults in the community using information and communication technologies. It investigates older-adult care provision and the role of technology within the partner organisations, Birmingham City Council, Worcestershire County Council, and Solihull MBC. The findings are interpreted in the light of the existing demographic, legal, and social contexts, the latest academic research on care technologies, and the experiences of other local authorities.

The main outcome is a formal approach to selecting appropriate technologies for individual older adults and a categorisation of care technologies that facilitates the process. The research also advises on how the selection method can drive pilots for care technologies or simply their implementation as part of upgraded care provision by health providers and commissioners.

The clouds gathering from increasing pressures of looking after an ageing population may turn out to have a silver lining for care technologies. This report looks at how that lining could be turned to gold for all protagonists: companies, care recipients, friends and family, professional providers, local authorities, and other health and social care support services.

## 1 General method and its rationale

The method used a mixture of desktop research, quantitative surveys by paper and online questionnaires, workshops, and semi-structured interviews. The academic review of recent studies was designed to gain insights from formal peer-reviewd studies. It was supplemented by more informal but aposite local authority experiences with implementing care technologies.

The results informed development of three questionnaires for older adults and their carers (see Appendix A). These were distributed by paper and online. The themes were used to conduct semi-structured interviews with a small number of participants and to run workshops with break-out focus groups. Other discussions and meetings took place in parallel, all with an informal, exploratory approach to check the questionnaires were not missing important issues and to include other protagonists in the technology-enabled care network.

The results from the mixed methods were pooled to determine the optimal approach for implementing older-adult care technologies. The goal was a formal set of steps and procedures that can guide both pilots and more general upgrades to care provision using technology. A typology of care technologies

was devised and populated by examples of each category to facilitate the linkage of older adult activities to appropriate technologies for supporting them.

### 2 User stories and associated research by the LDF partners

The older adult questionnaire provided encouraging support for the use of care technology in the home. Respondents have a reasonable level of technical knowledge and are willing to learn. They are also open to using technology in their health and social care, even to the extent of reducing the number of care visits. Loneliness might have been seen as a barrier because it was highlighted as a common issue for older adults but they appreciated how technology could positively address rather than amplify it. Another barrier could have been data security, especially given the importance of being able to share data in the co-creation of health and social care. However, only a minority was absolutely opposed to sharing data and most were happy with NHS organisations having them. The fact that more concerns rested with the formal and informal carers who have most contact with the older adults does suggest trust and collaboration need to be constructed for technology to be successfully adopted.

There was good news from the questionnaire for professional carers too. Respondents are very positive about the role technology can play in their care provision. Their vision for its application was wider than one might imagine, including the use of social networks and an understanding of how important it is to give the older adults technical support and training. However, there is a dearth of such training for the carers themselves, which providers and commissioners need to address.

These results are similar to those received from the informal carers who were not separately analysed because only eleven were received in the time given. However, all three questionnaires provide data on respondents that the academic and local authority studies identified as important to know when introducing and implementing technology. This means the questionnaires are an appropriate tool for understanding needs, attitudes, and contexts of participants in care provision using technology and can be incorporated within our proposed approach for implementing new technology-based care.

The more qualitative and informal interviews, workshops, focus groups, and meetings conducted over the three months of this study mainly supported the findings from questionnaires and desktop research. They served an important purpose of exploring narratives with people in a less structured way and providing a more nuanced human face to the same concerns uncovered by our parallel methods. They underlined the importance of keeping people, not technology, at heart: for example, just because technology *can* remove activities and tasks from a person doesn't mean that it should or that the person wants it to.

Our own local authority user research and stories were put into a wider context by looking at similar research conducted in other authorities. The consistent message from these is that both carers and recipients are willing to explore the use of technology for supporting and supplementing home care. At the same time, the enormous range of sensors and software involved is offputting. Choosing the right set is a daunting task and the best place to start is with the end users, especially the older adults. Once their needs have been identified, it is possible to select the general types of technology that can meet them. The questionnaires developed for older adults and carers are the primary tool for achieving this because they extricate the individual needs of and support required by each participant in the care network.

### **3** Principles and practice of implementing assistive-care technology

The LDF research allied with academic studies and experiences of other authorities provided the foundations for devising a formal approach for implementing care technologies. It is the primary deliverable for this report. It specifies three main steps for selecting care technologies and then applies them to setting



up and running pilots or, more generally, for implementing technologies as part of upgrading social-care provision.

The fundamental principle is that the whole process starts with the *activities* of the care network participants and *which ones need support*. This drives the choice of technology functions in general and, eventually, the specific products and systems, using the following three steps:

- 1. Identify all the participants involved in the care provision and establish all the activities that need supporting for each participant.
- 2. Map each participant's activities to the corresponding technology functions for supporting them.
- 3. Evaluate the candidate technologies for each function using a specially designed score sheet and choose the best set.
  - (a) This step is facilitated by organising technologies into functional categories, as shown by Part VI of this report.
  - (b) The categories are populated with example technologies and are a useful template for providers to add their own.
  - (c) The resulting classification helps ensure the methods of matching participants to the right technologies are more easily followed.

The score sheet for evaluating the technology is based on the Extended Technology Assessment Model (Pal et al., 2018) with a slant derived from ours and other people's research. It contains generic criteria that any technology should encompass. Those addressing similar actions are compared with each other, like with like, and the best set is chosen. The outcome should be an optimal holistic connected information and communication system incorporating all identified activities and dependencies revealed in Steps 1 and 2.

Narrowing down to specific devices, software, and services is then more about local contacts and knowledge than the sales and marketing raining down from corporate providers. Principles for making these choices and best practice for implementing the technologies have been embedded in a systematic method for setting up and running pilots. It is predicated on a justification for using action research that came out of the academic review.

#### **3.1** Piloting care technology

Selecting the technologies using the three steps comes first, followed by identifying the outcome measures for evaluating the impact of the technologies. Introducing the technologies to the care-network participants will feed off information already found out about them in choosing the technologies. It includes identifying and providing appropriate training and other technical support, ethics evaluations, ensuring data integrity, and monitoring the holistic care service as it operates. Performance is evaluated against desired outcomes and amendments to the service are made accordingly in the certainty that both the human and technological participants will need to adapt.

The goal is to optimise preparations for the system and collect the right data for evolving it. The blueprint for selecting technologies and implementing them is the main output of this report. It can be applied to prospective pilots for running within local authorities as part of their LDF alpha stages.



#### 4 Background review

The methods, results, and conclusions of this LDF project are grounded in academic research. This is where evidence has most credibility because it has been garnered from peer-reviewed studies that run over a long period of time, using principled methods and exhaustive, not to say exhausting, analysis.

The context for the burgeoning research literature is changing demographics and increasing access to the internet and its associated technologies by older adults. Aligned with the improvement in connectivity of devices and a massive expansion in the kind of information that can now be collected, the direction of travel is surely in favour of technology supporting home care.

#### 4.1 Social care context

An important factor is the social care context, the guiding policies and legislation, and the nature of home-care delivery. The new Integrated Care Provider (ICP) contracts should enhance the opportunities for care technologies to access information from all sources . . . but only if they are able to communicate seamlessly across services and systems. This has always been a major challenge. However, financial pressures are driving a number of initiatives to improve efficiency and reach of care. One is the Integrated Care Pioneers initiative, which is about new ways of delivering person-centered care. There are national workstreams involved in this, with one objective being to improve integration of informatics. At the same time, the Better Care Fund transfers resources from the health sector into pooled budgets managed jointly by local authorities and clinical commissioning groups, to enable integration and reduce pressures. The intended care integration is driven by cost savings as much as by trying to improve services but it does provide an opportunity for innovative approaches facilitating integration.

The rather unforgiving "austerity" financial climate could stimulate new approaches to care that are fit for purpose but save money. People have the option to pay for their own care, of course, or to obtain help from friends and family or other informal carers who may or may not be paid. Anything that can lessen the burden on this alternative care network would be welcomed in principle, which is where technology has an opportunity. Likewise, if the local authorities can use technology to provide better care more efficiently, they too should be highly motivated.

#### 4.2 Academic review

The literature review concentrated on the most recent ambient assisted living research and uncovered some high-quality in-depth studies. A number of common themes run through the results. The most important is the holistic, interactive, and dynamic impact of care technologies: they can only be understood in the real-world contexts where they are implemented. All protagonists are affected and how they react influences each other. Care technologies are complex interventions and multiple perspectives on how they are developed, rolled out, and continuously evolved are essential.

A hard, lesson from the academic review is how tough it is to get research into the market. A consistent problem is the technology-driven rather than user-driven approaches. Another is the competing interests of people involved in technology-assisted care. Gathering evidence to support the positive impact of technologies on care is a third, because they are interventions that don't fit well with traditional clinical trials. Instead, action research is a more appropriate approach, where the technologies are implemented and evaluated as they evolve in situ. Care technology should not be blocked because of a paucity of data justifying it but evidence collection should be built into the implementation and evaluation process.

The review crystallised many important lessons coming out of the academic research. Each one is highlighted where it arose and all are collated in the summary at the end. They represent an important set of issues and strictures for shaping how assistive technology should be managed. An overarching lesson is to be realistic about the challenges. It does not help anyone if promises are made that are not then delivered and commissioners, whether they be grant funders or care providers, should not have exaggerated expectations.

The other crucial lesson is to keep care recipients fully in vision at all times. Older adults are not a homogenous population when it comes to technology. Neither do they stay in the same place with regard to their health. Choice of technology for older adults needs to be monitored regularly because what is selected initially, in accordance with their demographics and lifelong experiences, can become redundant if their health status changes.

Technocentric development is more common than a process driven by the recipients and this needs redressing. The first step is to make sure everyone involved has an accurate understanding of the care recipients and their capabilitites. In particular, it is essential to know which activities people wish to support and how these influence their attitudes to associated technology. Social connectivity is a significant aspect and there is a common belief that it is being threatened by technology. Studies have been more optimistic and shown how the opposite may be the case. As ever, the reality takes into account each person's particular circumstances and motivations. The person's holistic life must be matched by holistic systems of support.

#### Part II

## User stories and associated research by the LDF partners: Birmingham City Council, Worcestershire County Council, and Solihull MBC

This section summarises the LDF user research conducted within the three partner authorities. It involved the creation of three questionnaires, some semi-structured interviews, and user workshops that included technology providers, users, and commissioners.

### 5 Background

As with the general population trends, the percentage of older adults is increasing in the three local authorities. The projected change for over 65 year olds in Birmingham is estimated to be 35% by 2035 (ONS Population Projections). In response to this, and along with positive attitudes from older adults to the use of technology in their care, Birmingham City Council (BCC) devised an Adult Social Care, Technology and Equipment Strategy (Assistive Technology) for 2019 to 2024. Discussion showed citizens welcomed the opportunity for greater flexibility around visits where, for example, some could be dropped if friends or family were visiting, and they were open to the idea of using technology for reminding them about medication and other care routines that may mean a home visit is not required. They saw how technology could help organise their own lives better and reduce their dependence on carers but they were also keen to point out that they would need plenty of help and support with that same technology. These initial findings mirror what other councils have found.

BCC's strategy for care technology is to reduce isolation, enhance independence and dignity, and support the carers. In accordance with the academic literature review, it focuses on outcomes and needs: starting with the people not the technology. Co-production is the name of the game where the technology is chosen and configured by the people using it. New and emerging technologies must be given a chance, too, with artificial intelligence opening up avenues of support that were not previously available.



Figure 1: An illustration of the range of technology included for consideration by Birmingham City Council's care strategy

Figure 1 shows the range of technoogy included for consideration by BCC, from simple mechanical aids to machine learning and robotics.

The BCC strategy links with the Birmingham and Solihull Sustainability and Transformation Partnership (STP), "Live Happy, Live Healthy" (2018). It emphasises the importance of technology on mental health and wellbeing, not just physical care. This holistic involvement of technology requires a radical overhaul of how residential and nursing care is provided at present. It motivated the ADASS report by the West Midlands Directors of Adult Social Services (wm-adass.org.uk, 2018) that proposed three components:

"firstly ongoing investment in housing schemes such as extra care housing or community care villages where people are enabled to live independently within a supportive communityled environment; secondly an extension of the role of residential care homes to meet resident's needs with good quality care, whilst also reaching out into the community to those who are at risk of entering residential care to respond to people's general desire to remain in their own home for longer by providing support to individuals and their families. The third part is the component that needs significant development and work proposes that for those with multiple and complex needs and/or who are at the end stage(s) of their life, care homes are developed and funded to ensure suitably qualified specialist staff with direct links to



GPs and Allied Health professionals are in place as well as the establishment of an alliance partnership with their local Community and/or Acute Hospital."

The ADASS report envisages care in the community progressing through integration of services and the technologies supporting them need to do likewise, with a seamless flow of data between them. This LDF discovery stage investigated the types of technology and data that are required for such integrated care and the attitudes of care recipients to them.

#### 5.1 BCC's current care technology

The following list is not complete but gives an indication of the type of technology being used in the local authorities. These are the ones with which care recipients and their carers will be most familiar.

- Careline: a box connects to the phone line and the service user wears a pendant with a button. Pressing this button calls a centre where they can ask for assistance.
- Telecare: add-on devices such as bed occupancy sensors and other needs-assessed support that link to and emergency response service.
- Connect2Support: online information and advice for people with care needs. Includes information about types of equipment available.
- Minor (e.g. installation of hand rails, lever taps) and major adaptations (e.g. stair lifts, room extensions) to the home. Financial assistance is available through the means tested Disabled Facilities Grant and an estimated 5,000 citizens in Birmingham living in adapted homes
- Just Checking sensors for monitoring activities in the house as part of assessing care needs.
- Birmingham Community Loan Equipment Service Medequip, which is a commissioned service, jointly funded by health and social care). It provies a wide variety of equipment and aids to daily living ranging from simple mobility aids, such as crutches and walking frames, to more complex items such as profiling beds and hoists. Items are provided to citizens free of charge, on loan or single issue. In 2017/18, 105,832 pieces of equipment were delivered to citizens.

The next section explores older adults and professional carers' attitudes to the use of such technologies and new ones that could be introduced.

## 6 General method and its rationale

The method used a mixture of desktop research, quantitative surveys by paper and online questionnaires, workshops, and semi-structured interviews. An academic review of recent studies into care technologies for older adults was first conducted to understand the issues impacting on succesful implementation. It revealed what types of information must be known for all the various participants in the care network. It also provided useful lessons on how to approach care technology implementation and the complex dynamics involved in subsequent provision.

The academic research was supplemented by a review of the grey literature surrounding, in particular, local authority experiences with implementing home-care technologies. This generated additional pragmatic details related to the organisational contexts that apply to our own LDF partners. The outcome of the combined reviews was a clear understanding of what has to be known about carers and the care recipients before any technology is considered. Three questionnaires were created (Appendix A) based on the reviews and our own discussions within the research team. Each one had a slightly different perspective but all were designed to understand the needs, attitudes, and profiles of individual respondents with respect to care technology. Most answers were quantitative with some supplementary qualitative text responses where appropriate. Frequency analyses on the different answers were conducted in the main but interesting potential interactions and correlations were also explored.

Semi-structured interviews were based on the themes covered by the questionnaires. The notes were written up afterwards for informal analysis. The objective was to validate the questionnaires, with a view to seeing whether there were any additional issues the questionnaires had not exposed. Similarly informal workshops and smaller focus groups were conducted with participants who were a mixture of care recipients, carers, and providers. Parallel discussions took place with technology companies and related organisations involved with helping authorities select appropriate technology.

The results of the questionnaires, workshops, and group discussions were used to devise a principled method for selecting and implementing technologies for older adults. The integrated desktop and field research provide a strong empirical basis for the method despite the limited time available for collecting, analysing, and interpreting the data.

## 7 Questionnaires

Three questionnaires were devised (see Appendix A), one for older adults, one for their informal care network of friends and family, and one for the professional carers. Each type was available either on paper or as a web survey and none of them collected any personal identification information. Distribution was through the three local authorities and their care providers involved with this LDF project and by asking for the weblinks to be advertised via networks known to the researchers at Aston University, particularly the Aston Research Centre for Healthy Ageing (ARCHA). Ethics approval for all questionnaires was obtained from Aston University.

The distribution and collection timespan for questionnaires was very tight for meeting this report deadline but we intend to continue gathering data to inform the alpha proposal and ensuing pilots. The total number of respondents is 99, with most being for the older adults. Questions were voluntary to encourage people to review all questions without having to answer every one, which does mean the frequencies of answers can vary. The text-based more qualitative ones were answered the least and are more difficult to analyse incrementally. Hence these have not been included here but will be processed when the numbers have increased sufficiently. This will be in time to draw up the pilots and further grant applications. The older adult and professional carer quantitative data are given in full in Appendices **B** and **C** respectively. Only eleven informal carer questionnaires have been completed at the time of writing and so we have not included them.

#### 7.1 Older adult questionnaire

The older adult care recipient questionnaire covered four main areas:

- 1. personal information about demographics, health, education, and with whom they live;
- 2. care and support currently being received;
- 3. experiences with and attitudes to technology in general and for healthcare;
- 4. data sharing and security.

In total, 65 responses were received with 57% female. The age range was 90% over 64, 68% over 74, and 28% over 84. Most people lived on their own (67%) or with their partner (24%) and in a city or town (86%). Equal percentages of 40% had no qualifications and a higher-education certificate. Half were in good or very good health with less than 20% in poor health.

Nearly all feel mostly or always safe at home (96%), which is encouraging. However, more than a half have had falls and other accidents but this may be a good sign in that despite being at risk of accidents, people continue to have a positive attitude to living at home. Loneliness is more of an issue, with 48% feeling it sometimes, and is why any technology solution must address this important aspect of wellbeing.

Regarding attitudes to technology, it is encouraging that three quarters of respondents are interested in learning, even if 25% never wanting to find out about new things is still rather high. The technology currently being used by respondents is a mixture of devices but about a fifth already have access to a smart television, which opens up some newer forms of telecare. Over half have internet access through smart phones, laptops, and tablets, which accords with nearly 50% having a general level of interest in smart technologies of one sort or another.

People were willing to consider using these technologies in their homecare, with 40% saying they would access health services and advice of one form or another. Nearly one quarter would use it to stay in touch with friends and family, which is an important incentive for adopting and learning to use technology as well as emphasising how it can improve rather than detract from social interactions.

Over half of the respondents had at least a reasonable level of technology competence but one third said they knew nothing about technology and introducing care technology for them will require considerable effort and support. Correlating with these proportions is that half of the older adults were interested in using smart technology for tracking activities, health, and wellbeing with most of the remainder open to persuadion. Less than one fifth would not even consider technology as a means of keeping them at home rather than in residential care, which means technology is seen as a positive way forward to some extent by over 80% of the respondents.

One of the areas where technology could save costs is in reducing the number of visits by care workers and we asked what people thought about this. Less than 40% were definitely against it but, as expected, most of these ones with little or no knowledge of technology. Hence their views may be more a reflection of their own confidence in and understanding of technology, with concerns about how they would have to relate to it within care. It emphasises the importance of providing help with using the technology and many people volunteered what they would need to this effect. It ranged from being shown how to use it, a "simple" manual, ecouragement and information, the ability to contact someone, or even a "personal technology assistant perhaps". It emphasises what the academic research has been reiterating: attitude to technology and training in its use are essential areas to address for building confidence and encouraging adoption.

Data security has come under the public spotlight in the last few years, partly because of the horrendous data breaches by social media companies such as Facebook and partly because of the General Data Protection Regulation that came into force in May of 2018. These may have reduced confidence of people in technology, especially if it holds sensitive care information. We asked specifically about sharing data that can personally identify the older adult. In general, the response was encouraging regarding trust in the services that would hold these data. Less than 10% would not share with their general practitioner or other NHS organisations. It increases to 15% who would not share data with family members and, perhaps surprisingly, jumps to nearly one third when it comes to sharing with formal carers and socialcare services. It is worst with informal carers, with 40% saying they would not share personal data with them. Work needs to be done on the trust relationship between carers and older adults with respect to the use of technology, which is probably because these are the care workers who have the most to do with the care recipients on a daily basis ... and therefore the ones who can detrimentally affect them the most. When exploring relationships between the variables, most were unsurprising, such as a positive relationship between being interested in learning and interested in smart gadgets; or a strong negative relationship between the level of technological competence and level of prior education. The latter is why knowing something about a person's education can help identify the need for additional help with the technology. It is, though, just one factor and the questionnaire as a whole gives a better picture of what kind of input is required to increase the chance of successful adoption. A less obvious relationship is between education and the number of care visits: the higher the education, the fewer the number of care visits received. This may be due to socioeconomic factors but could also suggest better ability to use self-help resources.

#### 7.1.1 Conclusions

The questionnaire has provided encouraging support for the use of care technology in the home. Respondents have a reasonable level of technical knowledge and are willing to learn. They are also open to using technology in their health and social care, even to the extent of reducing the number of care visits. Loneliness might have been seen as a barrier because it was highlighted as a common issue for older adults but they appreciated how technology could positively address rather than amplify it. Another barrier could have been data security, especially given the importance of being able to share data in cocreation of health and social care. However, a minority was absolutely opposed to sharing data and most were happy with NHS organisations having them. The fact that more concerns rested with the formal and informal carers who have most contact with the older adults does suggest trust and collaboration need to be constructed for technology to be successfully adopted. The academic research was in agreement with these findings.

#### 7.2 Questionnaire for professional carers

It was more difficult to get respondents for the professional carers' questionnaire (Appendix A) in the time given and 23 have so far been completed. Only two were by male carers and most were in the role for less than five years. Technical competence was felt to be generally good with only two saying they had no experience and nearly everyone used a desktop or mobile computer of one form or another. Most were educated to 18 or beyond.

The carers were asked to assess how useful various applications of technology would be to their roles. Looking up information on the web was universally useful and, surprisingly, only two people thought that developing material for publishing online was not useful at all. Carers may be appreciating the reasons for uploading their own experiences in blogs, newsletters, and other outlets because they like accessing it themselves.

Knowing how to maintain confidentiality and privacy is seen as universally useful, which is a result that should increase the confidence of care recipients in sharing their information with carers: older adults were more worried about their data with carers than healthcare organisations. With relation to different forms of care technologies, all had a heavy majority seeing them as very useful in the main or at least quite useful. This included systems monitoring health status, implementation of a variety of sensors, automated alerts, moving equipment, general administration, prompts for medication and other activities, supporting the care relationship itself, and maintaining people's ability to live at home. Encouragingly, the carers were also aware that they would need to know how to set up the digital technologies for themselves or the older adults and help with their training (only one person thought this was not required). Only three carers did not see the usefulness of social networks for collaborating with other care workers and most (77%) could see how such networks might help them link up with patients. Slightly more thought that patients communicating with each other via social networks would be a good idea.

When it comes to how much help or training the carers have had with using these technologies and delivering the related services, the picture is not so rosy. For the direct care technologies, in general less than half have been taught how to use them. The carers are aware of the usefulness of being able to train older adults to use technology but 80% have not themselves been given any training to do it. Training others to use technology is a skill in itself, in addition to knowing about the technologies and should be a high priority according to all our research.

#### 7.2.1 Conclusions

The good news is that professional carers are very positive about the role technology can play in their care provision. Their vision for its application was wider than one might imagine, including the use of social networks and an understanding of how important it is to give the older adults technical support and training. However, there is a dearth of such support and training for the carers themselves, which providers and commissioners need to address.

These results are similar to those received from the informal carers. We have not analysed them separately because only eleven were received in the time given. However, all three questionnaires provide data on respondents that the academic and local authority studies identified as important to know when introducing and implementing technology. They are therefore central to the proposed method for new home care provision based on technology.

## 8 Interviews and workshops

The older-adult questionnaire developed for the LDF project was also used for supporting semi-structured interviews with older adults. This was conducted alongside the care provider's normal visit. It was clear that one size fits all is not the answer to how technology will improve people's lives: each person is different and understanding their specific needs and attitudes is crucial. In particular, the technology should work alongside and fit with the person's normal activities and rhythms of life. For example, during a visit with a 90 year old citizen, the interview turned to daily life tasks. While climbing a mountain might be a step (or two) too far, completing these little life tasks, as she had always done, is important. Opening and closing the curtains, turning things on and off, were some of a hundred little things that gave her independence, kept her active and kept a sense of normality in her life. This is an important lesson for technology and care providers: equipment might be able to close the curtains or turn the television on and off to save the physical effort but is this a good thing and is it what the person wants?

**Lesson learned:** just because technology *can* remove activities and tasks from a person doesn't mean that it should or that the person wants it to.

When it comes to the users, firstly, we need to ensure that the individual human remains front and centre. Our interviews and accompanying questionnaires have clearly shown an interest in technology and reasons for its importance in care. But there can be unintended consequences where the quality of life can be lost because important activities are taken away from the person. The point about home care is to keep people active at home, not keep them at home fixed to the sofa.

#### 8.1 Workshop with care recipients

A workshop was conducted with people from independent-living villages, full-time carers, parent carers for those with learning disabilities, and service users. What soon became clear was a lack of understanding about what 'assistive technology' means to the layperson. It can include mechanical or digital





devices, ranging from stair lifts, grab bars, and sensory/functional Assistive Technology (AT) such as hearing aids and orosthetic limbs right across to assistive robots. The range is vast and confusing with frequent questions being "what technology can you provide for us?" and "how do we find out about it?". An important conclusion was to have a single, integrated model of delivery that ensures all citizens have access to the full range of AT and are genuinely enabled to get a personalised offer that meets their outcomes.

Barriers to AT echo those found in the academic research, the questionnaires, and other council's user views. Trust in technology needs to be built, particularly with its reliability and what happens if it fails, and people require more training and support to use it. Information is hard to absorb the first time and needs supplementing by online resources such as videos. As one person said: "Happy to try new technology but don't just leave me the box and walk away. Provide drop in centres and workshops to help us."

Social norms are important for engagement, as (neves-2019) found: who else is using it and how confident they are: "Maybe talk to family to see what they can do about showing me how to use gadgets when they visit. I would need to be shown lots of times". People may be more willing to use technology after discussing it with other service users of similar needs and demographics and proactive engagement of carers would help, to see how the technology is being assimilated. If people thought the result of technology use would be increased social isolation, it would not be welcomed. However, as the questionnaires found, technology can do the opposite and one person said "Alexa is great to help reduce social isolation, I'm even cooking again with Alexa's help and sharing this with friends, as I've cooked too much, so impressed".

Decision making must be given to the care recipients over selecting and rejecting technology. There were concerns regarding privacy and whether or not they would be "spied on" but carers felt that the same monitoring functionality was actually helpful because they can keep track of the older adults. This backs up the importance of ensuring all parties are involved and their motivations are aligned.

Stigma was a concern that came up for the wearable technologies, with people not wanting it to be obvious they are dependent on technology. They prefer wearables that look good and blend in as normal clothing or jewellery.

### 9 Overall summary and conclusions

This LDF research conducted an extensive review of the latest academic research into assistive technologies. It was supplemented by some recent and current investigations by local authorities into how their own home care provision could be improved by the use of such technologies. We then explored the technologies and strategies in progress within the three partner authorities of this LDF project. Surveys of users and carers were conducted using specially-constructed questionnaires accompanied by some semi-structure interviews and workshops. The consistent message from these various avenues of investigation is that both carers and recipients are willing to explore the use of technology for supporting and supplementing home care.

The enormous range of sensors and software involved is offputting at the same time as representing an opportunity. Choosing the right set of technologies is a daunting task and the best place to start is with the end users, especially the older adults. Once their needs have been identified, it is possible to select the general types of technology that can meet them. The questionnaires developed for older adults and carers are the primary tool for achieving this because they extricate the individual needs and support for each participant in the care network.

Narrowing down to specific devices, software, and services is then more about local contacts and knowledge than the sales and marketing raining down from corporate providers. Principles for making



these choices and best practice for implementing the technologies have emerged from the research. They have been embedded in the next part of the document that provides a systematic method for setting up and running pilots. The blueprint is the main output of this report and has been applied to prospective pilots that can be run within the LDF partners in the next alpha stage.

## Part III User stories and associated research from other local authorities

## **10** Local authority studies

Policy changes around home care and the implications for integrated care are stimulating action from Local authorities. A Local Government Association report (*Transforming social care through the use of information and technology* 2016) draws on findings from its Social Care Digital Maturity Self-Assessment (SCDMSA) and discusses how information and technology can be used to improve service delivery and integration. It emphasises meeting the needs of individuals, prevention of health issues, and the 'joining up' of information and systems. Five themes of social care innovations were identified where IT is already having an enabling role in delivery of services:

- 1. integrating services and information for children, families and adults
- 2. enabling people to interact with care services through digital channels
- 3. promoting independence and wellbeing through use of digital services and technology
- 4. integrating commissioning through improved use of information and analysis
- 5. enabling care professionals to work from any base at any time

Although the SCDMSA found 90% of respondents are involved in some form of information-sharing initiative across children's or adult's services, only 15% currently contribute to a consolidated view of the citizen's health or care record and even fewer (8% of adults) have access to this. If we are going to pay more than lip service to co-creation of health care, then recipients must be able to see and contribute to their own records. The SCDMSA survey itself emphasised the importance of obtaining public engagement with information-sharing initiatives to reduce fears around the use of personal data.

**Lesson learned:** Give care recipients access to their full health records and provide ways for their direct contribution to shared information.

Integrating information becomes a problem when people cross care settings. The SCDMSA found that phone calls and faxes can lead to errors and delays and only 40% of councils have access to information from health and social care providers to facilitate electronic referals. If integration can be achieved, it opens up the chance to save considerable amounts of money, as Cumbria found when they implemented Strata Pathways, which helps NHS Trusts to automatically and electronically make referrals to social care services (see Section 21.2, Item 4. Efficiency savings were estimated to be about £400,000 and the time needed to make a referral was been reduced.

**Lesson learned:** Sharing information and automated referrals can generate significant savings.

Over 95% of councils which responded to the SCDMSA provide telecare equipment supported by services which respond to personal alarms and alerts. There is increasing emphasis on the use of technology for proactive monitoring, rather than traditional reactive response calls; using e.g. discreet monitoring devices installed in care homes, sheltered housing or privately owned homes. Three years, later, the local authority territory should have become considerably more fertile, which is explored next.

#### 10.1 Stockport

Stockport has a commissioned Technology Enabled Care (TEC) service supporting 1,500 people at home to live independent lives but it is not being taken up as much as expected or having the desired impact. The existing TEC solutions require installation by technical staff who are under pressure and so waiting times and delays are endemic. Plus the technology is not really replacing existing services and so failing to save money. Hence Stockport put in for a discovery and implementation phase of the Social Care Digital Innovation Programme (*Maximising the impact of technology enabled care 2018*). It targetted older adults who were already using the current telecare service, Carecall, which made access and adoption of different technology easier.

The technology involved in the system is mainly reactive and not predictive or preventative. Half of the technology cost is due to the lifeline unit that manages the calls and the pendants worn by older adults. Existing problems with their telecare service included:

- False alarms: the number one reason for calls to the monitoring centre.
- No voice contacts: 86% are false alarms.
- Reassurance/anxiety: main reason for calls and one of the benefits to recipients.
- Fall Detection Accuracy: out of 1983 calls triggered automatically by the falls detector, only 24 (1%) were genuine. Nevertheless, recipients are concerned about falling, even though it is a rare occurrence.
- Actual falls need interventions and so are high cost.
- Long assessment lead time: it takes 8 weeks for a social carer to compelete an assessment for the suitability of technology.
- Long installation (lead) time: between 16 and 20 days to put the system in once a referral is made.
- Perception of service/eligibility: 16% of installations did not happen, mainly because the recipients refused to have them. Recipients were not clear about the technology, how it worked, or how useful it would be.

Solutions offered to address these problems included:

- 1. Easier installation of equipment or self-installation.
- 2. More regular re-assessments.
- 3. Change the hub unit and supplementary kit to make communications better.

- 4. Have multifunctional wearable devices.
- 5. Improve marketing and awareness about falls.
- 6. Conduct falls assessments within current care pathways.
- 7. Have reminders automatically generated to help with anxiety and reassurance.
- 8. Use the community for first responders. Note that many of these services already do this.
- 9. Combine data from numerous sources to improve triggering of falls alerts and voice calls.
- 10. Predictive analytics for proactive referrals.
- 11. Use video calling for reassurance.
- 12. Use automated voice interaction for reassurance, such as Alexa.

Some information about costs were that 3,196 Code 1 attendances were made in a 12-month period to homes by responders. Stockport says that people with a telecare service in place only required an ambulance for 8.66% events but it is not clear what this means compared to those without telecare. The project concluded that "Without the monitoring and responder service, the number of residents requiring an ambulance would have been significantly higher, as would the resulting costs of care. This further justifies the focus on the current telecare service." However, it is impossible to evaluate the claim without having much more data about who has the telecare service, how they compare to those without, and why ambulances would be required more often if the telecare people did not have the technology. And, of course, one has to factor in the costs of all the false alarms and other servicing the telecare system requires.

#### 10.1.1 Conclusions

This preliminary review of Stockport's telecare provides useful confirmation of the academic research studies showing their relevance to our own community-care services. In particular, the solutions confirm the need to have an intelligent communications hub for proactive referrals and to feed it with triangulated data from multifunctional sensors.

#### **10.2 Sunderland City Council**

Sunderland City Council conducted a discovery phase study as part of the Social Care Digital Innovation Programme Implementation Phase Application (**sunderland-2019**). It had the title of "Designing a Viable Platform to Capture and Present Data from Innovative Technological Solutions to Common Social Care Issues." The aim was to determine how assistive technologies could combine with and enhance their existing telecare service. They acknowledge what many others have observed: that the plethora of technologies makes it very hard to investigate them all and they quickly go out of date anyway. Their intended solution was to develop a score card to assess the most suitable assistive technology solutions and design a platform for presenting the data collected by the technology in a meaningful and simple way.

Three workshops were conducted but no details are given about how participants were selected, their specific roles, or the numbers. However, this is par for the course for local authorities compared to the academic studies that are necessarily more rigorous and scientific.



	Start with users' needs						
Score	Criteria						
0	technology-led rather than problem-led.						
3	indirect benefits to address a minor problem.						
5 part of a range of systems that in combination would directly address a minor pro-							
7	part of a range of systems combining to directly address a major problem.						
10	the main system for directly addressing a major problem.						
Be innovative							
Score	Criteria						
0	established technology with limited innovation.						
3	established technology but a new service/ way of working.						
5	new technology to improve an existing service/ way of working.						
7	new technology and a new service / way of working.						
10	new technology and a new service / way of working with automated decision-making.						
	Improve quality of life						
Score	Criteria						
0	no direct benefits for patients or carers.						
5	direct benefits for patients or carers.						
10	transformational benefits for patients or carers.						
	Reduce the level of care and support required						
Score	Criteria						
0	the care and support requirements are unchanged or have been increased by the introduction of the technology.						
5	the same level of care and support is required but the quality has been improved by the system supplementing it.						
10	the level of care and support required has been drastically reduced.						
	Protect users from potential avoidable harm						
Score	Criteria						
0	the pilot technology will not help to mitigate avoidable harm.						
5	the pilot technology will provide information or assistance to mitigate avoidable harm.						
10	the pilot technology will directly prevent a situation from occurring that would create avoid- able harm.						

Table 1: Sunderland method for scoring care technology

The most interesting output of the workshops was a scoring system to determine which use cases should be supported by what kind of technology. It underlines many of the lessons coming out of the academic studies and provides a useful basis for assessing assistive technology.

This score card system was used to rank the comments from workshop participants and determine use cases for implementing technology. The result was Medication Management; Monitoring Mood; Nutrition and Hydration; and Moving Around the Home. Each of these was justified by the workshops and given a solution brief. In essence, the scoring identified, for example, polypharmacy and taking medication as a major concern for people with dementia and frailty, which is why it is a use case.

The supportive care technologies "would have to make sense of all the data presented by a range of technology devices and turn it into meaningful consistent and understandable intelligence." The identified solutions were templated as "what", "who for", and "to support them in". For medication, it was a "connected device" for "people over 18 with multiple medication needs presenting with cognitive difficulties and living at home" to "support them in taking the correct doses and having family or carers monitor this". This is a good approach because it looks at the generic role of technology, not the specific technologies themselves.

**Lesson learned:** Match the generic functionality of technology to user needs before worrying about the specific technologies available.

Choosing appropriate technologies revealed the problem of proprietory technology not being able to incorporate devices from different companies providing them. "Overall we found that purpose built solutions failed to live up to our design principals of Openness, Scalability and Economic Viability." It is an important conclusion that our own pilots would do very well to heed.

**Lesson learned:** Choose technology that is scalable and has open standards to prevent being locked in to proprietory solutions.

Identifying suitable technologies was achieved using the same score cards for developing the use cases. The exact mechanism is not clear but it makes sense to focus on the needs and how they can be met, which was the objective of the scoring.

An important realisation was that the data and their use should drive decision making "recognising that it is possible to gather lots of data, but it is sometimes only by combining data sets that the data becomes meaningful." Triangulation of data from different sensors is key, as was found in the Stockport case study, and the real value "is in being able to see a range of metrics in one place in order that it becomes meaningful and manageable." It underlines why Sunderland emphasised interoperability of devices and avoidance of "lock in" to a particular supplier.

**Lesson learned:** Ensure technology solutions are open and flexible, with interoperability at the heart so that devices can be added and able to communicate with each other from different suppliers.

In terms of procurement, delays were a risk and so the group agreed to follow the Official Journal of the European Union (OJEU) model of procurement. Whether this will have a tangible impact remains to be seen. The more important principle for procurement would be one raised in the academic research: use technology providers who you know and trust, with the research and development team working collaboratively and responding in real time. Relationships are more important than ticking bureaucratic boxes.

#### 10.2.1 Conclusions

The score cards were the most influential outcome of the study. They resulted from local workshops but also reflect the conclusions coming from more academic studies. Taken together, it should be possible to adapt them for our own pilots to help identify appropriate recipients for AT and the technologies best able to support them.

#### 10.3 Utopia project

King's College London carried out an online survey of local authority telecare managers between November 2016 and January 2017 (Woolham et al., 2018). The aim was to determine how telecare is being used by local authority adult social care departments to support older people. The survey contained 58 questions and 114 valid responses were received.

The most important roles for telecare were seen to be delaying and reducing the need for care and support (97%), enhancing quality of life for people with needs for care and support (90%), helping with safeguarding (85%) and preventing carer breakdown (84%). Respondents thought that telecare carried out these roles by helping to manage risk and promote safety (100%), supporting unpaid carers (81%) and providing reminders and prompts (77%).

In terms of telecare adoption, access to telecare, advice, and support were not a problem but knowledge about the technology and skills required to improve skills needed attention. There were few concerns about the erosion of privacy, which is unsurprising since these are the managers not the recipients, but they did express concern about the potential to reduce human contact and face-to-face care. Other barriers included lack of skills amongst professional staff for assessing telecare, inflexibility of contracts with suppliers of technology, and lack of staff able to install telecare.

Telecare assessors included a range of professional backgrounds, from specialist telecare workers to care managers, social workers, and occupational therapists. Training for assessors was limited, mainly from suppliers (45%), sometimes peer-to-peer, which we take to mean you ask someone in the organisation who is already doing it, and sometimes the local authority. External educational establishments were hardly ever involved and there were no formal qualifications, with training lasting no longer than a day.

One quarter of respondents thought telecare saved money but they were not able to provide empirical evidence to justify the assertion. Only a fifth had local authorities with a specific telecare budget. The most common technologies were lifeline and pendant alarms (53%), fall detectors (50%), bed or chair occupancy sensors (48%), and smoke detectors/alarms (42%). Responses to alarms or messages from the telecare were mostly fielded by relatives and family (20%) followed by the local authority's own service (15%).

#### 10.3.1 Conclusions

The survey confirms what the more detailed studies have shown with few surprises. There is a clear role for technology but lack of training in its use is a problem. Savings are expected, with claims made despite little hard evidence. The next section examines some other councils making assertions about savings.

#### 10.4 Blackburn with Darwen and Hillingdon

A local government report with no authors but on the local government website (https://www.local. gov.uk/sites/default/files/documents/telecare-and-assistive-te-e36.pdf) gives information on two councils, Blackburn with Darwen and Hillingdon. The document is not dated but was probably produced in 2014/15, judging by the contents. It is interesting because of its claims about hefty savings achieved through telecare.

After a long lead-in of pilots from 2008 to 2012, Blackburn and Darwen established its "Safe and Well" telecare service from April 1st, 2012. A review of the pilots showed benefits to both recipients and the council, although there is no evidence how those benefits were measured. Likewise for how the cost efficiencies over that period were calculated but the figure is £2.2 million. One year after the Safe and Well programme, a further £1.2 million cost efficiences were generated. Although this programme won an award in 2015, there is little evidence of it on the council website after 2016 so it is not clear how it has progressed and the specific programme is no longer visible.

Hillingdon Council also investigated how telecare can reduce costs for older adults by helping them remain in the community. Hillingdon's TeleCareLine service provides eligible residents with a Lifeline Connect+ personal alarm, a MyAmie+ pendant, bogus caller alarm and a smoke detector as standard. Depending on individual needs, additional sensors might also be provided. The impact was that long-term residential/nursing care placements went down from 8.08 a week in 2010, before the telecare installations, to 2.13 per week by 2014. The council telecare and reablement serviced saved "£4,957,000 by March 2014". Again, it is not clear what period those savings covered, how they were actually achieved, or how they were calculated but it is probably safe to say that the improved telecare services were cost effective.

**Conclusion:** big claims, little substantiation, but it is certainly worth pursuing care technologies as a cost-effective solution.

#### **10.5** Council Local Investment Programmes

The Local Government Association is funding digital innovation in social care in collaboration with NHS Digital (www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/ informatics/local-investment-programme). It resulted in a number of reports in April 2018 for investigations into technology-assisted care. None of them have produced any definitive results yet but they are interesting by the choice of technologies to investigate. Hampshire County Council is trialling the use of voice interaction using the Amazon Echo and its assistant, Alexa, to reduce social isolatoin and increase informal carer reassurance. They estimate savings of £66,300 over 50 users in a year.

Essex County Council is hoping to reduce physical visits using video calls instead. They are using a secure system (SpeakSet) that exploits existing television sets to make video calls with friends, family and health and social care providers. They suggest that the technology "should be a more convenient and less intrusive method of interacting with a care worker", which is an interesting take on whether visits are seen as part of socialisation or not. One wonders whether this view has been substantiated with their own care recipients. Their initial results have not been too promising: the equipment has been unreliable, finding suitable recipients not easy, carers are struggling with applying the technology, and reduction in physical visits not obtained. All of which support the issues raised by researchers and highlight the challenges.

Other councils are involved in the same funding scheme. Their proposals are looking for similar savings and outcomes but are not specific about the assistive technologies used to achieve them. It is early days for all the councils with this scheme, of course.

#### **10.6 Hampshire County Council**

In a separate case study, Hampshire County Council developed a technology-agnostic approach to the provision of assistive technology: the technology provided was based on the barriers social care aims to address and the desired outcomes. While there was a risk of social workers not engaging, over 1,000



were trained and the council claims a net saving of  $\pounds 1.9$  million in 2015/16. Assistive technology was used by 2,931 older people that year. Senior management buy-in and willingness to give autonomy to staff were identified as key enabling factors.

**Lesson learned:** there are strong financial incentives for implementing care technology.

#### 10.7 Gloucestershire County Council

Gloucestershire commissioned an assistive technology pilot in three properties in 2011. The aim was to assess how AT could promote the independence of the 11 tenants (adults with learning disabilities), and to replace the need for 24/7 staff support with an AT system (Sanders and Rogan, 2017b) The homecare provider and technology supplier jointly assessed the environment and the individual needs of each tenant, then made personalised recommendations for technology to be installed. These recommendations included:

- A Door Contact Sensor for the bathroom door to indicate whether the bathroom was entered or left, as well as a flood sensor, for a service user who had a history of leaving taps on and causing floods.
- Sensors on the front and back doors to replace the chain currently used to prevent residents from going out, allowing them more freedom to move around the home.
- An epilepsy sensor for a resident with epilepsy to give a better understanding of what support is required during the night.

After assessment, assistive technology was installed in two of the three properties, with positive results and significant savings. In one property, the waking night care provision was able to be removed 4 weeks after installing of AT, resulting in savings of £839.79 per week. In the second property, waking night provision was able to be reduced to sleep-in night provision, resulting in savings of £559.79 per week. Annual savings in 2015/16 amounted to £72,178 and cumulative savings since the pilot began of £319,337 (accounting for maintenance and set-up costs of the AT).

Gloucestershire County Council now provides a range of assistive technology for people with different care needs and in different types of accommodation, including supported accommodation and sheltered accommodation. It identified some challenges and lessons during the pilot: training staff needed more time; service users and their circle of care (family, friends and carers) tended to be initially cynical about the potential benefits of assistive technology before seeing them in use; and earlier meetings with project staff would likely have improved initial engagement. This substantiates the academic studies that uncovered the importance of raising awareness in care recipients at an early stage.

#### 10.7.1 Case Study: Miss W

On their Telecare website, Gloucestershire County Council (2019) present the case of Miss W, who is in her 60s and lives alone, and has an undiagnosed learning disability. Rather than receiving some predetermined or standard set of assistive technology, Miss W attended a Telecare assessment. The case study shows how careful assessment can find ways of applying technology creatively. For example, Miss W is hard of hearing and may not be able to hear or react appropriately to smoke alarms. So the team connected the smoke alarm up to Miss W's lifeline unit', which maintains a connection with a 24/7 monitoring centre. Now, if smoke is detected, staff at the monitoring centre would be alerted immediately and could take the necessary action.

Similarly, during the assessment, it was noted that Miss W had previously missed her medication, and this was determined to be due to short term memory difficulties and her learning disability. Miss W was provided with a pill dispenser made by Pivotell, a company which develops products for dispensing medication or sending medication reminders (Pivotell, 2019). The dispenser would sound an alarm and show a flashing alert when medication is due, and it would automatically dispense the correct medication. Just like the smoke detectors, the medication dispenser was connected to the lifeline unit, enabling an alert to be raised if Miss W does not take her medication.

Using information collected by a movement monitoring system, Just Checking, care workers were able to confirm that Miss W was leaving her home. Property exit sensors were installed and connected to the lifeline unit so an alert was sent to the monitoring centre if Miss W left her house, allowing responders to find her. In addition, a device was installed which would play a pre-recorded voice message if detecting motion, encouraging Miss W not to leave her house at night.

The "disembodied voice" approach could be a little creepy to our minds and needs careful evaluation. Nevertheless, Miss W's case highlights the benefits of what Hampshire County Council call a technology-agnostic approach, as described in a report by the Local Government Association (2016): there was not a presumption that any particular technology was to be provided. Assistive technology was chosen on an individual basis with the aim of addressing specific risks and delivering defined outcomes.

Critical to the successful application of assistive technology for Miss W was establishing how Miss W's health affects how she can interact with technology. For example: knowing that Miss W has had difficulty managing her medication in the past, the Telecare staff decided that a medication dispenser would be helpful for her. However, Pivotell offer several products, and not all of them have flashing lights in addition to the alarm (Pivotell, 2019). Aware that Miss W had a hearing impairment, care workers considered not only the functionality provided by the products, but also the suitability of the interface. By specifically choosing a medication dispenser with flashing lights, Miss W will notice medication reminders without being able to hear them.

**Lesson learned:** understand the health and care needs of recipients in detail and then decide on the most appropriate technology.

#### 10.8 East and West Sussex

TeleCheck is a service used in East Sussex that provides proactive calls reminding service users to eat, drink and take medication, and to provide contact and reassurance. The council demonstrated an approximate cost avoidance value of about £32 per client per week and from 2016 were seeking to expand its telecare userbase to 14,000 by 2020/21.

The telecare service in West Sussex is jointly provided by West Sussex County Council and NHS West Sussex (Sanders and Rogan, 2017a). In addition to a home telecare unit and pendant, service users may have additional equipment installed in their homes depending on their individual needs, including fall sensors, bed/chair occupancy sensors, temperature extreme sensors, smoke, and gas and carbon-monoxide detectors. The aim is to enable timely discharge from hospital, avoid hospital admissions, reduce domiciliary care and delay admission to a residential care home. At the end of a 13 week funded period, about 70% of people choose to continue using the service on a self-funded basis, which is testimony to its end-user appeal.



#### 10.9 Care Quality Commission

The Care Quality Commission (www.cqc.org.uk/guidance-providers/all-services/how-technology-can-sup issued guidance for local authorities and other organisations intending to implement technology for supporting care in the community. It emphasised the importance of keeping people at the heart of care and not substituting person-centered care by the technology. It posed the following questions to providers:

- How will you involve people who use your service in your plans and putting the new technology into use?
- What do the people it will affect need to know to make an informed choice? Do they fully understand the implications of the new technology?
- Who will the technology affect and how will it affect them?
- What outcome do you want to achieve? How will you measure it?
- Will the technology fully meet the needs of the people using your service? If not, what else do you need to provide?
- Are there more appropriate ways to meet these needs?
- What are the practical and legal issues you need to think about before you introduce new technology?
- What are the risks and how will you manage them? Particularly during transition and early implementation of the technology or system. What is your contingency plan to keep people safe?
- How have you involved your staff? What information and training do they need so they can be confident and competent? This includes understanding their responsibilities and how to respond to associated risks.

These questions are a useful check on the background review, which has successfully covered and addressed the issues raised. The overall lessons and conclusions will help answer the questions and ensure the next phase of the LDF implements pilots that keep all interests in focus and at heart.

## Part IV Principles and practice of implementing assistive-care technology

This part of the report is the primary deliverable. It applies the lessons learned from the desktop research and user investigations to draw up three main steps for selecting care technologies. These are then applied to setting up and running pilots or for implementing technologies as part of upgrading socialcare provision.

## 11 Selecting appropriate technology for each older adult

Our research has consistently emphasised the importance of driving technology development and use by the needs, preferences, and attitudes of end users, particularly the older adults. However, it is not feasible



to obtain their views on each potential piece of technology. Instead, we require a more abstract approach that evaluates the functionality and specifications of generic technologies from results of questionnaires and discussions with end users.

The key point is that the whole process starts with the *activities* of the care network participants and *which ones need support*. This drives the choice of technology functions in general and, eventually, the specific products and systems, using the following three steps:

- 1. Identify all the participants involved in the care provision and establish all the activities that need supporting for each participant.
- 2. Map each participant's activities to the corresponding technology functions for supporting them.
- 3. Evaluate the candidate technologies for each function and choose the best set.
  - (a) This step is facilitated by organising technologies into functional categories.
  - (b) The final part of this report, Part VI, details the categories and provides example technologies within each one.

#### **11.1** Step One: Participant identification and specification of activities

- 1. Inclusion criteria
  - (a) all older adults living in the community independently and receiving care from the participating care providers.
  - (b) all professional carers of those older adults
  - (c) family, friends, and anyone else who provides some kind of care and support for the older adults and composes part of their informal care network.
  - (d) technology suppliers for the pilots
  - (e) care providers (the organisations employing the professional carers)
  - (f) commissioning organisations (if different to the care providers)
- 2. Ask care recipients and both professional and informal carers to complete the associated questionnaire developed for this research project to obtain a good understanding of their prior knowledge, attitudes, and experience with technology and what needs it can support.
  - (a) The questionnaire will evolve in accordance with feedback during this assessment phase. In particular, it will incorporate more details on the specific health and wellbeing needs of participants.
  - (b) Questions may be answered as part of an assessment discussion with the carers or independently by the older adults, depending on their preferences.
  - (c) Answers will help understand the support required by all three types of participant with respect to their own technology use and how they can help the older adults.
- 3. Analyse questionnaires and engage in clarifying discussions to:
  - (a) determine physical and mental health needs of the older adults
    - i. biomedical





- ii. mental health and wellbeing, that could include some or all of
  - A. historic factors
  - B. current life circumstances and context
  - C. factors that change on a daily basis (emotions, physical and mental health symptoms, motivation and engagement, etc)
  - D. mental-health risks, particularly self neglect and vulnerability but including suicide, self harm and harm to others
- (b) establish the different activities that need to be supported and any dependencies between them
  - i. Leave the home for activities outside
    - A. Exercise
    - B. Meet people
    - C. Shopping
    - D. Entertainment
  - ii. Activities of daily living (cooking, cleaning, personal hygiene, toilet, etc)
  - iii. Manage medication
  - iv. Remain active
  - v. Sleep well
  - vi. Eat and drink appropriately
  - vii. Maintain physical and mental health
  - viii. Communicate with
    - A. friends and family
    - B. carers
    - C. health and social care services
  - ix. manage the building and home environment
    - A. heating
    - B. light
    - C. security and access control
    - D. opening and closing (doors, windows, curtains, etc)
    - E. turning on and off (taps, gas, applicances)
- (c) identify motivations and incentives of the carers
- (d) Using the questionnaires, categorise older adults and carers into the appropriate level of technology training and support required.
  - i. For older adults, we will map from the answers to the type of user based on the Quan-Haase typology (Quan-Haase et al., 2018) and provide the training and other support associated with each type. This will be explored in more depth during the pilot itself.
  - ii. A similar approach will be used for the informal carers, including family and friends if they complete the questionnaires.
  - iii. From the informal carer mapping, identify those people with good skills who can be encouraged to be mentors of the older adults in their care. These are the crucial "social norms" that need to be given a high profile for the care recipients.



- iv. For professional carers, identify the level of formal training they require and provide them with online resources accordingly as well as encouraging their provider organisation to support appropriate training.
- 4. Evaluate current technology, if any, and check efficacy and ethics
- 5. Establish motivations and incentives of the technology providers, the care providers, and the commissioning organisations.
- 6. Identify any conflicting or misaligned interests between all participants and draw up a plan to resolve them.

#### **11.2** Step Two: Mapping technology functions to activities

This step uses a template we have created that identifies the general technology functions that are associated with and encompass the activities specified in Step 1, Part 3. The broad, top-level technology category is given a code in parentheses to help when associating a specific piece of technology to the recipient activities it intends to support.

- 1. Intelligent decision support (decision support)
  - (a) functions
    - i. integrate data from multiple sources
    - ii. predict future health and safety risk issues
    - iii. detect current health and safety issues
    - iv. activate appropriate interventions based on both the person and the environment
    - v. transmit appropriate alerts and messages in response to health and safety issues
    - vi. automate referrals if and when required
  - (b) technologies
    - i. software applications or hubs that collate and interpret data
- 2. Communications (comms)
  - (a) functions
    - i. from the person
      - A. socialising
      - B. obtaining advice
      - C. carer intervention
      - D. activate appliances, equipment, or technologies
    - ii. to the person
      - A. monitoring and reminders
      - B. reassurance and advice
      - C. delivering interventions
  - (b) technologies
    - i. voice call
    - ii. video call



- iii. email or communications via software applications
- iv. text messages
- 3. Movement and activities (*physical*)
  - (a) functions
    - i. outside the house
    - ii. within the house
  - (b) technologies
    - i. wearable sensors
    - ii. ambient sensors
- 4. Physical and mental health assessments (health)
  - (a) functions
    - i. physiological measurement
    - ii. mental health and wellbeing evaluation
  - (b) technologies
    - i. biomedical sensors
    - ii. software applications and information systems
      - A. manual data entry
      - B. streamed sensor data
- 5. Building and room management (environment)
  - (a) functions
    - i. control the ambient conditions (light, heat, noise, humidity, air quality, etc)
    - ii. monitor security
    - iii. control access
    - iv. open and close (doors, windows, curtains, etc)
    - v. turn on and off (taps, gas, applicances)
  - (b) technologies
    - i. mechanical appliances and equipment
    - ii. cameras
    - iii. remote controls for electronic appliances and equipment
    - iv. automated preprogrammed controls

#### 11.3 Step 3: Evaluating individual pieces of technology

Step 2 has specified the broad technology functions that can support all identified activities of the older adults, their carers, and the care providers. Step 3 selects specific pieces of technology that support those activities. This is facilitated by categorising candidate technologies under the same broad functions as those in Step 2, as specified in Part VI. The common categories help pick out candidates for each activity.

The candidates then need to be scored against a template shown in Table 2. It contains generic criteria that any technology should encompass. Technologies addressing similar actions are compared with each other, like with like, and the best set is chosen to produce an optimal holistic connected system incorporating all identified activities and dependencies between them. The next section explains how the technology selection and implementation works within a pilot.

Criteria	Scoring Scale (0 to 10)		Importance
fits its intended needs	0, not at all	10, completely	high
importance for the overall	0, trivial	10, critical	high
technology-led care			
services provided are worth the	0, total waste of money	10, absolute bargain	medium
cost for the provider			
services provided are worth the	0, total waste of money	10, absolute bargain	medium
cost for the care recipient			
technology provider willing and	0, corporate impenetra-	10, at our beck and call	high
able to work at the local level	bility		
can be configured to different	0, rigid as concrete	10, fits like a glove	high
care contexts and practices			
able to share information be-	0, not a word	10, talks to anything	high
tween systems and services			
supports collaborative health	0, everyone's an island	10, we are all in it to-	high
and social care		gether	
easy to set up and maintain	0, total nightmare	10, a dream	medium
removes tasks and responsibility	0, constantly demand-	10, looks after itself	medium
from the user	ing		
universal access from anywhere	0, never available	10, always in touch	medium
provides peace of mind about se-	0, leaks like a sieve	10, tight as a drum	medium
curity and privacy			
impact on human interactions	0, destroys desired in-	10, enhances interac-	medium
	teractions	tions	

## 12 Setting up and running the pilots

Although we are calling them pilots, this method is relevant for any service that is attempting to introduce new care technologies. Choosing the technologies is the precursor and must be driven by the needs of all participants in the pilots. This means we will already know a great deal about the various motivations, needs, and goals of the participants. The pilot should monitor and evaluate how well these are being met, which is best achieved using the method of action research.

In essence, action research is designed to understand the dynamics of complex systems in their local contexts. Although there are general principles for conducting it, the distinctive characterisation is a clear focus on what is happening in a specific setting rather than trying to generalise across all settings. It evaluates the activities as they take place and with all the people engaged in them fully participating in the research itself. This fits naturally with the principles we have already established for technology selection, implementation, and evaluation. It means the holistic system can be evolved in real time rather than sitting out a static evaluation period before any changes are implemented. The time lag between identifying a technology problem and receiving a solution is all too familiar for technology customers who have to wait for the next "upgrade" and its inevitable additional cost. Action research and willingness of the selected technology providers should mitigate such experiences.

#### 12.1 Rough guide for conducting action research pilots

- 1. Carry out the three steps for selecting the technology care system specified in Section 11, which will have produced a wealth of information about all participants and fully engaged them.
- 2. Identify the outcome measures for evaluating the new care provision, taking account of all participants. These should fall out of the discussions that have already taken place when selecting the technology.
- 3. Introduce the technology to the care network and older adults with the appropriate level of training and support as identified by the questionnaires. The objectives are to:
  - (a) boost confidence
  - (b) allay concerns, especially about security and privacy
  - (c) activate techno-champions in the social norm
  - (d) provide access to other technical help and tutorials
- 4. Conduct an ethics evaluation, especially for power relationships to ensure equal input to decision making.
- 5. Ensure older adult information profiles are up to date and fully informed by all parties, including the older adults themselves, their informal carers, their professional carers, and the care organisations that hold all their health data.
- 6. Montor ability of all parties in the care network to make assessments (or self assessments) that can be shared and that contribute to co-creation of health.
- 7. Monitor data collection from all technologies.
- 8. Monitor care provision based on the data analysis, predictions, and triggered interventions.

- 9. Evaluate the technology for each group of participants using the technology evaluation criteria along with the person's experience of it, including how helpful and easy to use they perceive the technology and how they intend to behave accordingly.
- 10. Compare care system against outcomes and amend accordingly.

## Part V Background research

## 13 Demographics and technology

The latest population figures released by the United Kingdom (UK) Office of National Statistics (ONS, 2018b) are for June 2017. They show that the UK population is 66 million people with an increasing proportion of older adult: 18.2% were aged 65 and over, which is nearly one fifth of the population, compared to 15.9% in 2007. It is projected to reach around one in every four people (24%) by 2037.

This dramatic and continuing shift in age demographics requires an equally dramatic change in how we look after older adults. There is acute and increasing pressure on residential care places but, more importantly, people would rather stay in their own homes where their friends and family live, if at all possible. One way of achieving this is by using new technologies to help their care network look after and support them.

Although there is an expanding choice of Information and Communications Technology (ICT) based tele-care systems available for older adults in the community, there is not the same expansion in the general competence of either carers or the older adults to use them. The problem is that the very population needing to increase its reliance on technology is also the population least experienced with and motivated by the same technology. The ONS figures on internet use (ONS, 2018a) showed 90% of adults in the UK were recent internet users in 2018, which is up from 89% in 2017, and adults who have never used the internet in 2018 are down from 9.2% to 8.4%. This same trend applies to older adults, even though the proportions decrease with age: almost all adults aged 16 to 34 years were recent internet users (99%) in 2018, compared with 44% of adults aged 75 years and over. In general, recent internet use by retired adults has increased by almost 25 percentage points since 2011, to 64% in 2018 by 18 percentage points to 88% by adults who were economically inactive.

**Lesson learned:** Demographics and internet use are steadily strengthening the rationale for technology-based home care.

It is clear that internet access and associated technologies are becoming more available to older adults. Aligned with the improvement in connectivity of devices and a massive expansion in the kind of information that can now be collected, the direction of travel is surely in favour of technology supporting home care. However, there are may obstacles in the way of providing older adults with technology that is truly accessible rather than hypothetically available. An important one is the social care context, the guiding policies and legislation, and the nature of home-care delivery.

## 14 Social care policy and legislation

Care services for health can be considered as formal or informal. Formal care services are paid for by the local authority or by the user; details can be found in the National Audit Office (NAO, 2018) review



of adult social care in England. At the time of the report, there were 152 unitary and upper-tier local authorities in England responsible for adult social services. These include:

- 5.4 million unpaid informal carers, 2011
- 1.5 million people working in adult care, 2012
- £10 billion estimated spending on care and support by self-funders, 2010-11
- £55 billion estimated value of informal care and support, 2011

87 per cent of adults live in local authorities that set their eligibility threshold to meet substantial or critical needs only. This means there is a huge market for helping people with less serious needs but ones that could make the difference between being properly supported at home or having deteriorating health that push them towards residential and more expensive care.

Social care comprises personal care and practical support for adults with physical disabilities, learning disabilities, or physical or mental illnesses, as well as support for their carers. Publicly funded care makes up only a minority of the total value of care, and this proportion is decreasing. Most care and support is provided unpaid by family, friends and neighbours (informal care), while many adults pay for some or all of their formal care services.

Local authorities typically only pay for individual packages of care for adults assessed as having high needs and limited means. These packages are usually commissioned from the private and voluntary sectors, with home care and care homes the most common services.

Legislative and other changes mean adults are having to define their own support, through increasingly more varied types of care. The Department of Health's Care Act (2014, www.gov.uk/government/ publications/the-care-bill-factsheets) is designed to rationalise local authorities' obligations, to introduce new duties based on individual wellbeing and to mitigate pressures on self-funders and carers.

The government paradox is to continue reducing public spending while maintaining care and improving outcomes for adults. In the 2017 election, the Conservative manifesto announced a policy of wealthier people with more than  $\pm 100,000$  in assets having to pay for their own elderly care out of the value of their homes, rather than relying on the council to cover the costs of visits by care workers. The resulting furore meant the Conservatives were forced to do a U-turn on the policy. It was one of the reasons cited for them losing their overall majority and demonstrates the strength of feeling residing in the heart of health and social care, especially for the oldest section of the population.

The National Audit Office have a diagram that illustrates the multiple and interrelated care needs of older adults, shown in Figure 2. It is a powerful motivator for the new policies on integrated care, with an explanatory memorandum having been put to Parliament this year in accordance with the NHS Long Term Plan (2019, https://www.longtermplan.nhs.uk/). It changes care regulations to support the new Integrated Care Provider (ICP) contracts. These intend to create a single contract for commissioning services from a lead provider organisation that is responsible for integrating those services. Licences for integrated care will be issued to providers, who have a number of choices for implementing the care: "Providers can take part in commissioner-led schemes or take their own steps to improve services aimed at delivering integrated care by, for example, developing compatible IT systems or improving handover notes" (Monitor, 2019).

There is quite a leap between improving handover notes and developing compatible Information Technology (IT) systems that we hope the Government understands. Otherwise, they will hopelessly underestimate the challenges, but at least there is an acknowledgement that it has to happen for any integrated solutions to work.



#### Adult care services and other services

How well adults' needs are met depends on a wide range of public services interacting effectively



Figure 2: National Audit Office adult social care service overlaps

**Lesson learned:** Effective home care depends on organisations, providers, recipients, and technologies all working together harmoniously.

The most common care services are home care, day care and residential care homes. An important role is to provide respite for informal carers (such as family members or friends). The duration of assistance can be a few hours, one day, or several days depending on the form of care. The respite itself can be via a community of self-contained properties for older adults, with on-site 24-hour support staff or through care when required, with varying degrees of autonomy provided. Villages supporting independent living build the support into the specialised community. For example, ExtraCare (https://www.extracare.org.uk) provides residential villages with provision for social housing and Audley Care (https://www.audleyvillages.co.uk) provides services at the top end of the market. Both require some financial commitment but they help to bridge the gap between full-time care in care homes and independent care in the community.

Informal care is often provided by unpaid family, friends and neighbours with personal and practical help, and coordination of formal services. The government has a Carer's Allowance that partly acknowledges this role. As it says on the Government website (www.gov.uk/carers-allowance/overview), carers "could get £62.70 a week if you care for someone at least 35 hours a week and they get certain benefits. You don't have to be related to, or live with, the person you care for. You won't be paid extra if

you care for more than one person."

However, the general austerity climate has, according to the National Audit Office survey, forced local authorities to save money by changing contractual agreements, paying lower fees, negotiating bulk purchase discounts and commissioning less care. This has resulted in a number of initiatives to improve efficiency and reach of care. One is the Integrated Care Pioneers (https://www.england.nhs.uk/integrated-care-pioneers), which is about new ways of delivering person-centered care. There are national workstreams involved in this, with one objective being to improve integration of informatics.

"The 25 integrated care pioneers are acting as exemplars to address local barriers to delivering integrated care and support locally, and highlight national barriers that the national partners can work to address. They support the rapid dissemination, promotion and uptake of lessons across the country and receive support to breaking down these barriers from the national partners." (https://www.england.nhs.uk/integrated-care-pioneers/ communities/).

In reality, the resources offered are patchy and not directed towards the community as much as towards commissioning and delivery services.

The Better Care Fund "is a programme spanning both the NHS and local government which seeks to join-up health and care services, so that people can manage their own health and wellbeing, and live independently in their communities for as long as possible." (https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/). There are concerns about the impact of moving £2 billion from NHS acute care to the Better Care Fund. The motivation is to transfer resources from the health sector into pooled budgets managed jointly by local authorities and clinical commissioning groups, to enable integration and reduce pressures. The intended care integration is driven by cost savings as much as by trying to improve services but it does provide an opportunity for innovative approaches facilitating integration.

In terms of how social care is provided, the NAO recognises the variety of needs that must be met if a person is able to live safely and healthily at home. These include being able to manage and/or maintain:

- 1. nutrition
- 2. personal hygiene
- 3. toilet needs
- 4. appropriate clothing
- 5. a habitable and safe home
- 6. social and family relationships
- 7. engagement in work or other community activities
- 8. access to and use of public services
- 9. caring responsibilities of any dependents.

If people need social care support, they can try the local authority social services but there will be a financial means test as well as an evaluation of what support is actually necessary. They will need to pay for the support in full if they have more than £23,250 in savings. Between £14,250 and £23,250, they will have to contribute £1 for every £250 of costs. Under £14,250, there is no cost but the pressure



on local-authority spending is likely to mean the assessment of needs does not match the recipient's perceptions.

This rather unforgiving environment should, in theory, create fertile grounds for finding alternative approaches. People have the option to pay for their own care, of course, or to obtain help from friends and family or other informal carers who may or may not be paid. Anything that can lessen the burden on this alternative care network would be welcomed in principle, which is where technology has an opportunity. Likewise, if the local authorities can use technology to provide better care more efficiently, they too will be very interested. These opportunities abound in a large number of services covering a wide range of organisations, all of which need to interact for supporting social care, as shown by Figure 2.

There may be a silver lining, then, due to the increasing pressures of looking after an ageing population if you are a technology developer. This report looks at how that lining could be turned to gold for all protagonists: companies, care recipients, friends and family, professional providers, local authorities, and other health and social care support services: all the people and organisations included in Figure 2 in fact. On the face of it, everyone should win but the reality is unfortunately rather different. Despite all the investment, it is very hard to produce real-world solutions and the next sections will explore some of the reasons why.

**Lesson learned:** there are heightened motivations and opportunities for implementing care technologies in this age of austerity.

### 15 Academic research into assistive technologies

Developing technologies for healthcare has a very long history that repeatedly demonstrates the difficulty of moving out of the research laboratories and into practice. Mycin (Buchanan and Shortliffe, 1984) is an expert system developed in the 1980s and one of the most famous. It was hugely influential for subsequent clinical decision support systems and artificial intelligence in general but never itself made it into healthcare. Fast forward twenty-five years to the The European Union's Ambient and Assisted Living (AAL) Joint Programme (ec.europa.eu/digital-single-market/en/active-and-assisted-living-joint-programme-aal-jp). It was set up to stimulate the use of technology for creating better living conditions for older adults. Funding began in 2008 and five further rounds were included in an evaluation of the program by Van Grootven (Grootven, 2019). These six rounds produced 152 projects funded by around 600 million Euros of grants. The focus was overtly on companies and commercialisation, similarly to the later EIT Health funding scheme, precisely because research was not having enough impact on society. Despite this, only 62 of the projects developed a business model and only two resulted in a marketable product. None of them provided any evidence that health and well-being outcomes had improved as a result of the technology.

Robot projects were popular, as one might expect with all the hype that surrounds them, but of the 107 grants, only six contributed to commercially available products. There was clearly a large discrepancy between the developers' published claims and what the robots actually could do in practice. It led Van Grootven to conclude that it will be a long time before robots are realistically able to enhance independent living. He concurred with a common theme of this literature review that products should not be technology driven, which was the case for most of the projects, but should be co-created and pushed by end users.

**Lesson learned:** co-production of technology with full collaboration of all stakeholders is essential, and especially the end users.
#### 15.1 Value for money

The AAL review by Van Grootven puts value for money under the spotlight but it is unfair to blame its lack entirely on the AAL research programme or its projects. Assessing value for money is extremely complex when it comes to technology in home care. The problem is that the multifarious protagonists have different motivations that cause a lack of alignment of objectives (Lehoux et al., 2017; Greenhalgh, Fahy, and Shaw, 2018). Policy makers see a problem and provide grants or other incentives to tackle it that are picked up by enthusiastic researchers with good ideas but not much business sense. Business analysts raise expectations to generate finance but investors have to think about the risks. The creative innovations are watered down to be "more realistic", which frustrates the researchers, and implementation comes up against a phalanx of gatekeepers for regulatory constraints, governance, procurement, provider demands, and change management, to name a few. The original funder and quite possibly many of the provider organisations, especially their regulatory bodies, often insist on empirical evidence before implementing anything, which, as we have seen, is very hard to obtain and puts back innovation by years, assuming the creators haven't dissolved in their own sweat and tears by then.



Figure 3: Greenhalgh's adapatation of Lehaux's value proposition of a new technology

Anybody who has tried to produce health technology will have come up against some, if not all, of these issues and, as Greenhalgh, Fahy, and Shaw (2018) point out, the patient has hardly been mentioned: "In what way is he ill (or at risk of illness) and what trade-offs is he prepared to make to reduce his actual or potential suffering? Taking account of those trade-offs, to what extent does he consider the new technology desirable? Has anybody asked him and even if they did, were his views incorporated in the series of non-linear decisions that followed?".

Greenhalgh, Fahy, and Shaw (2018) expand on Lehoux's identification of the influences on new technology's value, shown in Figure 3. It helps by explicitly identifying the various elements and processes involved from conception to implementation of new technology and emphasises the role of long-term collaborations throughout the process, between all stakeholders at all stages. Successful technology involves "clinicians, social and behavioural scientists, physiotherapists and psychotherapists, engineers, computer scientists, designers, as well as end-users and policy experts" (Pilotto, Boi, and Petermans, 2018) as well as organisational contexts and workflows. This may be why Lorenz et al. (Lorenz et al., 2019) note that, while there is a wide range of technology available, "there is very little evidence of widespread practical application". Their review of existing assistive technologies for the care of people with dementia found that most aimed to improve the safety, security, or memory of people with dementia in the community. This apparent usefulness clearly does not equate to actual use.

Network analysis approach	Key theoretical assumptions	Analytical focus
Realist evaluation	Change is produced by mechanisms Causality is generative: Mechanisms only activate in the right conditions, so context + mechanisms = outcomes	Programme theories – the ideas about how/why an intervention 'works' Contexts in which mechanisms do/do not activate
Social network theory (including online networks)	Knowledge is socially constructed in the context of relationships Social advantages and capabilities are conferred through connections	Social capital Informational flows Measures of 'wellbeing'
Actor-network theory	Relational ontology: humans, technologies and networks are not conceptually distinct, but entwine with each other	Real-world human-technology interaction (e.g. ethnographic study, narrative analysis) Unexpected, emergent, and paradoxical impacts of new technologies
Strong structuration theory	Social structure and individual agents are mutually constitutive Outcomes are produced by interactions between networks of 'micro', 'meso', and 'macro' levels of social practice	Power relations; individuals and their contexts Linkages between 'ontology in general' (abstract concepts) and 'ontology in-situ' (particular social practices at particular times and places)

Figure 4: Gomershall et al summary of approaches to analysing networks involved in assisted living technologies

Gomersall et al. (2017) also underline the importance of understanding all the protagonists. AAL technologies, by their very nature, depend on networks of people and organisations that have to be understood. Gomershall et al's approach is to focus precisely on the dynamics of these networks. They provide a useful summary of how this can be done, reproduced by Table 4. The changing nature of these networks cannot be easily predicted and yet these predictions are required to determine the value and benefit of the technologies involved. This is why many of the studies of new technologies are based on action research. There has to be an acknowledgement that costs and benefits are not able to be realistically quantified in advance of developing and implementing technology. This does not preclude thinking hard about these factors but they should not be used by gatekeepers to preclude the use of technology in practice.

McNamee et al. (2016) come to similar conclusions. They argue that "more-complex methods of economic evaluation are likely to be better able to capture fully the impact of the intervention on costs and benefits over the appropriate time horizon. This complexity includes wider measurement of costs and benefits, and a modeling framework that is able to capture dynamic interactions among the intervention, the population of interest, and the environment." Digital health interventions fit the description of a complex intervention and the Medical Research Council acknowledges that these have different expectations for their evaluation. Traditional randomised controlled trials (RCTs) are not likely to be appropriate for

AAL technology, not just because of the networks involved but also because the technology will evolve during its use. This is the modern approach for software development, where agile processes are based on users interacting with and changing the technology requirements. Enforcing a static state does not help the users and artificially constrains the benefits to a single point in time.

Pilotto, Boi, and Petermans (2018) equally bemoan the lack of empirical evidence for AAL technology and support the view that standard models for evaluating them are not appropriate. They suggest smale-scale trials and quickly executed studies that take place during development and implementation.

**Lesson learned:** Establish, understand, and try to align the interests of all parties involved in developing and using health technology.

**Lesson learned:** Be aware of potential costs and benefits but know that they depend on complex interactions of people, products, and processes that can only be evaluated in practice.

**Lesson learned:** Digital Health Innovations are very hard to evaluate but don't let that put you off if they seem like a good idea: they will improve through use, like quality walking boots.

#### 15.2 Technology adoption

Lack of evidence (Peek et al., 2014) is one obstacle in the way of digital health technology adoption, especially when considering the regulatory gatekeepers and the people with vested interests in not having the technology. It is easy to block and hard to convince. Fear of technology in all parties, from providers to recipients, is another big factor, whether it be around losing jobs or losing human contact. Education of care givers is important, with Pilotto et al (Pilotto, Boi, and Petermans, 2018) finding that older informal care givers with lower educational level were more positive than younger ones with higher levels of education.

All is not lost, though, with many studies reporting the benefits of digital health interventions. A systematic review (Madara, 2016) showed that assistive technologies improved the quality of life of caregivers by reducing their burden of responsibilities. These include reducing time, levels of assistance and the amount of energy required for caregiving, with concomitant reductions in levels of anxiety, fear and task difficulty.

Lindqvist et al. (2016) shed some light on the kind of activities that people with mild cognitive impairment wish to master in everyday life and the reasons for this. They included 16 qualitative studies and found four activity themes, with dependencies between them shown in Figure 5:

- Activities that convey social values and well-being: e.g. baking, walking, socialising, dancing
- Activities that support significant roles: e.g. being confident among others, handling economy, going to the cinema
- Activities that diminish negative influence on others: e.g. taking medicine, turning off the cooker, managing planned meetings
- Activities that increase health and safety: e.g. leaving the home in a controlled manner, paying safely, baking, handling administration of medical appointments



## Dependencies between difficult, valued activities

\* Related in varying degree to stress, fear, fatigue, embarassement

Figure 5: Lindqvist et al's chart of how people with MCI have dependencies between activities with which they would like to engage.

Researchers note that different people valued one activity for different reasons, or the same person had different reasons for valuing one activity. Safety was a clear theme for dependencies between activities and any technology development should take account of how it addresses these dependencies.

A very recent report by Karlsen et al. (2019) demonstrated feelings of increased safety, security and independence in older adults as a result of technology. Despite the challenges with understanding the technology, they continued to use the services after the study. There were benefits for the wider care network, too, with family caregivers reporting a reduction in their concerns. However, this was mixed with a feeling that they were taking on increased responsibilities by helping their care recipients to stay longer at home. Stress on the care network is an issue that needs consideration alongside reduction of stress and anxiety on the recipients: "family caregivers may benefit from telecare, but telecare may also add to their care burden".

**Lesson learned:** Understand the interactions between activities and how these influence attitudes to technology in different ways for different people.

Cook et al. (2018) looked in detail at the role of family caregivers involved with Cambridgeshire Assistive Telehealth and Telecare. The factors influencing adoption are entirely expected: usability,



perceived responsibility of the caregiver, how much caregivers already know about the technology, and how useful they think it will be. Reassurance of the patient's safety was a "key selling point" and the conclusions were clear: involve the carers in recruitment strategies for technology. In fact, there was a little too much influence from the caregivers on adoption, with the patient sometimes not being properly involved and care should be taken to balance perspectives.

Pal et al. (2018) conducted a survey that analysed the adoption of smart home services by older users. Their review of 30 relevant previous studies looked at how technology helps health and environment monitoring, social connectedness and communication, and recreation and entertainment. Their concern matches those of other researchers we have referenced, in that the reviews took an overly technocentric view without accounting for behaviour and perceptions of the older adults themselves. They produced their own survey of 239 older adults from India, Thailand, Indonesia and Malaysia. Their aim was to determine how well the Technology Assessment Model, TAM (Maranguni and Grani, 2015), encapsulated the issues involved in adopting digital health interventions.



Figure 6: Extended Technology Assessment Model

TAM has four main constructs for assessing adoption: attitude (ATT), perceived usefulness, perceived ease of use and behavioral intention. Pal et al extended these with nine additional ones that they thought should be explicitly considered (see Figure 6):

- self capability: self perception of ability to use a product or service without external help
- automation: execution of any task by a machine (usually a computer) that was previously carried out by a human-being
- universal connectivity: 24/7 access from anywhere
- security/privacy: the state of mind of the elderly people where they fear that their personal data will be lost and privacy will be infringed upon.
- affordability: the price which the elderly users' considers to be an appropriate monetary sacrifice in return of the services that they get from using the smart-homes



- enjoyment: the extent to which the elderly people perceive the smart homes to be enjoyable and provide recreational facilities
- satisfaction: general user evaluation of system
- subjective norm: the perception of the elderly people that most of the people who are close or important to them think that they should use smart homes
- compatibility: the extent to which the different devices/sensors from the different manufacturers can work and communicate among themselves

When applying these constructs to their results, they found that a person's behavioural intention was influenced by satisfaction, subjective norm, compatibility, attitude, perceived usefulness, and affordability but *not* enjoyment, which may be of some interest, and possibly chagrin, to the gamification enthusiasts. Positive influences on attitude were the perceived usefulness and ease of use but concerns about security and privacy had a negative effect. How useful they thought technology would be was partly mediated by how easy they thought it would be to use and their own capabilities with technology as well as how much they would need to be involved with it (the system's automation). Universal connectivity was not an issue.

Overall, the research provides a useful set of criteria to consider when evaluating technology and emphasises the importance of ease of use over extent of functionality. Monitoring medical data and having the reassurance of round the clock assistance if required were big influences on the attractiveness of smart homes.

**Lesson learned:** keep the user interface simple, explain what the technology does, and be very clear about security and privacy.

Social connectedness is clearly important, both with respect to people thinking technology may reduce it and with the opportunities it provides for extending social networks. Neves et al. (2019) explored this with 12 older adults using an in-depth qualitative approach. The recursive and mixed methods are a response to the issues earlier researchers have found with studies that fail to see how technology works when embedded as part of a complex and dynamic network. It "proved critical to flesh out the interplay between users, technologies, and context, adding to a deeper analytical understanding of technology in later life". They established the feasibility of using technology for communications, with an increase in social interaction resulting, but social connectedness was only really seen if the older adults had family members geographically distant. They noted four stages of technology acceptance: (i) introductory stage; (ii) associative stage; (iii) autonomous stage; and (iv) integrative stage. Acceptance was enhanced by how well the software would fit with their own contexts and existing communication behaviours.

Cahill et al. (2019) report on three studies that take an immersive "action research" approach to investigating both how to establish the technology and evaluate it. The studies concerned the specification and implementation of AAL technology infrastructures to support resident wellness and person-centered care delivery. The care context was a community residence rather than a private home and the results showed the importance of technology that supports social communication between residents, caregivers, and family members. Figure 7 displays the themes involved in understanding the technology context, with the requirements definition sitting between them and product development. A number of high-level goals for technology were identified by the participants, including:

1. Enable holistic care delivery, paying attention to wellness, relationship centered care and professionalism.





Figure 7: Themes, requirements, and product development from Cahill (2019)

- 2. Use sensor and tablet kits to build a resident profile that includes a picture of residents and their wellness, how they are living in the environment, their care, and the interactions between each of these.
- 3. Ensure the sensor and tablet technologies keep the resident profile up to data and optimising wellness.
- 4. Link up information flows arising from the diverse care processes admission, assessments, care planning, daily care, reporting, adverse events reporting.
- 5. Use predictive risk management in relation to resident wellness and stability so that state changes can be anticipated and interventions can be flagged as and when required.
- 6. Continuously monitor status of care delivery and notify care-givers and management as to status.
- 7. Flag need for interventions at the building or environmental level such as when to adjust room lighting and temperature.
- 8. Automate actions to ensure room settings meet the preferences and needs of residents.
- 9. Support staff communication with, for example, staff briefings and handovers.
- 10. Support resident/staff communications and care delivery.
- 11. Enable everybody involved in care to report on resident wellness, including the resident, family, practitioners of all disciplines, care assistant, and administrators.



- 12. Gather data about residents both individually and collectively to improve care planning and quality of care. These pictures should help establish the normal or baseline status so that changes can be easily detected and flagged. Cahill et al give the example of building up a picture of typical sleep patterns using triangulation from sensors, nurse reports, resident surveys, etc.
- 13. Remove responsibility for technology away from residents if possible, with ambient sensors being particularly liked because they work in the background.



Figure 8: Cahill's model of the players and relationships involved in AAL care

Some cautionary advice was also provided around the impact of technology on carers, who did express concerns about their own job status, and the ethics of data confidentiality. Information should only be shared with the permission of the recipients and social interaction should not be reduced to being activated by calls for help: "it is important to maintain the human element of care", which includes human presence, responsiveness and empathy. This is explicit in Cahill's model of the relationship between technology, residents, the living environment and care delivery shown in Figure 8.

**Lesson learned:** technology is part of and must encapsulate a holistic system, should take full account of the needs of all human protagonists, and be based on information that is up to date.

#### 15.3 Ethics of AAL technology

Gibson, Brittain, and Robinson (2019) point out that opinions about the ethics of technologies vary widely between practitioners, informal carers, and the older adults. This is particularly true for Geographical Positioning Systems (GPS), which social services worry about. However, other members of the care team my have fewer reservations. The point is that these judgements need to be understood in the context of how the services are using the technology and how it changes care relationships, especially if the technologies appear to be more about delivering a service than how they are received.

The technologies may be set up entirely independently of care services, by informal carers and family members. Devices, such as the Buddi wristband, Loc8tor tracker system, Pivotell medication dispenser, and different camera systems are all readily available at retail outlets. In addition, there are many online resources to help people and their care network learn about the various kinds of assistive technology that exist, such as Mick's House (http://www.mickshouse.info/) and the Social Care Institute for Excellence (http://www.scie.org.uk/publication (Gibson, Brittain, and Robinson, 2019)).

Gibson, Brittain, and Robinson (2019) describe a case in which a man, who cared for his wife with dementia, repurposed some spare CCTV cameras from his pub. He set up the cameras in the bedroom and connected them to his iPad, which he could use to monitor the room remotely. However, when the carer was asked whether his wife would approve of the cameras if she were aware of them, he admitted that she would likely have considered it an invasion of her privacy.

In a blog, Spink (2015), a developer at the Social Care Institute for Excellence, described his own experience of repurposing off-the-shelf products to help him care for his father with vascular dementia:

"Now, like many men, I hate shopping in the high street. So I used Google and Amazon. They seemed much more useful than some specialised online web stores. Before I knew it I had installed the following: talking motion sensors and personalised recorded messages that call Dad to the toilet, radio or front door; a cheap timer plug with a mains-powered talking motion sensor; and a personalised recorded message tells Dad to go back to bed if he tries to walk around during the night. I got them all on Amazon. Importantly, I bought different types to see what was the most efficient.

When Dad told me he was getting lost I realised that I could buy cameras that cover the downstairs living area. I bought four and can now keep an eye on him all day from my computer or my phone."

Spink claims the technology has given his father a better quality of life and more independence but what his father thinks is not so clear. Does he know how many eyes and ears are inside his life at all times?

In each case, there are ethical and power issues that need addressing when formal care is involved. What technologies are already in existence and how much has the care recipient participated in and agreed with the implementation?

**Lesson learned:** Formal care assessments should check any existing informal care technology and ensure it has been ethically implemented.

Greenhalgh, Fahy, and Shaw (2018) report on an important set of five studies that have a very similar intention to the motivation of this Local Digital Fund proposal. They were conducted in five different English health and social care organisations that wanted to introduce technologies to support independent living. The remit was to explore the organisational, social, political, and policy contexts along the lines of the hurdles and misalignments Greenhalgh, Fahy, and Shaw (2018) later identify. These studies highlight the importance of ecological solutions: ones that fully account for the immediate, distinctive, and holistic



Figure 9: The Studies in Co-creating Assisted Living Solutions (SCALS) research paradigm from Greenhalgh (2016)

care environments and include all the different participants. The new "research paradigm" is clear that there is no "one size fits all" or an easy way of taking the results from one place and applying it in just the same way somewhere else. Instead, the researchers stress that solutions must be "locally grown and collectively owned", at least in part. Figure 9 givens an example of the different levels of engagement that has to take place for a full picture.

**Lesson learned:** Collaborate with people you know and are easily accessible, especially the technology developers and researchers.

It is a "modernist myth" (Greenhalgh, Fahy, and Shaw, 2018) that technology can solve the challenges of an ageing society with a calm, scalable set of solutions, not least because of the healthcare institutions with which they have to work. These are often rigid, bureaucratic, and beset by procurement and governance issues. This has been our own experience with attempting to implement the GRiST mental health decision support system. Governance can end up as vapour ware: the reality of how people actually behave bears little resemblance to how their policies profess to dictate behaviour, but it is these self-same policies that can easily be used to block access.

#### 15.4 Conclusions

This literature review concentrated on the most recent ambient assisted living research and uncovered some high-quality in-depth studies. A number of common themes run through the results. The most important is the holistic, interactive, and dynamic impact of care technologies: they can only be understood in the real-world contexts where they are implemented. All protagonists are affected and how they react influences each other. Care technologies are complex interventions and multiple perspectives on how they are developed, rolled out, and continuously evolved are essential.

The review has attempted to crystallise important lessons coming out of the academic research. They have been gathered up along the way but an overarching one is to be realistic about the challenges in



implementing care technologies. It does not help anyone if promises are made that are not then delivered and commissioners, whether they be grant funders or care providers, should not have exaggerated expectations.

The other crucial lesson is to keep care recipients fully in vision at all times. Technocentric development is more common than one driven by the recipients and this needs redressing. The first step is to make sure everyone involved has an accurate understanding of the care recipients and their capabilities. This is considered in the next section.

## 16 Who are the care recipients?

Academic evaluations of assisted-living technology agree that the recipients must be at least an equal partner in all stages of development and implementation. Unfortunately, as Grootven (2019) review of the EU AAL programme found out, technocentricity is often the reality. This may partly be due to a misconception of the abilities and attitudes of older adults. In particular, there is a supposed "digital grey divide" that puts them on the other side to the younger technically-competent population. Is this a fair categorisation and view? Two very recent research papers think not.



Figure 10: Quan-Haase typology of older adults with respect to technology acceptance.

Quan-Haase et al. (2018) conducted 41 in-depth interviews with older adults and found, as one would expect, that they are not a homogenous population. Their typology ranges from non-users to go-getters and savvy users, as shown in Figure 10. They argue that overgeneralisation has obstructed policy development and that we should be far more aware that old age is not a "static demographic": older adults are products of the skills and attitudes they have developed over their lives. Past experience with digital media both educationally and at work was an important determinant of current orientation to IT, as was expertise in their social network. Knowing which digital type is most representative of an older adult helps devise the most appropriate training programs for their specific needs and desires.

**Lesson learned:** meeting technology needs of older adults requires understanding their education and experience with technology as well as the expertise in their social circle.

Neves et al. (2019) also dispute the age divide. Lumping older adults together in one homogenous group "masks multifaceted social and agentic processes that involve literacy, status, identity, and practices". As our own questionnaires are trying to explore, the digital divide is intersectional, with gender, socioeconomic status, living settings, practices, and norms all impacting on the way older adults orientate to and use technology.

**Lesson learned:** Older adults are not one homogenous group but have individual differences and typologies that need to be understood and accommodated.

Configuring technology for a given individual also concerns the particular health context of the person. Lorenz et al. (2019) mapped the various available assistive technologies by target user (i.e. a carer or a person with dementia), stage of dementia (i.e. mild cognitive impairment or early stages, or moderate or severe dementia), and intended care setting (i.e. living at home in the community, or institutional care settings). In their mapping, they showed that a large majority of technologies designed for use in mild cognitive impairment or early dementia were intended to be used by the person with dementia. Of those designed for use in moderate to severe dementia, a much greater proportion of technologies were intended for use by carers and professionals. This result reflects the progression of dementia. As the disease progresses, cognitive capabilities become more impaired. New care needs arise, and the technology currently in use may no longer meet the needs of the person with dementia. Lorenz et al. (2019) provide an anecdote from a blog which demonstrates this:

"This morning is driving me crazy. Since I have lost my auditory sense of direction, I can hear the sound but cannot tell what direction sound is coming from. And my memory is impaired so cannot remember what sounds the different appliances emit. I suspect the piercing chirps this morning were from smoke alarm somewhere. When I hear the other sounds I don't know whether to check the toaster, stove, the convection oven, the landline phone, my cell phone, or look around for what I have forgotten elsewhere. [...] For many years alarms were wonderful tools to meet need...but this year?... I think I have progressed past their usefulness. Grr-r-r-r!!" (*Sound disorientation as dementia symptom* 2015)

The author, who has dementia, once found various alarms throughout the home to be useful. However, due to the progression of their dementia, this is no longer the case and, more importantly, the person is no longer effectively alerted to certain hazards - leaving the oven on or the smoke alarm sounding.

This example illustrates how care needs can evolve: when someone has a progressive disease, their capabilities will change over time. While a particular piece of assistive technology may allow an individual to live more safely, if the effectiveness of this technology depends on user interaction, it is critical to predict how disease progression could affect the user's ability to interact with the technology before it is implemented; otherwise, the assistive technology (AT) may become ineffectual without carers or professionals realising.

Walls (2016) GPS monitoring system could hypothetically fail in the same way. If an older person is able to cross roads safely and remember to wear their Buddi, they are allowed to roam freely within a certain radius, and a carer is alerted if they fall or leave the safe zone. But what happens if the service user's cognitive functioning declines to a point where they are no longer able to cross roads safely? Until this is recognised by carers or the dementia team, they will continue to go for walks but be at significant



risk. Hence, the inclusion and exclusion criteria Walls' team apply to the use of Buddi is critical to improving outcomes.

This again highlights the benefit of personalised AT provision in which a thorough assessment establishes the needs, capabilities, condition (including potential progression) and desired outcomes of a specific person, and AT is chosen based on these factors. The local government case studies in Section 10 demonstrate this in practice.

**Lesson learned:** Choice of technology for older adults needs to be monitored regularly because what is selected initially, in accordance with their demographics and lifelong experiences, can become redundant if their health status changes.

#### 16.1 Conclusions

Treating care recipients as if they are a single group with homogenous qualities is fatal for the success of assistive techology. People are individuals and their needs change, which requires constant monitoring of technology and its continuing suitability. Studies have shown some useful groupings of older adults based on their health and life experiences that could help guide how to identify appropriate technology and ensure it is successfully adopted.

## 17 Overall conclusions from the desktop research

The general conclusions summarise the points and outcomes from our review of changing demographics, how government policies are addressing them for care in the community, academic studies on assisted living technologies, and how healthcare organisations have tried to implement technology for home care. They provide the foundations for specifying assistive technology pilots within our own local authorities, as follows:

- 1. The case for using technology to support home care is increasing year on year as a result of demographic changes, access to the internet, and the variety of communications technologies now available.
- 2. Means testing for public provision of social care and the cost of residential care are both motivators for finding cheaper ways of living independently at home for as long as possible. They are incentives for all parties to find cost-effective solutions, with technology top of the list.
- 3. Recent legislation on licences for integrated care puts a critical dependence on technology that facilitates sharing information across systems and services. The complexity of interactions between these services compounds the difficulties.
- 4. Translating innovative technology from the academic laboratories into the real world is a major challenge. Expectations should be realistic and new technology given a foothold so that it can evolve in practice. This "action research" will inevitably improve access to and involvement of the end users, whether they be carers or recipients of care. Too many projects are technology driven rather than people driven.
- 5. All the stakeholders in assistive technology need their motivations and incentives better aligned. If new technology has the potential to benefit older adults and their services then it needs to be given every chance to succeed. This should be the overriding aim of all interested parties who



must recognise and find ways around their own vested interests covering investment, profit, cost effectiveness, governance, change management, research trials, risks and maintenance of control.

- 6. Related to the alignment of interests is the avoidance of using bureaucracy as a means to blocking innovation. This is particularly true for local authorities and NHS trusts that can erect procurement, governance, security, and many other hurdles that, in reality, are often red herrings. We are not saying the issues are irrelevant but they should be addressed creatively and imaginatively with the intention of avoiding impasses.
- 7. Use technology providers who you know and trust, with the research and development team working collaboratively and responding in real time. Relationships are more important than ticking bureaucratic boxes.
- 8. Assistive technologies impact on networks of people and it is nigh on impossible to predict the dynamics. Simple evaluations of technology are unrealistic and allowance should be made for enabling and evaluating them in practice. In particular, lack of more traditional medical trials data should not be used as a barrier. Empirical evidence is certainly relevant but a more realistic and enabling approach to gaining it is required.
- 9. Identifying activities, their dependencies, and their value for health and wellbing is important for determining which technologies will facilitate the positive aspects and mitigate the negative. The relationships are complex and what may appear to be a benefit for care recipients may also be a burden and source of stress for the care network. It is important to understand all perspectives and how they inter-relate.
- 10. Increasing technology adoption means gaining "buy-in" from both carers and recipients. They should both be involved in the decision making and implementation process with heightened awareness, education, and training all essential elements. It requires a comprehensive model of technology acceptance such as the extended one, ETAM, proposed by Pal et al.
- 11. Technology adoption is enhanced by how well it fits with the contexts and life circumstances of care recipients. This is mirrored by how well it fits with the work contexts, expectations, and objectives of the care providers too.
- 12. Technology can help social communication but benefits depend on the nature of a person's social circles and their geographical dispersion.
- 13. Technology should serve the people not the other way round, so be aware of its impact on the human face of care.
- 14. Ethics should also serve the people, from all perspectives and accounting fully for power imbalances.
- 15. Ecology is everything: people, places, and technology can only be understood in their natural environment, which is why the same technology may be appropriate in one place and situation but not another. There is no universal solution applicable across the board and why it is better to adopt locally-grown solutions with collective ownership.
- 16. One size fits all is not only fallacious for the technology solutions but also for the people targetted by them. Care recipients are not a homogenous group, although they can be usefully subdivided based on attitudes, experience, and education to help direct adoption. Their social groups or "norms" also need to be understood because they influence expectations and may provide support.

- 17. It may seem obvious but health status affects the ability to make use of technology and needs to be understood. Ongoing monitoring is important to ensure changing health has not affected the technology "fit" for the person. In an extreme case, technology that is intended to assist a person may end up being a danger.
- 18. Information sharing between people, services, and IT systems is an essential quality of successful ambient assisted living. It requires clear policies on security and privacy as one would expect but it should also be fair and transparent. Care recipients should be fully involved in who sees their data and be able to trust them. And trust should be reciprocal: recipients should also be trusted to see data held on them by the care network.
- 19. Training and confidence in using technology are cited as barriers by many organisations attempting to implement it, both for care recipients and the carers. It must be accommodated in AAL plans.
- 20. Technology development should deliver functionality based on high-level goals of: holistic care; a fully fleshed out profile of the care recipient that is kept up to date; free information flow; monitoring current status and predicting future problems, with interventions to avert them; basing these monitoring activites on understanding the baseline or normative state so that deviations can be detected; basing predictions and deviations on multiple data sources for "triangulated"interpretations; including the ambient (building) status in everything that is being monitored and adjusting the environmental conditions autonomously; supporting communications between all parties, carers, recipients, and managers; and removing the demand of sensor management from recipients as far as possible, with ambient ones in place of wearables or interactive ones when feasible and appropriate. We can use these goals as contributing criteria to what established technology should deliver.

#### 17.1 Collated lessons

Demographics and internet use are steadily strengthening the rationale for technology-based home care.

Effective home care depends on organisations, providers, recipients, and technologies all working together harmoniously.

There are heightened motivations and opportunities for implementing care technologies in this age of austerity.

Co-production of technology with full collaboration of all stakeholders is essential, and especially the end users.

Establish, understand, and try to align the interests of all parties involved in developing and using health technology. Be aware of potential costs and benefits but know that they depend on complex interactions of people, products, and processes that can only be evaluated in practice.

Digital Health Innovations are very hard to evaluate but don't let that put you off if they seem like a good idea: they will improve through use, like quality walking boots.

Understand the interactions between activities and how these influence attitudes to technology in different ways for different people.

Keep the user interface simple, explain what the technology does, and be very clear about security and privacy.

Technology is part of and must encapsulate a holistic system, should take full account of the needs of all human protagonists, and be based on information that is up to date.

Formal care assessments should check any existing informal care technology and ensure it has been ethically implemented.

Collaborate with people you know and are easily accessible, especially the technology developers and researchers.

Meeting technology needs of older adults requires understanding their education and experience with technology as well as the expertise in their social circle.

Choice of technology for older adults needs to be monitored regularly because what is selected initially, in accordance with their demographics and lifelong experiences, can become redundant if their health status changes.

Give care recipients access to their full health records and provide ways for their direct contribution to shared information.

Sharing information and automated referrals can generate significant savings.

Match the generic functionality of technology to user needs before worrying about the specific technologies available.

Choose technology that is scalable and has open standards to prevent being locked in to proprietory solutions.

just because technology *can* remove activities and tasks from a person doesn't mean that it should or that the person wants it to.

information systems should have precise specifications of data and knowledge that are machine processable and enable sharing.

information systems should specify application program interfaces that facilitate data transfer and encourage third-party technologies to access them.

There are strong financial incentives for implementing care technology.

Understand the health and care needs of recipients in detail and then decide on the most appropriate technology.

The next part of the report details the investigations carried out within the partner local authorities for this LDF Discovery stage grant. The conclusions of the two parts will be combined to determine a best-practice template for implementing technologies within social-care services.

## Part VI Categorising assisted-living technologies

As many researchers have pointed out (Greenhalgh, Shaw, et al., 2016, for example), the world of assistive technologies is vast and highly dynamic: what is *de rigeur* one week is *passe* the next. Figure 11 is a good illustration of the huge variety of technologies that can be placed in a house and it does not even include the platforms and clinical systems to which they are often linked. It renders any snapshot of specific current technology somewhat pointless because the snapshot rapidly becomes out of data. Instead, it is more instructive to look at the types of technologies and give one or two examples of each to illustrate them.

At a very high level, technologies can be split into telecare (monitoring behaviour and environments, sensors etc) and telehealth (biomedical data, blood pressure, pulse, etc). In one of our case studies, we will be selecting sensor companies that explicitly but separately target each type. Telehealth is not so common in social care technologies but will become more so if it means biomedical data can be collected at home by untrained carers as accurately and reliably as by clinicians.



Figure 11: Smart communication architecture from Lloret

The following sections provide a more detailed categorisation with one or two examples to illustrate the kind of functionlity each type is able to provide. However, "categorising the wide range of existing technologies into discrete functions is a complex task, and there are some technologies for which there is an overlap between categories." (Lorenz et al., 2019). Lorenz uses categories based on the technology functions: 'memory and support of self-care and activities of daily living', 'treatments and intervention delivery', 'safety, security, monitoring and reassurance', 'training', 'care delivery, management and support', and 'social interaction and networking'.

Gibson, Newton, et al. (2016) used three high-level themes for their categories: technologies used *by* older adults, *with* older adults, and *on* older adults. Both Lorenz and Gibson's categorisation were for adults with various stages of dementia but they are applicable because adults with no mental-health issues at all are much less likely to need or want care technology.

Our categories are along the same lines as the alternatives discussed. The difference is that they are designed to facilitate our method for choosing technologies, which require mapping technology functions to older-adult needs, as explained in Section 11. The categories are as follows:

- 1. Intelligent decision support hub
- 2. Communications
  - (a) voice call
  - (b) video call
  - (c) email or communications via software applications



- (d) text messages
- 3. Movement and activities
  - (a) wearable sensors
  - (b) ambient sensors
- 4. Physical and mental health assessments
  - (a) biomedical sensors
  - (b) information systems
- 5. Building and room management
  - (a) comfort and safety monitoring
  - (b) mechanical appliances and equipment
  - (c) remote controls for electronic appliances and equipment

As discussed, trying to identify all potential technologies in each category and picking out "the best" is a fruitless task because they are often very similar to each other and companies come and go like Brexit meaningful votes. We will explore the different types and select representative samples, including those that we will be promoting in our pilots, with Greenhalgh's advice in mind: stay as close to the people involved with all aspects of the technology implementation as possible, including developers, researchers, carers, recipients, providers, and commissioners. In short, keep it local, close to home, and under your own control. So the choices here are not intended to be in any way definitive or necessarily better than the alternatives ... but they do possess the right criteria and are fit for purpose.

In the following categories, the general description will be provided followed by some candidate examples for pilots within the West Midlands.

### 18 Intelligent decision support

Intelligent decision support systems (DSSs) are not a tightly specified set. Many companies with a focus on ambient sensors will have a platform that attempts to detect anomalies and raise alerts accordingly. These could be regarded as decision support and we will include them here if the functionality overlaps enough. A fully-specified DSS would have the functions we specified in Step 11.2:

- 1. integrates data from multiple sources
- 2. predicts future health and safety risk issues
- 3. detects current health and safety issues
- 4. activates appropriate interventions based on both the person and the environment
- 5. transmits appropriate alerts and messages in response to health and safety issues
- 6. ability to automate referrals if and when required

Although each individual sensor company may have its own sensors, there is a market in providing a set of sensors from different companies and integrating them within a single platform. Either way, if there is a suite of devices pushing information into a decision support hub, the system qualifies under this category. So do more traditional DSSs that have been extended to link with external sensor data. All of them require some kind of software application for viewing and configuring functionality related to the sensors.

#### **18.1** Candidate examples

- 1. Shangatic technologies (www.connectedsmartthings.co.uk) has a variety of sensors connected to its platform that provide alerts to a smart phone. It is based in Birmingham and provides a complete kit for detecting motion, opening of doors and windows, cameras, call functions, and two-way audio. It pushes data to a smart phone when events trigger alarms and so is not, in itself, a very smart decision support system but it integrates a wide range of data sources.
- 2. Sensara (https://sensara.eu/en/) is an online lifestyle monitor that warns family, friends or neighbours when assistance is required. It qualifies as decision support because it claims to predict health risks, such as increased risk of falling or the possibility of dehydration.
- 3. Alcuris (http://www.alcuris.co.uk/) is assistive technology that has developed *memoTM*, which aims to prolong independence, provide reassurance and produce actionable insight. It monitors behaviour and flags changes to family, friends or professional care staff. It includes a telecare hub that connects a user to a help centre, while connecting all products in the range. The app allows family to set gentle reminders, receive updates and view wellbeing data in real time. The dashboard presents actionable insights to social services and care providers, coming from a range of devices such as; door, motion and fall detectors which link with the memoTM hub.

## **19** Communications

Communications cover a wide range of technologies. This section considers them as ways of getting data from one place to another or facilitating control over devices and equipment.

#### **19.1** Voice interaction with technology

Voice interaction is becoming increasingly popular with Amazon's Echo, Google's Home, Apple's Home-Pod and Microsoft's Cortana the major players. They enable technology to be operated by voice and are particularly useful for controlling equipment in the house, such as lighting, heating, televisions, curtains or blinds, etc. They also act as virtual personal assistants for reminders and other useful tasks.

Their usefulness is in conjunction with the technologies you want them to control and so the focus remains on those technologies rather than the voice communications *per se*. The technologies need to be enabled for voice interaction, which includes any apps that would benefit from this mode of communication. Amazon's Alexa Skills Kit (ASK) is set up to facilitate just this. It is " a collection of self-service APIs, tools, documentation, and code samples" according to Amazon and allows any third-party developer to link its technology to Amazon and apply voice interaction as a result.

An issue to consider with any of these cloud-based voice communication services is security and privacy. These services record your interactions and store them on the cloud, which means background conversations, noises, events, etc may also be recorded. They can be linked back to the person, time, and place, with all kinds of implications as a result. The speakers are always live and listening and even though they don't record unless woken up by the introductory command, it is unclear how secure they



actually are. James Vlahos writes in The Guardian (https://www.theguardian.com/technology/ 2019/mar/26/smart-talking-are-our-devices-threatening-our-privacy) that these technologies should not be allowed into your life without careful scrutiny of exactly how they operate. It is imperative to be very clear about when they listen, what they record, what happens to the data, and how well defended they are against hackers. For AAL, this is particularly important because you do not want to create vulnerabilities or opportunities for abuse.

*Cautionary question* Can developers linking their apps to voice communication cloud services control the use of data generated by their app? This would mean security and privacy remains entirely within the responsibility of the app and not, for example, Amazon or Google.



Figure 12: Lifepod voice interaction care system

- 1. iSmart (http://www.ismarthomecontrol.com/smart-services/) integrates voice control for lighting, heating, shading and more. It is mainly focused on building and room management.
- 2. Genie Connect (https://www.genieconnect.co.uk/) is a rather futuristic approach to voice interaction, coupled with claims of enhancing socialisation. The voice-enabled Genie chats, answers questions, plays music and video on request, etc along the lines of Alexa, Siri, and Google. It is interesting by integrating different functions for voice interaction, including direct video calling to family, friends, carers, and knowledgeable service centre representatives. It can also remind people to take their medication, attend appointments, and anything else that might be required for managing health and wellbeing.
- 3. Lifepod (lifepod.com) is a company focusing on voice interaction using smart speakers. Figure 12 shows how their system works and is a good illustration of the way voice interaction is being used. It exploits the capabilities of smart speakers by adding voice technology for use by older adults at home and their caregivers. It can be set up and controlled by a remote caregiver using an online portal that delivers personalized check-ins, reminders, and virtual companionship.

#### **19.2** Interpersonal communication

There are many well-established methods that all fit easily within ambient-assisted living environments. Messaging apps such as Whatsapp, Signal, and Viber are geared up for communicating by text, voice



calls, or video on a smart phone. Skype is the most well known web-based video communication service that supports conference calls but there are many others that are open source and thus more easily integrated, such as RocketChat and Jitsi.

Email and text messages are standard with the former often accessed via mobile phones. They can also be triggered by web applications and digital platforms as part of the overall decision support capabilities.

### 20 Movement and activities

#### **20.1** Ambient sensors

- TEC-Angel (https://www.tec-angel.co.uk/ "was created to help vulnerable people, living alone, stay in their own homes. Using discreet sensors around your home, door and room movements are monitored for unusual activity at odd times; sending text alerts to carers should something occur outside of the everyday routine." It sells its own branded sensors so does not have to link in to other manufacturers' data links but is in control of them itself, as far as we can tell from its website.
- Loc8tor (https://loc8tor.co.uk/healthcare/) is a remote tracker system marketed toward people with dementia and their care networks. It uses small tracker tags for attaching to items such as house keys, wallets, mobile phones, etc. using Radio Frequency. The website claims this offers "greater range and performance" than Bluetooth locators and "much greater accuracy than GPS trackers". A credit card-sized handset uses light and sound to direct the user to "within 2.5cm" (accuracy stated on website) of lost items which have tags attached with a tracking range of 122m. Loc8tor claims this can help those with memory loss find lost items, allowing them to live more independently. They also claim the product is suitable for the visually impaired, as it has braille-like textured buttons and provides audio cues for locating items.
- Canary Care (https://www.canarycare.co.uk) is a 10 sensor package requiring an initial layout and monthly subscription. It includes a Hub and power supply, sensors, visitor cards and a portal. The wireless sensors monitor movement, temperature and door activity, which can be viewed from anywhere via a portal and it can set up text and email alerts.
- RedGear Solutions (https://www.redgearsolutions.com/) is an ambient device with multiple onboard sensors. The communication hardware and power are built into the device to minimise any management by the user. The data collected includes:
  - Motion: Detect activity patterns in the room
  - Light: Optimal Light levels in the room
  - Sound levels: Detect the loudness of noise in the room
  - Temperature: Optimal temperature of the residence
  - VOC: Pollution levels
  - CO2: Detect the CO2 levels in the room

Data are transmitted to secure cloud facilities from where they are collected for further analysis. All data are anonymous and only associated with the device ID number so no personal information is captured or stored in the cloud.

- KemuriSense Smart Power Sockets and Kemuri Wellbeing Monitor service (www.kemuriSense. com) provide passive monitoring for any vulnerable people living independently. They can be deployed wherever there is a mains power supply, and so are not restricted to telecare. Smart Power Sockets can be installed in any building to monitor for movement of people, use of power and ambient conditions of temperature and humidity. They can provide information for building facilities managers, medical researchers and security companies. After transmission via the Internet, data processing is performed on servers located in the UK. Data is analysed every hour to build up a pattern of normal movement and power use sensor readings. Each hour is matched against previous patterns for the same hour of the day and recorded as normal, small change or large change.
- Just Checking (justchecking.co.uk/) is an activity monitoring system. It is used to reduce the need for sleep-in support for service users in supported accommodation by providing greater insight into service users' behaviour in the home, and identifying where individuals may be being oversupported. The system can also provide a sense of reassurance to family members and other carers through electronic wellbeing notifications

#### **20.2** Wearable sensors

- FitBit (https://www.fitbit.com/) is a very well know wearable activity tracker that can also monitor sleep and some physiological states. It is geared towards fitness but may be used to help monitor older adults at home.
- Buddi (www.buddi.co.uk/) is a wristband with alert buttons and a fall sensor. As with almost all wearables, it can be configured using a smartphone app to generate alerts as well as manually send them. It has a GPS for location monitoring and users can choose to sign up with a 24/7 service for responding to alerts. Gibson et al. (2019) describe the case of a woman with dementia who used a Buddi to move freely, even using the bus to travel between cities, while her daughter could monitor her position using Buddi's GPS tracking. The daughter explained that Buddi allowed her to stay in employment while caring for her.
- Activ8 (https://www.activ8all.com/) is a medically-validated activity tracker that automatically classifies daily activities using smart algorithms in the device. It can identify when and how long the person was lying, sitting, standing, walking, cycling or running.
- EmfitQS sleepmonitor (https://www.emfit.com/) is an approved medical device for monitoring sleep quality. It enables caregivers or family members to track the bed routines and sleep habits of the older adult who is living independently or unsupervised.
- Beddit (https://www.beddit.com/) is another sleep monitor with automatic and accurate tracking to provide a full picture of the night. It requires a thin strap to be placed under the sheet that has an electronic sensor connected to a bluetooth transmitter.

## 21 Pysical and mental health assessments

This category includes any information required for clinical health care, as opposed to social care. The two areas are obviously linked and it is important to interpret social care needs in the context of the person's overall health status. The latter can come from specialised sensors that are validated to provide medical data or from software information systems. Patient record systems are where the complete health records are intended to be stored but focused assessments of mental health and wellbeing are



more useful for health and social care in the community. The issue is how well data can be shared between the systems.

Privacy and confidentiality issues surrounding sensitive data about a person's health and wellbeing create a culture that is antagonistic to sharing and the NHS "Connecting for Health" programme was unable to resolve it. Movements along the road to an integrated system are happening but we remain a long way off.

There are two problems: one is the issue of services operating in data silos that militate against sharing; and the other is the myriad of information systems that all hold data in different formats and do not talk to each other. The first is about policies, legislation, and culture. This document is more concerned with the second issue because it is within the remit of developers to help resolve it.

The key to data sharing is not to force the same IT systems onto organisations but to allow a heterogeneous set of IT systems to communication with each other. One way is to ask organisations to code their data using a recognised shared coding scheme. SNOMED CT is one of them and it has just produced a user guide specifically for mental health (*SNOMED CT A user guide for Mental Health* 2019). Data in one organisation may be requested in a different way and held in different structures than in another organisation but if they both point to the same SNOMED codes, then each organisation knows that the data are actually equivalent and can be shared appropriately. It requires organisations to use machineprocessable data formats such as XML (Extensible Markup Language) and link the elements of the XML document to the corresponding SNOMED CT codes. For example, Aston University's mental-health decision support system, GRiST, (Buckingham, Adams, et al., 2015; Buckingham, Ahmed, and Adams, 2013) has a formal specification of its knowledge and data structures that is implemented in XML and facilitates translation into any medical coding scheme.

The second requirement for data sharing between information systems is a fully-specified application program interface (API) that enables two different systems to send and receive information from each other. It defines the protocols for how messages are passing and thus supports data transmission. Interpreting what the data mean at each end is another matter: it is where the coding schemes enter the picture, otherwise each information system has to agree its own coding matches.

**Lesson learned:** information systems should have precise specifications of data and knowledge that are machine processable and enable sharing.

**Lesson learned:** information systems should specify application program interfaces that facilitate data transfer and encourage third-party technologies to access them.

From the perspective of homecare, information systems are where sensor data and other information collected in the home can be collated with health records. They enable clinicians to obtain a holistic picture and should also allow care recipients to see that picture too. It requires a two-way data sharing approach involving both home-hubs and clinical systems. For social care, specialist mental health and wellbeing assessments are the most relevant but ideally, they would link in with the general health records of older adults that the patient information systems hold. This ensures data can be shared, prevents duplication of data entry, and helps provide an holistic view of the person's mental and physical state. Health data can also be collected by sensors, but they need to be medically validated if the data are to be trusted.

#### 21.1 Specialist mental health and wellbeing assessments

Mental health and wellbeing assessments are often just tacked on to patient record systems as a form filling exercise without any specialist validation. Some, such as FACE (Functional Analysis of Care



Environments, https://imosphere.co.uk) are more focused on health and care. Only one, GRiST, is a fully-fledged decision support system with machine-learning predictions that can generate its own expert judgements of mental health risks, safety, and wellbeing. This system was developed at Aston University and so we are not impartial in promoting its use, as follows:

1. GRiST is a web-based decision support system for assessing the risks of suicide, self-harm, harm to others, self-neglect and vulnerability. It is designed to reflect how mental health experts think about and assess risk, because it is based on the elicited expertise of multi-disciplinary mental health clinicians. The GRiST technology contains software simulations of how these experts assess low-level cues (e.g. lives alone), through higher level concepts (e.g. depression, anxiety, anger), to top-level risk categories such as suicide and harm to others (Buckingham, 2002). Based on psychological processes, GRiST can fully explain how a set of service user cues generates specific risk quantifications in a way that is intuitive, comprehensible, and resonates with clinicians' own understanding of risk.

GRiST also has the capacity to work as a decision hub because it contains the expertise of 3,000 mental-health practitioners who have conducted over one million different risk assessments. Machine learning algorithms are able to exploit this data set to predict problems and generate automated interventions (Zaher and Buckingham, 2016, for example). Its decision-support platform already links to sensor companies such as BeWell Innovations and RedGear to integrate sensor data and interpret them using its inherent health and safety expertise.

#### 21.2 Patient information systems

- 1. IAPTus (https://iaptus.co.uk/ is the largest provider for IAPT services and also supports online therapies itself. It "consists of two individual applications: iaptus adults and iaptus CYP, each specifically tailored to meet the needs of IAPT therapists and each containing all that a service needs to ensure time-efficient, streamlined workflow and smooth movement along the patient pathway." It is relatively flexible with respect to including additional assessments and also integrates with online therapy providers. An API exists and documentation on it can be provided on request: GRiST, for example, is already linked to it and can be launched from it.
- 2. EMIS (https://www.emisgroupplc.com/) "provides clinical software to customers across the healthcare sector, including providers in primary care, community pharmacy, community care, mental health, child health, secondary care and diabetic eye screening, as well as commissioners and public health and research organisations." It also has a patient platform, Patient.info, which is indicative of the general intention to share health information and include patients more actively in their care. It is modular and customisable with features and (optional) modules specifically designed for certain settings: Patient Tracking for urgent care services; Patient Access for GP surgeries; and EMIS Mobile for community services. It is recognised as a good organisation for interoperability: it is "working to make sure" that products comply with SNOMED CT coding and that interoperability meets FHIR (www.emishealth.com/about-us/our-interoperability/).
- 3. SystemC and GraphNet (www.systemc.com/) is another information system that tries to connect patients and providers. It "offers integrated health and social care IT solutions in the UK" with the aim of bridging the gap between care settings. It claims to have 49 Clinical Commissioning Groups using its CareCentric shared records and 49% of councils using its Liquidlogic software in social care.
- 4. Strata PathWays (http://stratahealth.co.uk/) is a cloud technology designed to match patients' clinical needs and preferences to available and appropriate resources, system wide and in



real time. Clinicians are presented with up to the minute information on the patient, available care options and waiting times. Patients can then be matched to the best option for their specific needs. Strata PathWays is configurable to each health region's individual requirements. The solution integrates seamlessly to existing IT assets, ensuring optimal workflow and clinician adoption.

5. ECLIPSE is used by BCC and is therefore potentially important for the proposed pilot. It is primarily for social care (care organisations, adult and children's social care), as well as education, and for helping health and social care services integrate. It consists of 9 modules that can be selected based on needs: different combinations of modules are recommended for different sectors. Eclipse for Social Care builds upon the standard features of Eclipse and adds a pre-set standard configuration. The Citizen Engagement module allows people with care needs and their carers to interact with the platform and their record in various ways, both to help with care delivery and to manage and administer services. It has a web app and is mobile-ready. Service users are provided with an account where they can manage their info and save documents. They can invite contacts and assign them permissions to allow them to perform specific actions on their behalf.

ECLIPSE supports multi-agency working across the care sector via sophisticated security and open APIs. An API obviously exists and documentation is available: "Our API enables integration covering all levels of functionality which enables client server calls through a non vendor provided client application."

#### 21.3 Biomedical sensors

- 1. Current Health (https://www.currenthealth.com/ is a wearable health sensor for the upper arm. Current's all-in-one wireless wearable continuously measures a patient's respiration rate, oxygen saturation, pulse rate, skin temperature and movement at ICU-level accuracy. Data can be integrated with a range of other devices, including for glucose, spirometry and weight, to obtain a comprehensive picture of a person's health. The associated platform uses the data for alerting healthcare organisations to intervene earlier.
- 2. BeWell Innovations uses other manufacturers' sensors and builds a platform that integrates information from each one. Its business model is around medically validated biomedical data collection that means clinicians can trust what has been sent in by the older adult or informal carers. It also has a well-specified API that the GRiST decision support system is already using to link BeWell data to its own assessments: A&D blood pressure device (MD); A&D balance (MD); A&D Thermometer (MD); Nonin oxysaturation (MD).
- 3. A&D Medical (medical.andprecision.com/) supply medically validated blood pressue monitors, thermometers, oxygen saturation and scales that can send data to clinicians directly from the home.

## 22 Building and room management

This is a separate section because it takes the focus away from the people and onto their living space. However, most of the companies offering ambient sensors of one sort or another are able to monitor both people and their accommodation. The areas covered by this section include security cameras that can see activities outside the house and especially who is coming to the door. The ambient conditions of the house come into this category, which many of the companies listed under the ambient sensors in Section 20.1 also provide. Their digital focus does not cover the mechanical aids so well, though, such



as drawing curtains, opening windows, etc. Ridley Electronics is an example company of the kinds of activities supported.

1. Ridley Electronics (http://www.ridleyelect.co.uk/) has designed systems to improve independence and quality of life for the disabled and elderly. It has a range of transmitters for controlling equipment in ways that best suits a person's particular problems. Transmitters and other equipment can be operated by a wide choice of switches touch sensitive, smack down levers, mouthpiece and spring switches. Examples of the environmental controls provided are curtain pullers, remote switches, swipe tags and maglock systems, and window openers.

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# A Appendix: Questionnaires for older adults, professional carers, and informal carers

The full paper versions of the questionnaires are included in the following pages.

2018 Local Digital Fund Grant Ministry of Housing, Communities & Local Government

## Questionnaire to understand how technology may be able to help support the care needs of people living at home



## Research project led by Aston University and funded by the Ministry of Housing, Communities, and Local Government in England

Link to online questionnaire: www.egrist.org/ldf-people

## 1 Introduction

Aston University invites you to take part in a research project funded by the Ministry of Housing, Communities and Local Government.

All information you provide is entirely anonymous and no stored information can or will be traced back to you.

Before you decide if you would like to participate, please read the information about the questionnaire carefully, which you are welcome to discuss with others.

If there is anything that is not clear or if you would like more information before you make your decision, feel free to contact one of the researchers whose details are given in Section 1.6.



#### **1.1** What is this research about?

The research is aimed at people aged 55 or over who receive home care support but we would like to know your views even if you are not yet 55 or receiving any support at the moment.

We are interested in your views and experience of using technology at home. This is to help identify opportunities where technology might enhance the quality of life and independence of home-care recipients.

'Technology' is a general term that covers a range of electronic devices and systems that help people perform tasks that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed. Computers, smart phones, and the internet are examples of technology.

This research involves completing a questionnaire which includes questions about the type of support you may need at home; the type of technologies, if any, that you use; and your views on the use of new technologies to support people to live at home. The questionnaire should take no more than 30 minutes to complete.

The questionnaire is completely anonymous. It does not include any questions that can identify you and therefore we will not be storing any personal information about you.

Your involvement in this research is voluntary. Taking part in the study is NOT an assessment of your care needs and will NOT in any way affect the support you currently receive. If you choose not to take part it will NOT affect the services you receive.

#### **1.2** How the results will be used

We will use your views to help us write a report for the Ministry of Housing, Communities and Local Government Local Digital Fund, which will also be made available to interested councils. The results may also be used for further research and analysis and published in scientific journals or conference proceedings. If the results of the study are published, they will not be able to identify you because we do not store any personal data about you. This means we are unable to provide you with copies of reports but they will be made accessible from the questionnaire website.

The aim of the report is to help councils and other care providers to identify where technology might be able to enhance the quality of life and promote the independence of people living at home with care needs.

#### **1.3** Who is leading the study?

Aston University is the lead organisation for this study and responsible for looking after the data.

#### 1.4 Who has reviewed the study?

The study was given a favourable ethical opinion by the Aston University Research Ethics Committee.

#### 1.5 What if I have a concern about my participation in the study?

If you have any concerns, please speak to the research team identified below and they will do their best to answer your questions.

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Director of Governance, Mr. John Walter, j.g.walter@aston.ac.uk or telephone 0121 204 4869.



#### **1.6** Research team contacts

If you would like to discuss this research with someone, please contact:

Dr Christopher Buckingham: Email, c.d.buckingham@aston.ac.uk; Tel, 0121 204 3450.

Dr Lilit Hakobyan: Email, l.hakobyan2@aston.ac.uk; Tel, 0121 204 3000.

Thank you for taking time to read this information and for completing the questionnaire if that is what you choose to do.



## 2 Questionnaire

#### **ABOUT YOU**

- 1. What is your gender?
  - □ Male
  - □ Female
  - $\Box$  Other
- 2. What is your age?
  - $\Box$  54 or younger
  - □ 55-64
  - □ 65-74
  - □ 75-84
  - □ 85+
- 3. What is your ethnic group?
  - □ White English/Welsh/Scottish/Northern Irish/British
  - □ White Any other White background (write in) —
  - $\Box$  Mixed/multiple ethnic groups
  - □ Asian/Asian British
  - □ Black African/Caribbean/Black British
  - $\Box$  Other ethnic group

Please state:

- $\Box$  Prefer not to say
- 4. Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?
  - $\Box$  Yes
  - 🗆 No
  - $\Box$  Prefer Not to Say



- 5. If yes, do any of these conditions or illnesses affect you in any of the following areas? (Select all that apply)
  - □ Vision (e.g. blindness or partial sight)
  - □ Hearing (e.g. deafness or partial hearing)
  - □ Mobility (e.g. walking short distances or climbing stairs)
  - Dexterity (e.g. lifting and carrying and carrying objects, using a keyboard)
  - $\Box$  Learning or understanding or concentrating
  - □ Memory
  - □ Mental Health (e.g. depression, anxiety)
  - $\Box$  Stamina or breathing or fatigue
  - □ Socially or behaviourally (e.g. associated with autism, attention deficit disorder or Aspergers syndrome)
  - $\Box$  Other

Please state:

- 6. What is the highest level of educational qualifications for which you received a certificate?
  - $\Box$  No qualifications
  - □ Certificates normally passed by the age of 16 (e.g. O level, CSE, GCSE)
  - □ Certificates normally passed at the age of 18 (e.g. A level, BTEC, VCE)
  - □ Higher education certificates (e.g. from a university, polytechnic, or other equivalent institution)
- 7. Where do you live?
  - □ City/Suburb
  - □ Town
  - □ Village
  - $\Box$  Rural or remote from other houses
- 8. Who do you live with (select all that apply)?
  - $\Box$  Nobody (I live alone)
  - $\Box$  Spouse/partner
  - $\Box$  Other family members/relatives
  - $\Box$  Friends/non-relatives
  - $\Box$  Paid caregiver
  - $\Box$  Someone under the age of 18



#### CARE AND SUPPORT AT HOME

By **home care worker** we mean someone who is paid, for example by a Council, to provide help in the home with daily life.

- 9. What is the maximum number of visits you receive from a home care worker in a day?
  - $\Box$  Never visited by home care worker
  - $\Box$  One visit a day
  - $\Box$  Twice a day
  - $\Box$  Three times a day
  - $\Box$  Four times or more in a day
- 10. What does your home care worker help you with? (Select all that apply)
  - $\Box$  I don't receive any help from a home care worker
  - $\Box$  Getting up/going to bed
  - □ Washing/bathing
  - □ Dressing/undressing
  - $\Box$  Using the toilet
  - □ Preparing meals/snacks/drinks
  - $\Box$  Eating
  - □ Drinking
  - □ Taking medication
  - □ Reminders/prompts to take medication, to eat or to drink
  - □ Laundry
  - $\Box$  Cleaning/tidying around the home
  - $\Box$  Shopping
  - $\Box$  Sitting service
  - $\Box$  Going out e.g. to shops, bank, social events etc
  - $\Box$  Other

Please state:

- 11. Do you or your family pay for someone to help you at home?
  - □ Yes
  - $\Box$  No



- 12. Do you have help with any of the following from an informal carer? An informal carer includes any person, such as a family member, friend or neighbour, who provides regular help without payment. (Select all that apply)
  - $\Box$  I don't receive any help from an informal carer
  - $\Box$  Getting up/going to bed
  - □ Washing/bathing
  - □ Dressing/undressing
  - $\Box$  Using the toilet
  - □ Preparing meals/snacks/drinks
  - □ Eating
  - $\Box$  Drinking
  - $\Box$  Taking medication
  - $\hfill\square$  Reminders/prompts to take medication, to eat or to drink
  - □ Laundry
  - $\hfill\square$  Cleaning/tidying around the home
  - $\Box$  Shopping
  - $\hfill\square$  Going out e.g. to shops, bank, social events etc
  - $\Box$  Other

#### Please state:

- 13. Do you feel safe in your own home (think about burglary, fraudulent visitors, unwelcome guests, etc)?
  - $\Box$  I feel absolutely safe in my own home
  - $\hfill\square$  I mostly feel safe in my own home
  - $\hfill\square$  I sometimes feel safe at home
  - $\Box$  I never feel safe at home

\*If you do not feel safe at home, please raise this with the home care provider or, if you do not have one, an appropriate alternative care service.

- 14. What help at home, that you do not already receive, would make the greatest difference to your quality of life and independence? (Please identify up to a maximum of 3 things you would like help with)
  - (a)
  - (b)


### YOUR HEALTH

- 15. How would you describe your health status?
  - $\Box$  Very good
  - $\Box$  Good
  - □ Fair
  - □ Poor
  - $\Box$  Very poor
- 16. Have you fallen over or lost your balance at home in the last year?
  - $\Box$  No, I am very steady
  - $\Box$  Yes, occasionally (a few times a year)
  - $\Box$  Yes, quite often (at least monthly)
  - $\Box$  Yes, very often (at least weekly)

\*If you have fallen over or lost your balance at home in the last year, please raise this with the home care provider or, if you do not have one, an appropriate alternative care service.

- 17. Do you ever feel lonely?
  - $\Box$  I never feel lonely
  - $\Box$  I sometimes feel lonely
  - $\Box$  I often feel lonely
  - □ I always feel lonely

### **USE OF TECHNOLOGY**

- 18. Are you interested in learning how technology might help you?
  - $\Box$  Yes, I always want to learn
  - $\Box$  I am interested in learning some things
  - $\Box$  I don't want to learn anything any more



- 19. Do you use any of the following technology in your own home (select all that apply)?
  - □ Desktop or laptop computer
  - □ Tablet computer (wireless touch screen personal computer that is smaller than a notebook but larger than a smartphone)
  - $\Box$  Smart television (one connected to the internet and allowing you to interact with services)
  - □ Motion sensors (sensors that monitor activity e.g. door/bed sensors, Just Checking etc)
  - □ Personal emergency alarm (e.g. Telecare, Careline pendant etc)
  - $\Box$  Smart phone/iPhone (i.e. a mobile phone with a touch screen display)
  - □ Voice-activated virtual assistant (e.g. Amazon Echo and Alexa)
  - □ Wearable fitness trackers (i.e. devices you wear to track your health and fitness)
  - $\Box$  I don't use any of the above
- 20. If you had access to the right technology and knew how to use it, what would you want it for (select all that apply)?
  - $\Box$  Access to health services and advice
  - $\Box$  Staying in touch with friends and family
  - $\Box$  Contacting public services
  - □ Contacting my home care worker/care provider
  - $\Box$  Access to cultural activities
  - $\Box$  Shopping
  - □ Access to people who can help with household jobs (repairs, maintenance etc)
  - $\Box$  Other

- 21. How would you describe your general level of technical knowledge?
  - □ I can understand pretty well any information technology
  - □ I am confident that I will be able to use most technology
  - □ I have reasonable knowledge and can do things like sending emails, interacting with social media, using packages for creating documents and spreadsheets, etc.
  - $\Box$  I know a bit but am only really able to do basic things like search the web and buy things online
  - □ I don't know anything about technology



- 22. Would you be interested in using any 'smart' gadgets that can track your activity and wellbeing (e.g. iphone/smart phone, activity sensor, sleep monitor, physiological monitors for heart rate, blood pressure)?
  - $\Box$  Yes, absolutely
  - $\Box$  Yes, depending on what they measure and how they work
  - $\hfill\square$  Not really, unless somebody can give me some good reasons
  - $\Box$  Definitely not
  - □ I don't understand what is meant by 'smart' gadgets
- 23. Would you be interested in technology that helps care for you in your own home and makes it less likely that you will need to go into residential care?
  - $\Box$  Yes, definitely
  - $\Box$  Possibly, depending on what it is and how it works
  - $\Box$  No, definitely not
- 24. What, if anything, would prevent you from using technology at home to help with care needs?

25. What, if anything, would encourage you to use technology at home to help with care needs?

Please state:

26. What support, if any, do you think you would need to use technology at home?

- 27. What would be your view if technology was available that could be used instead of a visit by a home care worker?
  - $\Box$  I would definitely be interested in this
  - $\hfill\square$  I would possibly be interested in this, depending on what the technology was and how it worked
  - $\Box$  I would definitely not be interested in this



### SHARING INFORMATION

28. Some technology collects data about your health and lifestyle that can be traced back to you because you are personally identified by the information.

Would you agree to share such personal information with the following people or services? For each one, please select the appropriate box

GPs (General Practitioners)	$\Box$ Yes	□ Maybe	🗆 No
NHS organisations	$\Box$ Yes	□ Maybe	$\Box$ No
Selected family members	$\Box$ Yes	□ Maybe	$\Box$ No
Formal, paid carers	$\Box$ Yes	□ Maybe	$\Box$ No
Informal carers	$\Box$ Yes	□ Maybe	$\Box$ No
Social care services	$\Box$ Yes	□ Maybe	$\Box$ No

29. What, if anything, would be your main concern about sharing information that identifies you?

#### Please state:

Thank you very much for taking the time to answer our questionnaire. If you would like to provide us with any additional information or comments, please email one of the researchers whose details are at the start of the questionnaire or add it below.

Any other comments:

2018 Local Digital Fund Grant Ministry of Housing, Communities & Local Government

# Views and experiences of professional home-care providers for older adults on the use of technology in the home



Research project led by Aston University and funded by the Ministry of Housing, Communities, and Local Government in England

### Link to online questionnaire: www.egrist.org/ldf-professional-carers

### 1 Introduction

Aston University invites you to take part in a research project funded by the Ministry of Housing, Communities and Local Government.

All the information you provide is entirely anonymous and no stored information can be traced back to you.

Before you decide if you would like to participate, please read the information about the questionnaire carefully, which you are welcome to discuss with others.

If there is anything that is not clear or if you would like more information before you make your decision, feel free to contact one of the researchers whose details are given in Section 1.6.

### 1.1 What is this research about?

This research is aimed at professional home-care providers who are carers of more than one person aged 55 or older.



We are interested in your views and experience of using technology at home. This is to help identify opportunities where technology might enhance the quality of life and promote the independence of the people for whom you are providing care.

'Technology' is a general term that covers a range of electronic devices and systems that help people perform tasks that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed. Computers, smart phones, and the internet are examples of technology.

This research involves completing a questionnaire which includes questions about the care you provide; the type of technologies, if any, that you use; and your views on the use of technology to help older adults with care needs to be as independent as possible. The questionnaire should take no more than 30 minutes to complete.

The questionnaire is completely anonymous. It does not include any questions that can identify you.

Your involvement in this research is voluntary. Whether or not you take part in the study will NOT affect your employment role or any services or support that the person you care for may receive.

### **1.2** How the results will be used

We will use your views and those of other informal carers to write a report which will be available to the Ministry of Housing, Communities and Local Government Local Digital Fund and interested councils. The results may also be used for further research and analysis and published in scientific journals or conference proceedings. If the results of the study are published, they will not be able to identify you because we do not store any personal data about you. This means we are unable to provide you with copies of reports but they will be made accessible from the questionnaire website.

The aim of the report is to help councils and other care providers to identify where technology might be able to enhance the quality of life and promote the independence of people living at home with care needs.

### **1.3** Who is leading the study?

Aston University is the lead organisation for this study and is responsible for looking after the data.

### 1.4 Who has reviewed the study?

The study was given a favourable ethical opinion by the Aston University Research Ethics Committee.

### 1.5 What if I have a concern about my participation in the study?

If you have any concerns, please speak to the research team identified below and they will do their best to answer your questions.

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Director of Governance, Mr. John Walter, j.g.walter@aston.ac.uk or telephone 0121 204 4869.

### **1.6 Research team contacts**

If you would like to discuss this research with someone, please contact:

Dr Christopher Buckingham: Email, c.d.buckingham@aston.ac.uk; Tel, 0121 204 3450.



Dr Lilit Hakobyan: Email, l.hakobyan2@aston.ac.uk; Tel, 0121 204 3000.

Thank you for taking time to read this information and for completing the questionnaire if that is what you choose to do.



### 2 Questionnaire

- 1. What is your gender?
  - □ Male
  - $\Box$  Female
  - $\Box$  Other
- 2. What is your ethnic group?
  - □ White English/Welsh/Scottish/Northern Irish/British
  - □ White Any other White background (write in) \_\_\_\_\_
  - $\Box$  Mixed/multiple ethnic groups
  - □ Asian/Asian British
  - □ Black African/Caribbean/Black British
  - $\Box$  Other ethnic group

- $\Box$  Prefer not to say
- 3. How many years have you been a professional carer?
  - $\Box$  less than 5
  - 0 6 10
  - □ 11 20
  - □ 21 30
  - $\hfill\square$  more than 30
- 4. What is the highest level of educational qualifications for which you received a certificate?
  - $\Box$  No qualifications
  - □ Certificates normally passed by the age of 16 (e.g. O level, CSE, GCSE)
  - □ Certificates normally passed at the age of 18 (e.g. A level, BTEC, VCE)
  - □ Higher education certificates (e.g. from a university, polytechnic, or other equivalent institution)



- 5. As far as you are aware, do any of the older adults you care for use any of the following technology at home (select all that apply)?
  - $\Box$  Desktop or laptop computer
  - □ Tablet computer (wireless touch screen personal computer that is smaller than a notebook but larger than a smartphone).
  - □ Smart television (one connected to the internet and allowing you to interact with services)
  - □ Motion sensors (sensors that monitor activity e.g. door/bed sensors, Just Checking etc)
  - □ Personal emergency alarm (e.g. Telecare, Careline pendant etc)
  - □ Smart phone/iPhone (i.e. a mobile phone with a touch screen display)
  - □ Voice-activated virtual assistant (e.g. Amazon Echo and Alexa)
  - $\Box$  Wearable fitness trackers (i.e. devices you wear to track your health and fitness)
  - $\hfill\square$  They don't use any of the above
- 6. What kinds of assistance do you provide to the older adult(s) you care for? (Select all that apply)
  - $\Box$  Getting up/going to bed
  - □ Washing/bathing
  - □ Dressing/undressing
  - $\Box$  Using the toilet
  - □ Preparing meals/snacks/drinks
  - $\Box$  Eating
  - $\Box$  Drinking
  - $\Box$  Taking medication
  - □ Reminders/prompts to take medication, to eat or to drink
  - $\Box$  Laundry
  - $\Box$  Cleaning/tidying around the home
  - $\Box$  Shopping
  - □ Helping with the paperwork such as dealing with bills, filling in forms, writing letters etc
  - □ Keeping the person company / providing emotional support
  - $\Box$  Taking them out e.g. to shops, bank, social events etc
  - □ Other



#### **USE OF TECHNOLOGY**

- 7. Do you use any of the following technology in your own home (select all that apply)?
  - □ Desktop or laptop computer
  - □ Tablet computer (wireless touch screen personal computer that is smaller than a notebook but larger than a smartphone)
  - □ Smart television (one connected to the internet and allowing you to interact with services)
  - □ Motion sensors (sensors that monitor activity e.g. door/bed sensors, Just Checking etc)
  - □ Personal emergency alarm (e.g. Telecare, Careline pendant etc)
  - $\Box$  Smart phone/iPhone (a mobile phone with a touch screen display)
  - □ Voice-activated virtual assistant (e.g. Amazon Echo and Alexa)
  - $\Box$  Wearable fitness trackers (devices you wear to track your health and fitness)
  - $\Box$  I don't use any of the above
- 8. How would you describe your general level of technical knowledge?
  - □ I can understand pretty well any information technology.
  - $\Box$  I am confident that I will be able to use most technology
  - □ I have reasonable knowledge and can do things like sending emails, interacting with social media, using packages for creating documents and spreadsheets, etc.
  - $\Box$  I know a bit but am only really able to do basic things like search the web and buy things online.
  - □ I don't know anything about technology

The following questions relate to the **use of digital technology** in home care (any computers, monitoring devices, the web and internet, etc). For each one, select the box equating to how useful it would be to you as a carer and whether or not you have ever had any training for it.

- 9. Technology that helps with finding information and advice online
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to use it? □ Yes □ No
- 10. Developing content and publishing it online:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No
- 11. Maintaining privacy, confidentiality, and security of everyone's data held electronically:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No



- 12. Systems that monitor the health status/signs of cared-for adults
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to use them? □ Yes □ No
- 13. Sensors that detect motion/activity of cared for adults (e.g. door/bed sensors, room movement monitors)
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to use them? □ Yes □ No
- 14. Systems that provide alerts when a cared-for adult has a problem at home (e.g. falls over)
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to use them? □ Yes □ No
- 15. Devices that prompt cared for adults to take medication, food or drink
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to use them? □ Yes □ No
- 16. Equipment that helps carers with moving/handling situations
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to use it? □ Yes □ No
- 17. Using digital technology to manage daily routines and tasks, including administrative work:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No
- 18. Using digital technology to support the care relationship, including helping to bond with the care recipient and building trust and cooperation:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No
- 19. Using technologies that allow people to take care of themselves in their own home:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No
- 20. Setting up and managing digital devices and systems for yourself or the older adults:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No
- 21. Training older adults how to use technology:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No



- 22. Using online social networks and related communication technologies to collaborate with other health workers:
  - $\Box$  Very useful  $\Box$  Quite useful  $\Box$  Not useful

Have you ever been taught how to do it?  $\Box$  Yes  $\Box$  No

- 23. Using online social networks and related communication technologies to collaborate with the people you care for:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No
- 24. Using online social networks and related communication technologies for helping older adults support each other with their health care:
  - □ Very useful □ Quite useful □ Not useful
    Have you ever been taught how to do it? □ Yes □ No
- 25. What, if anything, do you think might improve older adults' experience of home care?

### Please state:

26. What changes, if any, might help you perform your home care worker role even more effectively?

### Please state:

Thank you very much for taking the time to answer our questionnaire. If you would like to provide us with any additional information or comments, please email one of the researchers whose details are at the start of the questionnaire.

Any other comments:

2018 Local Digital Fund Grant Ministry of Housing, Communities & Local Government

## Views and experiences of informal carers of older adults on the use of technology in the home



Research project led by Aston University and funded by the Ministry of Housing, Communities, and Local Government in England

Link to online questionnaire: www.egrist.org/ldf-informal-carers

### 1 Introduction

Aston University invites you to take part in a research project funded by the Ministry of Housing, Communities and Local Government.

All the information you provide is entirely anonymous and no stored information can be traced back to you.

Before you decide if you would like to participate, please read the information about the questionnaire carefully, which you are welcome to discuss with others.

If there is anything that is not clear or if you would like more information before you make your decision, feel free to contact one of the researchers whose details are given in Section 1.6.



### **1.1** What is this research about?

This research is aimed at people aged 18 or over who are currently informal carers of one or more older adults. By 'informal carer' we mean any person, such as a family member, friend or neighbour who provides regular, ongoing unpaid help to a person without which the person they support could not manage. By older adult we mean anyone aged 55 or over.

We are interested in your views and experience of using technology at home. This is to help identify opportunities where technology might enhance the quality of life for informal carers and promote the independence of the people they care for.

'Technology' is a general term that covers a range of electronic devices and systems that help people perform tasks that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed. Computers and the internet are examples of technology.

This research involves completing a questionnaire which includes questions about the care you provide; the type of technologies, if any, that you use; and your views on the use of technology to help older adults with care needs to be as independent as possible. The questionnaire should take no more than 30 minutes to complete.

The questionnaire is completely anonymous. It does not include any questions that can identify you.

Your involvement in this research is voluntary. Whether or not you take part in the study will NOT affect any services or support that you or the person you care for may receive.

### **1.2** How the results will be used

We will use your views and those of other informal carers to write a report which will be available to the Ministry of Housing, Communities and Local Government Local Digital Fund and interested councils. The results may also be used for further research and analysis and published in scientific journals or conference proceedings. If the results of the study are published, they will not be able to identify you because we do not store any personal data about you. This means we are unable to provide you with copies of reports but they will be made accessible from the questionnaire website.

The aim of the report is to help councils and other care providers to identify where technology might be able to enhance the quality of life and promote the independence of people living at home with care needs.

### **1.3** Who is leading the study?

Aston University is the lead organisation for this study and is responsible for looking after the data.

### 1.4 Who has reviewed the study?

The study was given a favourable ethical opinion by the Aston University Research Ethics Committee.

### **1.5** What if I have a concern about my participation in the study?

If you have any concerns, please speak to the research team identified below and they will do their best to answer your questions.

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Director of Governance, Mr. John Walter, j.g.walter@aston.ac.uk or telephone 0121 204 4869.



### **1.6** Research team contacts

If you would like to discuss this research with someone, please contact:

Dr Christopher Buckingham: Email, c.d.buckingham@aston.ac.uk; Tel, 0121 204 3450.

Dr Lilit Hakobyan: Email, l.hakobyan2@aston.ac.uk; Tel, 0121 204 3000.

Thank you for taking time to read this information and for completing the questionnaire if that is what you choose to do.



### 2 Questionnaire

- 1. What is your gender?
  - □ Male
  - $\Box$  Female
  - $\Box$  Other
- 2. What is your age?
  - $\Box$  Under 18
  - □ 18 24
  - □ 25 34
  - □ 35 44
  - □ 45 54
  - □ 55 64
  - 🗆 65 74
  - 0 75 84
  - □ 85+
- 3. What is your ethnic group?
  - □ White English/Welsh/Scottish/Northern Irish/British
  - $\Box$  White Any other White background (write in) —
  - $\Box$  Mixed/multiple ethnic groups
  - □ Asian/Asian British
  - □ Black African/Caribbean/Black British
  - $\Box$  Other ethnic group

- $\Box$  Prefer not to say
- 4. Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?
  - □ Yes
  - 🗆 No
  - $\Box$  Prefer Not to Say



- 5. If yes, do any of these conditions or illnesses affect you in any of the following areas? (Select all that apply)
  - □ Vision (e.g. blindness or partial sight)
  - □ Hearing (e.g. deafness or partial hearing)
  - □ Mobility (e.g. walking short distances or climbing stairs)
  - Dexterity (e.g. lifting and carrying and carrying objects, using a keyboard)
  - $\Box$  Learning or understanding or concentrating
  - $\Box$  Memory
  - □ Mental Health (e.g. depression, anxiety)
  - $\Box$  Stamina or breathing or fatigue
  - □ Socially or behaviourally (e.g. associated with autism, attention deficit disorder or Aspergers syndrome)
  - $\Box$  Other

- 6. What is the highest level of educational qualifications for which you received a certificate?
  - $\Box$  No qualifications
  - □ Certificates normally passed by the age of 16 (e.g. O level, CSE, GCSE)
  - □ Certificates normally passed at the age of 18 (e.g. A level, BTEC, VCE)
  - □ Higher education certificates (e.g. from a university, polytechnic, or other equivalent institution)
- 7. Which of the following applies to you? (Select all that apply)
  - $\Box$  Retired
  - $\Box$  Employed/Self-employed Full Time
  - □ Employed/Self-employed Part Time (working 30 hours or less)
  - □ Doing Voluntary Work
  - $\Box$  Not in Paid Work
- 8. Where do you live?
  - □ City/Suburb
  - $\Box$  Town
  - □ Village
  - $\Box$  Rural or remote from other houses



- 9. Who do you live with (select all that apply)?
  - $\Box$  Nobody (I live alone)
  - □ Spouse/partner
  - $\Box$  Other family members/relatives
  - $\Box$  Friends/non-relatives
  - $\Box$  Paid caregiver
  - $\Box$  Someone under the age of 18

### ABOUT THE OLDER ADULT(S) YOU CARE FOR

- 10. For how many older adults do you provide informal care?
  - □ None
  - $\Box$  One
  - □ Two
  - $\hfill\square$  Three or more
- 11. Where does the older adult(s) you care for usually live? (Select all that apply)
  - $\Box$  With me
  - $\Box$  Somewhere else
- 12. As far as you are aware, do any of the older adults you care for use any of the following technology at home (select all that apply)?
  - $\Box$  Desktop or laptop computer
  - □ Tablet computer (wireless touch screen personal computer that is smaller than a notebook but larger than a smartphone).
  - □ Smart television (one connected to the internet and allowing you to interact with services)
  - □ Motion sensors (sensors that monitor activity e.g. door/bed sensors, Just Checking etc)
  - □ Personal emergency alarm (e.g. Telecare, Careline pendant etc)
  - $\Box$  Smart phone/iPhone (i.e. a mobile phone with a touch screen display)
  - □ Voice-activated virtual assistant (e.g. Amazon Echo and Alexa)
  - $\Box$  Wearable fitness trackers (i.e. devices you wear to track your health and fitness)
  - $\Box$  They don't use any of the above

### YOUR CARING ROLE

- 13. On average, how many hours of informal care do you provide in a week?
  - $\Box$  0-9 hours
  - $\Box$  10-19 hours
  - $\Box$  20-29 hours
  - □ 30-39 hours





- $\Box$  40 hours or more
- 14. What kinds of assistance do you provide to the older adult(s) you care for? (Select all that apply)
  - $\Box$  Getting up/going to bed
  - □ Washing/bathing
  - $\Box$  Dressing/undressing
  - $\Box$  Using the toilet
  - □ Preparing meals/snacks/drinks
  - □ Eating
  - $\Box$  Drinking
  - $\Box$  Taking medication
  - $\hfill\square$  Reminders/prompts to take medication, to eat or to drink
  - □ Laundry
  - $\Box$  Cleaning/tidying around the home
  - $\Box$  Shopping
  - $\Box$  Helping with the paperwork such as dealing with bills, filling in forms, writing letters etc
  - □ Keeping the person company / providing emotional support
  - $\hfill\square$  Taking them out e.g. to shops, bank, social events etc
  - $\Box$  Other

- 15. Do you have concerns about the safety of the adult(s) you care for\*
  - $\Box$  I have no concerns about their safety
  - $\Box$  I have some concerns about their safety
  - $\Box$  I have many concerns about their safety
  - $\Box$  I am always concerned about their safety

\*If you have concerns, please raise with the appropriate care service.

### YOUR HEALTH

16. How would you describe your health status?

- $\Box$  Very good
- $\Box$  Good
- 🗆 Fair
- □ Poor
- $\Box$  Very poor

- 17. Do you ever feel lonely?
  - $\Box$  I never feel lonely
  - $\Box$  I sometimes feel lonely
  - $\Box$  I often feel lonely
  - $\Box$  I always feel lonely
- 18. What support, that you do not already receive, would make the greatest difference to your quality of life as an informal carer? (Please identify up to a maximum of 3 things you would like help with)
  - (a)
  - (b)
  - (c)

### **USE OF TECHNOLOGY**

- 19. Do you use any of the following technology in your own home (select all that apply)?
  - □ Desktop or laptop computer
  - □ Tablet computer (wireless touch screen personal computer that is smaller than a notebook but larger than a smartphone)
  - □ Smart television (one connected to the internet and allowing you to interact with services)
  - □ Motion sensors (sensors that monitor activity e.g. door/bed sensors, Just Checking etc)
  - □ Personal emergency alarm (e.g. Telecare, Careline pendant etc)
  - □ Smart phone/iPhone (i.e. a mobile phone with a touch screen display)
  - □ Voice-activated virtual assistant (e.g. Amazon Echo and Alexa)
  - $\Box$  Wearable fitness trackers (i.e. devices you wear to track your health and fitness)
  - $\Box$  I don't use any of the above
- 20. How would you describe your general level of technical knowledge?
  - □ I can understand pretty well any information technology
  - $\Box$  I am confident that I will be able to use most technology
  - □ I have reasonable knowledge and can do things like sending emails, interacting with social media, using packages for creating documents and spreadsheets, etc.
  - $\Box\,$  I know a bit but am only really able to do basic things like search the web and buy things online
  - □ I don't know anything about technology





- 21. What would be your view if technology was available that could help you with your caring role?
  - $\Box$  I would definitely be interested in this
  - $\Box$  I would possibly be interested in this, depending on what the technology was and how it worked
  - $\Box$  I would definitely not be interested in this
- The following questions relate to the **use of digital technology** in home care (any computers, monitoring devices, the web and internet, etc). For each one, select the box equating to how useful it would be to you as a carer.
- 22. Technology that helps with finding information and advice online

 $\Box$  Very useful  $\Box$  Quite useful  $\Box$  Not useful

- 23. Systems that monitor the health status/signs of cared-for adults
  - $\Box$  Very useful  $\Box$  Quite useful  $\Box$  Not useful
- 24. Sensors that detect motion/activity of cared-for adults (e.g. door/bed sensors, room movement monitors)
  - $\Box$  Very useful  $\Box$  Quite useful  $\Box$  Not useful
- 25. Systems that provide alerts when a cared-for adult has a problem at home (e.g. falls over)

 $\Box$  Very useful  $\Box$  Quite useful  $\Box$  Not useful

- 26. Devices that prompt cared for adults to take medication, food or drink
  - $\Box$  Very useful  $\Box$  Quite useful  $\Box$  Not useful
- 27. Equipment that helps carers with moving/handling situations

 $\Box$  Very useful  $\Box$  Quite useful  $\Box$  Not useful

28. Technology that connects carers with other carers

 $\Box$  Very useful  $\Box$  Quite useful  $\Box$  Not useful

29. Another form of technology not listed that you would find quite or very useful

Please state:

30. What, if anything, would prevent you from using technology at home that could help you with your caring role?



31. What, if anything, would encourage you to use technology at home to help with your caring role?

Please state:

Thank you very much for taking the time to answer our questionnaire. If you would like to provide us with any additional information or comments, please email one of the researchers whose details are at the start of the questionnaire or add it below.

Any other comments:

#### Appendix: Quantitative data from the older adult questionnaire B

These data do not include the text-based answers that will be analysed when the data collection period for the questionnaires is completed.

Answers	Frequency	Percentage
Gender		,
male	28	43
female	37	57
others	0	0
Age		•
54 or younger	3	5
55-64	4	6
65-74	14	22
75-84	26	40
85+	18	28
Ethnic group		
Asian/Asian British	2	3
Black African/Caribbean/Black British	6	9
White - English/Welsh/Scottish/Northern Irish/British	57	88
Physical or mental-health condition	IS	
No	19	29
Yes	44	68
Prefer not to say	2	3
If yes, which particular mental or physical he	ealth issues	
Vision – e.g. blindness or partial sight	12	10
Hearing – e.g. deafness or partial hearing	8	7
Mobility – e.g. walking short distances or climbing stairs	30	26
Dexterity – e.g. lifting and carrying and carrying objects, using a	16	14
keyboard		
Learning or understanding or concentrating	8	7
Memory	15	13
Mental Health – e.g. depression, anxiety	13	11
Stamina or breathing or fatigue	12	10
Socially or behaviourally – e.g. associated with autism, attention	1	1
deficit disorder or Aspergers syndrome		
Highest educational qualification		
Certificates normally passed at the age of 18	5	8
Certificates normally passed by the age of 16	8	13
Higher education certificates	25	40
No qualifications	25	40
Where the person lives		
City/Suburb	54	86
Rural or remote from other houses	1	2
Town	5	8
Village	3	5
Who the person lives with		

Nobody (I live alone)	44	67
Spouse/partner	16	24
Other family members/relatives	5	8
Friends/non-relatives	1	2
Paid caregiver	0	0
Someone under the age of 18	0	0
Maximum number of carer visits per	-	0
Four times or more in a day	7	11
Never visited by home care worker	40	63
One visit a day	5	8
Three times a day	4	6
Twice a day	8	13
How the carer helps the person		15
I don't receive any help from a home care worker	33	28
Getting up/going to bed	6	5
Washing/bathing		
	14	12
Dressing/undressing	10	-
Using the toilet	3	3
Preparing meals/snacks/drinks	12	10
Eating	0	0
Drinking	0	0
Taking medication	5	4
Reminders/prompts to take medication, to eat or to drink	7	6
Laundry	7	6
Cleaning/tidying around the home	13	11
Shopping	5	4
Sitting service	0	0
Going out e.g. to shops, bank, social events etc	2	2
Other	1	1
Does the person have paid help		
yes	16	26
no	46	74
What help is received from informal of	carers	
I don't receive any help from an informal carer	35	35
Getting up/going to bed	1	1
Washing/bathing	1	1
Dressing/undressing	2	2
Using the toilet	2	2
Preparing meals/snacks/drinks	5	5
Eating	0	0
Drinking	0	0
Taking medication	2	2
Reminders/prompts to take medication, to eat or to drink	2	2
Laundry	9	9
Cleaning/tidying around the home	12	12
	12	12

Shopping	20	20
Going out e.g. to shops, bank, social events etc	7	7
Other	2	2
How safe does the person feel at hon	ne	
I feel absolutely safe in my own home.	55	85
I mostly feel safe in my own home.	7	11
I never feel safe at home.	1	2
I sometimes feel safe at home.	2	3
Health status		
Very Good	12	19
Good	19	30
Fair	22	34
Poor	9	14
Very Poor	2	3
Fallen or lost balance at home in the las	t year	
No, I am very steady.	27	45
Yes, occasionally (a few times a year).	25	42
Yes, quite often (at least monthly).	5	8
Yes, very often (at least weekly).	3	5
Is the person ever lonely		
I always feel lonely.	4	6
I never feel lonely.	30	46
I sometimes feel lonely.	31	48
Interested in leaerning how technology ca	an help	1
Yes, I always want to learn	27	42
I am interested in learning some things	21	33
I don't want to learn anything any more	16	25
What technology does the person use in th	ne home	
Desktop or laptop computer	32	19
Tablet computer – wireless touch screen personal computer that	26	15
is smaller than a notebook but larger than a smartphone		
Smart television – one connected to the internet and allowing you	35	21
to interact with services		
Motion sensors – sensors that monitor activity e.g. door/bed sen-	1	1
sors, Just Checking etc		
Personal emergency alarm – e.g. Telecare, Careline pendant etc	26	15
Smart phone/iPhone – i.e. a mobile phone with a touch screen	31	18
display		
Voice-activated virtual assistant – e.g. Amazon Echo and Alexa	10	6
Wearable fitness trackers – i.e. devices you wear to track your	3	2
health and fitness		
I don't use any of the above	4	2
How would the person want to use techn	ology	
—	lology	
Access to health services and advice	30	19
—		19 23

Contacting my home care worker/care provider	12	8
Access to cultural activities	20	13
Shopping	18	11
Access to people who can help with household jobs (repairs,	13	8
maintenance etc)		
Other	7	4
Level of technical knowledge		
I can understand pretty well any information technology.	6	10
I am confident that I will be able to use most technology	4	6
I have reasonable knowledge and can do things like sending	22	35
emails, interacting with social media, using packages for creat-		
ing documents and spreadsheets, etc.		
I know a bit but am only really able to do basic things like search	9	15
the web and buy things online.		
I don't know anything about technology	21	34
Would the person use gadgets for tracking activit	y and wellbei	ng
Yes, absolutely	11	15
Yes, depending on what they measure and how they work	22	31
Not really, unless somebody can give me some good reasons	19	27
Definitely not	5	7
I don't understand what is meant by 'smart' gadgets	7	10
Would the person be interested in technology that helps keep h	im or her ca	
Yes, definitely	32	52
Possibly, depending on what it is and how it works	18	30
No, definitely not	11	18
What technology would the person want to help w		
A personal emergency alarm or some other technology in your	21	15
home that tomatically calls for help if you have a problem $-$ e.g.		
when you press an emergency button or if sensors detect you have		
had a fall		
Virtual assistants that can prompt you to take medication, eat or	15	11
drink – e.g. Amazon's Alexa, Appleâs Siri, or Googleâs Assistant		
Medical consultations and help in case of an emergency at any	17	12
time		
Talking to a doctor or a nurse online at an appointed time	21	15
Ordering prescribed medicines that are then sent to your home	22	16
Accessing test results online or getting them by email	17	12
Have health and fitness data measured and sent to your doctor or	15	11
clinic	10	
Participating in an online forum where you could discuss health	11	8
matters with others		-
Views about using technology to replace ca	are visits	
I would definitely be interested in this	16	28
I would definitely be interested in this I would possibly be interested in this, depending on what the tech-	19	33
nology was and how it worked		
I would definitely not be interested in this	22	39
i would dominion not be interested in this		57

Willing to share personal h	ealth data with GPs (Genera	I Practition	ners)
Yes	4	7	77
Maybe	9		15
No	5		8
Willing to share person	nal health data with NHS org	ganisations	
Yes	3:	5	63
Maybe	10	6	29
No	5		9
Willing to share personal	health data with selected far	mily memb	ers
Yes	30	0	56
Maybe	10	6	30
No	8		15
Willing to share persor	al health data with formal,	paid carers	
Yes	1:	5	32
Maybe	18	8	38
No	14	4	30
Willing to share pers	onal health data with inform	nal carers	
Yes	12	2	26
Maybe	1:	5	33
No	19	9	41
Willing to share person	nal health data with social ca	re services	
Yes	22	2	45
Maybe	12	2	24
No	1:	5	31

## C Appendix: Quantitative data from the professional carer questionnaire

These data do not include the text-based answers that will be analysed when the data collection period for the questionnaires is completed.

Answers	Frequency	Percentage	
Gender			
male	2	9	
female	21	91	
others	0	0	
Ethnic group			
Asian/Asian British	15	65	
Black African/Caribbean/Black British	5	22	
White - English/Welsh/Scottish/Northern	2	9	
Irish/British			
Prefer not to day	1	4	
Highest educational qualification			
Certificates normally passed at the age of 18	9	39	
Certificates normally passed by the age of 16	3	13	
Higher education certificates	9	39	

	9
What technology does the person being cared for	use in the home
Desktop or laptop computer 6	9
Tablet computer – wireless touch screen personal9	13
computer that is smaller than a notebook but larger	
than a smartphone	
Smart television – one connected to the internet and 8	12
allowing you to interact with services	
Motion sensors – sensors that monitor activity e.g. 8	12
door/bed sensors, Just Checking etc	
Personal emergency alarm – e.g. Telecare, Careline 19	28
pendant etc	
Smart phone/iPhone – i.e. a mobile phone with a 9	13
touch screen display	
Voice-activated virtual assistant – e.g. Amazon Echo 8	12
and Alexa	
Wearable fitness trackers – i.e. devices you wear to 1	1
track your health and fitness	
They don't use any of the above 0	0
Assistance the carer provides	
Getting up/going to bed 22	÷
Washing/bathing 22	
Dressing/undressing 22	8
Using the toilet 21	8
Preparing meals/snacks/drinks 22	
Eating 13	
Drinking 12	
Taking medication21	
Reminders/prompts to take medication, to eat or to 20	8
drink	
Laundry 19	
Cleaning/tidying around the home 20	8
Shopping 16	6
Helping with the paperwork 4	2
Keeping the person company 18	7
Going out e.g. to shops, bank, social events etc 6	2
Other 1	0
What technology does the carer use in the carer use in the carer use in the carer use in the care of t	he h <mark>ome</mark>
Desktop or laptop computer 21	25
Tablet computer – wireless touch screen personal 18	21
computer that is smaller than a notebook but larger	
than a smartphone	
Smart television – one connected to the internet and 17	20
allowing you to interact with services	
Motion sensors – sensors that monitor activity e.g. 3	4
door/bed sensors, Just Checking etc	

	1	1
Personal emergency alarm – e.g. Telecare, Careline pendant etc	1	1
Smart phone/iPhone – i.e. a mobile phone with a touch screen display	17	20
Voice-activated virtual assistant – e.g. Amazon Echo and Alexa	3	4
Wearable fitness trackers $-$ i.e. devices you wear to track your health and fitness	4	5
They don't use any of the above	1	1
Level of technical knowled	ge	
I am confident that I will be able to use most tech-	18	75
nology		
I have reasonable knowledge and can do things like	2	18
sending emails, interacting with social media, using		
packages for creating documents and spreadsheets,		
etc.		
I know a bit but am only really able to do basic	1	4
things like search the web and buy things online.		
I don't know anything about technology	2	3
Usefulness with finding information an	d advice onlir	he
Very useful	18	86
Quite useful	3	14
Not useful	0	0
Have you ever been taught	how to use it	
Yes	10	53
No	9	47
Usefulness of developing content and pu	blishing it onl	ine
Very useful	9	43
Quite useful	10	48
Not useful	2	9
Have you ever been taught	how to do it?	
Yes	10	63
No	6	37
Usefulness of maintaining privacy, co	onfidentiality	L
Very useful	20	95
Quite useful	1	5
Not useful	0	0
Have you ever been taught	how to do it?	
Yes	10	50
No	10	50
Usefulness of monitoring the heat	th status	
Very useful	18	82
Quite useful	4	18
Not useful	0	0
Have you ever been taught	how to do it?	
Yes	9	45
	1	

11	55
ensors	
13	62
8	38
0	0
ight how to do	it?
10	50
10	50
rovide alerts	
15	71
6	39
0	0
ight how to do	oit?
11	52
10	48
take medicat	tion etc
13	62
4	19
4	19
ight how to do	it?
6	32
13	68
s moving/han	dling
20	91
2	9
0	0
ight how to do	it?
17	81
4	19
routines, adm	in
17	77
5	23
0	0
ıght how to do	it?
10	45
12	55
ionship and b	onding
14	64
6	27
2	9
ight how to do	it?
8	36
14	64
ke care of the	mselves
15	71
	isensors      13      8      0      ight how to do      10      rovide alerts      15      6      0      ight how to do      11      10      rovide alerts      13      4      11      10      otake medicat      13      4      13      4      13      4      ight how to do      6      13      9      20      20      20      13      smoving/ham      20      2      0      ight how to do      17      4      routines, adm      17      5      0      ight how to do      14      6      2      ight how to do      8      14      6

Quite useful	5	24
Not useful	1	5
Have you ever be	en taught how to do	it?
Yes	7	35
No	13	65
Usefulness of setting up and man	aging digital devices	s/systems
Very useful	11	52
Quite useful	9	43
Not useful	1	5
Have you ever be	en taught how to do	it?
Yes	9	43
No	12	57
Usefulness of training older ad	ults how to use tech	nology
Very useful	12	57
Quite useful	8	38
Not useful	1	5
Have you ever be	en taught how to do	it?
Yes	6	29
No	15	71
Usefulness of online social networ	ks with other health	n workers
Very useful	13	62
Quite useful	6	29
Not useful	2	9
Have you ever be	en taught how to do	it?
Yes	8	38
No	13	62
Usefulness of online social netwo	rks with the people	cared for
Very useful	10	48
Quite useful	6	29
Not useful	5	24
Have you ever be	en taught how to do	it?
Yes	6	29
No	15	71
Usefulness of online social networks	to support each oth	er (patients)
Very useful	10	48
Quite useful	8	38
Not useful	3	14
Have you ever be	en taught how to do	it?
Yes	8	40
No	12	60