
The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes

Working Papers from the AKTIVE project 2011-2014

AKTIVE Working Paper 2

Frail Older People and their
Networks of Support:
how does telecare fit in?

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Advancing Knowledge of Telecare for Independence and Vitality in later life

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1 Introduction and context

In this paper the focus is on the different types and configurations of formal and informal support in place, alongside telecare, to support frail older people, and on how having telecare in place affected, and was influenced by, these arrangements. Based on detailed research with older telecare users and people involved in their care, the paper defines and contrasts three ‘ideal types’ identified as: ‘complex’; ‘family-based’; and ‘privatised support’ caring networks.¹ It considers how telecare interacted with each type of caring network and explores differences in the relevance and applicability of each to frail older people in the AKTIVE study. Particular reference is made to differences between older people using telecare who lived alone or with others; and between those who had memory problems or were susceptible to falls.

In exploring these three types of ‘caring network’ (to which older people may, or may not, have access) the paper addresses the AKTIVE study research questions about the context in which older people use telecare; its significance for them, their carers and others who may support them to live at home; and the scope telecare may offer for redesigning and reconfiguring care support for frail older people. The analysis is based on the AKTIVE project’s ELA method, which involved repeat research visits to 60 older people in their own homes, and research contacts of various kinds with those supporting them, who could include family members (co-resident or otherwise); home care and other workers in the health and social care system; and neighbours or friends involved in caring for or supporting them.²

The paper begins with some introductory comments on ‘ageing in place’ as a key policy goal in England’s system of care and support for frail older people and on older people’s eligibility for and access to support in the current English system, including their access to telecare. It then outlines the caring network typology proposed, considering the role of telecare in each and its relevance to how such networks might develop in future.³ Three case examples, drawn from research participants in the AKTIVE study, are then presented, highlighting key features of the support in place in each. The paper concludes with a discussion of some policy implications of the analysis, with particular reference to the future role of technology in supporting frail older people to age in place.

The policy and social context in which caring networks may develop to support frail older people varies from place to place and from case to case, and is also affected by national arrangements for social care. In England’s system of care and support for frail older people, as in many others, ‘ageing in place’ is a well-established policy goal (Yeandle et al., 2012). This emphasises the benefits to older people of remaining in the homes and communities where they have lived, sometimes for decades, prior to entering late old age or before (for some) mental or physical frailties develop (Houben, 2000). While this broad, essentially simple and widely shared policy objective is seldom contested, in England it sits within a system of social care

¹ Ideal types are theoretical models used as a device in sociological analysis, which offer meaningful tools for analysis. They are based in empirical observation, and involve a method originally developed by Max Weber. Ideal types may not exist exactly as described in any individual case; they are heuristic devices, developed for theoretical and analytical purposes, to explore and understand social relationships, patterns of behavior, and social structures.

² The AKTIVE project’s ‘Everyday Life Analysis’ (ELA) methodology is presented in Yeandle et al., 2014.

³ These constructs do not map exactly on to the lived experience of the older people studied, and are not intended to be comprehensive. From the theoretical point of view, their incidence is relatively unimportant.

support which is complex, geographically variable and under frequent review (Commission on Funding of Care and Support, 2011; Law Commission, 2011). Older people and their relatives often find local social care arrangements hard to understand and to negotiate, especially compared with their access to NHS healthcare, which is free and accessed through their GP.⁴ When a care need arises they are often confused and dismayed by how their eligibility and need for support is assessed and addressed.⁵ Studies have shown many find it hard to know what public or private services are available, highlighting that this is often a time of great stress in which difficult decisions may have to be made quickly (Carers and Employment Task and Finish Group, 2013).

In recent years telecare services, mainly accessed through local authorities, have been added to the mix (Roulstone et al., 2013). Designed to offer older people and their carers more choice and greater peace of mind, they also involve assessment and decision-making about needs, eligibility and resources, through systems which are still developing and changing. Thus in Leeds and Oxfordshire, where the AKTIVE study was conducted, the telecare services were differently organised, producing different outcomes for users and carers, and each was subject to some re-organisation during the study (Yeandle, 2014, Paper 1). Telecare can be accessed privately, without recourse to local authorities, but the consumer market for it remains underdeveloped, and currently few older people in England obtain telecare through product retailers, or directly from suppliers or manufacturers (Down, 2014; Inventya Ltd, 2014).

In Department of Health (DH) guidance, and through some DH funding streams, local authorities have been encouraged to develop telecare services, and most have done so, although this is not a statutory obligation (Yeandle 2009; Roulstone 2013). For individuals, assessment for local authority telecare support may follow referral through different elements of the health and social care system, or self-referral, sometimes at the suggestion of relatives or others (Koivunen (2014, Paper 3). Telecare typically requires installation by a technician, the establishment of a connection with a monitoring centre offering 24 hour support, and nominated responders (normally people known to, and living near to, the older person, who can come to their aid rapidly if needed). Telecare thus provides multiple opportunities for engagement with other people involved in the older person's care, who, as shown below, may engage with it in a variety of different ways. The telecare in place when older people joined the AKTIVE study is shown in Table 2.1.

Many frail older people have the support of family, friends or neighbours, but this is not always the case and some experience considerable social isolation and loneliness (Koivunen, 2014, Paper 3). Nevertheless most participants in the AKTIVE study could name someone who provided them with reasonably regular informal help or assistance (56 out of 60) and 24 had formal home care support in place.⁶ The frequency of their contacts with these different people varied and forms an obvious difference between those living alone, for whom such contact was sometimes only weekly (or less often), and those living with others, who had more or less constant access to some support, albeit often provided by a spouse also coping with frailty of some kind in old age.

⁴ Social care arrangements in England are the responsibility of councils with social services responsibilities (CSSRs). Some changes to these responsibilities are expected when the Care Bill, before parliament in 2013-14, becomes law.

⁵ Assessment of an older person's need for home care and other community-based support are undertaken by social work professionals, normally through local authority Adult Social Care departments.

⁶ Having telecare was a condition of inclusion in the study. Home care was temporary (reablement) support in a few cases (Yeandle, 2014, Paper 1).

Table 2.1 Telecare in place at start of study, by research participants' circumstances

Research participants' circumstances	PAO ¹	Package	GPS	GPS+ package	Other	ALL
Main health condition(s)						
<i>Falls</i>	21	14	0	0	0	35
<i>Memory problems / dementia</i>	1	3	1	3	1	9
<i>Both falls and memory problems</i>	10	4	0	0	2	16
Living arrangement						
<i>Living alone</i>	23	14	0	2	2	41
<i>Living with others</i>	9	7	1	1	1	19
Other support in place						
<i>Carer</i>	30	19	1	3	3	56
<i>Home care</i>	11	13	0	0	1	25
<i>Home adaptations</i>	28	13	0	2	2	46
ALL ELA RESEARCH PARTICIPANTS (n=60)	32	21	1	3	3	60

Source: AKTIVE ELA database, CIRCLE, University of Leeds.

¹ PAO = pendant alarm only.

As earlier work in the AKTIVE project showed, there has been limited previous research on how telecare, families and professional care interact (AKTIVE Consortium, 2013). The ELA aspects of the AKTIVE project enabled the project's social researchers to explore this as part of their detailed research contact, over at least 6 months, with older people, their families and others involved in their support.

2 Complex caring networks

A 'complex caring network' is defined here as a network focused on a frail older person (or couple) comprising a variety of actors who interact with the older person / couple and with each other, supported by a range of systems and technologies.⁷ The actors in this type of caring network may include the older person's family members, neighbours, friends and other social contacts (who might, for example, be members of a church, organisation, club or informal group to which they belong) as well as a range of people in contact with them through their work (or occasionally as volunteers), including home care workers, occupational therapists, community nurses, social workers and others in the health and social care system. The network may also include others who call at their homes or who provide them with assistance or domestic services, such as cleaners, gardeners, pharmacists and others. A map of the full possible range of these was developed in the AKTIVE project's systems mapping work (Yeandle et al., 2014), and is discussed and shown diagrammatically in Buckle (2014 forthcoming, Paper 7).

In the AKTIVE study, some research participants had support which approximated to this 'complex caring network' (CCN), alongside telecare, and relevant ELA cases inform the analysis in this section. The arrangements in place to support one research participant exemplify this type of network particularly well and are described in Box 2.1. The analysis of these cases suggests CCNs may be associated with having any or all of the following: a desire, on the part of the older person, to remain as independent as possible (sometimes encouraged by family members); a variety of health problems, disabilities or frailties (which may include memory problems or dementia, although not at an advanced stage); complexity of caring needs, linked to change in health circumstances (sometimes including recovery as well as deterioration); and limited local family support and / or having no children.

Members of a CCN support frail older people variably and flexibly as circumstances alter, assisting them with a variety of tasks and activities and meeting a range of their changing needs or requirements. Examples of assistance with the following were found in data collected from older people with support of this type.

- *Household and domestic tasks*: shopping for daily needs (milk, bread etc.) or weekly groceries and other household requirements; doing odd jobs and minor household repairs (such as changing light bulbs or putting rubbish out); gardening; and getting technology, such as Sky TV, mobile phones, etc. to work when a fault developed or the older person found it confusing.
- *Help with essential daily practicalities*: supplying cooked food or helping to prepare meals; administering or reminding to take medicines and filling up medication dispensers; taking to hospital or doctor's appointments; daily checks, in case of worrying developments (illness, a fall, an unexpected need) or to ensure home care or other arrangements are working properly; Internet shopping for an older person unable to manage this alone; dealing with finances or bills; arranging home or day care, home adaptations, or setting up or adjusting telecare arrangements; and managing a personal budget or negotiating with the local authority or other agencies as an advocate.

⁷ This is a feature of the 'ideal type' (fn1). In practice few complex caring networks will comprise people all of whom interact with each other, but this is theoretically possible and, as explained in Section 5, it has policy implications.

- *Help with personal care*: using the toilet or commode; washing and bathing; dressing; doing hair or make-up; assisting into and out of bed; and changing dressings or appliances (e.g. catheters, peg feeding).
- *Social and emotional support*: calling on, telephoning or keeping company, either in person or remotely, often using Skype; and supporting at times of stress, including bereavement.
- *Emergency response*: responding to telecare alerts or alarms and dealing with other crises, for example calling, or ensuring others attend, when the older person had not been seen as normally expected.

Within a CCN, *household and domestic tasks* and *help with essential daily practicalities* are often provided by neighbours (often referred to as 'good neighbours'), local friends or visiting family members. *Help with personal care* is, if needed, often provided by home care workers or close (usually female) family members. *Social and emotional support* may be provided by friends, neighbours and sometimes through local associations or other community, friendship or activity-based groups. Distant or overseas relatives may also provide this type of support remotely, especially if the older person has access to or can use a personal computer, tablet, Skype or email. *Emergency response*, where telecare is in place, is usually provided through a 24 hour monitoring centre, which summons the support of the older person's nominated telecare responders (typically neighbours, family members or friends living locally) enabling them to attend the older person promptly and assess their immediate needs or requirements.⁸

A CCN evolves, adapts and changes over time, and may be instigated or co-ordinated by the older person or by one or more other people. Health and social care professionals can (but need not necessarily) be involved in the network; and where family relationships exist, or the older person has lived in the locality long enough to know some of their neighbours, family and neighbours are usually involved. Different members of the network typically know of and about each other, and may communicate through the older person or independently of them.

Telecare can be instigated by any member of the network, including the older person. Examples in the study included recommendations or referrals through hospital staff, occupational therapists, neighbours, family members and others. This sometimes followed an incident or accident or was advised as part of hospital discharge arrangements. The older people affected often commented that telecare was preferable to accepting home care, and almost always felt it was better than moving into residential care. Telecare was usually advocated as offering the older person greater security, rapid response in the event of an accident or sudden illness, and, above all, greater independence. It would, they were advised, help them stay at home, reduce worry for them and those who cared about them, and reduce their dependence on others (or as some older people put it, make them less of a 'burden' to others).

The reliance of telecare systems on nominated telecare responders (the recommended and usual arrangement) introduces a degree of formality into some older people's relationships which may subtly alter, and potentially strengthen, these existing relationships and ties. In the study, more than half of research participants had nominated responders, although some preferred, or needed to rely, on the 'default' response systems in place.

⁸ In some cases, different equipment is connected to different monitoring centres.

Mrs Tyne was a widow aged 94, living alone in Oxfordshire and at risk of falls. When she joined the study she described a complex caring network which sustained her well. This relied on a mix of friends, neighbours, family and occasional formal support and her recently installed pendant alarm. Her 'main carer' was her neighbour (whose husband also provided some support); her daughter and granddaughter visited two to three times weekly to check on her needs; and friends helped her with shopping. Her neighbour explained that telecare was introduced when Mrs Tyne was in hospital recovering from surgery:

'[She] couldn't go to her daughter's because she's got stairs. We've got stairs, there's no way she could go there. She wanted to come home. So that's why the hospital said they would start the ball rolling and put [telecare] in place. That's why she got it, because she'd had two major operations in the space of three months. So we needed backup, because if anything is wrong and she presses her button, I'm two minutes down the road to get here.'

Following her hospital discharge, Mrs Tyne briefly had home care support, but discontinued this as soon as she had recovered sufficiently to cope, even though her operation had left her with mobility problems and a tendency to fall. She used Skype to keep in touch with more geographically distant relatives, benefitting from their emotional support, and during the study was still occasionally able to attend the community centre in her Oxfordshire village. She and her neighbour described her pendant alarm as 'a godsend'. Her neighbour repeatedly mentioned the benefits of the pendant alarm: *'it gives you peace of mind, because you know she can contact you. Whereas before, yes, she could ring me up, but if she'd fallen and she wasn't near the phone she couldn't'*. Additional equipment provided through the AKTIVE project gave further reassurance, including a 'bogus caller' alarm which Mrs Tyne particularly valued:

'If she goes to the door and she doesn't know who it is, she can press that button [...] That is a good thing, because, I mean, there has been quite a lot of undesirables living in the parts over there [...] The police were always there [...] it seems to have quietened down a bit, but she was very frightened then.'

Neighbour of Mrs Tyne, 94, living alone, Oxfordshire, falls

Mrs Hibbs' support arrangements were similarly complex. Now 83 and a widow, she lived alone, managing both her susceptibility to falls and her dementia with the help of her pendant alarm. A former health professional, she had lived in the same village a long time, alone for the past 14 years. When the study began she was still participating in local activities. Her daughters (living about an hour away) visited at least weekly, and they and her nieces often invited her for meals and to family events, her daughters also helping by using their computers to buy things she needed and booking her holidays. Her complex caring network also included regular support from neighbours (who helped with shopping, medicines and daily chores) and from friends, one of whom visited daily (and held a key), another calling in weekly. Telecare had been introduced after two distressing falls when alone at night. Her daughters subsequently encouraged her to acquire a pendant alarm, which she accepted to be able to live on her own longer and give her daughters peace of mind, although she felt this had been imposed upon her. Hers is an example of a complex network of support in which family members were increasing their role as needs intensified and independence diminished (partly through having to give up driving). The implications of this shift from a CCN where the older person feels in control, to more family-based support as frailties grew, are considered in the concluding discussion in this paper.

Mr & Mrs Swallow (74 and 67 respectively) were a married couple living in Oxfordshire. Each had some disabilities and wore a pendant alarm. Mrs Swallow had suffered from lung disease much of her life; Mr Swallow had recently been diagnosed with heart failure. They spoke of working 'as a team'. Their caring network included practical support from a neighbour who checked on them if their curtains were not drawn by a certain time and brought meals if one of the couple was in hospital. Mrs Swallow's son lived locally and also provided practical support. The couple gained emotional support from family members living further away and were keen users of Skype. They had chosen Community Voice as their telecare responders. Mrs Swallow and her son found this reassuring for various reasons (described in Koivunen, 2014), and the pendant alarm allowed her to stay with her husband if he was ill, rather than going to the phone in a rush, which was crucial as she is oxygen-dependent. She also liked the idea that, if needed, the response service would ring her son and her husband's daughter *'and all that, free me up, so that my main concern will be [my husband] getting to the hospital'*. Mrs Swallow explained how mutual care between the couple was constrained by their health problems and supported by their telecare:

The feelings of fright and loneliness come in, because, you know, well - concern, obviously, because it's someone you love, and you don't want anything to happen to them. But also it is part of you, part of your help that is not well. I mean [my son] comes over, he takes over. [...] he's young and he's a social worker, so he knows. He's quite sort of business-like and deals with people for me and gets me sorted. But it was just that period; I've never, ever felt like that in my life before. I've always been in total control before, and this time it was just frightening and, as I said, now I've got the alarm that's a big weight off my shoulders, it really is.

Mrs O'Carroll was at risk of falls, suffered from memory problems and was terminally ill. She very much wanted to die in her own home in Oxfordshire. An 86-year old widow, she was proud of having nursed her late husband at home until his death, and her history of mental illness meant home was where she felt safest and most secure. Her support network was complex, comprising a telecare package (a pendant alarm and bed sensor), home care four times daily, assistance from family, especially her daughter, and periodic healthcare support.⁹ Mrs O'Carroll was very concerned about possibly being admitted to hospital and not returning home. She had a pendant alarm, supplied five years before following knee problems, which she had activated once. This led to hospital admission and she was determined not to use it again. She had already fallen at night and been found in the morning by her home care workers, on the floor, wearing her pendant, but not having pressed it. This worried her family who (by chance) heard about bed sensors and initiated an installation. This had mixed results; Mrs O'Carroll was losing weight rapidly (which seemed to affect the function of the sensor); on at least one occasion, either the bed sensor triggered an alert or Mrs O'Carroll used her pendant alarm to summon help. After a few months (during the study), she could no longer walk unaided, so the bed sensor was removed. Her daughter felt it would have been useful if installed earlier, and felt frustrated at the lack of information on what telecare equipment was available.

⁹ Mrs O'Carroll died shortly after the study. At times she also had Macmillan nurses / overnight home care support.

BOX 2.1 Complex Caring Network: Mrs Beech

Mrs Beech was 95 and lived alone in Oxfordshire with a pendant alarm in place. She had good social relationships with neighbours and friends, who visited her every week, and described herself as 'very active' until a few years ago:

I fell down and they sent me off to hospital to find out what was wrong, and sent me back home with a clean sheet and then rang up to say I must go back because I had an infection in the blood. That was it, I was in hospital, caught everything there was to catch while I was in there. I was in there for four and a half months.

Prior to her stay in hospital Mrs Beech had privately arranged home care in place, but when she was discharged reablement support was offered, with care workers who stayed with her overnight.¹⁰ When this service ended, she reverted to her previous arrangements, which were arranged by her son who had power of attorney. Care workers visited her four times daily and she also had regular visits from district nurses. She was positive about her home care, and pleased that the agency adhered to her request to send only female care workers. As she became frailer, a hoist was installed in her home to enable the care workers to assist her safely; she was unhappy with this change, and felt she had not been consulted about it.

Mrs Beech also paid privately for a cleaner and a gardener and was a private telecare client. During the study she changed her telecare provider, as her son felt she should use one which provided an emergency response in addition to her named responders, who were themselves becoming old. He lived an hour away, and her original responders were local friends and neighbours (one of whom became ill during the study).

Complex caring networks, comprising telecare support among other elements, as described in this section of the paper, helped many frail older people in the study to remain at home. While far from perfect, in many cases these arrangements were supportive of their independence (which many valued highly), helped boost their resilience, and enhanced the dignity with which they could manage their everyday lives and make plans for their future needs.

¹⁰ See Yeandle (2014, Paper 1) for information on the local reablement service.

3 Family-based caring networks

A family-based caring network (FBCN), as its name suggests, is a network focused on a frail older person (or couple) and their needs, in which family members take the lead in communicating with them about the support they require (or are thought to need) and ensuring appropriate assistance is available. In this type of network, one or more family members plays a key role in identifying the support needed; arranging what either family members and / or the older person feel is required; co-ordinating support arrangements; and keeping them under review and adapting them as is considered appropriate. Members of a FBCN may make arrangements with others, such as a home care agency, or purchase private support, but tend to control, or at least strongly influence, the choices made about what the older person needs or would like in terms of support, and how that should be provided.

Most older people in the study had some support from family members. As seen in the discussion of CCNs, not all had family living locally, some had no children, and for some 'being independent' meant keeping family members at a 'distance' in terms of how their needs were met. Others had family members actively involved in providing, organising or overseeing their care however, creating a FBCN around them.

Older people with FBCNs fell into several groups: older couples, one spouse arranging and co-ordinating the other's care (especially if one had significant care needs and the other was comparatively fit); older people (usually widowed) who were co-resident with one or more family members; and older people living alone, whose families, sometimes large and living close by, took 'control' of a situation they viewed as risky or chaotic. This often happened if memory problems or dementia were worsening, with families sometimes sharing the responsibility for support. Family and caring histories could also be important. Some older people had themselves been carers, for a spouse, parent or disabled son or daughter, and in some of these cases family members had long supported each other through problems, crises and difficulties, well before the older person became frail, and so felt to 'help each other out' was normal.

For these older people, telecare had often been introduced at the suggestion of relatives. This applied to some of the couples, caring for each other as they faced illness and disability together; to older people living alone, whose telecare installation sometimes followed bereavement and living alone for the first time in many years; and to those now residing with family members, who found it helpful in managing their situation. Some examples from the study exemplify how telecare fitted into these FBCNs.

Mrs Barnard was an 89 year old widow with dementia, living with one of her two daughters. They divided the care they provided between them, organising additional support, including a telecare package (pendant alarm, smoke and carbon monoxide detectors and later a medication dispenser), which they felt enabled them to continue in their careers, which were important to them. The co-resident daughter worked three days per week, caring for her mother on the other weekdays, and home care visits were arranged on the days she worked. At weekends, Mrs Barnard stayed at the other daughter's flat, giving her some variety and a pleasurable social occasion while the co-resident daughter had a break and some time to herself. On the co-resident daughter's work days, the sisters felt uncomfortable leaving their mother at home all day with only telecare in support, so arranged home care for her as well, saying also that the telecare was very reassuring to them when she was alone. One of the daughters explained:

Well, [telecare] has allowed me to go to work, it's made sure that once the care worker's been, mum's basically left on her own, which is no bad thing [...] Now she gets up and she might do one or two things, as I said, put the washing out if she can, that sort of thing [...] I have confidence in the way that [a crisis] will be handled [by the telecare service]. I just have to be confident in that mum will use it, I can't say any more than that.

The FBCN supporting Mrs Hall, who was 77 and susceptible to falls, also drew on both family and other forms of support, including telecare (a pendant alarm), healthcare and home care. Mrs Hall had three children, including a daughter living an hour away who visited every few weeks to take her shopping or out for lunch. She lived in Oxfordshire in an annex to her son's home (formerly her own), purpose-built for her and her late husband. When she joined the study, her daughter-in-law was providing much of the help she needed, mainly help with cooking and personal care. After a while, linked to changes in the daughter-in-law's job, Mrs Hall's family suggested home care a few times a week to help with her personal care. Health professionals visiting Mrs Hall proposed the telecare support. She explained: *'The nurses, and other various people, kept coming in, [and] thought it would be a good idea, and in the end I agreed it would be a good idea and got one'*, opting to have Community Voice as her responder as her family were not always available. She did not need to use her pendant during the study, but commented:

I think just wearing it tells me not to fall over. I think the great thing about the pendant is that it makes me remember that I'm not very steady on my feet [...] Ever since I had the emergency button I haven't had a fall [...] I think I go more carefully. I think I go very carefully.

Mrs Hall 77, living alone, Oxfordshire

Mrs Inigo's daughter was the central figure in her FBCN. Aged 77, with dementia and a past operation for a brain tumour which had left her prone to falls, she had recently moved in with her daughter and used a Buddi (GPS tracker device). Prior to this she had been living independently with a pendant alarm and reminder systems in place, but difficulties with the latter and with taking medication correctly had, she claimed, led her doctor to insist she either move in with her daughter or accept home care. She did not feel home care was necessary or desirable, but agreed to live with her daughter and grandchildren. Her daughter ensured she had activities to go to almost daily, which she enjoyed. Hopes that her other daughter (who was in poor mental health) would take her out on Fridays did not materialise, however, causing some tension. The co-resident daughter nevertheless felt her mother's presence was positive for her grandchildren and reflected that, despite initial apprehensions, she was pleased they all now lived together. Another area of tension was Mrs Inigo's assessment of risk when walking her dog, as she did not agree with her daughter that she risked getting lost unless she stuck to a particular route. To address this, her daughter obtained the Buddi device through the local carers centre, defusing some of this tension.

Mr Hodgkin, a divorcee aged 70, was at risk of falls and lived alone in Leeds. A wheelchair user, he had a telecare package (pendant alarm, plus smoke and carbon monoxide detectors) and a Personal Budget which, in effect, turned his local authority support into a FBCN. He used it to pay his granddaughter, who lived in the flat above, to care for him. He considered home care, which he had experienced in the past, expensive and of no real use. The current arrangement, seen as a creative combination by the family, had

been instigated and was managed by his daughter. It kept his care 'in the family' but drew on local authority resources. His telecare, he said, was for times when his granddaughter was at her part-time job. He much preferred his granddaughter's care, and without his daughter's help could not have coped with the paperwork associated with his Personal Budget. His arrangements had considerable complexity (nurses and his doctor also visited and he had good neighbours who provided some support), but the daughter's co-ordinating role was pivotal.

Box 2.2 Family-based Caring Network: Mrs Thompson

Mrs Thompson, in Oxfordshire, was 72 and lived alone following the death of her husband. She suffered from arthritis and back problems and was susceptible to falls. Prior to her death a few years before, her main carer had been one of her daughters with whom she had a close relationship. Now she relied on her son and elder daughter, from whom (following her other daughter's death) she was estranged for a time. During the study, her children were dividing the caring tasks between them, the daughter focusing on heavy cleaning and housework while her son drove her to town regularly and helped her with shopping. Her grandchildren also visited, as did neighbours and nieces and nephews. Her diary revealed that she had visits from family and neighbours most days.

Mrs Thompson said her telecare (a pendant alarm) had dramatically reduced her worries about not being able to summon help and felt it gave peace of mind to her family. Her best friend, who had one herself, had recommended it to her. The pendant also made her feel cared for, less isolated, and confident that even if her children were unavailable, someone would come to her aid. She explained: *'My daughter thinks it's wonderful and everything, because she said, "I used to worry myself to death about you." She worries about me, but not like she used to.'* Mrs Thompson received upgraded telecare equipment through the AKTIVE project which included a bogus caller alarm. This significantly increased her sense of safety, as she had previously been the victim of crime in her neighbourhood.

Family based networks worked extremely well for some in the study, and to some research participants and their family members seemed the 'natural' way to manage their increasing frailties. Through effective co-operation and judicious use of telecare and other services, some families were managing well and had created a good network of support around the older person. They were not always harmonious, however, and some older people spoke about friction, tensions and difficulties within the network which upset them. Some FBCNs made proactive and effective use of telecare (and other available support) which significantly enhanced the safety, security and well-being of both the older person and their carers. This type of network cannot be the solution for all, however, as it was not available to those without local family willing and able to assist, and was not the arrangement of choice for those who preferred to be independent and autonomous in old age.

4 Privatised care support networks

In a privatised care support network (PCSN), assistance is obtained through a market, parts of which may be very informal, in which services can be purchased to meet the older person's needs, preferences and requirements. This type of system may be put in place with or without recourse to family members or carers, and is likely to be established without the assistance of the local authority or a community care needs assessment. A PCSN requires financial resources, so is available only to those with the means, as well as the opportunity, to purchase support. It also relies on there being services available on the market. Frail older people who have purchased domestic or household services earlier in their lives, or who have experience, perhaps through their work, of sourcing or commissioning goods or services, would be likely to find it attractive. It may be established with the support of family members or through systems available through local authorities (such as through a Direct Payments system), but does not necessarily involve either of these factors. It is potentially available to a frail older person who has no family or carers and is ineligible for, or does not wish to use, local authority support.

Support services purchased privately by older people in the study (including some in Oxfordshire paying privately for means-tested telecare) included: cleaners ('for heavy work', as Mrs Bramley, 90, living alone in Oxfordshire explained); gardeners (for example for Mrs Allen, 84, in Oxfordshire who was both visually impaired and prone to falls, and Mrs Murray, 86, in Leeds, who also employed a 'handyman'); and private-pay home care and befrienders (discussed in examples which follow). Some also sourced technology, assisted living devices or other equipment, or arranged adaptations such as stair lifts, showers or wet rooms via the private market. Purchasing such goods and services came naturally to some; they had substantial financial resources, were experienced consumers and in some cases used to employing others to carry out work in or around the home. Some viewed their expenditure on creating a supportive environment or network for themselves in old age as a means of exercising choice, retaining control, or preserving privacy; others did so reluctantly, disliking needing help, but preferring to buy it for themselves rather than submit to needs assessment, particularly those who were aware their relative affluence made them ineligible for local authority support.

Telecare was, to some, another service that might be useful and which they were willing to try; in Leeds, where telecare was free with no means test applied, some thought it worth doing so even though they could afford to pay for the service. While there were fewer older people in the PCSN group than in the family-based or complex networks already discussed, given shifts towards paying for care and increasing marketisation of some services for older people, their experience is of considerable interest.

Mr Whittaker was a 77 year old widower, living alone since the loss of his wife, for whom he had cared during a long illness prior to her death a few years before. He had some visual impairment and was prone to falls, but was managing in the house where he had lived for 50 years with home adaptations and telecare (a pendant alarm and smoke detector), first installed for his wife. During his wife's illness, he secured a grant to fund a regular sitting service (provided by a charity) which gave him a regular break from caring. He no longer had the grant, but the sitter (Jane) had become his friend and continued to assist him in return for modest sums and petrol money. She phoned him every morning and evening, visited at least three times a week, took him shopping and on trips out and provided companionship, advice and support. This helped

him manage with minimal input from his family, who although local were busy with their own lives: as he explained: *'They don't come that often. Jane's the main help for me. She ... Well, I can talk to Jane, I can't always to me family, you know what I mean?'*

Mr Harper was a retired scientist living alone in Leeds. An affluent widower aged 73, with a heart condition and prone to falls, he had many home adaptations in place which he had purchased privately to help support his late wife, who suffered multiple sclerosis. These included a lift from his lounge to the bedroom, sophisticated air conditioning, and a downstairs toilet. He used sticks, a caddy, and other items to get around his house. Through the local authority he had free telecare (originally provided for his wife) which he valued in case of 'a crisis'; his son and his wife, who lived nearby, were nominated as his first responders. He felt 'lucky' to be able to buy in what he needed. He felt his telecare was keeping him independent at home, although he foresaw a time when more support might be needed. He did not want to accept home care, but was considering moving nearer to his daughter and her family in another part of the country. Mr Harper purchased things he needed, but tried to get along without them as far as possible (for example, he did not always use his lift, as he thought exercising his legs important), explaining:

I do occasionally [use my lift]. I try not to, but as the hip, you know, it's beginning to hurt me a bit more ... It's going to get worse, oh, I mean I realise that. But I don't want to use it, so I tend to climb stairs during the day. I might [use it] when it gets late at night, go up in the lift and maybe first thing in the morning. But I mean, that will be useful - and of course [my pendant] will be useful if my hip does [fail me].

Mrs White was an affluent 76-year old widow, living in Oxfordshire, who had a long-standing gardener and cleaner. After her husband's death, she had a pendant alarm installed privately, but found the speaker and receiver insufficiently powerful for communication with the response centre to be possible throughout her property (a large house and garden). She felt it was important, in the event of an accident, to be able to explain what had happened and where she was, as she feared lying undiscovered for some time. She also wanted to choose who would be contacted, as in some situations she felt it would be more appropriate for her daughter, rather than her neighbour, (her nominated responders) to attend. Not fully satisfied with the equipment she had, Mrs White was experimenting with various simplified mobile phones with 'SOS' buttons, and looking into other private solutions available on the market.

Privatised care support networks worked well for some, but to be effective require significant financial resources which many in the study did not have. The examples cited indicate that some older people, and others involved in their care, are willing to seek solutions on the market (or through informal arrangements in which some money is exchanged) for goods and services appropriate to their needs. Some were already finding equipment which they considered met their needs better than the telecare devices available through their local telecare service. Their willingness to act as consumers of such products may indicate the existence of untapped demand for goods and services which the telecare market could exploit more effectively than at present, and which will need to be developed if a technology-enabled health and social care system is to become a reality for all in the English system.

Box 2.3 Privatised Care Support Network: Mr Weston

Mr Weston was an affluent widower aged 87 who lived 'alone' (see below) in Oxfordshire. He was prone to falls and had recently recovered from surgery. His care arrangements, he explained, were initially 'inherited' from his late wife who had Alzheimer's disease. After her death, he retained the support then in place, including a privately paid cleaner and someone who helped with cooking. By the end of the study, however, he had hired a 'live-in' care worker who had been with him for several months. During research visits he spoke about the importance in later life of space and familiar surroundings, and of his wish to remain in his own home. He had acquired telecare (a pendant alarm) and home adaptations (handrails and a stairlift) privately, researching into available products and selecting some to try out. His family were not local and could not provide the level of practical support he required, but he valued their support:

The really important thing is to have two good daughters. They don't live nearby. They can't look after me. They have their own jobs to do, but they can advise me and, for instance, arranging this thing (his pendant alarm). They drew up the contract and that type of thing. I haven't got the family to rely on in that way, so you have to form a setup. Fortunately, I have a good enough pension that I can afford to do that and I live in a place that has everything.

The live-in care support, arranged and paid for privately, was set up in consultation with family.

My family decided that I couldn't go on being here by myself with various part-time people in to attend to my various needs, and so we decided to look for someone, and started to look through agencies. We spoke to one of the people who had supplied us with the - she said, 'I seem to remember that a friend of mine has a relation who wants to come back from Germany', or something, and it turned out that she had most of the experience we wanted. She's been here for two months. We've got a very nice flat, as it were, upstairs there, you see.

Mr Weston recognised the value of being able to summon support and had once used his pendant alarm. The responder had not come quickly, however, and one of his privately employed care workers had found him where he had fallen outside. This put him off using it again, so he purchased a small mobile phone which he wore around his neck (as well as his pendant alarm), describing this as his 'back up' arrangement.

5 Discussion and conclusions

This paper has set out three caring network ‘ideal types’, describing conceptually distinct categories based in the AKTIVE study’s ELA data: complex caring networks (CCNs); family-based caring networks (FBCNs); and privatised care support networks (PCSNs).

It has shown that CCNs may offer, and be especially well suited to, frail older people who have the desire and capacity to remain independent and who wish to be in control of the way others help them, giving examples of older people in the study who had arrangements closest to this type of caring network. In some cases, their CCN was protective of their social identity and sense of self (discussed further in Hamblin, 2014a, Paper 5), and drew on a wide range of people who had been involved in their lives and significant to them for many years. It suited those with physical frailty (but in the absence of a trusted advocate was less appropriate or sustainable for people with dementia), and offered an approach valued by some older people living alone, particularly if they lacked a local supportive family (although some with local families also seemed to prefer the relative autonomy it gave them).

Family-based caring networks offered some frail older people loving, dependable and familiar support. FBCNs were seen in the sample among those living with their relatives (either their spouse or a son or daughter) and by some living alone. They seemed to support frail older people with dementia particularly well, although for older people who retained significant mental capacity, but were becoming physically frail, their FBCN could be constraining, reduce their independence, or bring into play tensions about ‘risk’, ‘coping’ and ‘managing’ (Hamblin, 2014a, 2014b, Papers 5 and 6). A few in the study revealed that they felt controlled or ‘bossed about’ by family members and resented this; for others, lacking nearby relatives, or without close family, this type of network was not an option.

Privatised care support networks seemed to suit some, who valued being able to purchase goods and services of their own choice, whether on the market or through informal channels, remaining in control of as much of their everyday lives as possible. This arrangement required means, so was fully accessible only to the most affluent older people in the study, but was attractive in modest ways to those with more limited resources who preferred to minimise contact with their local authority and disliked being assessed for needs or means (or felt this was pointless given their financial circumstances and / or current local criteria for meeting need).

In real life, these three caring network ‘ideal types’ overlap and change. The shift from a CCN to a FBCN, for example, could be seen in some cases cited in this paper. No frail older person in the study had care arrangements which exactly matched any of these categories, although it is argued here that they are potentially helpful in thinking about older people’s needs, wishes and everyday realities, and how these can best be supported.

Telecare enhanced all three types of network, in at least some examples in the study, although no network type was dependent, or solely reliant, upon it. This highlights that telecare is not a panacea, a substitute for human care or an adequate solution in and of itself. Some older people (and those who supported them) who had adopted telecare early and had access to information about telecare options (including how the

items supplied worked and how they could be enhanced with other equipment), gained immensely in terms of quality of life, peace of mind, reduced anxiety and fear, and the ability to continue doing things they enjoyed, wished to manage alone, or were used to doing. This was evidenced in a number of cases where older people responded favourably to the modest telecare 'upgrades' introduced through the study. When telecare 'got in the way' or caused frustrations, it was usually because its installation was 'too late' or inappropriate, because necessary support or information was missing, or because human aspects of the system around it (response times, behaviour on arrival, etc.), technical aspects (range, ease of operation, false alerts and equipment sensitivity), or equipment design (attractiveness or ease of operation) let the telecare user down. These problems, which had real and important effects in some cases in the study, are all ones which the telecare industry, and a technology-enabled health and social care system, can potentially fix (Buckle, 2014, Paper 7).

A unique feature of telecare systems, compared with other forms of support, is their reliance on nominated responders, local social contacts who agree to be contacted, and to attend the older person, if an alarm is raised. These arrangements contribute to all caring networks, as they require a degree of negotiation, forethought and planning, and involve choice for the telecare user, and commitment on the part of those who agree to be nominated. Such contacts, where they draw on close family, may not change much, except making it possible to know when help is needed. But where (as is often the case) they draw on neighbours, friends or people known through local associations (for example a church or community group), they give some strength to relatively 'weak ties', ties which Granovetter (1978) has theorised are especially productive of social cohesion.

The 'strength of weak ties' may help explain what, when supported by telecare, CCNs (and potentially PCSNs) offer that is different from the FBCNs which may seem more familiar, and which policy in England has often seemed to promote, placing, some argue, too much strain on families, particularly female relatives and co-resident carers (who are quite often men). For policymakers and practitioners, ensuring older people have the opportunity to sustain and develop networks of 'weak ties' may be important for future planning of support systems capable of assisting large numbers of frail older people to live safely and independently in their communities. In making such plans, attention is needed to how to support and sustain different types of caring network, taking into account ambiguities in people's identities and self-images (Hamblin, 2014a, Paper 5), changes in their bodily competence and frailties (Fry, 2014, Paper 4) and changes in their social relations, which are not static, and over which they have limited control (Koivunen, 2014, Paper 3).

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