

Ageing Well?

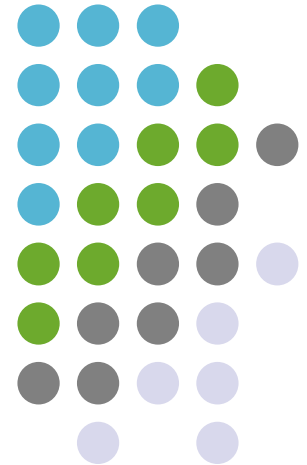
everyday life with telecare support

Evidence from the AKTIVE project

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Acknowledgements:

Prof. Andreas Hoff -project development
Technology Strategy Board - main funder
Tunstall Healthcare (UK)Ltd; Inventya Ltd,
 project partners/co-funders

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 E Bianchera, at Leeds & Oxford Universities

Policy into Practice Workshop

Queen's University Belfast

9 June 2015



Project Design

AKTIVE Partnership

- *Marketisation*
- *Product Development*
- *Social Research*
 - Qualitative and mixed methods for 'Everyday Life Analysis'

AKTIVE Consortium

- Telecare services: Leeds, Oxfordshire
- Medical experts
- Design, systems and AT experts
- National organisations – Age UK, Carers UK, Skills for Care

Dissemination Strategy

- www.aktive.org.uk

Social Research Design

- Stakeholder perspectives
- Carer / care worker interviews
- Telecare monitoring data
- Systems mapping / prospective hazard analysis
- Everyday Life Analysis
 - 60 older telecare users
 - Focus on falls and dementia
 - 4-6 repeat visits over > 6 months
 - Holistic, longitudinal, creative method
 - Person-centred focus: outcomes, experiences; perspectives, and preferences



AKTIVE: aims and ambitions

Focus: older people living at home with **two types of frailty:**
susceptibility to **falls** and dementia / **memory problems**

Addressed

- **challenges** arising from population ageing
- **opportunities** arising from technological progress

Aimed to:

- add to knowledge of the **lives, needs and aspirations of older people, their families and carers**
- enhance understanding of **how they and home care / other service providers** who attend them might **access, engage with and make best use of 'telecare' equipment**

Everyday Life Analysis of Telecare Use



● Inclusion criteria

- Aged 65+ (34 were 80+ / 6 were under 70)
- Living in the community (Leeds / Oxfordshire)
- Falls / frail **OR** memory problems / dementia **OR** both
- New or established telecare user



● Recruitment

- Telecare services (+ NHS dementia research recruitment scheme)

● Retention

- 60 of the 70 people recruited were available for full ELA analysis (in study 6+ months, 4-6 research visits)

● Focus

- Technology use, attitudes, perspectives; daily life; other support
- Interviews / observations with their carers / care workers as well





Selected characteristics of the AKTIVE Everyday Life Analysis sample

Characteristics		Marital status		Health	
Male	21	Widowed	33	Memory*	9
Female	39	Married	17	Falls	35
Living alone	41	Single	2	Both conditions	16
		Divorced	8		

Telecare user		Telecare at start		Telecare upgrade	
New user	22	Pendant alarm only	32	AKTIVE	22
Established user	38	Telecare package	21	Other	9
All ELA cases	60	GPS/other	7	None	29

* Memory problems could include different types of dementia



Positive impacts of having telecare in place

For frail older people

- Help in an emergency
- Managing medication
- Feeling safer at home
- Feeling connected / less alone
- Continuing valued activities
- Improved relationships
- Strengthened ties (responders)
- Enhanced resilience
- Avoidance of 'intrusive' support

For carers

- Reduced conflict over safety
- Peace of mind
- 'A life of their own'
- Eased daily care (dementia carers)

For home care workers

- More varied support options
- Less anxiety on arrival
- In emergency, carers or care workers can stay with older person while summoning help.





Networks of support with telecare in place

Research Report Volume 2 - Working Paper 2

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

- ***Complex caring networks***
- ***Family-based caring networks***
- ***Privatised care support networks***



Family-Based Caring Networks

- Traditionally ‘what families do’; seen as ‘natural’ by some
- Co-ordinated by families who identify needs / arrange support
- May involve other help, but family controls choices
- Rely on ‘strong ties’ and local, supportive family
- Often work well with telecare, which many families value
- Supported some people with dementia well
- Some older people have no local family, so not for all
- Conflict, tensions, being ‘organised’ upset some older people
- These networks may not suit older people who want to be ‘fully in control’ in later life

Family-Based Caring Network:

Mrs Barnard, 89, widow, dementia, lived with daughter



- Two daughters shared her care, arranging support and telecare
 - Pendant alarm; smoke/carbon monoxide detectors; medication dispenser
- Both daughters wanted to continue in their careers
- Co-res. daughter worked 3 days pw, cared for mother on other weekdays
- Home care visits were arranged on the days she worked
- At weekends, Mrs B. stayed at 2nd daughter's flat, which she enjoyed
- This gave the co-resident daughter a break and time to herself.

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.



Complex Caring Networks

- Involve many different people:
 - Family, neighbours, friends, contacts in local community
 - Care and health workers, cleaners, gardeners, others
- Are built by / around the older person
- Often rely on and maintain contacts established earlier in life
- These networks of ‘weak ties’ support independence, boost resilience and enhance dignity and control
- Telecare can strengthen these ‘weak ties’, which are vital for social cohesion



Complex Caring Network: Mrs Tyne 94, widow, living alone, Oxfordshire

- **Complex caring network which sustained her well**
- **Friends, neighbours, family, occasional home care support, pendant alarm**
 - **‘Main carer’ her neighbour (whose husband also gave support)**
 - **Daughter and granddaughter visited 2-3 times per week**
 - **Friends helped regularly with shopping**
 - **Her neighbour explained that, after surgery, Mrs Tyne:**

‘... couldn't go to her daughter's, because she's got stairs. She wanted to come home. So the hospital said they would put [telecare] in place. She'd had 2 major operations in 3 months. So we needed back-up, because if anything is wrong and she presses her button, I'm two minutes down the road to get here’.



Mrs Tyne (cont.)

- Mrs Tyne had home care on discharge, but discontinued it once she could cope, despite mobility problems and risk of falls. She and her neighbour saw the pendant alarm as ‘a godsend’ :

‘It gives you peace of mind, ..you know she can contact you. ... Before, yes, she could ring me up, but if she'd fallen and she wasn't near the phone she couldn't’.

- A ‘bogus caller’ alarm, added later, was valued too:

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



Privatised Care Support Networks

- Accessed through the market, sometimes via very informal arrangements: involve payment or exchanges
- Can be set up without family help
- Attractive to those who did not want care assessment through a local authority
- Some older people chose to purchase technology, equipment or services to meet needs they had identified themselves
- Rely on financial resources to purchase, beyond reach of many
- Only possible if telecare / other goods & services available
- Current telecare market not oriented to meet these needs

Privatised Care Support Network: Mr Weston

Widower, 87, lived 'alone', falls, recent surgery



- Care arrangements 'inherited' from late wife (with Alzheimer's)
- Retained support in place; private cleaner, help with cooking
- Later hired 'live-in' care worker
- Valued familiar surroundings, wished to remain in own home
- Acquired telecare (pendant alarm), handrails, stairlift privately
- Researched available products, selected ones to try out
- He commented:

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 set-up. Fortunately, I have a good enough pension that I can afford to do that and I live in a place that has everything.



Mr Weston (cont)

- Mr Weston's care support, arranged and paid for privately, was set up in consultation with his family

“We decided to look for someone, and started to look through agencies. ... She's been here for two months. We've got a very nice flat, as it were, upstairs there, you see.”
- He valued being able to summon support and had once used his pendant alarm
- The responder did not come quickly and one of his privately employed care workers found him where he had fallen outside
- This put him off using it again
- So he bought a small mobile phone which he wore around his neck (as well as his pendant alarm), calling this his 'back up' arrangement

How telecare fits in with different networks



- Enhanced all three types of network, but none solely reliant on it
- Not a replacement for human care / adequate solution in itself
- Some, esp. early adopters who understood it, gained immensely:
 - Quality of life
 - Peace of mind
 - Reduced anxiety and fear
 - Ability to continue doing things they enjoyed or preferred to do themselves
- Sometimes telecare ‘got in the way’ or caused ‘frustrations’
- This was usually because of ‘fixable’ issues:
 - Installed too late or equipment inappropriate
 - Necessary support or information missing
 - Human or technical aspects in some way deficient
 - Equipment design let the user down or did not appeal to them



Strengthening 'weak ties'

- Develops Granovetter's idea*: weak ties support social cohesion
- Unique aspect of telecare is use of local social contacts
- Arrangements require negotiation, forethought and planning
- Choice for telecare users, commitment by named responders
- When neighbours, friends, people in local groups/associations involved, telecare can build strength into 'weak ties'
- Over-reliance on families can impose strain and tensions
- Important to enable older people to sustain / develop their networks of 'weak ties', but critical to recognise:
 - Older people have and want different kinds of caring network
 - Ambiguities in their identities and self-images matter (Hamblin, Paper 5)
 - Changes in bodily competence / frailty affect how systems work (Fry, Paper 4)
 - Social relations change; older people have little control of this (Koivunen, Paper 3)



Avoidable frustrations with telecare

Experienced by frail older people

- Difficulty using some items
- (Re)assessments, installations not timely
- False alarms cause distress, can adversely change behaviour
- Cost implications were sometimes unclear causing anxiety
- Information given inadequate
 - what specific items are for
 - how they work
 - how to troubleshoot problems
- Unclear how to modify responder arrangements as circumstances change

Experienced by carers / care workers

- Limited knowledge of how system works: information and support not designed for their needs
- Anxiety of having to 'trust' a system they did not really understand
- Confusion / poor coordination: some found new devices installed without instructions, guidance or any explanation of their purpose
- Poor information on what may cause false alerts / how to prevent these

Missed opportunities to achieve better outcomes using telecare systems



For frail older people

- Monitoring centre could offer continuous support to lonely, depressed, grieving users
- Service (*'my intercom'*) could help them access other support / avoid some use of emergency services
- Shift from 'needs' to preferences; for activity, independence, resilience.
- Regular monitoring centre contact would build confidence in TC use
- For PWD, TC memory aids etc. could be prescribed as standard;
- 'Holistic' assessment would improve use of 'active' / 'passive' devices
- Information on equipment for future use is often lacking

For carers

- Co-resident carers would benefit if their concerns/needs re TC were taken into account fully
- Better understanding of equipment would enable carers to support the older person's use of telecare
- Carers also need information on equipment for future use.

For home care workers / agencies

- If better informed, could signpost older people to initial/upgraded TC
- Could help older people recognise usefulness of TC if they feel unwell, anxious or frightened, not just in an emergency.

Learning applicable to telecare commissioners and assessors



- Timely provision is crucial; telecare is often installed ‘too late’ to be accepted / useful
- If provided at a time of crisis / stress, special follow-up and support are needed
- Older people and their carers need well-planned help to use telecare effectively
- As their needs change, older people / those supporting them need to know how to get extra or different equipment and support
- Consultation with older people and everyone in their ‘caring network’ should be the standard approach
- Routinely, an equipment package, tailored to individual circumstances and preferences, not just to assessed ‘needs’, should be identified
- Everyone in the ‘caring network’ needs understanding of how the equipment works, generates a response, and can be adjusted or changed.
- Clear information about the telecare service should be provided at installation; always including how to report a fault, who to contact for reassessment, and details of the charging policy.

AKTIVE PUBLICATIONS RELEASED IN 2014



Research Report Volume 1: Literature Review

The Role of Telecare in Meeting the Needs of Older People: themes, debates & perspectives in the literature on ageing and technology

Research Report Volume 2: The AKTIVE Working Papers

1. ***Researching Telecare Use using Everyday Life Analysis*** S. Yeandle
2. ***Frail Older People and their Networks of Support: how does telecare fit in?*** S. Yeandle
3. ***Telecare and Older People's Social Relations*** E.-R. Koivunen
4. ***Coping with Change: frail bodies and daily activities in later life*** G. Fry
5. ***Lifestyles in Later Life: identity, choice and stigma*** K. Hamblin
6. ***Risk, Freedom & Control in Older People's Lives: the relevance of telecare*** K. Hamblin
7. ***Human factors that influence the performance of the telecare system*** P. Buckle

Research Report Volume 3: Research Methods

The AKTIVE project's social, design & prospective hazard research: research methods S. Yeandle, P. Buckle, G. Fry, K. Hamblin, E.-R. Koivunen and C. McGinley.

<http://circle.leeds.ac.uk/projects/completed/technology-it-care/aktive/>

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