

Using telecare to support the independence of older people and people with dementia: policy, practice, and the impact of evidence.

British Geriatrics Society Spring Meeting 2022

Online 7th April 2022 Dr John Woolham Visiting Senior Research Fellow

> Dr Nicole Steils Research Fellow



This presentation summarises independent research partly funded by the National Institute for Health Research School for Social Care Research. The views expressed in this presentation are those of the author and not necessarily those of the NIHR SSCR, NHS, the National Institute for Health Research or the Department of Health.

The Advisory Group for the NIHR funded work on which this presentation draws study included service users, carers, industry representatives and representatives from NGOs. We are grateful for their advice and feedback throughout that project.

Structure of the presentation



- The emergence of assistive technologies and telecare early factors that shaped its development
- Evidence for its effectiveness
- Responses made to this evidence by policy makers and local authorities responsible for publicly funded telecare services, and how local authorities are using telecare
- What may need to happen for telecare to meet policy aspirations and service users' needs



What does it do, and who is it for?



What do we call it? [7]

- Electronic assistive technology
- Telecare
- Telehealth
- Technology enabled care









The Problem:

- Mrs Smith forgets to light gas cooker after turning it on
- Risk of suffocation or explosion
- High level of concern from neighbours and relatives

The Solutions?

- Admission into care
- Substitute gas for electric or microwave
- Disconnect cooker
- Use technology to manage risks



What does it do, and who is it for?

Devices can be:

- 1. 'Stand-alone' / send information
- 2. User activated / passive
- 3. Static objects / wearable
- 4. Described in terms of function:
 - Remind and prompt
 - Help people stay in touch & communicate
 - Support people to use their leisure time in meaningful ways
 - Promote safety, comfort and well-being
- 5. ... or, what they are used to try to achieve
 - Keep someone safe and manage risk
 - Keep them out of hospital / residential care
 - Reduce care costs
- The gap between desirable consumer gadgets and technology to support frail / disabled people is converging at the moment – pros and cons



NIHR



Policy Research Unit

in Health and Social

Care Workforce



LONDON











History & policy development since 1998



- Several policy strands housing, social care, community equipment & health. Telecare = a way to achieve key NHS & housing priorities & solution to demographic pressures [2, 5,11, 17, 20]
- 2. Policy development 1998-2003: various mentions in strategy and policy documents but no mention of who should lead, or pay [18, 20, 21]
- 3. 2005: Building Telecare in England Strategy and the Preventive Technology Grant - 80m over 3 years for all English local authorities. [6]
 - To pump prime and stimulate demand
 - Good for industry which was seen as needing help
 - Came with strings: PIs which encouraged local authorities to get telecare and electronic assistive technologies into homes of as many older people as possible in a very short time
- 4. Recognised the need for better research [3]; commissioning the Whole System Demonstrator (WSD) study *significantly, after the strategy and funding had been announced*

Policy objectives



Telecare is supported by the Government:

- Promotes independence
- Enables people to remain living safely in their own homes for longer
- Reduces unnecessary admissions into hospital
- Saves money by reducing the cost of other services





Evidence from later research is very much at odds with current telecare policies: reliable studies suggest telecare:

- does not reduce unplanned hospitalisation
- does not have much impact on reducing levels of other services and support
- doesn't keep people living independently for longer
- doesn't necessarily do much to support wellbeing or improve other desirable outcomes
- doesn't save money





How did we get here?

- Early studies were positive, but not robust
- Building Telecare Policy (2005)[6] came with 'strings'
- DH also wanted robust evidence of telecare's beneficial impact
- It was 'expected' that evidence from the Whole System Demonstrator study (WSD) would support policy decisions already taken





The Whole System Demonstrator project [23]

5,806 participants, RCT over 12 months

Designed to assess if telecare produced beneficial outcomes for recipients which were cost effective.

'In this trial, telecare did not significantly alter rates of health or social care service use or mortality over 12 months' (Steventon et al. 2013 p.6)

The authors also suggested that telecare wasn't cost-effective

The Assistive Technology and Telecare for Independent Living in dementiA (ATTILA) [12]

495 participants, pragmatic RCT over 24 months

Designed to test if assistive technology and telecare (ATT) delayed a move into residential care

> 'Time living independently outside a care home was not significantly longer in participants who received full ATT and ATT was not cost effective...the study suggests that ATT does not enable people with dementia to maintain safe independent living for longer in their homes'. (Howard et al. 2021 p.2)



WSD and ATTILA findings = problems for:

- The Government: policies support the development of services offering no advantages over traditional care & support
- Local authorities: some have invested very large sums at a time of unrelenting budgets cuts
- Telecare manufacturers: ability to offer shareholder dividends jeopardised if care industry disinvests.
- Telecare 'pioneers' and early evaluators whose results were very positive [4, 14, 15, 16, 29]

Investment case studies:

 Birmingham, (14m) North Yorkshire, (3.5m?) Hertfordshire, (5m?) Manchester & Newcastle

Reactions to WSD

KING'S College LONDON NIHR Policy Research Unit in Health and Social Care Workforce

ADASS & Local Authority telecare manager responses: views about the WSD

- ADASS: own research: an alternative perspective?
- The Better Care Technology Survey (2015)
- 'The findings of the survey, based upon a response rate of 49% of councils will be considered by the ADASS policy networks and ADASS regions to inform how to best support councils in taking forward the use of technology.'
- Call for Evidence Report (2015)
- 'to allow councils to share practice and case studies to sustain and accelerate momentum in the use of technology in meeting improved health and wellbeing outcomes'
- Neither report mentions the WSD

Some views of the WSD from telecare managers: [27, 28]

'As I understand, analysis of the data was complicated with many factors to consider and so it was difficult to isolate the impact of telecare leading to fairly inconclusive results'

'I felt the outcomes were disappointing and missed an important opportunity to look at the positive side of telecare provision'

'Its finding does not tally with what customers and carers /friends tell us about telecare'

'There are questions over the methodology used and how scientifically robust the trials were'

'The sample size was limited, with mixed results, which are probably out of date now. Technology has moved on improving the range of options available especially in the area of telehealth and mobile solutions'



UTOPIA: Using Telecare for Older People In Adult social care

NIHR/SSCR funded study over 24 months

UTOPIA's objectives: post WSD, why still use telecare? Exploring Adult Social Care Department (ASCDs) perspectives about:

- Strategic aims of telecare use for older people?
- Local evidence to enable ASCDs to assess achievement
- How aims are operationalised and delivered

More information and report at: <u>www.kcl.ac.uk/research/utopia</u> <u>https://kclpure.kcl.ac.uk/portal/files/87</u> <u>498580/Utopia project report.pdf</u>

Mixed-methods study design:

• Online survey of all 152 English local authorities: 75% response rate

LONDON

- Interviews with managers leading on telecare provision in 25 English local authorities
- Case studies in 4 English local authorities



Policy Research Unit

in Health and Social

Care Workforce

NIHR

John Waniform, King Villeting Lander, Mande Tarlis, King Villeting Landers, Milletin Hell, De Minelen Dir en der Leitenen Jamme Parene, Henrige um Thieme Leitenen ein Angeweinen Neuentis und Kiner, Freisele, Quer-Weigene Lienenwy Electrospi





Objectives

- Keeping people safe, avoiding or managing risk
- Supporting family carers

Assessment

- Formal assessments were not always completed
- What was included varied from ASCD to ASCD
- Integrated with or separated from assessment of needs
- Was completed by a wide range of different people
- Did not always take place in the user's home
- Was usually a single event
- Was inevitably shaped by what technology was available
- Follow-up review by telephone (if at all)



The technology

- Mostly '1st generation' devices
- Pendant alarms and fall detectors most used
- 'Prescriptive' provision/packages
- Self installation was being considered in some ASCDs

Response systems

- Almost half said the 'first responder' was a family member
- Most shire councils did not have a response service

Training for staff

- Widely provided
- Short duration, by manufacturer or 'on-the-job'

Information (e.g. for non-eligible users, direct payment users)

- Unspecific
- Provided by manufacturers



- UTOPIA survey findings may help to explain findings from RCTs
- These findings suggest that telecare services are sub-optimal in many places
- We think that effective use will depend on a number of preconditions

We speculate that the rejection of the WSD and creation of alternative information may have prevented ASCDs from a critical examination of the effectiveness of telecare



"Ladies and gentlemen of the jury, let me present the alternative facts of the case."





- Investment in accredited training for telecare assessors and installers
- Rigorous, person-centred assessments done in the home of the telecare user and seeing assessment more of a process than an event
- The availability of a wider range of technologies to improve matching with need and which can be adapted by the user and/or their family carers
- Accurate and clear information to selffunders or direct payment users. Not marketing
- The development of arrangements for social response services in all areas, including clear protocols



Investment in accredited training for telecare assessors and installers

Rigorous, person-centred assessments done in the home of the telecare user

- Telecare should be seen as a complex intervention, not 'plug-andplay'. [10] Even simple devices have significant impacts on physical and social environments which need to be understood.
- 2. Adequate training is needed: marketing is not training
- 3. Deep levels of knowledge are needed:
 - Person centred assessments using 'trusted assessor' frameworks, for example. [24]
 - A good understanding of which technologies will best meet someone's needs and fulfil their goals and expectations
 - Involve paid/unpaid carers [22]

- 1. There are important reasons that assessments should always be carried out, and in the person's home.
 - Vital to understand the context into which technology is being introduced
- 2. Assessment should not be seen as a single event but a *process* [10]
- 3. It should be focused on the needs and aspirations of the person who will use it
 - A close match between need and technology is essential if technology is to be valued and not abandoned [26]
 - Assessors should have access to a wide range of different kinds of device/system



The availability and design of technology & responses to it

- Assessors need to be able to 'mix and match' for telecare to be truly person-centred. [9]
- 2. People's needs change and they will seek to adapt the technology, using it in new ways. This isn't necessarily a bad thing, but has implications for designers, manufacturers, and service providers. (e.g. Why can't a lonely person use a pendant alarm to talk to someone?)

Accurate and clear information to self-funders or direct payment users. Not marketing

- Little help or advice is available there is a risk self-funders may make unwise decisions without professional guidance.
- 2. Self –funders will know about what their needs are, but not about the best devices to meet these needs.



The development of arrangements for social response services in all areas, including clear protocols

- 1. The lack of availability of a paid response service in some areas is inequitable
- 2. Technology is supposed to support carers: the transfer of responsibility is not a good thing. (e.g. triaging calls)



Conclusions

NIHR Policy Research Unit in Health and Social Care Workforce

- Best evidence suggests telecare isn't effective
- This may be due to how it is used by local authorities
- Matching needs to technology is difficult
- Telecare policies focus on maximising use not careful matching with need
- In some places assessment activity may be fragmented, superficial and technology-led rather than person-centred
- More research is needed to map adult social care practice and to develop and deliver good quality telecare services
- A survey of clinicians and academics with research interests in telecare [25] suggested three priority areas for future research:
 - Assessment and matching of technology to need
 - Ethical issues
 - Co-production

Conclusions: questions for practice?



- LA strategic focus is on risk management and safety. Should it be wider than this?
- Does the focus on saving money have ethical implications?
- When is OK to use telecare without an assessment?
- What might be the consequences of non-assessment?
- Who should assess for telecare?
- What matters in telecare assessments?
- Is it ever OK for assessments/reviews not to be done in a user's home?
- Is access to a limited range of telecare sufficient?
- Does telecare support carers or add to carer burden?

Are person-centred approaches to telecare compromised by:

- focus on risk management and safety?
- austerity and cost-savings?
- the withdrawal of other ways of meeting needs?
- remote assessment?
- tendency to see the assessment as an outcome not a process?
- access to a limited range of devices?
- the absence of mobile response service?
- Limited training for telecare staff?
- Varied responses to self assessment and use of Direct Payments or private funding?

Selected references

- Association of Directors of Adult Social Services. (2015). Better Care Technology: Results of Call for Evidence. London: Association of Directors of Adult Social Services. Retrieved from: https://www.adass.org.uk/media/4233/call-forevidence-report-july-2015.pdf
- 2. Audit Commission (2000) Fully Equipped: the provision of equipment to older or disabled people by the NHS and Social Services in England and Wales. Abingdon, Audit Commission Publications.
- 3. Barlow, J., Singh, D., Bayer, S., & Curry, R., (2007) A systematic review of the benefits of home telecare for frail elderly people and those with long term conditions. Journal of Telemedicine and Telecare 13 172-179.
- 4. Bjorneby, S, et al. (1998) Technology Ethics and Dementia. Sem, Norway. Norwegian Centre for Dementia Research.
- 5. Department of Health (2001) The National Service Framework for Older People London, Department of Health.
- 6. Department of Health (2005) Building telecare in England. London Department of Health.
- 7. Fisk, M., Woolham, J. & Steils, N. (2020). Knowledge and Skills Sets for Telecare Service Staff in the Context of Digital Health. *Journal of the International Society for Telemedicine and eHealth* 8. <u>https://doi.org/10.29086/JISfTeH.8.e15</u>
- 8. Fisk, M. (2003) Social alarms to telecare Bristol, Policy Press.
- 9. Gibson, G., Newton, L., Pritchard G., Finch, T., Brittain, K., & Robinson, L. (2016). The provision of assistive technology products and services for people with dementia in the United Kingdom. Dementia 15 (4) 681-701.
- 10. Greenhalgh, T., Wherton, J., Sugarhood, P., Hinder, S., & Rouncefield, M. (2015) What is quality in assisted living technology? The ARCHIE framework for effective telehealth and telecare services. BMC Medicine Vol 13 No. 1 1-15.
- 11. House of Commons Select Committee on Health (2002) Delayed Discharges Third Report of Session 2001-02 Cm5645 London, The Stationery Office.
- 12. Howard, R., Gathercole, R., ... & Woolham, J. (2021) The effectiveness and cost-effectiveness of assistive technology and telecare for independent living in dementia: a randomised controlled trial. *Age and Ageing* 50(3), 882–890. https://doi.org/10.1093/ageing/afaa284
- Knapp, M., Barlow, J., Comas Herrera, A., Damant, J., Freddolino, P., Hamblin, K., Hu, B., Lorenz, K., Perkins, M., Rehill, A., Wittenberg, R. & Woolham, J. (2015) The case for investment in technology to manage the global costs of dementia. (2015) PIRU, LSE, PSSRU. <u>https://piru.ac.uk/assets/files/Dementia_IT_PIRU_publ_18.pdf</u>
- 14. Marshall, M. (ed.)(2000) ASTRID: a Social and Technological Response to meeting the needs of Individuals with Dementia and their Carers. London, Hawker Publications.
- 15. McColgan, G, & Bowes, A, (2009) Smart technology and community care for older people: innovation in West Lothian, Scotland. Edinburgh, Age Concern Scotland.
- 16. Mitchell, R., (unpublished) (1996) Mobile Emergency Care Dementia Project An Evaluation. Falkirk Social Services.
- 17. NHS (1998) An Information strategy for the modern NHS 1998-2005 London, Department of Health.

Policy Research Unit

in Health and Social

Care Workforce

NIHR

LONDON

Selected references

- 18. House of Commons Science and Technology Committee (2005) 1st report of session 2005-06. Ageing: Scientific Aspects HLP20 London, The Stationery Office.
- 19. Royal Commission on Long Term Care (1999) With Respect to Old Age: Long term care rights and Responsibilities (Cm4192-1 London, the Stationery Office.
- 20. Secretary of State for Health (2000) The NHS plan: a plan for Investment, a plan for Reform CM 4818-1 London, HMSO.
- 21. Secretary of State for Health (2005) Independence Wellbeing and Choice: Our vision for the Future of Social Care for Adults in England Cm6499, London, the Stationery Office.
- Steils, N., Woolham, J. G., Fisk, M., Porteus, J. & Forsyth, K. (2021). Carers' involvement in telecare provision by local councils for older people in England: perspectives of council telecare managers and stakeholders. *Ageing and Society* 41(2), 456-475. <u>https://doi.org/10.1017/S0144686X1900120X</u>
- 23. Steventon , A, Bardsley, M, Billings, J., Dixon, J, Dioll, H, Beynon, M, Hirani, S, Cartwright, M, Rixon, L, Knapp, M, Henderson, C. Rogers, A, Hendy, J, Fitzpatrick, R, & Newman, S, Effect of Telecare on use of health and social care services: findings from the Whole Systems Demonstrator Cluster randomised Trial (2013) Age and Ageing 42 (4) 501-08. doi:10.1093/ageing/aft008
- 24. Wey, S., (2005) One size does not fit all: person centred approaches to the use of assistive technology. In Marshall, M., (ed.) Perspectives on Rehabilitation and Dementia pp 201-210 London, Jessica Kingsley.
- 25. Woolham, J., Freddolino, P., Gibson, G. & Daniels, S. (2021) Telecare at a crossroads? Finding researchable questions. Journal of Enabling Technologies 15(3), 175-188. <u>https://doi.org/10.1108/JET-11-2020-0049</u>
- 26. Woolham, J., Steils, N., Fisk, M., Porteus, J. & Forsyth, K. (2021) Outcomes for older telecare recipients: The importance of assessments. *Journal of Social Work* 21(2),162-187. <u>https://doi.org/10.1177/1468017319883499</u>
- 27. Woolham, J., Steils, N. Forsyth, K., Fisk, M. & Porteus, J. (2021) Making use of evidence in commissioning practice: insights into the understanding of a telecare study's findings. *Evidence and Policy* 17(1), 59-74. <u>https://doi.org/10.1332/174426419X15730452200823</u>
- 28. Woolham, J.G., Steils, N., Fisk, M., Porteus, J. & Forsyth, K. (2018) The UTOPIA project. Using Telecare for Older People In Adult social care: The findings of a 2016-17 national survey of local authority telecare provision for older people in England Social Care Workforce Research Unit, King's College London. <u>https://kclpure.kcl.ac.uk/portal/files/87498580/Utopia_project_report.pdf</u>
- 29. Woolham, J. (2005) The Safe at Home Project London, Hawker Publications.

Policy Research Unit

in Health and Social

Care Workforce

NIHR

LONDON