

Differing Perspectives on
Telecare: an attitudinal survey of
older people, professional care
workers and informal carers

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What this Presentation will Cover

- In the next twenty minutes I shall:
 - Describe some of the findings from a short, six month study of attitudes to telecare, that we carried out between June and December 2004.
 - Discuss the different attitudes to telecare held by older people, their informal carers and by professionals involved in delivering support services to older people living in the community, and
 - Outline how these findings might relate to existing service frameworks in the three areas of the country where the study took place, namely Barnsley, South Buckinghamshire and Plymouth.

Updating the Proceedings

- Because time is short, I shall not go into the context for the study nor explain in detail what is meant by telecare services, because these points are covered in the conference proceedings, though maybe the illustration will give some clues.
- Nor shall I describe the research methodology or the characteristics of our sample of informants, other than to say that it involved presenting three ‘scenarios’ for different situations where telecare could be used to meet a need, to focus groups of older people, informal carers and care service providers and then facilitating a discussion about the issues raised.

Voting

- After this discussion, focus group members were asked to respond by a show of hands to 9 standard questions, asked of each group, to gauge people's opinions about different aspects of telecare services that had been identified as controversial by the literature.
- Though 'quick and dirty', the advantage was that this could be done easily and informally and without taking up a great deal of time or generating any paperwork.
- The risk that people might be influenced by one another was reduced by holding 22 separate focus groups, and aggregating and comparing the results afterwards by group and by region, to determine whether opinions differed according to people's roles and / or circumstances.
- The findings reported here are based on a sample of 186 individuals, including 92 older people, 55 professional stakeholders and 39 informal carers

Technology

- Many participants spoke favourably of the potential preventative benefits of telecare, especially the reassurance and peace of mind it could give to older people and their carers.
- Critical comments were made in the context of design, particularly of devices that are meant to be worn.
- The main issues related to gender, forgetfulness in using devices, over-sensitivity of the equipment and consequent concerns about false alarms, problems with voice prompts and finally concerns over the reliability of devices, possible system failure and the need for speedy repairs.

Increased Choice

- Telecare was seen to increase people's options, a way of 'staying put' for longer, as well as to remain less obligated to friends and family for daily monitoring.
- Lifestyle monitoring of people's domestic routines was viewed positively by informal carers and professionals, who spoke about consequent better understanding of people's daily patterns of behaviour and how this would help to construct a more informative profile of the individual that would allow them to deliver a more personal service or detect gradually deteriorating health.

Privacy and Confidentiality

- All groups were concerned about the confidentiality of sensitive data, in the context of what was portrayed as ‘a creeping culture of surveillance’.
- Concerns were also voiced about the possibility that telecare could undermine individual choice and independence.
- The phrase ‘Big Brother’ occurred spontaneously in just about all discussion groups.

Needs Assessment

- There was general agreement that a thorough and holistic needs assessment should underpin an individual, tailor-made approach to the provision of telecare services. There is no scope here for ‘one size fits all’.
- The concern was often-voiced that assessment should not be resource-led, and it was strongly disputed that the provision of a standard package of telecare should ever be used to compensate for a lack of attention given to complex individual needs.

Dementia

- The majority of participants shared the view that the provision of telecare services to people with dementia is fraught with difficulties.
 - Concern centred on the level of understanding required to obtain co-operation and informed consent from the client.
 - If someone had received a diagnosis of dementia it may already be too late for them to benefit from the technology, and closer monitoring by professional carers should be the priority.
 - Though there was an acknowledgement that benefits could ensue, a precautionary note was sounded that a lack of understanding and co-operation in respect of monitoring devices could lead people into potentially dangerous situations like trying to ‘mend’ a cooker that has been shut off.
 - ‘Disembodied’ voice prompts were a particular cause for concern.

Human Contact

- Whilst it was acknowledged that telecare had the potential to broaden people's 'virtual community' by introducing them to new social contacts, the point was made many times that it should not take the place of human contact.
- The role of informal carers and community support workers in 'keeping an eye' on someone older and spotting small, telltale signs of a deteriorating condition were mentioned many times in discussions, thus suggesting that people as well as health monitoring devices have an important role to play in pre-empting a chronic condition turning into an emergency.

Replacing Staff

- A fear often-voiced was that telecare technologies will be used to replace traditional ‘human effort’ and that staff will inevitably be withdrawn as a consequence of the introduction of telecare services.
- Most participants thought that if the service were introduced and resourced as it deserved, it would actually increase demand for face-to-face contact, by teasing out unmet needs among older people.

Back-Up Services

- Concerns were raised that it would not be possible to guarantee an appropriate and timely response to an emergency alert without a large injection of resources.
 - Many older participants referred critically to the already overstretched arrangements for ‘care in the community’, and speculated that the service will only be as good as its response to an emergency and that the back-up support systems need to be in place to ensure that this happens.
 - In the minds of many participants, either informal carers (a cheap alternative to statutory services) or emergency services will be relied upon to provide the initial response.
 - They were under no illusion that telecare will require a ‘terrific input’ and a ‘colossal back up staff’ if it is to ‘work properly’.

Costs of Telecare

- Participants across all types of focus group were concerned about how much the service would cost to provide.
 - There was little support for the idea that older people themselves should pay, and professionals doubted whether people would invest in the service late on in life, when they might not see any long term benefits.
 - Most thought that government (notably the NHS) should fund telecare, especially if the service is intended to keep people out of hospital, but as basic community equipment is currently under-resourced, doubt was cast on this as a way of funding the service.
 - Clearly, telecare needs to be properly costed and resourced if it is to gain the confidence and trust of potential service users and professionals.

Differences

- These were the main areas of broad consensus, and the feelings expressed are rather predictable and not particularly controversial.
- What is of interest, though, are the responses that the participants in the various groups gave to the 9 standard questions that we asked at the end of each session, and so it is to these that we now turn.

1. Understanding

- Do you feel you understand the purpose of telecare and how it works?
 - 100% of professionals, 98% of carers and 96% older people said ‘yes’, which is good for us as if they had not, it would have reflected badly on our presentation.

2. Would you be happy to have such a service in your own home?

- A clear difference emerged here between professionals and the rest. Over 9 out of 10 of professionals said ‘yes’, whereas only 68% of carers and 64% of older people agreed, showing that the professionals are keener to see this service put into place than their ‘customers’ are.
- Interestingly, though, interviewees in Barnsley were more ready to accept the service (88%) than were those in either South Bucks (63%) or Plymouth (63%)
- Looking separately at each of the nine sub-groups, older people in South Bucks (42%) and carers in Plymouth (40%) were markedly more dubious about accepting the service than any of the other seven groupings.

3. Electronic Monitoring

- Would you be confident to have your blood pressure etc. monitored electronically? (as opposed to going to the doctor or having a community nurse visit you at home).
 - 7 out of 10 older people would, but with pronounced regional differences, in that 100% of South Bucks residents would be happy, whereas only 75% of Barnsley residents and just 48% of Plymouth residents would.
 - Only 47% of informal carers agreed, which is interesting because the literature and the intention of the service itself stress that they are one of the groups who ought to be reassured by this happening automatically as a passive form of background monitoring. Again regional differences were pronounced, with Barnsley carers much more happy (73%) than in either Plymouth or South Bucks (33% and 44% respectively)
 - Overall, 7 out of 10 professionals also said ‘yes’, but perhaps this is a lower percentage than their enthusiasm for the service in principle would have predicted, and moreover whereas 100% of the Barnsley professionals and 7 out of 10 Plymouth professionals would be happy to receive this service, only half of the South Bucks professionals agreed that they would have confidence in using such a service themselves.

4. Staying Put

- Do you think people with telecare will be able to stay in their own home for longer than those who do not?
 - 98% of older people thought so, as did 79% of carers but just 43% of professionals agreed, which again is interesting as this is one of the main justifications for the technology.
 - Here, however, the professionals who are responsible for commissioning the service are probably more conscious of the actual ‘trigger factors’ that prompt a move up the care ladder, and are markedly more sceptical about its benefits than are the end-users.
 - There were no marked regional differences on the responses to this question.

5. Visits

- Will telecare reduce the need for face to face visits by care workers?
 - Here a profound north-south divide emerged among the older service users. Just 7% of older people from Plymouth and no older people at all from South Bucks agreed with this proposition, whereas 9 out of 10 of the older people from Barnsley agreed that the need for face to face contact would indeed diminish with telecare.
 - Among informal carers the split was equally pronounced. No informal carers in Plymouth and just 7% from South Bucks thought that care needs would reduce, whereas 100% of Barnsley's informal carers saw telecare as a way to reduce the need for face-to-face visits by care professionals.
 - 49% of care professionals also agreed, with no marked regional differences, but over half disagreed with the proposition. Barnsley (55%) and Plymouth (54%) were more in agreement that care needs would be reduced than their Plymouth colleagues (39%). A good proportion of service providers, though, predicted that the need for face to face visits will actually increase with telecare.

6. Safety

- Are people likely to be safer at home with telecare?
 - Older Plymouth residents were much more doubtful (58%) on this count than the older people from the other two regions (96%, South Bucks and 100%, Barnsley)
 - Informal carers in Barnsley were also 100% convinced, whereas in South Bucks the figure was 78% and in Plymouth only just over half of the informal carers thought telecare would make older people safer in their home
 - However, 97% of professionals across all three regions agreed with the proposition, with no regional differences.

7. Risk Management

- Should someone older and known to be ‘at risk’ ever be prescribed a package of telecare, ‘for their own good’? The answer was a resounding ‘No’.
 - Only 1 in ten older people agreed, with only a slight degree of regional difference in that 4% of older people in South Bucks and 10% in Plymouth agreed, compared with 14% of Barnsley residents.
 - Carers were even more emphatic, with just 2% (all from South Bucks) agreeing.
 - No professionals were prepared to recommend this, but whereas representatives from Plymouth and South Bucks declared a definite ‘No’ on this issue, all the Barnsley professionals abstained.

8. Lifestyle Monitoring

- Question eight specifically related to lifestyle monitoring and asked, ‘Do you have any concerns about the kind of information on lifestyle patterns that telecare is able to gather about how people are living at home?’
 - half of the older people said ‘yes’, with very little by way of regional differences.
 - as did half of the carers, with the proviso that, in the case of Barnsley, this figure was just 9% whereas the other two regions scored 60% and 63%.
 - 8 out of 10 professionals also agreed, but whilst 9 out of 10 professionals in Plymouth and S.Bucks had reservations about lifestyle monitoring, only 6 out of 10 Barnsley professionals shared these concerns.
 - This suggests that many service providers are, at this point in time, slightly uneasy about the potential of the service to redefine the boundaries of what personal information should be available to professionals when making decisions about individual cases.

9. The Offer of Telecare

- The final questions concerned the point in people's lives at which they should be offered such a service. At 65 perhaps?
 - Here there were marked regional variations in the responses. 1 in 10 Plymouth residents and just under half the informal carers and care professionals in Plymouth said 'Yes'. So did nearly one in three of the professional service providers in Barnsley.
 - Everybody else said 'No'. Most older people seemed to think that this was too early on in the 'third age'

The Offer of Telecare

- However, aside from this, a simple majority of older people in South Bucks thought telecare should be offered in every situation that might be construed as vulnerable, as people could always refuse it, but not if they could be construed as managing independently - at 65 or when living in sheltered housing.
- The majority of Plymouth residents thought that the service should be reserved for people suffering from dementia, community alarm users or where the alternative was institutionalisation, but not when people were ill or living alone.
- The majority of Barnsley residents thought the service should only be available to people who were ill or at risk of entering a care home.

Care Providers

- The majority of care providers in South Bucks and Plymouth agreed with one another in their assessment of when an offer of telecare should be made, and thought that it could be beneficial to people in all situations except at turning 65 or when living alone. The majority of Barnsley's professionals did not think that it should routinely be offered in any of the situations we had described.
- Unlike their clients, South Bucks and Plymouth providers possibly saw telecare as an asset in sheltered housing, probably because they could envisage benefits to the support staff rather than to the individual, whilst for people living alone they were less likely to see this as a presenting problem and so did not perceive that this, on its own, would be a sufficient reason to offer the service.
- However, unlike their clients, Plymouth care providers also saw telecare as an asset to someone who was chronically ill.

Informal Carers

- The majority of informal carers thought that telecare should only be offered to people when they were ill, but but not in any other circumstances, the exception being in Plymouth where the majority of informal carers also thought it would benefit existing social alarm users.

Prevention v. Crisis Management

- Older people in South Bucks and Plymouth seemed to be thinking of the service as more of a ‘preventative’ strategy, and so argued that it would be beneficial to be offered the choice of telecare in any situation where it might have the potential to avert a crisis some time into the future, and on the whole the local support service professionals also took the same view.
- Older people in Barnsley seemed to have adopted a slightly different attitude to telecare. Their attitude could be interpreted more as ‘crisis management’ (it could be useful when ill or at risk of going into a care home), but otherwise most people’s realistic assessment was that the situations described would not be assessed as a sufficiently high priority.
- This seemed to be a correct assessment of local health and social services priorities, as most Barnsley professionals did indeed judge that telecare was not an appropriate service for most of the situations we suggested, and none of the situations we described attracted more than 1/3 of the professional vote in Barnsley.

How Could This Be?

- This is unlikely to be the result of different states of prior knowledge about the new technology / service delivery mode, as neither the older users nor the professionals we spoke to were particularly *au fait* with telecare.
 - On the contrary, most had come to the focus group ‘out of curiosity’ to find out more and to become more informed. In this respect, everyone actively engaged with the topics and thought deeply about the implications of telecare not just for their own situation but for the care system as a whole.
 - Nor is it likely that these differences in voting patterns could be explained by different group dynamics, as they are the aggregate result of several sessions in each region that were run to a standard format, and our initial reading of the transcripts seemed merely to confirm that discussions took a fairly predictable trajectory, raising similar points, observations and dilemmas for professionals and service users alike across all three field sites.

Service Frameworks

- The population in Buckinghamshire is twice the size of the other two authorities, with a population of nearly half a million as opposed to just over 200,000 and a quarter of a million for Barnsley and Plymouth respectively, but the proportion of older people in all three areas is similar, about 15%-16%.
- However, our three telecare sites show considerable variations in terms of the kinds of services they already offer and their effectiveness.
- The differences in voting patterns are therefore more likely to be 'explained' by people's prior knowledge of the patterns of service delivery in the three areas, and the assumptions, attitudes and values that shaped and underpinned expectations generally in each area of the country about the quality and availability of support and care in the community.

Home and Institutional Care

- For example, Barnsley provides considerably more home help / home care than the other two authorities. Based on the contact hours of home help per 10,000 households, compared to the England average Barnsley provides 34% more, Buckinghamshire 6% more but Plymouth 36% less than the national average.
- In respect of the number of households receiving help, again standardised per 10,000 households, Barnsley provides care to the most households, comparable with the average for England, whereas Buckinghamshire's figure is 24% below and Plymouth's is 52% below the national average.
- Plymouth, on the other hand, has 40% more residential care places and 27% more nursing home places than the national average. Barnsley also has slightly more residential (11%) and nursing home (13%) places than the average, but Buckinghamshire has 12% fewer residential places and 4% fewer nursing home places than the average for England.
- Buckinghamshire has more hospital beds per 1,000 population aged over 65, 38 (over twice the national average of 17) as opposed to 29 in Plymouth and 17 in Barnsley. In terms of intermediate care, Barnsley's emphasis is towards preventing admission to an acute hospital setting, whereas the focus in Buckinghamshire is on facilitating early hospital discharges with more intensive short term support and rehabilitation. Re-enablement towards independent living is less well-developed in Plymouth.

Different Expectations

- It could therefore be that the health care professionals in Barnsley are more opposed to telecare as they believe that their existing services are effectively offering sufficient support and care to people living in the community. Barnsley also has a slight over-provision of placements in care homes and so may not be quite so concerned about the need to keep people in their own homes.
- People in Buckinghamshire have more access to hospital beds and aim to discharge people early with short term support at home, but they have less access to long term home care, residential care and nursing care than in other parts of the country, so maybe service users and professionals in Buckinghamshire view telecare as a way of speedily addressing imbalances in the supply of all these services.
- Plymouth has many more care home places than the norm, and would seem to have historically placed people in residential or nursing care earlier than in other parts of the country, and this may shape people's expectations to look to this sector and not telecare to meet older people's care needs. However, there are significant problems in recruiting care staff in Plymouth that affect their ability to provide care in the community, so telecare could be perceived as a solution to this particular issue too.

Attitudinal Barriers to Mainstreaming

- If so, this is an important finding in terms of the government's ambitions for telecare, for these attitudes are likely to be an intervening variable that will force commissioning of telecare in different directions as well as providing a 'barrier to mainstreaming' in some parts of the country.
- Both the demand for and the supply of telecare services is therefore likely to be influenced just as much by how different actors and agents perceive the entire *raison d'être* of the emerging health/care marketplace, particularly the extent to which it should function as a rapid response to an individual crisis or a preventative service for everyone.