

Ethical implications of using lifestyle monitoring data in ageing research

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Abstract Lifestyle monitoring systems, intelligent proactive systems incorporating passive monitoring capabilities and allowing contemporaneous remote access to data, promise potential benefits to service providers, service users and their carers and families, and those engaged in ageing research. Research to date has focused primarily on technical issues, generally at the expense of detailed consideration of the ethical issues raised by these systems. The paper identifies ethical issues and questions around surveillance and the passivity of monitoring; informed consent; working with people who are cognitively impaired; and using and linking lifestyle monitoring data. It concludes by emphasizing the importance of all parties exploring and discussing the tradeoff between potential benefits to multiple stakeholder groups and actual costs to the individual.

Background

There is widespread recognition of the economic, social and health benefits of facilitating ‘ageing in place’ and enabling frailer older people and those with manageable chronic conditions to remain in their own homes for as long as possible. But this is only feasible or desirable where there are sufficient resources to support the older person. These include formal health, care and social services provided through, by or paid for by the state and informal, unpaid care and support such as that provided by family and friends. However, greater demand for services and increasing costs of provision are affecting the ability of the state to provide required services. In addition, factors such as decreasing family size, increase in the average age at which people start families, changing working patterns for women and greater geographic mobility may mean that today’s older people have smaller and more geographically dispersed pools of potential unpaid carers than previous cohorts.

Increasing need and finite resources have provided both push and pull factors for the introduction and rapid evolution of increasingly sophisticated technologies to support care at home. Several distinct phases have been noted in the development of what have been variously termed as ‘telehealth’ or ‘telecare’ systems. ‘First generation’ telecare systems were technically simple systems without imbedded intelligence based around community alarms that relied on the user to activate a call for help (Doughty et al 1996). In contrast, third generation telecare systems are characterised as intelligent and proactive. They incorporate an array of automated environmental (e.g. gas build-up, water overflows) and personal detection

systems (e.g. fall detection, incontinence monitoring), and make widespread use of telecommunications to allow the capture, transmission and remote interrogation of lifestyle and medical monitoring data by health and care professionals (Brownsell and Bradley 2003).

This paper focuses on the deployment of third generation telecare systems in older people's homes and the subsequent use of 'lifestyle monitoring data' (LMD). Such systems promise potential benefits to service providers, service users and their carers and families, and those engaged in ageing research. Once installed in an older person's home, these systems are able to collect detailed data about day to day behaviour such as eating, sleeping, moving about and using facilities and appliances in the house. If LMD produced by such systems can be analysed to demonstrate 'normal' routines for an individual against which unusual activity can be identified, it may be possible to detect or predict health-related problems (Hensel et al 2006), potentially saving lives by alerting family and non-family carers and indeed older people themselves to changes in routine which may indicate serious illness or threats to health and well-being (Sixsmith et al 2007). Third generation systems can thus in theory provide reassurance to service users and those who care for or about them, whilst bringing to service providers' early attention the need to investigate further or to take steps to prevent or ameliorate developing health conditions which might otherwise lead to hospitalization or institutionalization. LMD may also be valuable to the wider ageing research community, for example to researchers seeking better understanding of behaviours in late life to inform optimal services, or those seeking to improve estimates of the costs of care for older people under different future economic or policy scenarios.

However, there is some evidence that enthusiasm for the possibility and ease of collecting LMD and its theoretical usefulness has run ahead of consideration of the actual uses to which the data might be put. At least one study (Hanson et al 2007) has reported significant uncertainty about the use of data once collected, and problems in integrating it into a system of care and support for older people. Brownsell et al (2008) were unable to link collected data to imminent health problems, and suggested that there were still technical issues to be resolved in terms of the capability of the technology used.

Ethical issues

Our concern in this paper is that the development of the technology has also run ahead of detailed discussion of the ethical issues raised by the collection and use of LMD. These are classic issues – relating to the key principles of non-maleficence, beneficence, justice and autonomy – which require renewed consideration in relation to the nature of these data and the manner of their collection and use.

We found no detailed accounts of ethical considerations specifically in relation to lifestyle monitoring in ageing research (but see Perry Bayer and Holm 2009 for a rare example in the context of telecare for people with intellectual disabilities). Based on their systematic review of literature on home-based telecare interventions for older adults, Marziali et al (2005) questioned the extent to which the ethics of research and practice have been fully considered in technology-based contexts. Ethical issues are generally not explicitly considered within the literature on the development and implementation of third generation telecare systems. Some papers do give limited consideration to certain ethical issues. For example Rowan and Mynatt (2005) briefly discuss privacy and obtrusiveness as part of the account of a field trial of a lifestyle monitoring system. Their concept of 'a sweet spot of utility and acceptance' acknowledges a central ethical difficulty in finding an appropriate balance between benefit and harm to the individual, but fails to appreciate that there is in reality no single 'sweet

spot'. The perceived location of this varies according to stakeholder group, and there are important ethical questions around whose views should prevail and in what circumstances.

We argue that the subject demands more direct and detailed discussion. Accordingly, in this paper we identify and discuss some key concerns relating to surveillance and the passivity of monitoring; informed consent; using and linking data; and working with older people who are cognitively impaired. Our intention is to put these issues on the research agenda – they remain as yet unresolved. One approach to analyzing ethics, suggested by Marx (1998) in the context of surveillance, is to separately consider the means, context and conditions of data collection, and the intended uses and goals of the activity. For each, a series of questions probes issues of harm to those who will be monitored, crossing of personal boundaries or borders without notice, violation of trust in relation to collected data, and (in)validity – the ability of the surveillance to measure what it claims to measure. In the following sections we consider some of these questions in relation to lifestyle monitoring, paying particular attention to the 'altered existential conditions' (Agich 2003) of long term home-based care of older people.

Surveillance and the passivity of monitoring

The word 'surveillance' often conjures up negative, dystopic images such as Benthamite panopticons or Orwellian 'Big Brother' states. However, lifestyle monitoring systems could be argued to provide a classic example of the 'Janus face' of surveillance (Lyon 2001), the tension that exists between safety and control. The efficacy of such systems relies on constant monitoring of the people in whose homes they have been installed. The potential for benefit is usually framed in terms of safety, but Kenner asserts that 'For all the benevolent and lifesaving scenarios one may come up with.... There might be an equal number of negative and oppressive situations that monitoring technologies enable' (2008: 253).

When considering lifestyle monitoring, the means, context and intended aims of surveillance become entangled. For example, in relation to privacy the home is a traditional spatial border; the front door is a barrier beyond which we normally expect not to be observed. Lifestyle monitoring transgresses that border. Surveillance technologies that provide an obvious reminder of reduced privacy, eg, cameras and microphones, (Sixsmith et al 2007) may cause discomfort to the individual and subsequent rejection of the system. Recognising the link between obtrusiveness and user acceptability, systems for capturing LMD have been designed to be unobtrusive (Hensel et al 2006), allowing people to go about their lives without being conscious of data being collected. However, in a research context, particularly with older participants experiencing increasing cognitive impairment, this could lead to a situation in which continued monitoring becomes, in essence, 'covert' observation. There are ethical questions around whether this method could be justified in this research context.

On one level, having decided on the appropriateness of the intrusion caused by the technologies employed to collect LMD the question of 'harm' in relation to lifestyle monitoring seems unproblematic. The process of data collection is not physically injurious to the individual and the discomfort caused by surveillance is minimized. However, there is arguably a threat to autonomy, in the sense that some decisions about if or when to call in health or care professionals are taken out of the hands of the individual. A perception that this is the case might cause the older person to withdraw to some extent from self-care activities. Lifestyle monitoring might also have an impact on relationships with non-resident unpaid carers. For example, reassurance that the system is 'looking out' for the older person might affect the frequency of visits and/or other contact. The consequences of this could be positive or negative.

Informed consent

This is a fundamental ethical requirement in research involving ‘human subjects’. Participants must be fully informed about the research taking place, what participation will involve, any potential effects of the research, how the data will be used and how their confidentiality will be protected (or, in some cases, not protected). If a potential participant lacks capacity to give informed consent themselves, proxies can sometimes be asked to do so to allow participation.

Lifestyle monitoring raises difficult questions in relation to informed consent. First, requesting consent for research implies that data collection has a specific purpose, and is not being collected simply because it is possible to collect. Studies to date suggest difficulties in making sense of LMD and delivering the hoped-for benefits. There has to be consideration of the balance between benefit and harm, and no research should proceed unless the former is greater than the latter. It is unethical to ask older people to participate in research where we are unable to justify the intrusions required to collect LMD. Second, there is a limit to which the research community can ‘inform’ potential participants when we have limited evidence of the potential effects of lifestyle monitoring on older people. For this reason there is an urgent need for systematic consideration of the evidence of effects of analogous systems deployed in other contexts. Third, it is important to consider the context in which consent is sought and how this affects individual autonomy. Given the potential benefits of lifestyle monitoring to these groups, older people may perceive pressure from family and/or service providers to participate in research. Fourth, there is a related danger that research into lifestyle monitoring, driven by aspirations of wider beneficence, fails to give appropriate attention to the balance between potential harm to and benefit to participants. It follows that both research-orientated and service-orientated questions of consent will need careful consideration, and to justify lifestyle monitoring the clarity of purpose of data collection must be significantly improved.

Working with people who are cognitively impaired

Despite developments in ethically acceptable approaches to consent, such as gaining informed consent of family caregivers in addition to communication with the person concerned, that have increased the inclusion of people with dementia in health and social care research in recent years, Marziali et al’s (2005) systematic review found that only a tiny minority of studies had considered any issues concerned with involving people with cognitive impairment or dementia in telemedicine and related interventions. Yet the issues identified above are magnified and made more challenging when working with this group.

At the same time, third generation telecare involving the use of LMD has been presented as particularly useful for supporting people with dementia, as it does not require intervention by the user, can detect problems such as getting lost, offer prompts to carry out activities of daily living that might otherwise be forgotten and, it is suggested, detect illnesses which the individual is unable to report, and alert others to departures from ‘normal’ behaviour. Thus those least able to comprehend, learn and consent – all capacities that dementia reduces – may be those most likely to be seen as appropriate for technological intervention. People with dementia frequently experience intimate intrusions as part of the care they receive. The extent to which care regimes have upheld dignity and respect for older people, including people with dementia has been questioned in much critical research on quality of care. Recent research has identified that older people prioritise personal identity and autonomy in care provision (Calnan et al 2006), human rights (Woolhead et al 2004), self-esteem, self-worth and wellbeing (Tadd and Bayer 2006). The actual impact is as yet unknown, but the potential of passive monitoring to undermine these aspects of life for a person with dementia is clear.

Ethical scrutiny of research involving people with dementia has recently been strengthened in the UK with both English (Mental Capacity Act 2008) and Scottish legislation (Adults with Incapacity (Scotland) Act 2000) explicitly addressing issues of inclusion of people with dementia in research and the need for ethical rigour. And the UK Government's Dignity in Care Campaign (launched in 2006 in England, and in keeping with legislation in the devolved administrations) has sought to uphold respect and support for capacity, rather than an emphasis on incapacity. Researchers wanting to use LMD collected from people with dementia thus face multi-dimensional safeguards against their misuse, and need to be particularly clear about the point of using these data.

Using and linking data

The intimacy and detail of the data that lifestyle monitoring can collect is one of its central attractions if it is to be used to detect threats to well-being. Every move, every action, many bodily functions, activities of daily living, whereabouts, comings and goings from the house can all be recorded in great detail. The extent of data collection about an individual is unprecedented, and will be of interest to many within the e-research community. For example, LMD could be used to explore whether antecedents of chronic conditions or acute illnesses can be identified by changes in patterns of daily activity, or to evaluate the impact of health interventions. Findings from analyses of LMD could, for example, be incorporated into microsimulation models such as OPERA (the Older PEople's Resource Allocation model), being refined via DAMES, to produce finer grained estimates of the future costs of care.

Despite the commercial availability of lifestyle monitoring technologies, there has been limited adoption such systems on a larger scale, primarily due to a paucity of published information on cost and clinical effectiveness (Brownsell et al 2008). Perhaps as a result, issues around ownership and access to LMD have not been properly explored. We are used to concepts of centrally owned and protected health-related information, strict regulation of access, and legislative protection of personal data. It is unclear to what extent these will apply to LMD. Depending on the business model under which wider scale deployment of lifestyle monitoring systems takes place, the collectors and owners of LMD may be neither centralised nor in the public domain. This has implications for e-researchers in terms of access to LMD for secondary analysis and linkage to other datasets. LMD may or may not come within the definition of 'personal data' under the Data Protection Act 1998 – this has yet to be explored. If it does, then the data protection principles set out in the Act apply, including that data collected should be adequate, relevant, and not excessive and that processing should be limited to the purposes for which it was collected. Given current difficulties linking LMD to events such as illness or falls (Hanson et al 2007; Brownsell et al 2008) this may be problematic. If LMD does not fall within the definition of personal data, and therefore regulation under the Act, we need to consider what controls are appropriate and who should exercise them.

Conclusion

In this paper we highlight the need for an explicit, detailed discussion of ethical issues raised by the collection and use of LMD. We found that reported trials of lifestyle monitoring have mostly involved small numbers of participants over relatively short periods and seem primarily concerned with questions around validity rather than how systems are emotionally, psychologically and socially experienced by the parties concerned and how this may affect relationships of care. In each of the areas that we focus on, we find a need to balance the benefits which *may* accrue to different stakeholder groups with costs which are borne

exclusively by the individual. The particular nature of this cost-benefit tradeoff needs to be explored and discussed by all those concerned, including and especially older people, whilst there is still time to positively influence the development and use of lifestyle monitoring.

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