Ethics of ICT

A. ECCLES (Convener). Ethical considerations around the use of information and communication technologies with older people. Gerontechnology 2010;9(2):83; doi:10.4017/gt.2010.09.02.033.00 **Participants**: *A. ECCLES (UK), M. GILHOOLY (UK), and L. DAMODARAN (UK)* **ISSUE** The rapid development of ICT for older people raises questions about the extent to which there is adequate ethical engagement in conducting ICT research and if there are suitable ethical frameworks in ICT policy implementation and evaluation. **CONTENT** The three papers pull together policy discourse, the use of ethical frameworks, and the impact of performance indicators in public policy; the connexion between Quality of Life research, ICT promotion and the ethics of public policy expenditure; and ethical questions about research agendas and research conduct in the field of ICT and older people. **STRUCTURE** Eccles' paper makes three arguments. First, current policy discourse may have an underlying bias towards technological solutions to complex demographic and social trends. Second, the (predominantly biomedical) ethical frameworks in use in Telecare policy discussion and assessment underplay wider ethical approaches that are more socially grounded. Third, drawing on the UK, there is potential tension between good ethical practice and the performance indicators around the implementation of Telecare. Gilhooly reviews the methodological issues and research findings around Quality of Life (QoL) indicators and notes little evidence that ICT has improved QoL for older people. The argument that healthcare and social interventions should be evidence-based prompts the question if it is ethical to distribute public resources towards ICT expenditure. This is relevant to current public policy in the United Kingdom where projected use of ICT in long term health and social care is leading to investment in household connectivity for technology in anticipation of telecare and telehealth programmes. Damodaran, Olphert and Hardill review the procedures for undertaking research with older people on issues around assisted living technologies. They note the complex ethical questions raised by surveillance and monitoring technology, and contend that there is a lack of engagement with this complexity in the research itself. They argue that the conduct of ICT research with older people appears largely to disregard the sensitivities, concerns, self-respect and dignity of research participants and their role as key participants in the research process. They note also that older people participating in ICT research are often treated as passive subjects or patients to be tested and assessed, and not as active partners in research, a deficiency in approach not adequately challenged by the procedures of University Ethics Committees. **CONCLUSION** There is a lack of ethical engagement in research with older people around ICT. Ethical discussion used in ICT policy implementation needs to be revised. Alternative forms of ethical engagement that address these deficits are discussed.
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A. ECCLES. Ethical issues in the implementation of telecare policy. Gerontechnology 2010;9(2):83-84; doi:10.4017/gt.2010.09.02.034.00 **Purpose** Assistive Technology (AT) has become an increasingly important aspect of policy making and service delivery for older people in the United Kingdom. There are three key reasons for this. First, technological advances have broadened the range of possibilities: assistive technology is faster, more flexible and

more discreet than ever. Second, there remains, in principle, a policy bias towards 'care in the community', within which there is a priority of finding ways of maintaining older people in their own homes and outside institutional care. Third, demographic trends - in particular, the expanding population of the over 75 age group - put pressure on the need to reconfigure traditional post-war patterns of - or attitudes to - social care delivery, as the implications for costs and labour supply are significant. **Method** This paper looks at ethical issues raised by Telecare, a major strand of AT policy in the United Kingdom. It is based on a review of literature around Telecare, the ethical frameworks currently in use, and interviews with 'front line' professionals who deal with assistive technology. The paper examines three areas. First, the ethical issues that are raised by the prevailing discourse around 'dependency ratios' and the 'demographic time bomb' which often underpin policy discussion. Second, the utility of ethical frameworks, which have essentially been drafted for biomedical enquiry in acute medical settings, in their application to complex social care settings involving the use of Telecare. Third, it considers the implications for ethical practice of performance indicators, which are used to measure outcomes, in the implementation of Telecare policy. **Results & Discussion** The paper will draw a number of conclusions. First, it acknowledges there is strong and wide-ranging evidence of benefit to be conferred from the use of technology, but argues that the current policy discourse may have an underlying bias towards technological solutions for complex demographic problems. Second, the ethical frameworks in use are limited and - being predominantly biomedical - tend to fall short of what could contribute to good social care practice. A greater range of ethical approaches would make assessment for the use of technology more complex, but ought at least to be employed in the wider conceptual discussion around the use of technology in social care policy. Indeed, this deficit in enquiry may be exacerbated by the trend toward single shared assessment procedures across professional boundaries - part of a wider policy thrust towards greater inter-professional working - in which there is a risk of minimising complexity in the quest for common professional language. In this respect, additional areas of enquiry that offer a useful approach to the dilemmas encountered in social care settings would include an ethic of care and intuitional ethics. Third, drawing on early evaluations of Telecare policy in the United Kingdom, there is a potential tension between, on the one hand, good ethical practice by front line professionals and, on the other, the ability to meet performance indicators around the application of Telecare which have been set by policy makers.

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Purpose The past ten years have seen considerable interest in exploring ways to promote active and successful ageing. The view that assistive technologies (AT) and information and communication technologies (ICT) are key methods of promoting successful ageing is widespread. It is frequently argued that the current digital divide between the young and the old leads to social exclusion and, hence, a lower quality of life for older adults, and correspondingly, teaching older people how to use ICTs will hugely improve their quality of life (QoL). Assistive technologies are also believed to have the potential to allow older people to stay active and productive for longer. Although the term 'quality of life' pervades discussion of health and social policy, and improving quality of life is an avowed aim of many Western governments, there is remarkably little consensus on what this term means, let alone if improvements in quality of life are a realistic outcome measure of policies, interventions, or government expenditure[1]. **Method** The aim of this paper is to examine the definitional challenges associated with the term quality of life, measurement challenges, the challenges associated with enhancing quality of life, and the role of ICT and AT in quality of life in old age. **Results & Discussion** The term quality of life started as an index of the relative well-being of whole populations, i.e. the state of states[2]. Nowadays QoL is more likely to be viewed as an individualized aspect of the modern psyche. This shift in conceptualisation is

problematic in that, if QoL is individualized, it cannot be meaningful to assess it in the same way for everyone. Because wealth, health and social relations have all been found to be prime determinants of subjective QoL, if ICTs and ATs are to enhance QoL for older people, they need to mediate the relationships between these three important factors and QoL. To date, there is little evidence that ICT and AT has improved QoL for older people[3]. If there is little evidence that ICT and AT has made a significant impact on quality of life for older people, and given that it is frequently argued that healthcare and social interventions should be evidence-based, is it ethical to distribute resources in this way? One of the explanations for the lack of impact is associated with how we assess quality of life; the measures are too remote, blunt and multifactorial to be affected. Moreover, 'absence of evidence is not evidence of absence of impact'. This presentation is drawn to a close by asking if quality of life is a meaningless term and if the future is bleak for old people in a modern information society. The answer to both questions is no.

References

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 Purpose In the context of use of ICTs in telehealth and telecare there are major ethical issues relating to individuals giving informed consent to routine monitoring and surveillance - yet there are few tools and techniques in use to help people understand the far-reaching implications of surveillance (for example the fact that complete strangers to them may be observing their behaviour in their own homes) radically changing the character of what have been traditionally regarded as safe, secure and private spaces. Provision of information, meaningful explanation and opportunities for gaining understanding and learning about the implications should, in the view of the authors, be a prerequisite for seeking consent to the presence and use of such technologies. This does not appear to be part of the contractual arrangements between telecare or telehealth providers and customers (usually local authorities in the UK), yet consent forms are routinely signed by end-users (often vulnerable older and disabled people) without question. A related concern arises in relation to the recruitment of older people to provide research data for projects, including those conducted in UK universities. While it is generally a necessary requirement in gaining ethical approval to provide an information sheet for recruits which explains the research procedure, there is little or no information given on the implications and nature of their engagement in the research, or on the relationship with the researchers. It appears that older people are often regarded as passive, component parts of user panels to be drawn for use as required to meet research design criteria. In this 'instrumental' model of research participation, older people are treated as passive 'subjects' or patients to be tested and assessed. This approach fails to acknowledge older people as active members of a research community, with their own knowledge, lived experience, interests, questions, hopes, fears and aspirations – and playing a key part in research of potentially significant relevance for them and for wider society. It also fails to take into account deep concerns that the research experience itself may raise for individuals. Further, the question of 'what is in it for them' arises. While modest tokens of appreciation are sometimes offered (such as gift vouchers), the intrinsic rewards of being valued and seen as part of an on-going relationship are often not offered – nor are copies of research reports, newsletters, knowledge of outcomes or impact of the research routinely offered. Yet, in most cases, the absence of such provision does not appear

not to be regarded as a relevant consideration in ethical approval procedures in UK universities. **Method** In the light of these and other concerns, the authors are conducting a review of some of the criteria used as a basis for granting ethical approval in seven UK universities. **Results & Discussion** The findings of this review and recommendations to improve both the mechanisms and processes for gaining informed consent to use of assisted living technologies and to the ethical standards regarding the involvement of some of society's most vulnerable people in research will be presented.