

scottish universities insight institute

mobilising knowledge for a better Scotland

Assistive Technologies: the social dimension

2014

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Introduction

This is the final report on the Scottish Universities' Insight Institute funded series of events around *Assistive Technologies: the Social Dimension* which took place between May and October 2013. This report was written in August 2014 to take account of developments subsequent to the events taking place. There are four sections here (1) Background (2) the participants (3) the discussion (4) dissemination and further activities.

(1) Background

Assistive Technologies (ATs) - which aim to enhance the independence and safety of their recipients have become an important aspect of social care policy in Europe, with a particularly ambitious programme of implementation in Scotland. Technological advances mean that ATs are seen as a way of upholding a policy of 'care in situ', instead of institutional care, in a period of demographic change and escalating costs. This proposal focused in particular on the technologies associated with Telecare, the remote delivery of personal care, and drew on the research expertise of the proposers: ethical & policy issues (Andrew Eccles, University of Strathclyde), social informatics (Professor Flis Henwood & Dr Mary Darking, University of Brighton) and the experiences of technology user groups, specifically older people (Dr Ike Kamphof, University of Maastricht) and disabled people (Professor Jennifer Harris, University of Dundee). In addition the group had agreement to participate and present at the event from Glasgow City Council, North Lanarkshire Council and from representatives of assistive technology service user organisations.

We proposed to explore a tension in technology policy, viz. while there is strong and wide-ranging evidence of benefit from the use of these technologies, a greater range of ethical enquiry and understanding of the impact on technology users is needed. This tension is made complex for a number of reasons. First, there is a policy discourse around the need for ATs which weaves together demographic change, dependency ratios and costs into an assumed necessity for technological solutions to care needs, such that space for policy debate is restricted. Second, ethical considerations around the use of ATs draw on a limited, essentially biomedical framework which fails to recognise the questions raised by broader ethical enquiry (such as contextual ethics and an ethic of care). Third, research on the efficacy of these technologies is limited; on cost-savings, for example, through methodological weakness, and on user experience by the pre-dominance of Randomised Control Trials over qualitative research enquiry. The programme brought together technology designers, end users,

care technology practitioners and social scientists with recognised research expertise in the field to explore further the social impact of technology based care in Scotland and in comparative context.

In addition to the personnel approached to contribute to the SUII sessions, Professor A.J Pols from the University of Amsterdam agreed to contribute to proceedings, providing a presentation and contributions thereafter. Prof Pols is a leading European authority on assistive technologies subject area and was able to strengthen the comparative element between the UK and the Netherlands. In the October sessions the event was joined by Dr Maggie Mort and Dr Celia Roberts from the University of Lancaster who presented findings from the EU funded EFFORTT project which had explored ethical issues in the use of assistive technologies and on which they were the lead researchers. The Telecare operations manager for North Lanarkshire Council, Fiona Taylor, also agreed to participate and offered an invaluable insight into the complexities of implementation across ethical issues, performance indicators and suitability of assessment for technologies. Contributions also came from two University of Strathclyde departments: bioengineering (Dr Arjan Buis) and Electronic and Electrical Engineering (Dr James Irvine and Dr Jamie Banford). All three gave presentations at the events and gave the proceedings a much wider inter-disciplinary scope than had been envisaged at the outset. The major change to the original schedule was the withdrawal of the service user representatives at short notice. This stymied the exploratory research with service users between the May and October events, but the contributions of the additional incoming participants was strongly oriented towards this area in any case. Overall this loss was administratively vexing rather than detrimental to proceedings.

(2) The participants

A total of forty two participants were spread across the two blocks of time (May 30/31 and October 17/18) dedicated to the events. This included a core of repeat attendees with others participating as their schedules and interest in particular presentations/discussions allowed. There was a conscious decision by the organisers to aim for around twenty people at each session, with a maximum of twenty five. The format allowed for presentations, lengthy small group discussions and subsequent plenaries. Included among the participants were representatives from NHS 24, NHS Scotland, the Scottish Government, the Scottish Parliament and four Local Authorities, as well as four universities from the UK and two from the Netherlands. The break-out sessions were organised to allow the best possible mix of group participants. Given the quality of discussion, the organisers would commend this small group format to future proposers.

The discussion

There were a number on invited presentations which were accompanied by break-out sessions and debate. Where applicable, slides from these sessions have been uploaded onto the SUII website to give the detail of the presentations. These presentations broadly fell into five categories (1) the engineering potential and design problematic of assistive technologies (2) ethical issues arising from the design/policy implementation (3) the policy programme and competing discourses for assistive technologies (4) the experiences of front line professionals in engaging with assistive technologies and the way in which ATs reshaped relationships to service users/patients (4) the experiences from users of assistive technologies, ranging across applicability, adaptability and issues around privacy.

The presenters, and areas under discussion, are outlined below. The detail from these presentations discussion is available on the SUII website.

- Assistive technologies: where are we and where are we headed? Dr. James Irvine & Dr. Jamie Banford, University of Strathclyde
- Response: where do social sciences need to engage?
 Prof. Jennifer Harris, University of Dundee
- Delivering the care in telecare: The case for practice-based evaluation methods and the involvement of users

Prof. Flis Henwood & Dr. Mary Darking, University of Brighton

- Assistive technologies: ethical issues and ethical research Andrew Eccles, University of Strathclyde
- Assistive technologies and disability: research findings
 Prof. Jennifer Harris, University of Dundee
- Experiences from the Netherlands (1) Research and policy agendas Prof. A. J. Pols, University of Amsterdam
- Experiences from the Netherlands (2) Observation of technology users using technologies Dr. Ike Kamphof, University of Maastricht
- Operational issues and pressures of responding to the policy agenda Fiona Taylor, Local Government
- Securing Privacy. Technology and the (re)articulation of values Dr Ike Kamphof, University of Maastricht

- Ageing, the new disaster; telecare, the promised solution. Findings from the EFORTT project.
 Dr. Maggie Mort & Dr. Celia Roberts, University of Lancaster
- A participative, 'practice-centred' approach to Electronic Patient Records and telemedicine Dr. Mary Darking, University of Brighton
- Operational issues in using Assistive Technologies: a local government perspective Michael Gillespie, Local Government
- The potential for real time monitoring in daily life Dr. Arjan Buis, University of Strathclyde

The event thus aimed to facilitate an exchange across academic different disciplines but, as importantly, across different agencies. There was common agreement that this had been very successful and it was perhaps particularly noteworthy that this had been an opportunity for the Scottish Government to discuss, in detail, issues around policy implementation with key academic researchers in the field and front-line practitioners. A further highlight of the event was the range of research methodologies on display in the presentations. These drew on randomised controlled trials, discourse analysis, ethnography and phenomenology, and thus crossed over historic boundaries between positivist and interpretivist traditions. Again, this was a fascinating aspect of bringing together disciplines. The detail of the discussion is available in the slide presentations. Key points that emerged were as follows:

- Assistive technologies can confer clear benefits to end users but are inherently more complex than the discourse of technologists suggests. Issues of inter-operability of equipment, multiple morbidities of end users, and the lack of 'personalised' approaches to design and functionality, in part given the economies of scale sought by manufacturers, were all discussed. These technologies also alter relationships across the care process; homes may become more medicalised spaces, while the interaction between users and technologies cannot be assumed to be a standardised process.
- The policy instruments engaged by UK governments to advance the assistive technologies policy agenda were overly 'top down' and methodologically contestable. Examples of the difficulties in gathering data that was required of implementing agencies were offered, as was a critique of the performance indicator system which had accompanied the introduction of the

government led policy strategy. The contrast with the Netherlands – where government had taken a more *laissez faire* approach – was instructive.

- Discussion around 'users' of these technologies over simplifies the complex interconnectedness of assistive technologies in use. Users extend to care practitioners, who have to make judgements about interpreting data from monitoring technologies. These judgements are not straightforward, as they will be conducted at a distance from the patient/end user. It became clear from the discussions that practitioners were using professional discretion to interpret data, since not all data was relevant to the tasks in hand. There may be a tension here between the requirements of performance managers and the practical wisdom of front-line staff. There may also be legal issues arising if data is ignored that might subsequently prove relevant if there is a system failure. There is no standard response across practitioners about the use of these technologies; responses varied across professions and there was discussion about how different age groups – across professionals and end users alike – might interact with the potential for technology use. It was noted also that constant review of the suitability of technologies - particularly, for example, where they supported end users with dementia was needed but not always readily available from implementing agencies.
- On a number of levels privacy, surveillance and the dynamics between humans and technology ethical issues come to the fore. The ethical frameworks in use in policy circles are almost wholly derived from bio-medical literature. Our discussion noted that care relations in distinction to medical intervention do not sit easily with these frameworks, which may benefit from engagement with an alternative, relational ethics, literature. It was noted also that the 'primacy of autonomy' in ethical frameworks became a more complex consideration given the dependencies on technology and thus lack of autonomy –which attended the use of some assistive technologies. Thus the much heralded increase in independence afforded by these technologies was in reality underpinned by often complex and unseen support via families, monitoring centres and practitioners.

(4) Dissemination and further activities

Discussion on outcomes from the events should be prefaced with two caveats. First, outcome measurement in these circumstances is imprecise (and may indeed be counter-productive if too prescriptive). We are grateful to the SUII not to be saddled with such a framework in advance. Second, that the event took place and was regarded by participants as successful is, of course, an outcome in itself. As social scientists who have been engaged in measuring impact for the Research Excellence

Framework have noted, impact is likely to be by osmosis through the nuances of discussion and gradual reflection rather than categorical evidence. That said, there has been significant follow up to the events, particularly in terms of the wider reach of academic research and debate into policy and implementation circles, although this has cut both ways with some of the local authority practice under discussion offering excellent exemplars and ideas for further academic engagement. Seven specific outcomes, discussed below, are perhaps worth consideration.

(a) There has been agreement across the academic and local government representation at the events to pull together a bid for funding from the EU Horizon 2020 programme. This is on track for April 2015. We have identified a funding stream and specific area of engagement. Academic partners from

Catalonia and Norway have also thus agreed to participate, generating а UK/Netherlands/Spain/Norway bid. This is likely to have two major strands; (1) the discourses of policy and actual practice across the three polities and (2) the experiences of service users using second and third generation assistive technologies (respectively care monitoring technologies and GPS based care) and ethical issues therein. There is likely to be some spin off from the materials gathered for this in terms of other funding proposals.

(b) There has been an approach from the editorial board of the journal Ethics & Social Welfare to the event organisers to submit proposals for a special edition of the journal on the issue of ethical and social issues arising from the use of technologies. This would be realised, in part, by drawing on the papers and discussion from the SUII events.

(c) The SUII events have given rise amongst participants to proposals for a textbook aimed at front line practitioners and drawing from the different disciplines at the event (for example engineering, social sciences, ethics). This was submitted (format, content, potential market) to Sage after an initially very positive discussion; it was subsequently declined on the grounds of the available student/practitioner market. We propose to take the proposal elsewhere.

(d) There has been more detailed follow up with the Scottish Government civil servants who were at the event. They are now drawing on papers from the sessions around costs and efficacy and a further paper drawn on at the event is now issued in response to queries to the Scottish Government on the question of ethical considerations around using some assistive technologies. There will be a forthcoming Scottish Parliament review of Scottish Government policy on e-health and telecare, which Andrew Eccles has been approached to attend and from which SUII discussions will be offered in evidence. More recently, in August 2014, there was a meeting with the Joint Improvement Team of the Scottish Government to discuss support for the EU H2020 bid arising from the event. These talks were

very positive and productive, with the Scottish Government offering a commitment to be a partner to the research proposal as outlined.

(e) A link, centred on the work of Dr Maggie Mort and Dr Celia Roberts at Lancaster University, who presented at the October sessions, has been established between Lancashire Council and North Lanarkshire Council for discussions around the transfer of best practice in the use of assistive technologies.

(f) Andrew Eccles presented at the AKTIVE conference in the University of Leeds, UK, exploring issues of methodology and findings from recent telecare research. Again, this paper drew heavily on discussions from the SUII event. The upshot of this presentation was a meeting in July 2014 at Queen Mary University, London, with Professor Trishia Greenhalgh, Dean of Research Impact, and QMUL colleagues with a view to a funding bid, in part based on cross national policy comparisons of telehealth/care implementation. This this bid is, at the time of writing, well advanced.

(g) There have been publications, in peer reviewed journals, which have drawn on the research presented, and subsequent discussions at the event. Please contact the event proposer, Andrew Eccles, for further details at: andrew.eccles@strath.ac.uk