Institution: Lancaster University

Unit of Assessment: Sociology (UoA23)

Shaping ethical provision, care quality and design sensitivity in new health technologies

1. Summary of the impact

In a context of austerity and shrinking public provision, developed societies are turning to new technologies such as telecare for health/social care provision, and biosensors to facilitate citizens' active self-care. Maggie Mort, Celia Roberts and Adrian Mackenzie's research explores the overlooked ethical and social aspects of this trend focussing on ageing, reproduction and genetics. Through innovative engagements with policy makers, industry, citizens, health experts and practitioners, we provide empirical intelligence about how remote care for older people living at home (telecare) and providing users with bodily data (biosensing) work in practice. Because the views and experience of users and citizens underpin our research, our interventions confer much-needed legitimacy on subsequent decisions about health care technologies and provision. Our recommendations are adopted in local authority service re-design and have shaped corporate decision-making about product development.

2. Underpinning research

Our empirical research shows that developing remote care and biosensing technologies without adequate consideration of their social and ethical implications results in poorly understood and underused systems, with high risk of wasting scarce economic resources. Rather than addressing care 'deficits', such poorly designed systems can also increase loneliness and anxiety for users. In contrast, attending to users' and citizens experiences of and concerns about these technologies facilitates development of more ethical and socially intelligent systems that will avoid exacerbating social inequalities. Our recommendations have been taken up by both public and private sector actors, feeding directly into the service specification and commissioning of telecare systems and the design of new biosensors.

This case study rests on a decade of sustained, wide-reach engagement with citizens, policy makers, consumer groups, and social/health care workers to develop an empirically rich understanding of the ethical and social aspects of health, care and biosensing technologies. Our competitively-funded research - MEDUSE (2006-8), EFORTT (2008-2011) and Living Data (2011-2014) - addresses interactions between providers and users of remote health care/biosensors in highly sensitive domains (ageing, assisted conception, genetic testing), arguing that such technologies risk failing (practically and commercially) unless users' concerns and resistances are carefully considered by designers, service providers and commissioners/policy-makers.

MEDUSE: (Mort & Roberts 2005-8, www.csi.ensmp.fr/WebCSI/MEDUSE/) EC-funded FP6 Thematic Network developing dialogue between social scientists, practitioners and users directly concerned with the emergence of new technologies and responsibilities for health care at home across the EU. Through two participative conferences (Utrecht: *Telecare: Dialogue and Debate – The emergence of new technologies and responsibilities for healthcare at home in Europe* (http://www.lancs.ac.uk/efortt/eventsArchive.html) and Barcelona: *Ageing with technologies: a participative conference on care in Europe* http://psicologiasocial.uab.es/efortt_conference/Efortt/Conference.html), as noted below, we achieved recognition for the views of older people's organisations, voluntary organisations, homecare networks and citizens in shaping the future of new healthcare technologies, demonstrating the need for EFORTT (below).

EFORTT: (Ethical Frameworks for Telecare Technologies for older people at home, Mort & Roberts 2008-11, www.lancs.ac.uk/efortt) EU FP7 Science in Society Collaborative Research project. This investigation of the social/ethical implications of remote care technologies worn, installed or embedded in the homes of older citizens involved observations at local authority meetings, social work offices, older peoples' homes, housing association offices, 'smart homes', practitioner training meetings and remote care monitoring centres. Building on our sustained dialogue with stakeholders, findings revealed 'empirical ethical' concerns, a key divergence/departure from the more standard 'principle ethics' approach. Drawing from Mort & Kashefi's (2004) and Mort & Finch's (2005) engagement with citizens' panels and juries, EFORTT staged 22 older citizens' panels (10 citizens per panel) over 18 months in England, Netherlands, Spain and Norway (2008-10). Participants explored their aspirations for care and the role that care

technologies might play in these. Recommendations are now being implemented with major local authority commissioners; older people's NGO providers (AGEUK, Spanish Red Cross; and discussed with lobby groups (Age Platform Europe,). Our Ethical Framework for Telecare is now used in Local Authority telecare service specification and procurement and by AGEUK in its latest knowledge transfer initiative.

LIVING DATA: Although industrial/design advisors (BT, Chubb, Phillips) participated in both MEDUSE and EFORTT, their participation was limited by commercial confidentiality/government contracting processes. To achieve meaningful routes for our research to influence design, development and practice, a closer relationship with industry was indicated. In 2010, Roberts was invited to bid by Intel Labs, and with Mackenzie and Mort received funds for participatory research and two PhD studentships (Living Data, 2011-14, www.intel.com/content/www/us/en/research/intel-labs-data-society.html). Working with Intel's corporate anthropologists, engineers and designers and an international group of researchers, we have explored the social and ethical aspects of using biosensors to record personal biological data in assisted conception and direct-to-consumer genetic testing. In parallel we ran a two-day Citizens' Panel (May2013) with 15 participants and four expert witnesses to debate ethical and social questions arising from these technologies. Citizens expressed serious concerns and made recommendations for government, NHS/service commissioners and industry (Intel). As noted below, this work has impacted on Intel's strategic investment decisions in the biosensor arena.

3. References to the research

MEDUSE: EU FP6 €199 540 www.csi.ensmp.fr/WebCSI/MEDUSE/; EFORTT: FP7 €784,600 www.lancs.ac.uk/efortt; LIVING DATA: Intel Labs £153,424, www.intel.com/content/www/us/en/research/intel-labs-data-society.html

Mort, M., Roberts, C., Pols, J., Domenech, M. and Moser, I. (2013). Ethical Implications of Telecare for Older People: A framework derived from a multi-sited participative study. *Health Expectations, early view DOI 10.1111/hex.12109* (Double peer reviewed journal)

Roberts C, Mort M & Milligan C (2012) Calling for Care: 'Disembodied' work, teleoperators and older people living at home, *Sociology,* 46: 490-506 (Double peer reviewed article)

Mort, M, Roberts, C & Callen, B (2012), 'Ageing with Telecare: Care or Coercion in Austerity?' *Sociology of Health and Illness* first published 25 OCT, DOI: 10.1111/j.1467-9566.2012.01530.x (Triple peer reviewed paper)

Milligan C, Roberts C & Mort M, (2010) Telecare and Older People: Who Cares Where? *Social Science & Medicine* 72(3): 347-54 (Triple peer reviewed article)

Mort M, Roberts C & Milligan C (2011) Telecare and Older People: Re-ordering social relations, in von Schomberg, R. (ed) *Towards Responsible Research and Innovation in the ICT and Security Technologies Fields,* European Commission: 151-166. (Output from competitively funded EC FP7 research). Available at http://renevonschomberg.wordpress.com/ict-and-security-technologies/

Roberts C & Mort M (2009) Reshaping what counts as care: older people, work and new technologies, *ALTER: European Journal of Disability Research,* Vol 3, No2, 138-58 (Double peer reviewed article)

4. Details of the impact

1. Shaping public policy and local authority commissioning of telecare

Local authorities and the NHS are aiming for a substantial increase in telecare provision. Lancashire County Council (LCC) is currently using our (EFORTT) Ethical Framework in preparing specifications for procurement of a new telecare service. Our Framework emphasises the importance of sharing information about usage patterns amongst actors in the telecare network, the value of pro-active calling, the significance of monitoring centre workers in providing care to lonely users and the need to protect local networks of care while expanding the service. All local authority/NHS services must demonstrate the highest levels of effectiveness: our recommendations are assisting the Council's Adult Services Directorate to shape a service that will

be well used. Mark Luraschi, LCC Locality Commissioning Manager said:

> *Whilst in the role of Telecare Project Manager for Lancashire County Council, I was pleased to collaborate with and support the EFORTT project. Our engagement was a two way process with lots of questioning and examination of policies, processes and methods of delivering Telecare within Lancashire. The process of investigation and subsequent published articles did lead to myself and various colleagues re-examining aspects of Telecare and its delivery to the citizens of Lancashire, especially around issues such as technology as replacement for human care, and the potential for increased social isolation amongst older and vulnerable adults due to heavier reliance on technology based monitoring systems.*

Our research has been presented to policy makers and service providers at regional, national and European levels such as senior managers at LCC (May 2011; Oct 2012; Sept 2013), a North West NHS/EU Innovation event (Oct 2011), presentation to the MADoPA/ACCOMPANY FP7 project (Paris June 2012). As invited participants at the EC High Level Workshop on Future Technology and the Workshop for European Parliamentarians on Responsible Innovation (Brussels Nov 2010), EFORTT has been instrumental in initiating the *Responsible Research and Innovation* agenda and shaping EU FP8/Horizon 2020. We contributed a chapter to the EU policy report *Towards Responsible Research and Innovation in the ICT and Security Technologies Fields* and ran a workshop at the *Does Europe Care?* conference (www.careconference.eu/site/). Our work has also highlighted social and ethical issues for social workers prescribing telecare (article in the UK's leading practitioner publication) and third sector providers (AGEUK radio debate Nov 2012, expert briefing, May 2013 and commissioned knowledge transfer publication July 2013; Spanish Red Cross). An unsolicited response from Anne Tidmarsh, Director of Older People and People with Disability at Kent County Council describes the significance of our work for service development:

> *I attended the [*MEDUSE*] conference last year and received your publication [*Mort et al, 2008*] a few weeks ago. I would just like to thank you for sending this to us. It was very good to see all the information together in your study. I would also like to say that Dr Robert Stewart and I are still building on the information provided at your seminar and are hoping to take quite a few elements forward……. Our Telecare Board was extremely interested; they are keen to look wider than our standard format now.*

And from an unsolicited email from Craig Frost, Locality Commissioning Manager, Adult Services, Lancs Co Council:

> *Many thanks for producing this paper for us – it's really helpful. I will forward to relevant colleagues, including Tony Pounder and Roger Hulme, and we can certainly use it when we start to get into detailed discussions with One Connect Ltd and the chosen Service Provider about the service model and design.*

Our work has led to improvement in remote care service provision internationally: following our participative conference a key figure in the Red Cross (Catalan telecare provider) stressed our project's success in opening up 'a stronger connection with users' and a (re)orientation towards meeting users' specific needs rather than providing a generic service. This is a shift towards more ethical, socially-aware and effective care:

> *Participation in this research group with professionals from different sectors and countries has provided us a great number of contributions, debates and perspectives that have enriched us enormously and let us improve with important and different ideas from our daily work. It has opened us a range of practices and comprehensions about elder people care. In this way, we have a stronger connection with our users and are able to adapt present and future projects to their necessities and particular features* (Oliver Cubells, Mobile Telecare Service and Technological Support for Older People, Red Cross.)

2. Shaping corporate investment in biosensing

Our contributions to developing more ethical and socially aware forms of telecare and biosensing recently found new reach in the corporate world. In face-to-face and virtual engagements with anthropologists, engineers, designers and managers from Intel Corporation (the microchip-manufacturing multinational), we have exposed the limits and potentials of the use of sensing technologies to collect personal biological data (biosensing) in two fields: reproduction and

personalised genomics. Our empirical research and most recent citizen's panel (May 2013) highlight both the potential for biosensing devices to create anxiety in some users and the keen interest that many display in 'playing with' personal biological data. Members of the citizen's panel raised concerns around regulation, trust, security, accuracy and personal, familial and societal impact of biosensors. Our research has had a significant impact on Intel's decision to invest in this new field. In face-to-face meetings at Intel, Santa Clara and regular international teleconferences, as well as via written reports, we have provided empirically-informed arguments about the social and ethical implications of particular biosensing practices (for example, our strong concerns about the impact of home ultrasound scanning for pregnant women). These interactions have influenced investment and design decisions at Intel. Dr Dawn Nafus, Intel Lab Biosensors Project Lead, writes,

> *The Living Data project have been close collaborators for Intel, both in its internal R&D capacities and in strategic planning functions... researchers at Lancaster have informed Intel's decisions with respect to a new, and potentially significant market for us: consumer-driven biosensing. This includes decisions we have to take in terms of investments, acquisitions, and technical designs).* [NB: the precise nature of this investment is commercially sensitive.]

3. Staging citizen/public deliberation and opportunity for influence over telecare and health biosensor development

'Upstream' engagement and informed debate about major policy directions and new technology development has been a key focus, involving a wide range of citizen actors in England and Europe. This has been achieved through 1) Staging 22 older citizens' panels about remote care systems (average 10 people per panel) over 18 months in England, Netherlands, Spain & Norway 2008-10; 2) Radio debate on AGEUK's The Wireless (audience 100,000) available as podcast: https://itunes.apple.com/gb/podcast/agenda-on-wireless-14th-november/id541099875?i=125432886; 3) Blog on AGEUK website: http://ageukblog.org.uk/2012/10/21/will-the-sensors-look-after-us/; 4) Production of a booklet for telecare users and carers, concisely summarising the EFORTT Ethical Framework as a series of critical questions that older people, families and carers can ask when debating whether to install telecare systems, (1,000 hard copies circulated in the UK through older peoples', carers' and local authority networks and downloadable from: www.lancs.ac.uk/efortt and Age Platform Europe: http://www.age-platform.eu/en/age-policy-work/accessibility/links; 5) A two-day citizens' panel (May 2013) to gauge public opinion about reproductive/assisted conception devices and direct to consumer genetic testing; 6) Invited Expert Briefing to AGEUK organisation May 2013 and invitation to participate in AGEUK's current 'major Knowledge Transfer project: summarising research about what works in service interventions for older people'.

5. Sources to corroborate the impact

Shaping public policy and local authority commissioning of telecare

1. Head of Commissioning, Adult & Community Services, Lancashire County Council
2. Director of Mobile Telecare Service and Technological Support for Older People, Spanish Red Cross

Shaping corporate investment in biosensing

3. Anthropologist, Intel Labs

Staging citizen/public deliberation and opportunity for influence over telecare and health biosensor development

4. Research Advisor, AGEUK London
5. Director, GeneWatch, UK