



## Digital families across the lifecycle:

### Briefing from Seminar 3 Digital Technologies, older age and caring



Digital families across the lifecycle is a knowledge exchange project from the Centre for Research on Families and Relationships, funded by the Scottish Universities Insight Institute.

## Background

There is increasing interest in the influence of digital technologies on everyday life. The Scottish Government's ambition is to increase the use of broadband across all communities in Scotland. Aims to improve the digital health of our population, to promote internet safety, and use technologies to support learning are well established. The digital families programme aims to add to this growing body of knowledge by providing opportunities to explore the increasing presence of domestic digital technologies within family life, and to debate both the benefits and pressures these technologies bring. Organised within three groupings – childhoods, family life and older age and caring – the programme will address a range of issues, including:

- the different experiences of rural and urban families;
- the role of digital communication in the lives of trans-national families;
- the impact of digital technologies on cross generational relationships within families;
- the contributions that digital technologies can have in maintaining and developing social networks across the lifecycle;
- the effect of digital technologies on education, work/life balance, lifelong learning and wellbeing; and
- the social and economic inequalities that arise from different access to, and adoption and use of, technologies across the lifecycle
- the differential experiences of 'digital natives' vs 'digital immigrants'

The digital families programme aims to consider these issues within a broader political and social context, to focus our understandings of the impact of domestic technologies on family life and to create a vision for research, policy and practice in Scotland in 2016 and beyond.

Key aims of the Digital Families programme:

1. Understand how digital technologies are impacting on family life and personal relationships in Scotland.
2. Identify the issues that families are grappling with in relation to digital advances, and stimulate new ways of addressing these.
3. Foster innovative collaborations between academics and non-academics with the potential to both raise new questions and inform policy and practice.
4. Establish a 'digital families' research network.

### Seminar 3: Digital technologies, older age and caring

56 people attended the Seminar, held at the University of Edinburgh on 13 April 2016. Delegates included academics, practitioners, policy makers and voluntary sector representatives from a wide range of organisations.

The aims of the seminar were:

- To explore how digital technologies are being used by older people, their families and by carers
- To identify key issues in relation to digital technologies, older age and caring
- To develop new collaborations between researchers, practitioners and policy-makers interested in taking issues forward

### Speakers and presentations

Professor Heather Wilkinson (Director of the Edinburgh Centre for Research on Experience of Dementia and Co-Director of the Centre for Research on Families & Relationships) welcomed everyone to the seminar. Professor Sam Punch (Professor of Sociology) from the University of Stirling provided some background to the Digital Families Across the Lifecourse Programme.

[Download the presentation here](#)

Caroline Marchant, Early Career Fellow in marketing at the University of Edinburgh Business School gave a presentation on 'Children and their grandparents: practices across the generations in the digital world.' The aim of the research was to understand the relationship between grandparent/ grandchildren socialization using PCDs (person communication devices) and any resulting consumption practices between them. This research is part of a 3 generational study into 5 extended families across central Scotland.

4 key themes emerged in the grandparent/ grandchild relationship

1. Goal driven, reverse and reciprocal socialization – grandparents often pro-actively sought 'digital communication' (often driven by their own peers) but sometimes younger generations encouraged digital communication to ensure greater ease of contact and inclusion in family life.

2. Private communications networks facilitating embedded routines – grandparents using PCDs to maintain relationships with grandchildren – sometimes with the parent as a mediator and sometimes not.

3. The influence of family role ‘technical experts’ – some family members were regarded as the technical experts in the family, but did not always want to be, while grandparents were sometimes regarded as the ‘family glue’ informing various family members about the activities of others, digital means of communication.

4. Generational ‘othering’ – Stereotyping grandparents’ lack of ability whilst assuming grandchildren’s expertise (digital immigrants vs digital natives?) – highlights the dangers of exclusion resulting from assumptions

This research:

1. Led to a greater understanding of cross-generational family network socialization, specifically between grandparents/children in the digital age.
2. Recognised the establishment of embedded communications practices across the generations, strengthening rather than weakening bonds, via PCD communications. PCDs allow usurping of the middle generation controllers via the establishment of routine private communications channels (although PCDs also enables easier middle generation coordination and sharing)
3. Highlights the awareness of, and expectations on, family technical experts and reluctant socializers – from any native or immigrant generation!
4. Warns that active ‘othering’ and self-exclusion creates dangers: limiting the opportunity to build cross-generational relationships and limiting family inclusion.

[Download Caroline’s presentation here](#)

Dr Grant Gibson, Lecturer in Dementia Studies at the University of Stirling gave a presentation on ‘How people with dementia and their carers make technology work for them.

Use of AT (assistive technology) is being mainstreamed within the UK but there has been little consideration of how people with dementia and their carers actually use AT in the context of their everyday lives. Until recently, most studies of AT related to technological development, trials of AT products or evaluations of local AT services. This research identified the range of AT products and services being used by people with dementia and included a qualitative study of the everyday use of AT devices.

AT can be used ‘by’ people with dementia (tools and aids for orientation and reminders/prompts), ‘with’ people with dementia (communication aids, play & enjoyment, reminiscence) and ‘on’ people with dementia (telecare systems, alarms, GPS). People use ‘formal’ AT, usually accessed by care providers, ‘off the shelf’ AT provided by the private sector and ‘do it yourself’ AT – everyday devices developed or adapted by families. This is sometimes called ‘bricolage’ i.e. ‘making do with what is at hand’

Carers tend to be more positive about AT than people with dementia, as it can bring them peace of mind. People with dementia rarely perceived the benefit but some used the AT to keep their carers happy. Negotiations about the use of AT are common. It is very important to support carers to become 'bricoleurs'.

Grant concluded that bricolage provides a useful tool to explore the everyday use of AT in practice - combining AT with other technologies in the home and showing up the everyday arrangements required to put AT into practice. Currently AT and AT services for dementia do not enable 'bricolage' - AT is not easily adapted to individual circumstance and there is little ongoing support as a person's needs change. Carers not supported in the bricoleur role. There is a need to reconfigure AT services for people with dementia - supporting bricolage based use of technology, supporting carers to act as 'bricoleurs' and being sensitive to technology related needs as they change over time.

[Download Grant's presentation here](#)

Professor Maggie Mort, Professor in the Sociology of Science, Technology and Medicine at the University of Lancaster gave a presentation on 'Telecare for older people at home: some ethical issues'. This project was funded by the EU (European Commission FP7 – Science in Society) as part of the EFORTT programme 'Ethical Frameworks for telecare technologies for older people at home'. Maggie outlined the different generations of telecare and introduced the ethical principles – autonomy, beneficence, non-maleficence and justice.

The research uncovered many issues relating to the use of telecare – refusal, intermittent use, misunderstanding, installation to meet targets, 'misuse', adaptation, creative use, customization and supplementation. Telecare networks are very complex. Concerns raised by both telecare 'users' and telecare workers included – loneliness (use of telecare for 'social' reasons classified as 'misuse' but highlights a need for contact and the isolation faced by many older people), widespread concerns about the 'replacement' of face to face care, the need to integrate telecare with existing strategies, the active/ passive distinction (pendants seen as active and sensors seen as passive) and intrusion in the home (especially by more complex systems).

Maggie illustrated the difficulties faced by telecare workers using some great quotes from her qualitative research. The research highlights that telecare relies on 'traditional' networks of people and practices of caring (on 'society'). It is clear that telecare cannot actually provide care and that 'telecare workers' attempt to repair 'the social network' with limited resources, which costs them a lot emotionally.

The recommended practices for ethical telecare are:

- Consultation: establish older people's telecare groups
- Address social isolation: specify pro-active contact; address 'misuse'
- Consent as a process: revisit as conditions change
- Technology: review sourcing to minimise intrusion; bottom-up feedback to address design problems
- Intelligence: patterns of use fed back to prescribers
- Consider both economic and social costs in evaluation

[Download Maggie's presentation here](#)

[Link to booklet for carers and users](#)

## Perspectives from other sectors

Agnes Houston, Vice-Chair of the European Person With Dementia Working Group gave a presentation to provide her perspectives as a person with dementia. Agnes described how technology is vital for her in her everyday life. For example she can zoom in to read in large print, re takes photos to help with memory recall (she can take photos while shopping for clothes to ensure she doesn't buy the same item twice), she can colour code her speeches to make them easier to deliver and she has many 'virtual friends' all over the world she communicated with for peer support. She is involved in the Dementia Alliance International and feels that her ipad is her 'window to the world'. She is impressed by all the apps being developed to support people with dementia but reminds us that people need to be taught how to use the apps effectively. She would love to see more inter-generational work, with school children helping older people to use technology. She concluded by reminding the audience that one size does not fit all – everyone with dementia is different.

Gregory Hill-O-Conner, ehealth Officer with the Health and Social Care Alliance Scotland (The ALLIANCE) provided some perspectives from the Voluntary sector. Gregory outlined the health and policy context, the landscape of supportive technology and challenges and opportunities for the future. Challenges include avoiding the 'administrative convenience' of health and social care integration, the fragmentation of the third sector, the increased prevalence of digital monitoring devices and finding solutions for the life course. Opportunities include the move towards person-centred care and person-centered care records. The ALLIANCE can support the third sector in Scotland by fostering innovation in partnership with the Digital Health & Care Institute, bringing people together across sectors, horizon scanning on behalf of third sector organisations, being the 'eHealth Department' for smaller organisations and bringing the patient voice to the debate. Gregory emphasised that co-design is essential for meaningful, sustainable innovation in care.

[Download Gregory's presentation here](#)

[Link to ALLIANCE Publication 'Digital technology for Health and Wellbeing'](#)

Dr Val Bissland, from the Centre for Lifelong Learning at the University of Strathclyde presented some perspectives from the Scottish Older People's Assembly (SOPA). Val outlined the role of SOPA in giving strong voice to older people. SOPA would like older people to have funded access to the internet and digital technologies through the relevant supported services. Digital participation is important because being able to contribute, participate and engage is an important factor in the wellbeing of the older population. However, technology should be presented as the means to an end, not the end in itself.

In terms of care, Val asks whether 'person-centred' care systems are designed to also include family and carers. There is a need to focus on individual outcomes and use technology to facilitate this, but only where appropriate.

[Download Val's presentation here](#)

[Link to SOPA telecare film](#)

## Discussion

Discussion 1 – delegates participated in smaller group discussions and were asked to consider the following questions:

1. How are digital technologies being used by older people and their carers?
2. How are digital technologies being used to manage long-term conditions and to support independence? What are the ethical issues associated with this?
3. How can older people and their carers be supported in using technology to improve their health and wellbeing?

Facilitators asked the discussion groups to:

1. Reflect on what you have heard so far. What do you recognise? What is new to you?
2. Consider the 3 questions above and identify your top 3 issues – for action and/or for further research?

From these discussions, the following topics were identified for further discussion.

1. What can we do about capacity, consent and control issues – including privacy vs security?
2. How can people be supported to learn new technologies throughout their lives?
3. How can we get players in the care system to work better together around new technologies?
4. What is the role of technology in relationships between the generations?
5. How can we take forward research into the use of technology in older age?

## Key questions and action points from the discussions

1. What can we do about capacity, consent and control issues – including privacy vs security?

Judging 'capacity' is not a 'one-off' it is a process and needs to be regularly re-evaluated. For people with dementia, 'capacity' is a spectrum and can come and go.

Installing some form of AT in someone's home is not a one-off solution. There is a need to look at each individual and identify their needs, in discussion with family members and carers. Should also recognise that needs will change over time.

Privacy – people should discuss these issues with their family members earlier so rights are not compromised at a later time. The use of AT and telecare has issues for privacy – balance required.

Some technology can backfire.

Sometimes, bureaucracy can prevent the implementation of known technical solutions.

2. How can people be supported to learn new technologies throughout their lives?

To support older people in their use of technology, we know what works – peer support, informal teaching, 'knowledge exchange'. The types of interaction are so important – they need to be warm, encouraging, compassionate, patient.

To encourage older people to attend groups and classes, you need to advertise in places where the information will be seen (i.e. not online!) – local newspapers, shops, chemists etc..

Not all older people want to attend a regular group or class but would benefit from a 'drop-in' service e.g. at the local library or at lunch clubs – for quick queries/ 5 minute refreshers etc.. there is a real lack of these services.

Issue of training for volunteers – relationships skills can be more important than technical skills.

There is support out there but we need to identify what is available. It is difficult to keep on top of the range of support and activities for older people (not just in relation to supporting digital skills – but the full range of activities)

3. How can we get players in the care system to work better together around new technologies?

3 key points – 1. huge variation across different parts of the country 2. long waiting times for assessment and 3. Installing 'tech' is not a fix – technology is not the problem or the solution. There is a need to change attitudes so that people are assessed in a way that identifies the real issues.

Why do assessments have to be carried out by a social worker and are we too focussed on equipment and technology? The system works better when individuals feel more in control and feel able to have an informed discussion.

Issues around the evaluation of telecare systems and gathering views from users.

#### 4. What is the role of technology in relationships between the generations?

There is not much knowledge about this and what there is tends to focus on the 'digital divide' but as Caroline's presentation highlighted, some older people are becoming increasingly aware of the need to use digital tech to communicate with family members.

We should consider what content is being shared across generations, not just skills.

We should also consider how the 'sandwich generation,' caring for both children and elderly parents, make use of tech (and some grandparents are caring for young children)

Looking at telecare/ telehealth - there is a mismatch between 'care' and 'control'. In discussing telehealth, we should remember that it is not all about health needs – technology can be used to support everyday more 'invisible' forms of care.

There are lots of telehealth groups/ providers doing similar things – they should co-ordinate to establish a network for good practice e.g. The Alliance, NHS24, Living it Up, disability groups. [Talking Mats](#) – an example of good practice (Talking Mats is a social enterprise whose vision is to improve the lives of people with communication difficulties, and those close to them, by increasing their capacity to communicate effectively about things that matter to them.)

#### 5. How can we take forward research into the use of technology in older age?

There is a lot of research around on ageing and digital technologies but mostly focussed on telemedicine. Despite meta reviews, a Cochrane Collaboration and several decades of work, findings have been inconclusive. Telemedicine was hailed as a major step forward in the delivery of diagnosis and care in the 1990s but it has drifted into a service linked to more sparsely populated rural communities. Research findings on the relevance of this service were marginalised by attitudes, resourcing and implementation factors.

There is no standard method for assessing technologies and many technologies in everyday use with older people are analogue, not digital. Could we make more use of the data that phone providers collect? Private sector research by the major technology companies is likely to take off during the next decade as the technology market for the over 65s expands. We should seek to influence this research so that it can look at quality of life, as well as 'markets for gadgets'.

Possibilities for co-production of research, with recently retired experienced people working with older users and developing technologies? This would require researchers

to use knowledge and experiences from across the lifecourse and move away from the stereotyped image of the young, geeky male in front of a device.

Ethical and knowledge exchange issues. Should companies be obliged to share data for the wider social good? Collecting data online and conducting research in these ways presents a range of ethical issues.

A good example of new research and - Information on a new project [memoryfriendly.org.uk](http://memoryfriendly.org.uk) – a Knowledge Exchange project exploring how local communities can support people with dementia. The second phase of this project will focus on the ‘virtual neighbourhood’ looking at how people with dementia use and navigate online environments.

## Feedback from delegates

A selection of comments received through the SUII Evaluation forms:

*Really great speakers – very stimulating. Good facilitators. I found the session on assistive technology very interesting.*

*Great to have someone with a diagnosis of dementia – a very good programme. The talks were all different but interlinked.*

*This seminar was different to events I have attended before i.e. to hear academic perspectives was really interesting and challenging at times. I am interested in the intergenerational perspective from a professional and personal point of view (as a grandparent who texts and facetimes grandchildren)*

### **What will you take away with you from today’s seminar?**

*Technology is an enabler but cannot replace face to face contact*

*We will review our service to look at required outcomes for individuals – using technology as an enabler and will review after 6 weeks. Useful contacts.*

*Ideas to take into practice and research. The importance of the involvement of older people.*

*To make more time for research and hopefully make contact with people I have met today.*

*I work in the broader context and made some excellent contacts.*

## Twitter

A number of delegates tweeted throughout the day using [#digifam1516](https://twitter.com/digifam1516). Following the seminar, a Storify was produced to summarise the proceedings and to capture the views expressed through Twitter.

[Link to Storify record of Seminar](#)

## Programme team

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## Project webpages

<http://www.crfr.ac.uk/digital-families-across-the-lifecourse/>

<http://www.scottishinsight.ac.uk/Programmes/Programmes20152016/DigitalFamilies.aspx>