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Technologies for care – the imperative for upskilling carers

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Key policy recommendations

- Enhance digital/digital health literacy skills of family carers, care workers and cared-for people by increasing opportunities/programmes for digital health literacy- based on health conditions
- Raise awareness of opportunities arising from telehealth, telecare, online services and eHealth for carers, care workers, cared-for people and health care professionals
- Ensure seamless linking between care workers, carers, services, information and online communities via 'one stop shops'
- Enable care-home residents to use digital devices as currently there is little provision for them to access or learn to use such devices
- Adequately resource/accelerate NHS app approval process
- Improve linkage of data from approved apps to GP surgeries, consultant clinics, etc
- Ensure fast broadband coverage for all communities: urban to remote rural
- Ensure good mobile phone signals – urban to remote rural

Abstract

Ageing populations, coupled with increasing retirement ages and lower ratios of workers to retirees, are negatively impacting health and social care resources (European Commission 2015). Currently, 11.8% of Northern Ireland (NI) residents are carers (Carers Trust 2017) but it is predicted that by 2025 the number of people aged over 65 will increase by 42% (NISRA 2015). These projections place increasing demands on carers, especially when considered within the 'changing ethos of health care in NI' towards a self-management model (NIPEC 2012). Carers increasingly use the internet

for health information, yet worldwide many people lack health literacy and/or digital skills (International Longevity Centre 2012).

The EU-funded DISCOVER project involved over 650 carers, careworkers and stakeholders in co-designing and co-producing an online learning platform to enhance health literacy, and digital and caring skills and enable carers to share supportive practices to help reduce social isolation. Surveys and interviews revealed (Waights 2015a) that carers and care workers gained new digital skills (59% and 67%), and increased their knowledge of health conditions (83% and 71%) and technologies for care (89% and 76%). DISCOVER enhanced participants' wellbeing and over 80% would recommend DISCOVER to others (Waights 2015a). Healthcare professionals reported that through DISCOVER carers and care workers participated more knowledgeably in consultations with care recipients.

Recommendations for policy makers and health care professionals include: ensuring seamless linking between care workers, carers, services, information and online communities via 'one stop shops', enabling care-home residents to use digital devices, reducing the mismatch between technologies and older people through co-production (Waights 2015b), accelerating the NHS app approval process and linkage of data from approved apps to clinicians and other health care professionals.

Introduction

As the population of Northern Ireland increases in age, the demands on health and social care services are also increasing. It is predicted that by 2025 the number of people aged over 65 will increase by 42% (NISRA 2015), and many of these older residents are living with long-term conditions and co-morbidities. They are the members of the NI population that are the main users of health and social services, accounting for 43.5% of all hospital acute admissions during 2016/7 (DoH 2017).

This increase in population age is coupled with financial constraints, such as the predicted reduction across the EU, including the UK, in the ratio of people of working age to retirees from 4:1 to 2:1 (European Commission 2015). This reduction in the working population also affects health care. The World Health Organisation is estimating that by 2030 there will be an 18 million shortfall in healthcare workers worldwide, over twice the 7 million shortfall that they estimated in 2013 (WHO 2016). Health and social care professionals in NI are already experiencing challenges due to staff shortages [see Overloaded GPs (The Irish News Feb 2018), Nursing shortage (Nursing Times Dec 2017) and Care worker shortage (UKHCA 2016)].

Taking all these factors into account means it is unlikely that NI services will be able to meet the demands for health and social care. Currently, 11.8% of Northern Ireland (NI) residents are carers (Carers Trust 2017) but these projections place increasing demands on carers, especially when considered within the 'changing ethos of health care in NI' towards a self-management model (NIPEC 2012). However, it is estimated that by 2025 an additional 20 million family carers will be needed across the EU, including more demand for family carers in NI (European Commission 2012).

Many initiatives see digital technologies as the way forward to enable services to support more people more cost effectively. It is estimated that ICT and telemedicine have the potential to give a 20% increase in service efficiency across Europe. Such initiatives range from daily telemonitoring and the use of alarm buttons and sensors (such as those used extensively in Scotland), through video consultations allowing service users to remain at home rather than attending hospital appointments, to text messaging to remind citizens of hospital and GP appointments, to take medications, or to encourage healthy lifestyles. One such messaging service in Florence, Italy involves over 70 local authorities and is already used by over 22,000 citizens.

In recent years there has been a steady increase in online access to local services, booking hospital and GP appointments and ordering repeat prescriptions. There also has been an explosion in eHealth services and mobile phone apps, although to date few of these apps have been approved by the NHS, and in future robotic assistants may become more commonplace (European Commission 2017).

Using such services requires citizens or their carers to be digitally literate, yet in 2017, 4.8 million adults in NI (14.6%) have never used the internet, and a further 0.9 million (1.4%) had not used it during the previous 3 months (ONS, 2017). These 2017 figures for non-use of the internet (16% in total) have decreased significantly since 2011, when non-use was 30%, but are the highest out of all the regions of the UK. Non-use of the internet by adults in other regions ranges from 15% down to 7%.

The majority of the adults in the ONS statistics who have never used the internet are aged 75 years or older (58%) and may be living with long term conditions. Also, a high proportion (55%) of those adults who have not used the internet during the previous 3 months are living with disabilities. These are the very people who are the primary users of health and social care and whom the new digital technologies for heath need to reach. New initiatives in the UK and the Netherlands expect care workers to support citizens to use digital technologies, but digital skills are rarely included in the training programmes for domiciliary or residential care workers. Also, many family carers are older people themselves and may be unfamiliar with digital technologies. In our project, only 30% of carers and care workers used technologies to care and 80% were unaware of the technologies available to support them and the care recipients, echoing previous surveys, such as CarersUK (2013).

Digital health literacy

It has long been recognised that health literacy – 'the cognitive and social skills needed to access, understand and use health information' (Nutbeam 2000) - is a pre-requisite for empowering individuals to take control of their own health. However, in the 21st century it is imperative that individuals develop digital health literacy skills to enable them to make full use of digital health information and current and emerging ehealth tools and services.

Carers increasingly use the internet for health information, yet worldwide many people lack health literacy and/or digital skills (International Longevity Centre 2012). Also, a recent survey (European Commission 2014) of EU citizens who used the internet to search for health-related information within the previous 12 months has identified that there are a number of barriers preventing them from being fully digitally health literate. Even though 94% of NI respondents agreed 'they know how to use the health-related information they find on the Internet', more focussed questioning revealed that

- 16% of NI respondents did not know 'where to find reliable health-related information on the Internet'
- 13% of NI respondents did not feel 'able to distinguish high-quality from low-quality health-related information on the Internet'
- 33% of NI respondents would not 'trust information from the Internet to make health-related decisions'.
- 31% of respondents from NI agreed that 'after looking online for health-related information, they generally feel more confused than before'

DISCOVER is helping carers to use computers and the internet, to embed digital technology in their day-to-day lives.

DISCOVER - A novel approach to upskill carers

DISCOVER, an EU funded project involving 9 partners across 5 member states, has designed a single Portal - the DISCOVER Skills Zone, to enable carers, both family carers and care workers, to develop their digital and health literacy skills. The Skills Zone was developed through iterative, co-design (Cambridge University) Living lab processes, involving carers, care workers, older people and range of stakeholders including health and social care professionals, care agencies, voluntary agencies supporting carers, and local authority policy makers.

Carers were clear that they did not wish to undertake a dedicated computing course as such. Although they were interested in gaining one or more of specific skills such as emailing, using social media, participating in online communities and keeping safe on the internet, they were primarily interested in health literacy, joining online communities and enhancing their caring and employability skills. Some family carers were interested in becoming care workers but the majority wished to regain their confidence to enable them to re-engage with the career or activities they had given up to provide full time care for their relatives.

The DISCOVER Sklls Zone was trialled in 4 pilot sites in Greece, Spain, Netherlands and the UK. Carers and care workers from these countries had differing social and economic backgrounds and were carrying out their caring roles in a variety of settings: their own homes (for resident relatives), the homes belonging to relatives or friends, homes belonging to people who are not family or friends, day care centres and residential care homes. Carers, both family carers and care workers, feel very time poor and pressured so the Skills Zone takes a flexible approach, enabling carers to select topics of interest and learn at their own pace. It spans a range of activities including websites, videos, interactive media and educational games, and carers can gain certificates of achievement to evidence their learning.

Research

The impact of DISCOVER was explored from the perspectives of carers, care workers and stakeholders, such as carer organisations, care agencies, hospital units, day care centres and residential care homes. Data was collected through pre and post questionnaires (Greece, Spain, and the United Kingdom), interviews (Greece, The Netherlands and the United Kingdom) and focus groups held in each pilot site: Greece, Spain, The Netherlands and the United Kingdom.

Ethics Approval for the project as a whole was given by Birmingham City Council and for recruiting participants, and collating and analysing data collected from across the 4 pilot sites by The Open University. All partners also agreed to abide by the ethics guidelines of the European Commission and their own country. Information sheets were provided to participants. Completed consent forms, questionnaires etc were kept in locked units in the pilot sites. All electronic data was stored on password-protected PCs. Each participant was given a unique code so their progress could be followed throughout the project, whilst maintaining confidentiality and anonymity.

For the pilot phase, carers could be current or past carers and there was no restriction on the age of the person they were caring for. For the main phase, carers were currently caring for at least one older person (aged 65 and over). Partners worked with carer support and community organisations that support carers to approach participants. This ensured that communication with carers happened through a trusted intermediary and that venues for meetings were well-known. Care workers were recruited through their employers.

Table 1: Number of participants recruited for pilot and main phases [by country]

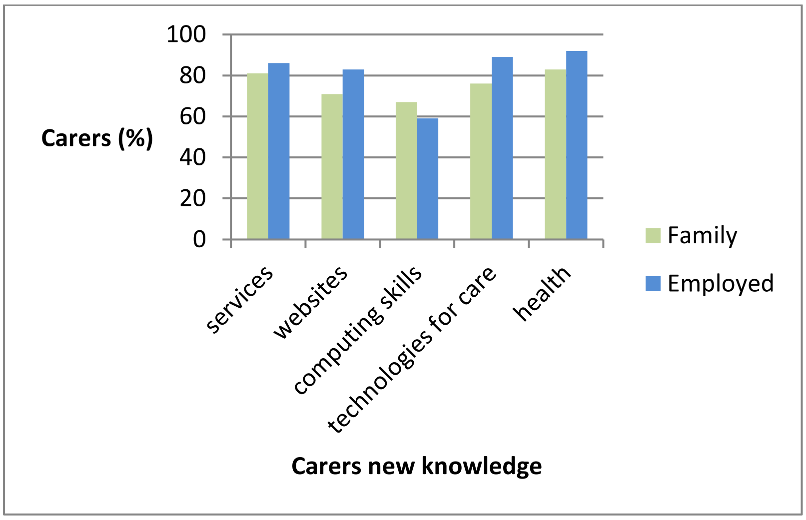
	Greece		**Spain**		**The Netherlands**		**UK**	
	Pilot	Main	Pilot	Main	Pilot	Main	Pilot	Main
Family carers	16	65	15	67	23	40	22	96
Carer workers	9	40	15	37	3	8	3	18
Cared-for people		6		2		2	3	8
Total	25	111	30	106	26	50	28	122
Stakeholders	3	15	16	13	14	50	17	35
Total		18		29		64		52
Total number of carers and cared for people across all 4 pilot sites: 498 Total number of stakeholders: 163								

Family carers and care workers ranged in age from 18-97 and the majority were female (77% and 79% respectively). Some older carers were reciprocal carers with another friend or relative, mainly spouses, where both people had care needs and they acted as carers for each other.

Findings

Family carers and care workers described how they had enhanced their digital and health literacy skills They valued DISCOVER as a one stop shop – bringing together services, high quality information that had been validated by a range of health care professionals and academics, and opportunities to talk to other carers online.

Figure 1. Knowledge and skills acquisition through DISCOVER



Carers felt DISCOVER had great potential when people first become carers, often in response to a crisis in the lives of their relatives or friends. Generally, a slightly higher percentage of care workers than family carers reported gaining new knowledge and skills through DISCOVER, with the exception of developing their computing skills where the situation was reversed. Carers stressed the importance of finding high quality information

'sometimes the information you find is deceptive, it could scare you more than help you… so you have to know how to differentiate the good information' female carer, Spain

'*I didn't realise at the time but not knowing enough about strokes, he would have been better off being transferred to a hospital in Birmingham. There's a dedicated stroke unit … nearer to his house, but I knew none of this at the time, that he could have done that'* female carer, UK

Carers also explained how they are using their new health literacy skills to improve their quality of care, such as

i) Understanding how to cope with challenging behaviour

'Dementia was an 'unknown terrain for us' …I not only know more about dementia through DISCOVER but now understand the 'change of behaviour that goes with that' female carer caring for mother in law, Netherlands

'[I wanted to know] how to better for the care person because Alzheimer is difficult to understand. Sometimes I became angry even I know it's not his fault. Now I can do this' female carer for father, Spain

'I have changed the way I talk with my son [who has had a stroke]'. female carer, Spain

ii) Enabling people to maintain their independence through using technologies such as alarm buttons, automated pill boxes and under mattress epilepsy sensors

'[I] didn't know about automatic pill boxes and think this would be a great idea for my mother. Currently my sister is making sure she takes her pills on time'. female carer, Spain

'When you have epilepsy it's really dangerous if you have a fit in your sleep… she {my mum} won't wear her medical bracelet because she can't stand things on her wrist and round her neck so the full sensors are out… but the one under the bed seems like a really good fit for her. To be honest I never even heard about it'.

young adult carer, UK

iii) Reducing the risk of falling for the people they care for

'I have learned to help her do specific exercises to prevent another fall' man caring for his mother-in-law, UK

'I found the falls scenario interesting and have changed the living space of the older person that I care for to protect them'. female carer, Greece

'*What to do yourself when you fall. Not to panic and do what you have to do (phone for help etc)'*
94 yr old reciprocal male carer/cared for person, Netherlands

This improvement in the quality of care was supported by health care professionals caring for the relatives and clients of the carers and care workers. They noted that carers and care workers showed an increased understanding of health conditions and technologies for care, which improved the consultations.

‘Generally, there was a better understanding of health conditions, but simultaneously there was an improvement of carers’ knowledge about the use of technologies’ Psychologist at Care Home, Greece

‘Caregivers who participated present generally a consistent positive feedback having also pointed out during consultations what they have learned with DISCOVER’. Psychiatrist at a Memory clinic, Spain

Many carers and care workers joining the project were unsure of the value of their relatives and clients acquiring digital skills. However by the end of the project the number of carers and care workers wishing to pass on digital skills to their care recipients had increased from less than 25% to over 80%.

Implications for policy

An unexpected finding of DISCOVER was that although many carers and care workers had access to digital devices they were not making full use of them. Nearly 30 % of carers and 60% of care workers wanted to improve their digital and digital health literacy skills and many care managers felt their staff lacked such skills. Development of such skills, including the use of technologies to care, therefore needs to be embedded in training programmes for care workers, but through contextualised learning rather than computer courses, which is comparable to the approach taken by the Open University to help their students develop such skills.

Many carers feel devalued by society and lonely and that they are struggling on alone, with little respite. Over 80% of carers and care workers felt more supported through the project, through face to face workshops and online interactions. Many family carers are in the lowest income percentile and the remuneration for care workers is very low. Carers, especially family carers, need more support and to be empowered to fully participate in society and to remain part of the workforce, thus lifting many of them out of poverty as well as contributing to the economy.

Many older people want to maintain their independence and autonomy, which could be further enhanced by digital technologies. However, unless carers and care workers have the confidence to use technologies themselves they are unlikely to facilitate their use by the older people they are caring for. The findings demonstrate that DISCOVER can provide an effective solution for carers across a number of European countries, with differing digital infrastructures.

In this digital age, advances in ehealth and mobile health are regarded as important factors in managing the challenges to services presented by ageing populations coupled with financial constraints and declining health and social care workforces. However, unless we upskill the digital and digital health literacy skills of family carers and care workers, they are not empowered to fully engage with these advances, either for their own roles or to assist the people they care for to develop and use these skills to self-manage their own health. Policy makers need to also accelerate the NHS app approval process and the linkage of data from approved apps with health care professionals, and to ensure good broadband and mobile phone coverage across Northern Ireland.

Key policy recommendations

- Enhance digital/digital health literacy skills of family carers, care workers and cared-for people by increasing opportunities/programmes for digital health literacy- based on health conditions
- Raise awareness of opportunities arising from telehealth, telecare, online services and eHealth for carers, careworkers, cared-for people and health care professionals
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- Ensure fast broadband coverage for all communities: urban to remote rural

- Ensure good mobile phone signals – urban to remote rural

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