# Effective implementation and monitoring of telehealth and telecare in Ireland: learning from international best practice.

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## NDA
### Údarás Náisiúnta Míchumais
### National Disability Authority

This document synthesises the information provided in a number of papers relating to Telecare/Telehealth commissioned by and developed for the National Disability Authority between 2014 and 2017. The papers in question were developed by researchers in Work Research Centre (WRC), the National Disability Authority and the University of Ulster, and this report has taken key learning and information from each of them to create this composite briefing paper. We take this opportunity to acknowledge the work done by each of the research parties in question.

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## List of Acronyms

| | |
|---|---|
| AENOR | Spanish Association of Standardization and Certification |
| ARCC | Aberdeen Regional Communication Centre |
| ASSDA | Andalucian Agency for Social Services and Dependency |
| ATHENE | Assistive Technologies for Health Living in Elders: Needs Assessment by Ethnography |
| CAC | Consumer Advisory Committee (USA) |
| CAS | Community Alarm Service (Scotland) |
| CCHSC | Centre for Connected Health and Social Care (Northern Ireland) |
| CEAPAT | Centre for Personal Autonomy and Technical Aids (Spain) |
| CEUD | Centre for Excellence in Universal Design |
| COPD | Chronic obstructive pulmonary disease |
| DALLAS | Delivering Assisted Living Lifestyles at Scale (Scotland) |
| DHSSPS | Department of Health, Social Services and Public Safety (Northern Ireland) |
| EC | European Commission |
| EHR | Electronic Health Record |
| ETSI | European Telecommunications Standards Institute |
| EU | European Union |
| FCC | Federal Communications Commission (USA) |

| | |
|---|---|
| FEMP | Federation of Municipalities and Provinces (Spain) |
| FESOCA | Federacio de Persones Sordes de Catalunya (Organisation for Deaf Persons, Catalunya, Spain) |
| GDPR | General Data Protection Regulations (EU) |
| HbA1c | Glycated Haemoglobin |
| HCI | Human Computer Interaction |
| HCN | Health and Care Number (Northern Ireland) |
| HMO | Health Management Organisations |
| HSC | Health and Social Care (Northern Ireland) |
| HSE | Health Service Executive |
| ICT | Information and Communication Technologies |
| IHI | Individual Health Identifier |
| IMERSO | National Institute for Elderly and Social Services (Spain) |
| IoT | Internet of Things |
| JIT | Joint Improvement Team (Scotland) |
| mHealth | Mobile Health |
| MIDAS | Miniature Intelligent Domiciliary Alarm System |
| MOIC | Medicines Optimisation and Innovation Centre (Northern Ireland) |
| NDA | National Disability Authority |
| NIECR | Northern Ireland Electronic Care Record |
| NIHE | Northern Ireland Housing Executive |
| NISAT | Northern Ireland Single Assessment Tool |

| | |
|---|---|
| OLDES | Older People@Home |
| PIR | Passive Infrared |
| QSF | Quality Standards Framework (UK) |
| R&D | Research and Development |
| RTNI | Remote Telemonitoring Northern Ireland |
| SAAD | System for Autonomy and Support of Dependency (Spain) |
| SAS | Seniors Alert Scheme (Ireland) |
| SAT | Andalucian Tele-Assistance Service (Andalucia, Spain) |
| SBRI (Healthcare) | Small Business Research Initiative (Healthcare) (UK) |
| SCIE | Social Care Institute for Excellence (Great Britain) |
| SCT | Scottish Centre for Telehealth |
| SCTT | Scottish Centre for Telehealth and Telecare |
| SSA | Single Shared Assessment (Scotland) |
| ST | Servicios de Teleasistencia S.A. (Madrid, Spain) |
| SWAN | Scotland Wide Area Network |
| TD | Teleasistencia Domiciliaria (Spain) |
| TDP | Telecare Development Programme (Scotland) |
| TEC | Technology Enabled Care |
| TH/TC | Telehealthcare |
| TSA | Telecare Services Association  (UK) |
| UD | Universal Design |
| UX design | User Experience Design (Interfacing) |

# 1.0 Introduction

This working paper is based on a synthesis of three previous phases of research commissioned by the National Disability Authority in 2014, 2016 and 2017, exploring some of the main issues around telecare and telehealth provision, and examples of good practice in other jurisdictions.

The impetus for this research has arisen from a number of areas but perhaps the most important development has come from Ireland's ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Article 19 of the convention states:

> States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
>
> a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
>
> b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
>
> c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.[1]

Telehealth and telecare initiatives are considered elements of eHealth and may utilise assistive technologies. Ageing population demographics are likely to increase health and social care needs into the medium and long term. As such,

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[1] UN General Assembly (2007) *Convention on the Rights of Persons with Disabilities : A/RES/61/106.* Available at: http://www.refworld.org/docid/45f973632.html (accessed June 2018).

exploring innovative, efficient and elegant solutions to meet these needs is necessary.

With regard to an ageing population and Article 19, telehealth and telecare (along with a range of assistive technologies) have the potential to support independent living for persons with disabilities. As a result, understanding how telehealth and telecare could be effectively implemented and monitored in the Irish context is of particular interest.

Learning from these earlier phases of research was brought together to answer the research question:

> How can the learning from international best practice in telehealth / telecare contribute to a blueprint for effective implementation and monitoring of telehealth / telecare in Ireland?

To this end, this paper aims to

1. understand how current systems, services and structures of telehealth / telecare provision in other jurisdictions can be applied to Ireland, and

2. incorporate issues and evidence from the universal design perspective on TH/TC.

Using the information from the earlier research phases, the systems in place in three jurisdictions were examined – Northern Ireland, Scotland and Spain. The review of these jurisdictions looked at

1. where telehealth / telecare systems sit within the structure of health and social care
2. how policy influences the development of these systems
3. how roles and responsibilities are shared
4. how systems of telehealth / telecare operate
5. costs relating to these services
6. evidence of outcomes.

The rationale for choosing these jurisdictions is that each one is at a different stage of development, or has a novel approach with which Ireland can compare and learn from.

- Northern Ireland – a telehealth system that was contracted to a consortium of private organisations over a period of six years, providing telemonitoring services across the country. Both in operation and procurement, it offers interesting lessons - for instance, the relationship between the national

healthcare staff and these private providers, and how Ireland might use the competitive dialogue tendering process if seeking telehealth / telecare services on the open market. Northern Ireland also has a relatively separate telecare system which is provided by private organisations and evolved from the housing sector.

• Scotland – an example of policy-driven development (top down) in telehealth and telecare where smaller-scale initiatives are being trialled and scaled up with a view to being implemented nationally. Many initiatives have been built on existing structures, for instance the Community Alarm scheme. Scotland also offers interesting evidence on the use of co-production in the design of services which is named as a key element in their strategy.

• Spain – a well-established system of telecare is in place nationally and is mainly administered and funded through the regional / municipal authorities. Telecare is provided for in the country's Dependency Law, while standards for setting up and operating telecare services are explicitly outlined (Normas Generales Del Servicio De Teleasistencia Domiciliaria and UNE 158401). Standards also include some design requirements for devices. This strong regulatory and standards environment offers interesting insights.

This working paper will also seek to present evidence on:

• how telehealth / telecare is being integrated into the design of social care and housing (mainly by understanding telecare systems)

• the Universal Design perspective on telecare and telehealth

• challenges to adopting telehealth / telecare systems.

It is important to note that the three phases of research forming the basis of this paper took place between 2014 and 2017. The area of telehealth and telecare is fast moving in some respects, both in terms of technology and policy. For instance, since the first phase of this research in 2014 the HSE has appointed a Chief Information Officer, formed eHealth Ireland, and developed Ireland's eHealth Strategy.[2]

This paper has not conducted a fresh review of the telehealth / telecare landscape in 2018. That said, many of the issues and opportunities for policy,

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[2] Department of Health (Ireland) (2013) *eHealth Strategy for Ireland*. Available at: http://www.ehealthireland.ie/Knowledge-Information-Plan/eHealth-Strategy-for-Ireland.pdf (accessed July 2017).

practice and implementation that were highlighted in these three phases offer relevant learning for what works, and why.

## 1.1 Structure of the Report

| Chapter | Description |
|---|---|
| 2 | What is telehealthcare? <br><br> A look at terminology |
| 3 | How is telehealth / telecare being integrated into the design of social care and housing? |
| 4 | Northern Ireland <br><br> An overview of the system and practices |
| 5 | Scotland <br><br> An overview of the system and practices |
| 6 | Spain <br><br> An overview of the system and practices |
| 7 | Universal Design in telehealth / telecare <br><br> Evidence on issues and barriers, best practice and models, and learning from the jurisdictions |
| 8 | Challenges to the adoption of telehealth / telecare <br><br> Barriers, issues and opportunities – learning from the literature and jurisdictions |
| 9 | Conclusions <br><br> Key learning, opportunities and pitfalls that should inform the effective implementation and monitoring of TH/TC in Ireland |

## 2.0     What is telehealth/telecare?

A variety of terms are used in the broad field of healthcare and Information Communication Technologies (ICT). This poses challenges, not only for professionals working in this area, but for defining the scope of this overview. This section will look at the issues relating to terminology and will seek to define telecare, telehealth and eHealth as a whole.

### 2.1 Telecare

Telecare generally refers to social care services delivered from a distance, using technology. There tends to be an emphasis on risk management/mitigation and user safety, remote monitoring, and supporting independent living.

Telecare can be deemed active or passive. In active systems of telecare, the user consciously initiates the connection with services when they need to. Passive systems connect to services automatically, usually through sensors or other mechanisms that detect and trigger contact when a relevant situation arises.

As telecare has been utilised since the 1980s, there are seen to be three waves of sophistication – first, second and third generation telecare.

- First generation telecare (sometimes known as basic telecare) can refer to active systems which rely on the user to initiate an alert. Traditionally, first generation refers to monitored personal alarms that utilise call centres to pick up alerts. Example: personal alarms used in the context of the Seniors Alert Scheme in Ireland; Community Alarms in Scotland.

- Second generation telecare systems are proactive, intelligent systems that utilise sensors to automatically alert designated call-centres or healthcare staff. Example: worn fall detectors; door sensors.

- Third generation systems process and analyse information coming from sensors to construct user profiles of activity patterns and lifestyles. There may also be an emphasis on user assessment and learning to inform care. Third generation systems usually involve broadband, wireless, and/or Audio-Visual technology, allowing virtual contact between users and their care team. Example: global positioning system (GPS) monitoring of persons with dementia who may be at risk of getting lost.

Other interesting and informal uses fall under the category of 'DIY' telecare. These are methods often employed by family members who improvise telecare systems using existing technology. For instance, they may use Skype to link in with family members, or monitor home CCTV.

## 2.2 Telehealth

Telehealth incorporates a broad set of activities using electronic devices and ICT to support the remote delivery of services that go beyond the doctor-patient relationship. These services include remote preventative and curative healthcare, health promotion, and patient and provider education. As with telecare, telehealth applications are continuously expanding as technology evolves and methods of implementation are developed.

Telehealth technology, applications and services often focus on

- the long-term management of chronic conditions, and

- shorter-term, post-hospital discharge support.

Telehealth takes place in the home and online, through a range of health and wellness services and health-related smartphone apps. Examples of services include telecounselling, online support groups, education provision and video conferencing with health professionals. Telehealth in the home often takes the form of telemonitoring, for example, of vital signs and using (often nurse-led) telephone-based services.

Increasingly, telehealth approaches are adopting everyday technologies that are accessible to patients. This is known as 'simple telehealth'. These technologies are often known to the users, are low-cost, at scale, and easy to roll out. One example of this is the 'Florence' or Flo System widely used by NHS Trusts in the UK. Text-messaging is used to send tailored health reminders and/or requests for information to patients. Patients can then send back information to healthcare professionals, e.g. blood pressure readings.[3]

More sophisticated systems of telehealth in the home might involve a unit or 'hub' which is installed in the person's home and gathers information from peripheral devices (e.g. blood glucose meters, thermometers, pulse oximeters). The hub can then transmit health data to a central monitoring system where triage arrangements can be made if necessary.

## 2.3 eHealth

In Ireland and other jurisdictions eHealth is an overarching term used, particularly in strategies. eHealth encompasses, but is not limited to, telehealth and telecare.

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[3] The Health Foundation (2018) *Overview of the Florence Simple Telehealth Text Messaging System – Flo*. Available at: http://www.health.org.uk/content/overview-florence-simple-telehealth-text-messaging-system-flo (accessed March 2018).

This nomenclature is used throughout this report to represent the broad field of activities that links ICT and healthcare.

Specifically, eHealth involves

> the integration of all information and knowledge sources involved in the delivery of healthcare via information technology-based systems for the purpose of exchange between cooperating parties.[4]

Figure 1 shows the relationship between different aspects of eHealth, including mHealth – health supported by the use of mobile devices.
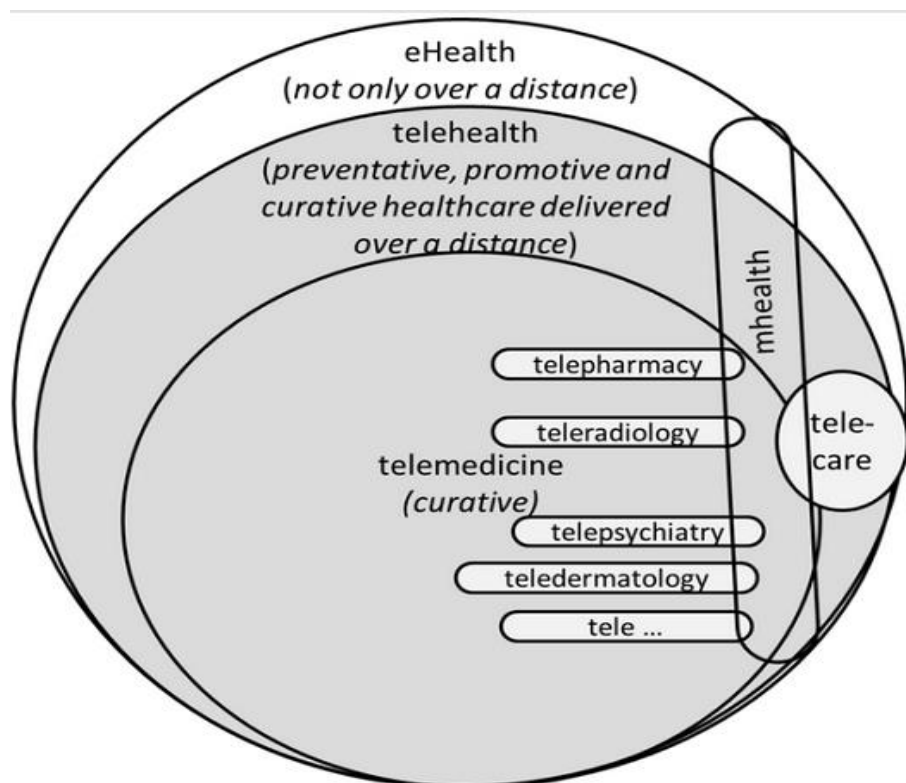


**Figure 1 Liezl van Dyk's illustration (2014) of eHealth, Telehealth, Telemedicine, Telecare and mHealth5**

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[4] Department of Health (Ireland) (2013) *eHealth Strategy for Ireland*. Available at: http://www.ehealthireland.ie/Knowledge-Information-Plan/eHealth-Strategy-for-Ireland.pdf (accessed July 2017). p.15

[5] Van Dyk, L. (2014) 'A Review of Telehealth Service Implementation Frameworks'. *International Journal of Environmental Research and Public Health*, 11(2), 1279-1298.

## 2.4 Telehealth / Telecare (TH/TC)

For clarity and comparative purposes, both telecare and telehealth will be used as distinct terms describing specific activities where appropriate. For instance, when describing activities in jurisdictions which view TH/TC as separate endeavours, they will be discussed separately. However, there is considerable overlap in telehealth and telecare activities as can be seen in Figure 2. At times, TH/TC will be used in this report to denote activities that span both telehealth and telecare.

## 2.5 Defining terminology is problematic

There are myriad terms being used to describe ICT combined with health and social care practices and definitions can be problematic.

Terminology choices can reflect the system and this may account for some variation in whether TH/TC are used interchangeably or as distinct activities. Where health and social care systems are divided, or there is one area more developed than the other (e.g. Spain's telecare system) telehealth and telecare may be seen to describe different sets of activities. The distinction may relate more to the different roles, responsibilities and funding streams in these different systems than a strict definition of activities.

Terms change quickly. Those developing devices and networks (e.g. engineers, computer scientists) may use new terms to reflect the evolution of technologies and services. As the technology advances apace, newer terms are constantly being added to the eHealth lexicon.

Different actors have different language and worldviews. The wide range of professionals working internationally to develop these technologies leads to great variation in the terms used. One ambitious solution would be to seek agreement between all stakeholders, including academics, clinicians, and commissioners, on the use of terminology. The broad absence of international standards contributes to the lack of agreement on terminology.

One solution in the shorter term would be to focus on the applications of TH/TC, rather than adhering to ambiguous terminology. For instance, should one wish to study GPS motion trackers for people living with dementia, this

application of technology should be the focus rather than getting bogged down in choosing the relevant term (telehealth, telecare or assisted-living technologies).[6]
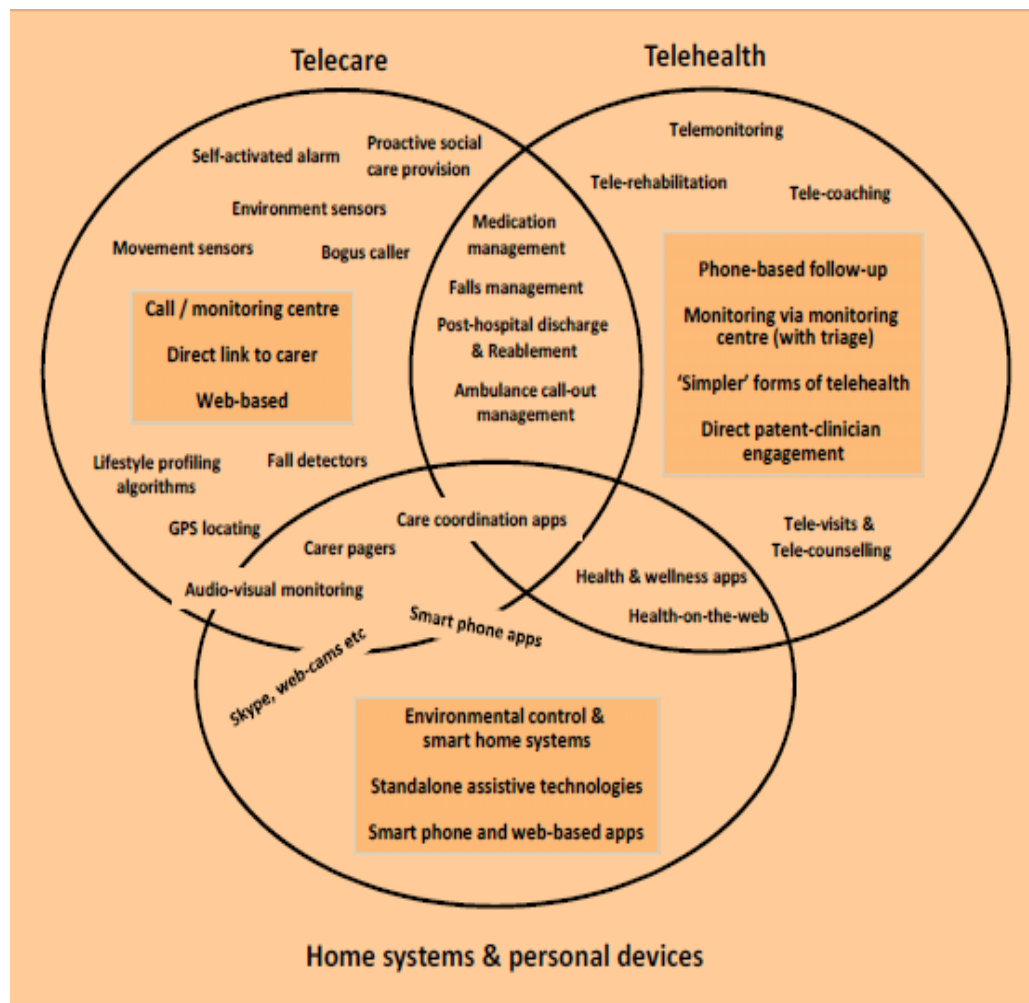


**Figure 2 Cullen et al.'s (2012) illustration of emerging TC and TH ecosystems[7]**

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[6] Biobusiness (2010) *Connected Health in Ireland: An All Island Review.* Available at: http://www.cardi.ie/userfiles/Connected_Health_in_Ireland_An_All_Island_Review.pdf (accessed during 2014 phase of research).

[7] Cullen, K., McAnaney, D., Dolphin, C., Delaney, S., Stapleton, P. (2012) *Research on the provision of Assistive Technology in Ireland and other countries to support independent living across the life cycle.* Available at: http://nda.ie/File-upload/Research-on-the-provision-of-Assistive-Technology1.pdf (accessed July 2017).

# 3.0 How is TH/TC being integrated into the design of social care and housing?

In Spain, Scotland and Northern Ireland telecare initiatives are focussed on risk management – checking-in with the user, allowing for the user to alert responders in a crisis, and raising alarms in the event of disaster (fire, etc.), falls or unusual behaviour (e.g. leaving the house).

In Scotland and Northern Ireland, these services grew out of existing organisations and initiatives of the housing and elder care sector. Telecare emerged as a bottom-up solution linking residents with wardens, informal carers or other staff. Vulnerable older persons were the traditional target user group for first generation telecare, including people living in ordinary (dispersed) housing in the community and in sheltered housing complexes. This is still the case today, both for basic and more advanced telecare.

The Supporting People Programme was introduced in Northern Ireland in 2003. It funds housing-related support services that a landlord (such as a housing association for example) or other service provider (such as a voluntary organisation) can provide to help vulnerable people to live independently. Residents of sheltered or supported housing provided by other housing providers may have their personal alarms funded via the Supporting People Programme. Residents' monthly charge includes the cost of the alarm and monitoring. If a resident has high support needs, they may have additional specific peripherals which would be paid for by the Health and Social Care Trust.

Facilitated by the emergence of more advanced telecare systems based on sensors, the range of users of telecare has expanded to include people with dementia, physical disability, intellectual disability, and chronic health conditions. Telecare has potential to make a variety of forms of contribution across the spectrum of user groups and contexts, depending on how it is conceptualised and implemented.

Likewise, home telehealth as a formally provided service is positioned to support healthcare at home using a wide variety of technology-supported consumer- and patient-facing health services and applications. Where many telecare programmes focus on risk management, telehealth has focussed on supporting the long-term management of chronic conditions and shorter-term, post-hospital discharge support; various forms of tele-delivery of therapy and rehabilitation services; remote consultation (tele-visits); and health and wellness coaching.

Funding streams may complicate the integration of TH/TC into the design of social care and housing. Northern Ireland illustrates this issue. The Trusts do not have a specific telecare budget and as a result these packages were funded within the overall budget, mainly using the funding stream for older person's services. Consequently, Trust-funded telecare packages as of 2014 tended to be targeted at the elderly population, though there are some younger users – especially those with intellectual or physical disabilities. The source of funding for telecare and/or telehealth initiatives can affect the users targeted and the degree to which innovative technology is used.

For example, the Northern Ireland Housing Executive (NIHE) commissioned research into the role of electronic assistive technology in supporting older people within local communities (Martin, 2010).  The study interviewed 22 respondents from regional housing associations, voluntary agencies, funding organisations and health care providers (statutory and voluntary). The respondents represented key stakeholders involved in the development and implementation of supported housing options for older people.

While all 22 respondents thought technology had a role to play in meeting the housing and care needs of older people, only 15 were in organisations engaged in the provision of technology-enriched supported housing options for older people. There was a general view on the part of respondents that the (then) lack of a Northern Ireland wide strategy for telehealth or telecare represented a barrier to mainstreaming telecare, inhibited development and innovation in the field and led to fragmentation of services.

In many respects, the extent that TH/TC is integrated into *design* is unclear – it has often been implemented as a reactive response, where a need is identified and the user receives services. Hubs and devices have been installed in the user's home as a response to social isolation, risk or medical necessity. This reactive model has limited the scope of pro-actively integrating TH/TC to social care and housing. That said, there are a number of directions that could be taken to broaden the use of TH/TC in these areas.

## 3.1 Broader social care provision

Spain's telecare system has an emphasis on social contact and explicitly encourages non-emergency social calls from clients to the monitoring centre, as well as through calls initiated from the monitoring centre for social purposes or for provision of more structured social care inputs (e.g. morning calls or agenda and reminder calls).

## 3.2 More self-directed care

In principle, telecare can be used to support more self-directed care if this is built into the way it is applied in care services.  This has been explored by West Midlands Adult Social Services in England within the context of the application of personal budgets.[8]

Care scheduling and coordination applications could be used to facilitate more client-driven services. Examples might include scheduling the timing of social care services around client preferences and informal carer availability, and logistical support and flexibility in organising personal assistant services.

Telecare could also be used to support care-on-demand where assistance is provided as and when required.  One of the key requirements for such applications is the availability of a flexible response service ready to travel to the client to address needs as they arise (for example, formal responder services). The opportunities for telecare to be applied in these ways could be given more attention in addition to the focus on the risk management dimension that has tended to predominate to date.

## 3.3 Support for informal carers

Telecare may sometimes be implemented as a direct support for the family carer and indirectly for the vulnerable person. This can be especially the case in applications of telecare for people with dementia.

Telecare can provide direct support to carers in their caring role, give reassurance about the safety of the person and offer periods of respite. The service may be provided as part of the repertoire of social care supports directly targeted towards informal carers as a client group. For example, the Moving Forward Telecare Project carried out by Caring for Carers in Ireland focused on people with sensory or physical disabilities and their carers as beneficiaries.

On the other hand, there might be more downsides than benefits for the carer if the telecare situation is one where frequent responding to alerts is required. Provision of formal responder services can mitigate this and enhance the level of support that can be provided by telecare for family carers (e.g. in the Municipality of Madrid). Providing peace of mind and respite for carers was one of the main reasons for offering a community alarm to new clients according to the Joint

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[8] Reported in 2014 phase of National Disability Authority research.

Improvement Team report on the National Telecare Development Programme in Scotland.[9]

## 3.4 Targeted support for key care processes and pathways

There has been growing interest in applying telecare to enhance service provision in specific care processes and pathways. Examples include support after hospital discharge as part of reablement approaches, falls management programmes and monitoring of medication usage. Application of telecare for care planning purposes is another emerging area.  Data generated by monitoring centres on patterns of alerts and response events can be made available to social care providers. This can be used to identify care needs and support care planning.

More targeted applications to assess level of functioning and care needs through activity and lifestyle monitoring have been developed and are being applied in some fields. Such systems are being used in a number of social care services in the UK to assess level of functioning in everyday life, and the need for support for people with dementia and intellectual disabilities.

## 3.5 Resource optimisation and cost savings

The potential of telecare to provide overall cost savings by reducing avoidable utilisation of more expensive services has been one motivator for its implementation – particularly in the context of ageing populations and increased care needs in future.  This might include savings in hospital bed days (through earlier discharge or avoided admission), and the delay (or avoidance) of a move to long-term nursing home care. The potential in specific areas such as avoidance of unnecessary ambulance call-outs in falls management has also been given attention. For example, in Madrid formal responders can provide first aid and assist the user after minor falls.

In general, telecare is seen primarily as an additional support for clients rather than a substitute for homecare services.  There is potential for telecare to facilitate staffing efficiencies in some aspects of homecare and residential services (e.g. unwanted check visits and night sleepovers)[10].

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[9] Joint Improvement Team (2010) An assessment of the development of telecare in Scotland: 2006-2010. Available at: http://www.gov.scot/Resource/Doc/328586/0106225.pdf (accessed during 2014 phase of research).

[10] Joint Improvement Team (2007) Telecare Development: Revised Business Case/Benefits Realisation Plan (May 2007). Available at: http://www.jitscotland.org.uk/cgi-sys/suspendedpage.cgi (accessed during the 2014 phase of research).

However, an ethical balance needs to be kept between exploiting the benefits of telecare while not excessively replacing human care services. It is imperative that telecare does not increase social isolation.

## 3.6 Reablement and telerehabilitation

Despite the fact that a range of functional impairments and activity limitations are common consequences of chronic ill-health, the emphasis within the field of home telehealth has been focused more towards monitoring physiological parameters than on rehabilitation.

Recently, there has been an increasing reference to home telehealth and telecare in the context of reablement in the UK.[11] In addition, there is an emerging field of 'telerehabilitation' that encompasses a range of rehabilitation-oriented services and applications. This includes the remote delivery of rehabilitation programmes for specific medical conditions such as stroke, chronic heart failure, and chronic obstructive pulmonary disease (COPD). It also includes more specific rehabilitation specialties such as speech and language therapy, occupational therapy, etc. The growing body of telerehabilitation activity in these fields is beginning to be documented.[12][13][14] Interventions that have been developed include:

- Cardiology: home exercise programmes; information; counselling
- Neurology (stroke, traumatic brain injury, multiple sclerosis, spinal cord injury): motor rehabilitation, exercise; linguistic therapy; cognitive therapy, memory training; information, education; counselling; support for caregivers
- Urology: continence training; pelvic floor exercises
- Rheumatology (arthritis and fibromyalgia): physical activity; self-management and coping skills

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[11] Doughty, K. (2011) 'Telecare and Reablement - the great hope for managing the care and support of older people'. *The Link: The quarterly magazine of the Telecare Services Association in the UK*. Spring, 8-9.

[12] Haily, D., Roine, R., Ohinmaa, A. and Dennett, L. (2011) 'Evidence of benefit from telerehabilitation in routine care: a systematic review'. *Journal of Telemedicine and Telecare*, **17(**6), 281-287.

[13] Hill, A. (2010) 'Telerehabilitation in Scotland: Current Initiatives and Recommendations for Future Development'. *International Journal of Telerehabilitation,* **2(**1) Spring, 8-14.

[14] Parmanto, B. and Saptono, A. (2009) 'Telerehabilitation: State-of-the-art from an informatics perspective'. *International Journal of Telerehabilitation*l, **1(**1) Fall, 73-84.

- Orthopaedics: exercise and rehabilitation programmes.

The telerehabilitation and reablement perspectives may prove useful in prompting attention on the potential for telehealth to support independent living.

## 3.7 Access to mainstream health care services for people with disabilities

One of the benefits of home telemonitoring for chronic conditions can be a reduction in the need to travel to a healthcare facility. A wider possibility to have phone and video-based tele-visits, instead of physical visits to a doctor, may be helpful for persons with disabilities as well as older people who may have difficulty travelling.[15]

There have been some examples of ensuring that persons with disabilities can access and gain benefits from mainstream telehealth developments.  The Australasian Telehealth Society identifies persons with disabilities as a priority group in a national strategy for telehealth.[16]  In the United States, the Mobile Health (mHealth) Task Force of the Consumer Advisory Committee (CAC) of the Federal Communications Commission (FCC) has made recommendations on including and addressing the interests and accessibility needs of persons with disabilities when evaluating and making recommendations regarding "affordable connectivity and compatibility for telehealth devices."[17]

The opportunities presented by telehealth for persons with disabilities warrant more attention.  This would include targeting this field in telehealth policy and development programmes as well as ensuring that mainstream telehealth services are accessible for persons with disabilities. However, these approaches to telehealth should not be viewed in isolation – rather, as part of a suite of assistive technologies that can support independent living, accessibility and inclusion.

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[15] NOTE: Interestingly, the availability of online tele-visits has been taken up by consumers in general, not just the traditional target groups - for example, WebDoctor  offers a range of consultation and prescription services online for roughly half the price of a traditional GP visit. Convenience is a selling point. www.webdoctor.ie

[16] Australasian Telehealth Society (2013) *Towards a National Strategy for Telehealth in Australia 2013-2018.* Available at http://www.aths.org.au/wp-content/uploads/2016/06/TelehealthStrategy.pdf (accessed during the 2016 phase of research).

[17] Mobile Health Task Force of the Consumer Advisory Committee (2002) *People with Disabilities and Telehealth Development.* Available at: http://wirelessrercarchive.gatech.edu/content/newsroom/people-disabilities-and-telehealth-development (accessed during 2016 phase of research).

# 4.0 Northern Ireland

## 4.1 System Overview

Northern Ireland has a combined system of health and social care administration under the Department of Health, Social Services and Public Safety (DHSSPS). Health and social care are managed and funded through five Health and Social Care Trusts, though private providers are also present. Northern Ireland had significantly developed telemonitoring, more than in the other jurisdictions examined in this review, and these services were in place across the country through the Telemonitoring NI six-year programme (2011-2017). Telecare is present in the system also though this has evolved from private provision and is dominated by private providers emerging from the social housing sector. Both telemonitoring and telecare will be examined.

### 4.1.1 Key Policy Developments

In 2008, the European Centre for Connected Health (now called the Centre for Connected Health and Social Care – CCHSC) was established under the Public Health Agency. Faced with an ageing population, strategy documents[18][19] highlighted the need for health and social care services to meet changing demands. A key element of these strategies was for changes to reflect new ways of working, new technologies and the development of new treatments.

The CCHSC issued a tender for remote telemonitoring in 2008 using a competitive dialogue process. This process allowed for the evolution of products and services and is of interest to Ireland as a model of procurement for TH/TC.

> A competitive dialogue process was used for the procurement of RTNI (Telemonitoring NI). Although this process is lengthy and effort intensive it is appropriate for use in a situation where the solution sought is innovative and the market is immature, as is the case with e-Health solutions. The competitive dialogue allows for the development of appropriate solutions alongside the

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[18] Department of Health, Social Services and Public Safety (2004) *A Healthier Future - A Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005-2025*. Northern Ireland. Department of Health, Social Services and Public Safety.

[19] Department of Health, Social Services and Public Safety (2005*) Caring for People Beyond Tomorrow: A Strategic Framework for the development of Primary Health and Social Care for Individuals, Families and Communities in Northern Ireland*. Belfast: Department of Health, Social Services and Public Safety.

development of specifications and enables bidders and procurers to learn in synchronisation what is possible and to realise the actual costs. The dialogue allowed for a comprehensive set of detailed commissioner requirements to be developed which secures the aims of the procurers... The dialogue is also particularly appropriate for procurement of larger service packages as it allows for relationships of trust and understanding to develop between bidders and procurers. Such a relationship might not be as essential when only the provision of equipment is required, but where the service requires intense supplier involvement a partnership of understanding is necessary.... Close attention to stakeholder management and buy-in were also essential for ensuring ownership of concepts and vision and eventual acceptance of the solution. Stakeholders were involved and referred to within the process and their needs were accommodated within commissioner requirements. The use of specialists with the right skill set and expertise was found particularly useful by the RTNI procuring team. This is particularly relevant for the area of e-Health where investments are often innovative and so standard guidelines are either not available or properly applicable. This expertise was enhanced by the allocation of committed project staff whose main task was to enable the smooth running of procurement operation. Transparency was another key feature of the RTNI procurement. Resources were applied to each step of the procurement to ensure transparency... A significant characteristic of the RTNI experience was standardisation of terminology. This was due to the novelty of the end-to-end solution. Consistent and specific terminology for ensuring common understanding and preventing unexpected outcomes was therefore important and the RTNI contract contained a schedule of defined terms.[20]

The **Telemonitoring NI** (formerly known as Remote Telemonitoring Northern Ireland – RTNI) tender was won by the TF3 consortium of private players – Fold Telecare, Tunstall Healthcare and S3 and the DHSPSS invested £18m in the six-year commission (2011-2017). Though initially focussed solely on telemonitoring,

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[20]Vogt, J., Jones, T., Hammerschmidt, R., Artmann, J., Stroetmann, K., Sibbel, R., Stroetmann, V. and Dobrev, A. (2012) *Study on enhancing procurement of ICT solutions for healthcare.* Bonn/Brussels: DG Communications Networks, Content and Technology Contract Number – 30-CE-0387926/00-81 D5.3.

the contract awarded in 2011 was future-proofed for both health and social care, and included telecare as an additional service.

Telemonitoring NI was established as a scalable, mainstream, end-to-end telemonitoring service providing a 7-day clinical triage service.  It ultimately aimed to enable improvements in the quality of care and quality of life for patients, reductions in inpatient admissions and optimised use of staffing resources.[21] To this end, the scheme objectives were

- to provide better-targeted and more plentiful proactive supports to patients

- to enable patients to learn more about, and have control of, their condition

- to enable patients to live more independent lives, and

- to bring timely information to professionals to inform patient-centred case management.

In 2011, the DHSSPS began work with Northern Ireland's economic development agency, Invest NI, to develop a joint **Connected Health and Prosperity agenda**[22]. The aim was to contribute to improved health and well-being and patient care, while also supporting the economic development strategy. Initiatives within this include

- The establishment of a Connected Health Ecosystem to promote collaborative working across the health, academic and industry sectors.

- Promotion of Connected Health Research and Development (R&D) and Innovation. This has included targeted investment in Life and Health Sciences R&D, with a focus on pharmacology, medical devices and diagnostics sub-sectors.

- The development of links with European regions with a view to identifying future areas of collaboration and maximising opportunities for drawing down EU funding support (e.g. Basque Region and the City of Oulu in Finland) however, in the Brexit context it is uncertain how future collaboration will continue.

- Pre-Procurement competitions linked to the Innovate UK Small Business Research Initiative (Healthcare) (SBRI Healthcare) programme launched.

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[21] Originally found on Telemonitoring NI website during 2014 phase of National Disability Authority research. This website has subsequently been deactivated as the Telemonitoring NI project has finished.

[22] Invest NI (2018) *Connected Health.* Available at: https://www.investni.com/invest-in-northern-ireland/connected-health.html (accessed June 2018).

Innovative pre-procurements have taken place in medication management, medication adherence for care workers, and gestational diabetes.

- The establishment of the Economy and Jobs Initiative Task and Finish Group to identify potential opportunities for job creation and economic growth through Northern Ireland's health and social care sector.

- Economic investment in collaborative networks in Connected Health Integration Platforms, International Health Analytics, Mental Health Technologies and Care at Home. These networks are funded by Invest NI for economic growth and have academia and healthcare partners in the collaborations.

- Establishment of the Medicines Optimisation and Innovation Centre (MOIC).

In 2016, an eHealth and Care Strategy23 was launched after consultation with various staff and leaders across the organisations. The strategy is built around the key objectives of supporting people, sharing information, using information and analytics, fostering innovation, modernising the eHealth infrastructure and ensuring good governance.[24]

Areas highlighted in the strategy of relevance include booking GP appointments, ordering repeat prescriptions, portals for access to personal health records, increasing capacity for mobile working and building capacity for self-care.

The eHealth strategy in 2016[25] highlighted a number of policy documents critical to the development of eHealth thus far:

- Transforming Your Care (2011)[26] outlined the need to move more care to the community and for technology to support this development; and,

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[23] Health and Social Care Board (2016) *eHealth and Care Strategy for Northern Ireland*. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/interactive-ehealth-strategy.pdf (accessed during 2017 phase of research).

[24] Health and Social Care Board (2016) *eHealth and Care Strategy for Northern Ireland*. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/interactive-ehealth-strategy.pdf (accessed during 2017 phase of research).

[25] Health and Social Care Board (2016) *eHealth and Care Strategy for Northern Ireland*. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/interactive-ehealth-strategy.pdf (accessed during 2017 phase of research).

[26] McCreedy, P., Hodkinson, A., Hunter, E., Carey, S., Dunbar, F., Higgins, M. and Houston, J. (2011) *Transforming your Care: A Review of Health and Social Care in Northern Ireland*. Belfast: Department of Health, Social Services and Public Safety.

- The Bengoa (2016) report, also known as Health and Wellbeing 2026 Delivering Together (HSC Services 10 Year Plan, 2016)[27] and HSC R&D Strategy (2016) all referenced innovation and technology being critical to the future of healthcare provision.

These strategies propose a new framework for the delivery of health and social care which would put the patient and client at the centre of the system. The imaginative use of innovative technologies was recognised as one of the key enablers to the delivery of such a service model.

A critical first step operationally over the last two decades was the **foundational investments** in areas such as unique patient identifiers (Health and Care Number), regional data warehouses, performance management systems and anonymised research databases. Additionally the regions moved towards more regional software procurements such as PACs (Imaging), Theatre Management, LIMS (Labs) and Electronic Health Records (EHRs) to increase the ability to share patient information and leverage investments.

Northern Ireland introduced a region-wide Electronic Care Record (NIECR) in July 2013[28]. The system is used to access patient data across the whole NI hospital network and other parts of the service. This has been a highly praised asset for the health service with both clinicians and external bodies recognising the substantial contribution this has made to reducing bureaucracy, preventing unnecessary tests and improving patient outcomes.

The use of technology within healthcare opens up opportunities and requirements for research in many domains. Furthermore, the range of disciplines engaging in such research highlights the varied skills, knowledge and expertise required to develop the devices and services required both to meet current healthcare needs and move beyond that to innovative options for the future. Collaboration has been a consistent theme in developments with partnership between the HSC, Academia, Industry and Third Sector Organisations.

As of 2018, there had been no further developments of telehealth in Northern Ireland beyond the Telemonitoring NI programme. The status of telehealth

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[27] Bengoa, R. (2016) *Health and Wellbeing 2026: Delivering Together*. Available at: https://www.health-ni.gov.uk/publications/health-and-wellbeing-2026-delivering-together (Accessed October 2017)

[28] NOTE: A major second procurement of a more integrated electronic health record was being developed as of 2017 through business case and procurement routes.

implementation through the Trusts, without this funding and implementation structure, is unclear. With Brexit and the suspension of devolved government in Northern Ireland, it is also unclear how telehealth initiatives will be taken forward.

## 4.2 How did Telemonitoring NI work?

The Telemonitoring NI programme represented a top-down strategy of TH/TC as much as a system of delivery and as of 2014 was one of the largest such programmes internationally. The programme ran from 2011 to 2017 and had two main components:

- Telemonitoring of vital signs for chronic conditions management
- Fall detection (and other) sensors in the home.


### 4.2.1 Who was responsible for Telemonitoring NI?

The Telemonitoring NI consortium (TF3) delivered telemonitoring services across Northern Ireland funded by the Trusts and implemented by the TF3 Telemonitoring consortium members who

- delivered, installed, maintained and repaired home equipment

- provided training to healthcare professionals

- collected monitoring data

- provided a triage service which validated monitoring data

- delivered patient advice, and

- escalated cases to the local response team where needed.

Though implemented by the consortium, close contact between Trust-based clinicians was maintained (Figure 3). With the advent of GDPR in 2018, it is unclear how such a model of collaboration would be affected by these new regulations.

**Clinical triage** was provided by consortium member Fold Healthcare who also provided the monitoring element of the service. Fold employed triage nurses who received specific training in all of the conditions monitored from specialist nurses from the Trusts. Triage nurses had clear protocols around triaging the clinical data and took actions on the basis of these. Where patient readings were outside of set parameters, they escalated this to the patient's clinician. Triage nurses would also have provided advice to a patient (e.g. advising a COPD patient

to take antibiotics or steroids) if this had been specified as an option by the clinician in the patient's triage notes.

In the **'track and trend'** model of telemonitoring the clinician, together with the patient, decided how often the patient was to take and remotely send their readings. There was no triaging with these patients, who tended to be those whose conditions were stable. Patients uploaded their health readings and remotely sent them to a central database where they were reviewed by the patient's clinician on a regular basis. Track and trend monitoring could be used for a short period of time or be on-going. Clinicians could look at the patients' trends over a period of time, for example, a diabetic nurse tracking a patient's blood glucose levels.
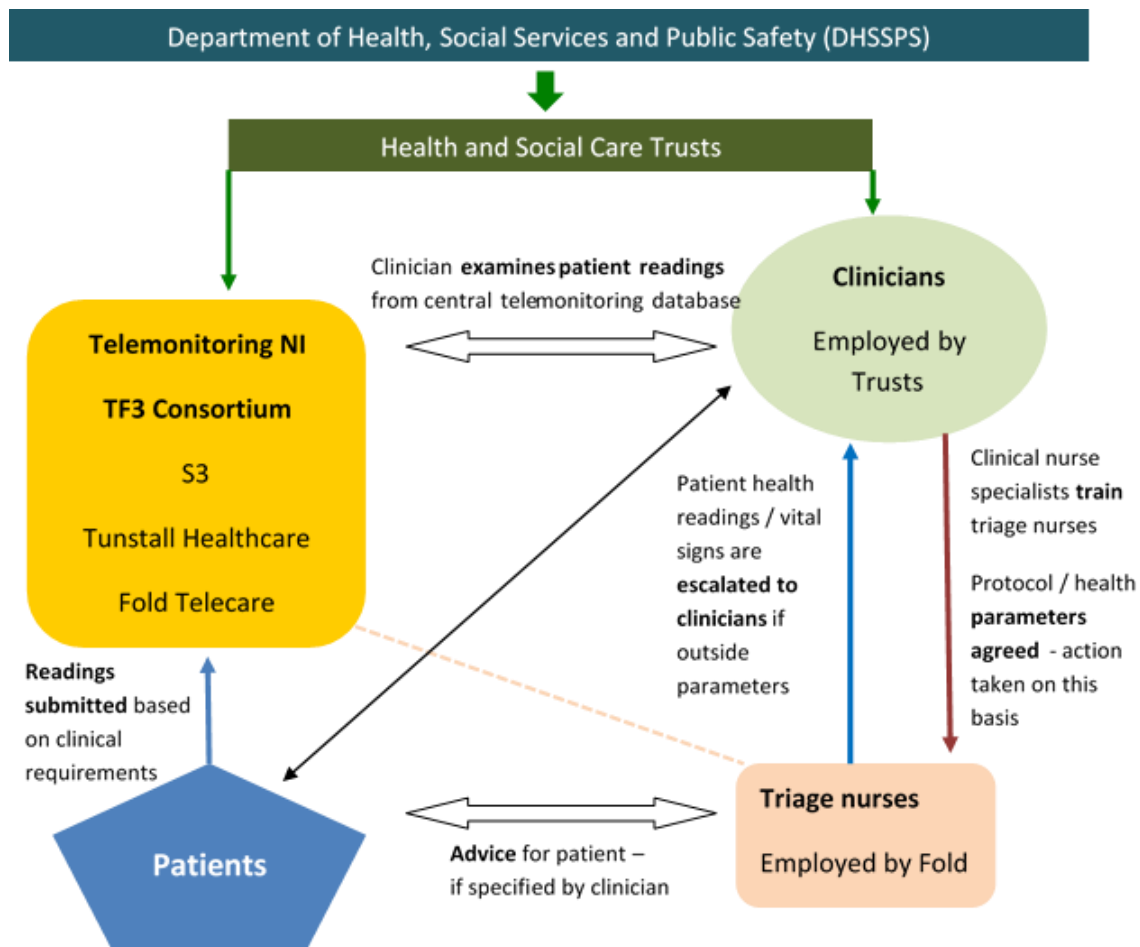


**Figure 3 Key stakeholder relationships in telemonitoring service provision**

Clinicians, typically the patient's consultant or a clinical nurse specialist, were the primary sources of **referrals** to the telemonitoring service (Figure 4). The point

of referral was usually when an in-patient was referred to the specialist nurse team on their discharge from hospital or if a patient was on the case load of a specialist nurse within the community.

**Clinician** refers patient to telemonitoring service

- Assesses patient suitability
- Patient consents to using service
- Specifies equipment package to be provided

**TF3** install equipment, train user

- TF3 contact patient and arrange installation of home hub
- Train users to take readings of vital signs and submit to telemonitoring centre
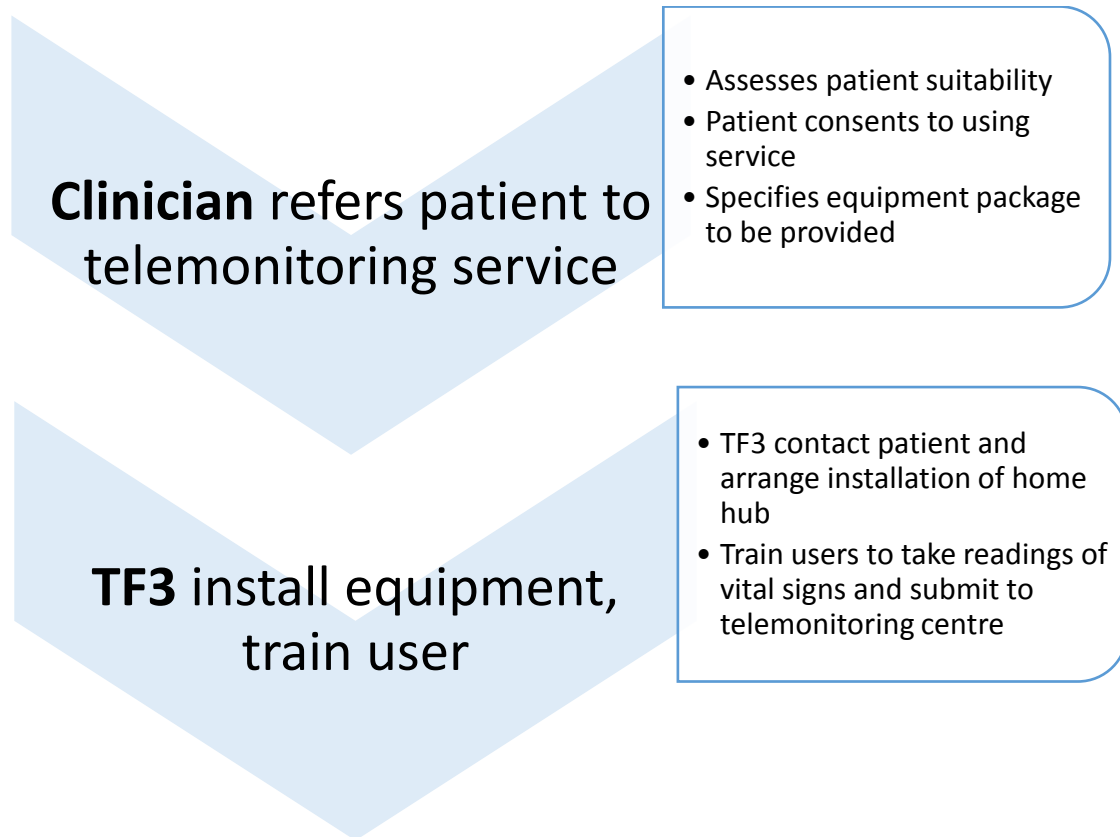
**Figure 4 Referral pathway to telemonitoring service**

Age was not an exclusionary criterion for referral for telehealth monitoring. However, if a patient who met all of the clinical referral criteria did not have the cognitive ability to learn the process of monitoring or could not physically use the equipment, and no other alternative solution could be found (e.g. having a carer present or other technological solution), they may have been excluded from the service.

A patient who demonstrated a lack of motivation or did not agree with self-monitoring could also be excluded.  More practically, if a patient did not have a landline or accessible electrical sockets and TF3 could not provide an alternative solution for them (e.g. mobile based) they would not be able to avail of telemonitoring.

A set of documentation was developed to support health professionals in making referrals to the service including standard referral form, generic- and condition-specific referral criteria, and guidance on obtaining patient and carer consent. The service commitment was that urgent referrals would be completed within 20 working hours of referral and standard referrals within 48 working hours, but that the latter could be extended to 80 working hours with the approval of the patient or carer.

### 4.2.2 Who could use the service?

Following pilot programmes and a high-level review of the evidence[29], telemonitoring services were aimed at the management of chronic illnesses like diabetes, chronic heart failure and COPD.

As of 2014, 2,000 people suffering from COPD, stroke, diabetes or heart failure, were reported to have benefited from home telehealth monitoring under the Telemonitoring NI programme, approximately 1,000 of whom were using the service at any one time. This should be viewed against a target for 5,000 telehealth users by 2011. There were 4,216 referrals to the telehealth service between December 2011 and May 2015, for a total of 3,944 individual patients, with 1,030 patients on the service at the end of July 2015. The reasons for lower uptake are unclear.

On a smaller scale, the Northern Irish telemonitoring service had moved into supporting weight management through a large regional pre-pregnancy programme for obese women who were planning a pregnancy. Some of the Trusts engaged with this programme.

The Northern Trust also used Telemonitoring NI to monitor the lifestyle behaviour of patients, including individuals and families, in a motivational weight management programme. The aim was to monitor these clients' behaviours to see if they aligned with what had been prescribed in behaviour therapies undertaken on the programme.

### 4.2.3 Equipment packages and funding

Core telemonitoring equipment packages were defined for each condition (COPD, diabetes, chronic heart failure and stroke) and the reimbursement model for the telemonitoring providers worked on a 'per package' and per 'monitored patient day' basis. This model of core packages per condition is regarded as best

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[29] O'Brien, M. (2008) *Remote Telemonitoring: A Preliminary Review of Current Evidence*. Belfast: European Centre for Connected Health.

practice. There was some flexibility in equipment provision for patients with co-morbid conditions. For example, a COPD patient might also have had diabetes, requiring a blood glucose monitor in addition to the devices to monitor their COPD. Conversely, a patient may not have required all of the equipment in a given core package and therefore may not have been given some of the devices included in that package.

## 4.3 What is the system of telecare in Northern Ireland?

Like other jurisdictions, telecare in in Northern Ireland has been concerned with safety and risk management functionalities using active and passive telecare systems.

The feasibility paper produced to scope out Telemonitoring NI placed its emphasis solely within the telehealth field.  However when the contract for telehealth was awarded in 2011, it was future-proofed for both health and social care, and included telecare as an additional service.  The TF3 consortium was therefore empowered to deliver telecare as well as telehealth in Northern Ireland though this service had not been widely provided.

However even before telecare fell under the remit of Telemonitoring NI, personal alarm services have been provided through private organisations (mainly non-profit) from the housing and older persons' organisation sectors.[30]

The Northern Ireland Federation of Housing Associations, and their individual members, developed onsite alarm services to connect residents and scheme coordinators (formerly known as wardens) in sheltered housing schemes.  This model expanded to include shared services across sheltered housing schemes. Eventually this extended to include access to social alarm services for people living in dispersed housing in the community.

The two largest providers of personal alarms are Fold Housing Association and Age NI which are both private providers. Between these two providers, approximately 23,000 personal alarms have been installed for users living in the community and in sheltered or supported housing units across Northern Ireland. When combined with users of other services (like Telemonitoring NI) and the smaller numbers of users with more advanced telecare packages, the total

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[30] Fisk, M. (2003) *Social Alarms to Telecare: Older Peoples Services in Transition*. University of Bristol: The Policy Press.

number of users in Northern Ireland was estimated to be between 25,000 and 30,000 as of 2014.

Fold and Age NI offer subscription-based services across Northern Ireland on a private basis where users are charged directly, as well as catering directly for their clients. However, grant-based public financial support is available to eligible users who apply for these schemes and satisfy the applicable financial criteria set out under the Community Care Grant.[31]

Using an international benchmark, based on the number of users as a percentage of the population aged 65 and over, the coverage rate for Northern Ireland ranges from 9% to 11%. This rate is a little higher than coverage estimates for Spain and lower than Ireland and Scotland.[32]

### 4.3.1 Who is responsible for telecare?

Current approaches to the provision of advanced telecare by the five Trusts are not well documented though variation between Trusts in the level of provision is apparent. This can partly be ascribed to the geographical area and the spread of clients, and partly to the availability of funding. Trusts covering more rural areas appear to have greater provision, using telecare to manage risks for isolated clients.  Other factors that influence the provision of telecare include the characteristics of target groups and the care pathway being addressed, for example, hospital discharge, domiciliary care, dementia, mental health, older persons and rehabilitation services.

Based on the information available and the views of those consulted in the National Disability Authority's first research phase (2014), the approach of the Trusts to telecare provision can be characterised as reactive. Telecare packages were provided to individuals when they reached a level of high dependency.

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[31] NOTE: Community care grants assist low-income citizens to live independently at home by paying for things like furniture, fuel connection, removal costs and minor house repairs. Grants can also help ease exceptional family pressures caused by disability, chronic illness or major changes, and cover urgent travel expenses. More details available at:

Age NI (2018) *Help with urgent or one-off expenses*. Available at: https://www.ageuk.org.uk/northern-ireland/money-matters/claiming-benefits/the-social-fund/who-can-help/ (accessed June 2018).

[32] NOTE: Not all telecare users are older persons but the majority are; the yardstick is used to enable some degree of consistent comparison across countries that takes the different age structures of national populations into account

As of 2014, all of the Trusts were reviewing their telecare provision, in collaboration with the CCHSC and the TF3 consortium, to identify future opportunities to increase telecare usage and to extend its use to groups other than older people, e.g. people with disabilities and patient reablement programmes.

The possibilities for increased interlinking of the Northern Ireland Single Assessment Tool (NISAT)[33] and telecare are also being examined. NISAT has been specifically designed for the health and social care system in Northern Ireland to bring consistency to the assessment of older people across the region. Appropriate linking of telecare to this would increase knowledge about telecare amongst health and social care professionals. Future reviews should follow up on the success (or challenges) of this linkage to inform Ireland's approach.

### 4.3.2 Who can use the service?

Clients can be referred to telecare services by health and social care professionals (usually an Occupational Therapist or Social Worker), who identify that telecare would be appropriate to meet a client's health or social care need during client assessment. An assessment report and recommendation for telecare is then submitted to the relevant care programme manager within the Trust for approval. If approved, the referral is forwarded to the telecare provider.

However, the market also reflects private provision by organisations direct to their clients, and to private consumers.

### 4.3.3 Fold Housing Association

Fold Housing Association provides affordable social housing for families, single people, couples and people over 55 years of age. The association has over 100 housing schemes, 5,000 homes and a presence in almost every city and major town across Northern Ireland. Fold provide a personal alarm pendant service to tenants and residents in Fold's own housing schemes, residents of other housing providers, and directly to people in their own home.

The telecare programme targets people

- over 65 years
- with dementia

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[33] Department of Health and Social Services (Northern Ireland) (2018) *Northern Ireland Single Assessment Tool and Guidance.* Available at: https://www.health-ni.gov.uk/publications/northern-ireland-single-assessment-tool-and-guidance (accessed June 2018).

- at risk of falls

- with poor mobility

- at risk of wandering

- with chronic or persistent illness which impacts on day-to-day life

Depending on the setting, different devices may be provided. The telecare equipment utilised includes a Lifeline 4000 care phone and pendant, radio pull cord, fall detector; smoke detector, flood alarm, temperature extremes alarm, bed occupancy monitor and alarm; passive infrared (PIR) motion detectors, and MIDAS (miniature intelligent domiciliary alarm system) lifestyle monitoring system.

For users in dispersed housing in the community, the equipment provided includes an alarm unit and portable personal pendants that link to Fold TeleCare's 24 hour Response Centre. In sheltered housing units some residents simply have pull cords and smoke detectors, while others may also have pendant alarms.

When triggered, the system either alerts scheme-based staff or Fold TeleCare's 24 hour Response Centre. Most sheltered housing schemes have a scheme coordinator who may be contacted.  In the event of an alert being triggered by a home-based user, Fold's 24/7 Telecare monitoring centre, if required, contacts one of the client's nominated contacts or, if necessary, the emergency services.

### 4.3.4 Age NI

Age NI is a charitable and campaigning organisation providing support services to older people in Northern Ireland. Its Personal Alarm Service has representatives/installers who provide coverage in all counties and who are normally based within a few miles of potential clients. The service aims to be flexible and provide alarms quickly when circumstances require.

The majority of clients are older people, with younger people with physical or intellectual disability making up a smaller percentage of clients.  Referrals come from various professionals and services in the Trusts, including hospital social workers who want to ensure that someone has adequate care services in place before they are discharged from hospital.

Monitoring of the alarms is done by the centre at Age Concern's UK headquarters in Asburton, England.  The Age NI Personal Alarm Service does not provide a responder service. Instead, clients must nominate two contacts in order to register (although in most cases clients have up to six contacts).

A single nominated contact can be accepted if the person agrees to have a key safe installed outside their home and in a small number of cases formal care provider staff may be involved as contacts. These exceptions are usually context-specific, for example in a social-service supported, clustered housing scheme for people with intellectual disability where an overnight duty staff member may act as a responder.

## 4.4 Costs

### 4.4.1 Telemonitoring NI

The DHSSPS invested £18 million over the six-year span of the Telemonitoring NI contract. The total cost of the telehealth service for the period 2011-2015 has been estimated at approximately £6,745,000.

Reimbursement arrangements for the telehealth providers were based on the equipment package installed and a tariff based on monitored patient days.

A 2016 evaluation of the Telemonitoring NI service found no evidence within the dataset of any marked impact of telehealth services on hospitalisations and hospital based service usage. One aim of the evaluation was to analyse the non-elective healthcare service costs of telehealth patients in each of five target conditions. In general terms, the number of hospitalisations, length of hospital stay and outpatient clinic attendance (which contribute to the overall cost of healthcare provision) did not differ between the quasi-control group of patients who had never had telemonitoring equipment installed, and any of the groups who received some amount of telemonitoring (whether services were successfully used or only partially used, e.g. in the case of non-compliance with the programme).[34]

### 4.4.2 Telecare

More detailed data on telecare costs are more forthcoming, perhaps due to the systemic structure of private providers.

The Supporting People Programme was introduced in Northern Ireland in 2003 and it funds housing-related support services that a landlord (such as a housing

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[34] McElnay, J., Clarke, M., Hughes, C., Agus, A., Gardner, E., O'Reilly, D., Hart, N., Ferrett, A., Cole, J., Faith, V., Al-Azzam, S. and Wilson, J. (2016) *Evaluation of past and present implementation of Telemonitoring NI: Telehealth component (including supplement on Telecare component)*. Belfast: Queens University. Available at:
http://www.research.hscni.net/sites/default/files/Telehealth%20Final%20Report.pdf.

association for example) or other service provider (such as a voluntary organisation) can provide to help vulnerable people to live independently.[35]

Residents' monthly charge includes the cost of the alarm and monitoring. If a resident has high support needs, they may have additional specific peripherals which would be paid for by the Trusts. Residents of sheltered or supported housing provided by other housing providers may have their personal alarms funded via the Supporting People Programme.

Users can also purchase telecare services privately. For non-Fold Housing Association residents, monthly charges include the cost of the alarm and monitoring. The cost of a personal alarm to a private purchaser is one initial payment of £120 (which includes installation and the first 3 months monitoring) followed by a quarterly fee of £30.[36]

Fold does not administer an application for the Community Care Grant on behalf of the purchaser. They report that many private purchasers want the alarm in a hurry and opt to pay for it outright themselves rather than having to go through the process of applying for the grant, even if they may be eligible.

A substantial proportion of Age NI's Personal Alarm Service users have their personal alarms funded by the Community Care Grant. Age NI applies for the grant to cover the cost of the service on the client's behalf. The client signs an agreement and the service completes the application form. The information given by the client is checked by the Social Security Agency in terms of eligibility. If the applicant is deemed eligible the grant is paid into Age NI's bank account.

The Personal Alarm Service offers a choice of five payment options - each structured around how long the user feels they may be likely to use the service.[37] Each option includes the cost of the equipment, 24 hour monitoring, and on-site maintenance. Charges also include installation and demonstration of the equipment. Prices range from:

- a one off charge of £254 and a quarterly fee of £17.60
- a one off charge of £99 and a £31.05 quarterly fee

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[35] This was reported in the 2014 phase of the National Disability Authority research

[36] Costs as outlined in 2014 on Fold's website http://www.foldgroup.co.uk/telecareforindividuals

[37] Costs as outlined on Age NI's website in 2014 http://www.ageuk.org.uk/northern-ireland/buy/age-ni-personal-alarm-service/payment-options/

- a monthly fee of £29 for the first 6 months followed by a £31.05 quarter fee

- a 'Lifetime' once off payment £585 with no further charges, to

- a 'Self-connect' option with an initial charge of £69 and a quarterly fee of £45.10.

All prices exclude VAT, which may not be applicable to certain users (e.g. those with a disability or chronic illness).

In addition the personal alarms, the service installs a very small number of smoke detectors and fall detectors but these extra devices are not grant aided under the Community Care Grant and the costs must be covered by the client or his or her family.

## 4.5 Quality Assurance

Northern Ireland does not have an overarching system of compliance and regulation for TH/TC services. Rather, issues of quality fall under existing health and social care legislation and guidance, e.g. Quality 2020.[38]

The eHealth and Care Strategy focusses on areas for improvement and development objectives. For example, the Strategy highlights several achievements that have led to better quality.

- a Health and Care number for everyone, which is used by the HSC to maintain data quality.

- a world-class electronic care record, providing care staff with an up-to-date record covering a range of patient and client information.

- the regional X-ray system, NIPACS, allowing all X-rays to be viewed and reported electronically.

- computerisation, networking and the introduction of two-way electronic communication for all GP practices.

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[38] Department of Health (Northern Ireland) (2017) *Quality 2020 - a ten year strategy to protect and improve quality in health and social care in Northern Ireland*. Available at: https://www.health-ni.gov.uk/publications/quality-2020-ten-year-strategy-protect-and-improve-quality-health-and-social-care (accessed during 2017 phase of research).

- major improvements to networks, data centres and other major eHealth infrastructure. [39]

The Strategy has 6 Objectives to support implementation and which drive quality and improvement in several areas (Table 1). More specifically on telecare, the CCHSC has worked to develop standard eligibility criteria, forms and governance procedures for telecare.  It is planned that each Trust will be provided with a budget and set of targets for telecare activity and more consistent approaches across the Trusts will be expected.

The procurement framework of Telemonitoring NI also provided for quality and consistency of approaches.

### Table 1 Objectives for the eHealth and Care Strategy for Northern Ireland[40]

| 1. Supporting people | 2. Sharing information |
|---|---|
| Provide eHealth services, supporting electronic access for everyone where that is their choice. This will include electronic information services, electronic records access, on-line support and care services, appointment booking and remote care. | Give care professionals appropriate access to information to improve the speed and quality of the care decisions they make, and the outcomes for the individual. |
| 3. Using information and analytics | 4. Supporting change |
| Develop ways to transform data and information into knowledge (informatics) that supports care, from being able to suggest personalised preventative care through to | Make thinking about eHealth central to planning any changes to health and care services to make sure we are making the most of technical opportunities and the potential for improved information flows to support improvements. |

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[39]Health and Social Care Board (2016) *eHealth and Care Strategy for Northern Ireland*. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/interactive-ehealth-strategy.pdf (accessed during 2017 phase of research). p.4

[40]Health and Social Care Board (2016) *eHealth and Care Strategy for Northern Ireland*. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/interactive-ehealth-strategy.pdf (accessed during 2017 phase of research). p.6

| supporting population-level health and care planning. | |
|---|---|
| **5. Fostering innovation**<br><br>HSC will work with businesses, colleges and universities, community and voluntary organisations, other government departments and international partners to develop uses of eHealth to help improve health and wellbeing, recognising there may be opportunities where such work contributes to developing sustainable economic growth in Northern Ireland. | **6. Maintaining and improving what we have**<br><br>Maintain a modern, reliable eHealth infrastructure, including investment in supporting, modernising and replacing key systems and HSC networks and hardware as needed. |

## 4.6 Outcomes

### 4.6.1 Telemonitoring NI
A commissioned evaluation in 2016 in relation to telemonitoring, concluded that, in general terms, hospitalisations, length of hospital stay, outpatient clinic attendance, and costs of healthcare provision did not differ between the 'Never installed' group and those receiving telemonitoring (and is reflected in the findings related to cost-benefits).  The most striking finding of the quantitative evaluation was a higher mortality rate (33.3%) within the quasi-control 'Never installed' group compared to the 'Installed' group (13.9%).  The authors acknowledge other studies[41] have also found decreased mortality rates however whilst it is tempting to infer that the results are indicative of the alerts generated by telehealth monitoring which facilitate early implementation of life saving interventions, it is likely that at least some of these patients did not have equipment installed because they had become morbidly unwell.[42]

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[41] Dendale P,. De Keulenaer, G., Troisfontaines, P., Weytjens, C., Mullens, W., Elegeert, I., Ector, B. Houbrechts, M. Willekens, K., Hansen, D. (2012) 'Effect of a telemonitoring-facilitated collaboration between general practitioner and heart failure clinic on mortality and rehospitalization rates in severe heart failure: the TEMA-HF (Telemonitoring in the Management of Heart Failure) study'. *European Journal of Heart Failure*, **14**, 333-40.

[42] McElnay, J., Clarke, M., Hughes, C., Agus, A., Gardner, E., O'Reilly, D., Hart, N., Ferrett, A., Cole, J., Faith, V., Al-Azzam, S. and Wilson, J. (2016) *Evaluation of past and present implementation of Telemonitoring NI: Telehealth component (including supplement on Telecare component)*. Belfast:

The qualitative aspect of the study revealed that support for the telehealth service was overwhelmingly positive, particularly from patients (and their carers). The view expressed was that within the telecare study, the high number of 'calls' from patients who had the equipment installed indicate that these were high dependence patients and it seems likely that appropriate actions by the telecare team led to the prevention of negative health outcomes for them. Telecare service data were available for 1,883 individuals who were referred between 26 February 2010 and 22 February 2016 and had data covering a minimum of 6 months pre- and post-installation date. No control data was available and there were significant increases in mean healthcare use after installation.

With the same Northern Ireland population, another study explored the self-management of diabetes mellitus with remote monitoring[43]. Following a retrospective study of 214 case notes it was concluded that allowing patients to be remotely supported to self-manage diabetic control at home led to significant improvement in their HbA1c (glycated haemoglobin levels) and better overall management of their diabetes.

The research team also completed a prospective study on remote monitoring (telehealth) to achieve self-management of Type 2 Diabetes Mellitus[44]. An interrupted time series design was adopted to evaluate the impact of three different telemonitoring solutions provided by one large combined health and social care Trust with technology-naïve people, aiming to manage their Type 2 diabetes mellitus.

A total of 166 patients met the criteria at the diabetes clinic, with 29 patients consenting to take part in the study. Three telemonitoring solutions (Hygieia (dNav); UTell; Telemonitoring NI were available for prescription by medical staff. Whilst this study was limited in size and to one site it has shown the feasibility of using telemonitoring in clinical routine and its potential benefits for diabetes care.

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Queens University. Available at:
http://www.research.hscni.net/sites/default/files/Telehealth%20Final%20Report.pdf.

[43] Mushcab, H., Kernohan, W.G., Wallace, J., Harper, R. and Martin S. (2017) 'Self-Management of Diabetes Mellitus with Remote Monitoring: A Retrospective Review of 214 Cases'. *International Journal of E-Health and Medical Communications*, **8**(1), 52-61. Available at: https://www.igi-global.com/article/self-management-of-diabetes-mellitus-with-remote-monitoring/171162 (accessed September 2017)

[44] Mushcab, H., Kernohan, W.G., Nevill, A. and Martin, S. (2016) 'Remote Monitoring To Achieve Self-Management of Type 2 Diabetes Mellitus: A Prospective Study'. *Current Trends in Biomedical Engineering and Bioscience*, **1**(1). Available at: https://juniperpublishers.com/ctbeb/pdf/CTBEB.MS.ID.555554.pdf (accessed September 2017).

One of the solutions (d-Nav) exhibited significant improvement in HbA1c levels over the other telemonitoring solutions. In addition, participants showed acceptance of the service, significant satisfaction using all three solutions, and exhibited improved quality of life.

### 4.6.2 Telecare

Telecare Think Tank (2007) evaluated Fold Healthcare's pilot TC model in Northern Ireland. A large majority of service users and family carers reported that they believed telecare had reduced the level of stress placed on carers (91%) and that telecare had helped to keep the service user in their own home (82%). Key workers and formal carers were asked for their assessments of the impacts of telecare on the extent of clients' reliance on other care services.  There were varying perceptions in this regard, with 46% indicating that the telecare service had not reduced the reliance on statutory services provided and 41% indicating that it had (14% did not answer this question).  A small proportion of key workers reported that the telecare system had provided them with useful information to better inform or influence future care planning (23%).

The evaluation report concluded that a value for money estimate for telecare was not easy to calculate because of the diversity of users' needs, variability in cost commitments and the range of impacts relevant to different stakeholding groups (Telecare Think Tank, 2007:  15-16). Nevertheless, it accepted that telecare provision has the potential, through releasing capacity elsewhere in the system, to result in some financial benefits for carers (e.g. being able to take up employment as a result of telecare provision) and to achieve health and social care economies in the longer term.

The evaluators proposed that telecare services should be accompanied by stand-alone equipment and assistive technology to prevent accidents and promote well-being in the home.  The lack of a 24/7 formal responder service, trained to respond to falls and other emergencies in the community, was viewed as a missed opportunity to improve outcomes and value for money.

## 4.7 Key learning points

Faced with an ageing population, Northern Ireland is an example of top-down, policy-driven implementation. A clear national strategy has been outlined[45] with the purpose of implementing changes to reflect new ways of working, new

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[45]  Health and Social Care Board (2016) *eHealth and Care Strategy for Northern Ireland*. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/interactive-ehealth-strategy.pdf (accessed during 2017 phase of research).

technologies and the development of new treatments in order to cater for an ageing population. Northern Ireland, like Scotland, has also linked TH/TC development with jobs and investment policy, i.e. Invest NI are positioning to create jobs and investment in telehealthcare and establish the country as a site of excellence for both products and services.

Telemonitoring was rolled out nationally following a tender for services. The particular method of tendering for the Telemonitoring NI contract was competitive dialogue. This is an interesting practice for Ireland to consider if tendering for TH/TC on the open market (as opposed to directly providing TH/TC through the national health and social care system). Competitive dialogue grants flexibility in immature market places (i.e. Ireland's eHealth landscape) and is also catered for within Ireland's national procurement practices.[46]

Telemonitoring NI was provided by a consortium of private players but close links were maintained to clinicians and the trusts, e.g. through staff training, and clinicians setting parameters for vital signs for each patient which were used as a basis for action by private provider staff.

An interesting consideration is the practice of setting a client up with telemonitoring under the Telemonitoring NI system. The clinical nurse specialists/clinical specialists in the Trusts assessed the patient's suitability for the telemonitoring service. These staff also decided on which equipment was needed. For this model to work well, the clinicians need to be au fait with the technology, available devices and usages, and future developments. In other jurisdictions, evaluators have cautioned that TH/TC needs expertise and that it can put much workload onto clinicians. For a truly pro-active TH/TC system, elegant and innovative use of technology will need constant research and upskilling and how viable this will be for clinicians with large workloads remains to be seen.

Telecare emerged in a more organic way from existing services in housing and older persons' organisations. The Trusts do not have a specific telecare budget and these packages were funded within the overall budget, mainly using the funding stream for older person's services.  As a result, Trust-funded telecare packages to date have tended to be targeted at the elderly population. To extend the use of telecare to other groups, funding streams will need to be readily available to accommodate other potential target groups, including persons with

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[46] eTenders (2010) *Public Procurement Guidelines – Competitive Process*. Available at: http://etenders.gov.ie/Media/Default/Page/Public_Procurement_Guidelines_-_Competitive_Process_2010.pdf (accessed June 2018) (p.23)

disabilities. In the Irish context, consideration should be given to the funding streams for TH/TC services so a wide user base can be accommodated.

For private purchasers of telecare services, it is interesting to note that one organisation (Age NI) processes grant applications on behalf of the client while the other (Fold) does not. Fold report that many private purchasers go ahead and pay for the alarm rather than having to go through the process of applying for the grant, even if they may be eligible. This is interesting as it speaks to the power of consumers to choose appropriate devices for their needs, but also that when the need is present, the purchase of services will not necessarily be influenced by financial incentives.

## 5.0      Scotland

Scotland is recognised for its approaches to both telecare and telehealth which are largely in the process of being trialled with a view to mainstreaming initiatives into health and social care programmes and practice. In implementing TH/TC initiatives, Scotland has built on existing coordination and cooperation networks. No nationally administered system of service delivery is in place. However, there is a concerted effort at policy level to drive initiatives forward.

## 5.1 Overview

The Scottish government has given policy importance to both telecare and telehealth, setting out to establish Scotland as a recognised global leader in telehealth (Scottish Government, 2007).  Coordinated national approaches have been set-up and large-scale trials funded to drive and support development of these fields across Scotland (most initiatives have tended to be in trial / pilot phase). There is a specific public agency, the Scottish Centre for Telehealth and Telecare (SCTT) in place to promote developments.

### 5.1.1 Key Policy Developments

Policy-driven development programmes have targeted both telecare and telehealth.

Until 2011, the Joint Improvement Team (JIT) led activities in telecare through the Telecare Development Programme (TDP). The Scottish Centre for Telehealth (SCT) led activities in telehealth.  In April 2011, these agencies were integrated into a single Scottish Centre for Telehealth and Telecare (SCTT). A more integrated perspective and approach to telecare and telehealth under the 'telehealthcare' umbrella is now being pursued, including at the national strategy level.

In 2010, SCT was integrated with NHS24, the nationwide telephone-based service providing health advice and information to callers as well as offering clinical assessments by qualified health professionals over the telephone.  This was intended to help position the centre as a national resource with mainstream relevance and remit.
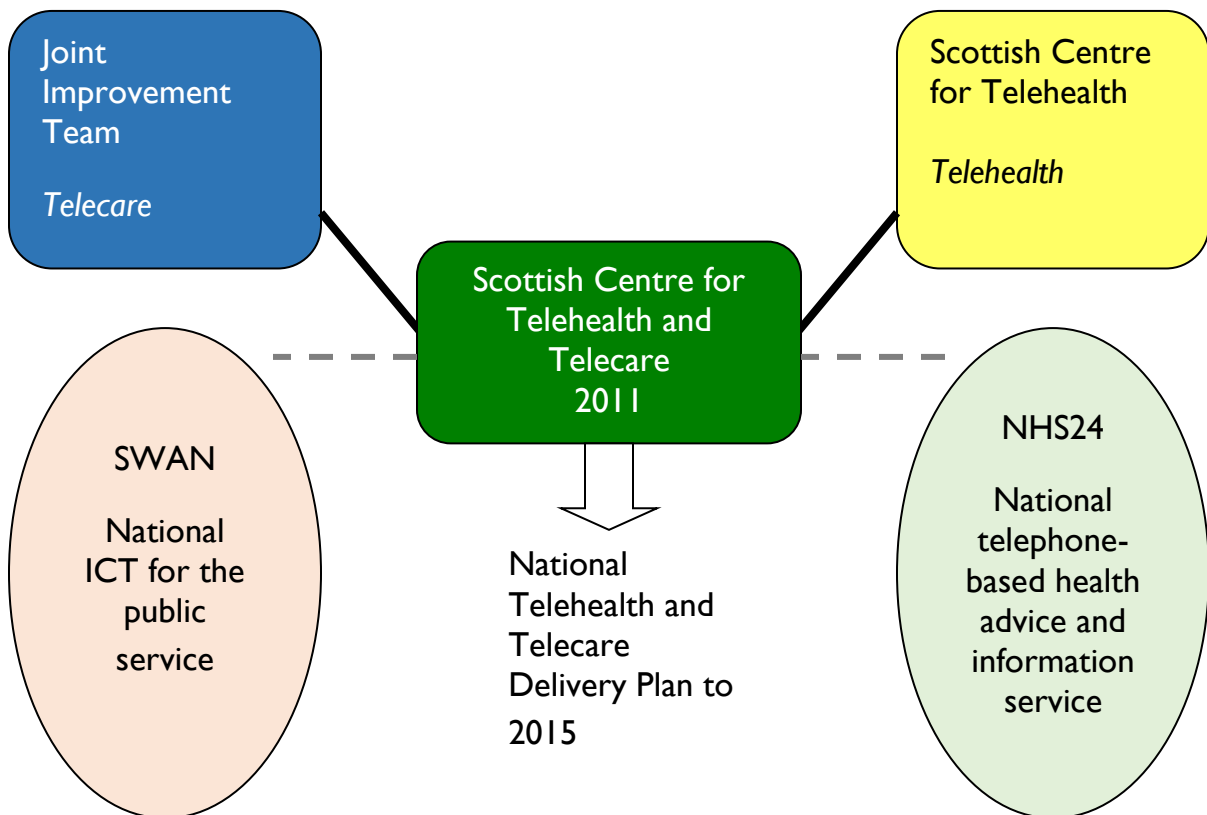
**Figure 5 Evolution of telehealthcare policy in Scotland**

The SCCT was also linked with the Scotland Wide Area Network (SWAN)[47]. SWAN aims to deliver a single shared network, and common ICT infrastructure for every public service across Scotland, thereby supporting the creation of public services that are efficient and responsive to local needs.

### 5.1.1.1 Early developments in telehealth
SCT had aimed to develop and deliver telehealth across Scotland through four areas of work: stroke, paediatrics, COPD and mental health.[48]  To this end, a

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[47] SWAN (2018) *What is SWAN?* Available at: https://www.scottishwan.com/about (accessed June 2018).

[48] Scottish Centre for Telehealth (2010) *Scottish Centre for Telehealth strategic framework 2010-2012*. Aberdeen: Scottish Centre for Telehealth.

number of telehealth pilots, trials and smaller-scale projects were put in motion. Approximately £4.7 million was spent between 2006 and 2011 on telehealth initiatives. The largest was the Telesecot project, involving a series of trials addressing people with a range of chronic diseases. The other large initiative involved the trial of a paediatric telehealth service involving remote access to paediatric centres of expertise.

Audit Scotland identified approximately 70 telehealth initiatives that had been introduced across the NHS Boards since 2006. However, it noted that while there were quite a large number of telehealth initiatives across Scotland, these tended to be mainly small-scale (average of 34 patients) and about 50% were pilots and not part of routine services.

One of the actions set out in the SCCT's National Telehealth and Telecare Delivery Plan to 2015 was to expand the existing Scotland Excel procurement framework to include improvements in efficiency, quality, and integration of telehealth and telecare data equipment and services.[49] When the Scotland Excel framework expires, the new contract will include telehealth. This will make it easier for partnerships (local authorities) to run telehealth as well as telecare.

### 5.1.1.2 Early developments in telecare
In August 2006, the Scottish Telecare Development Programme (TDP) provided telecare grants to 32 local health and social care partnerships for the period 2006-2011. Some partnerships embedded telecare into their local service structures. Two-thirds of the partnerships included telecare in their development plan and just over 40% formulated a coherent telecare strategy. Those who integrated telecare into their care packages used standardised protocols for service delivery, with some using standardized assessment processes to check for eligibility criteria.

A formal national system for telecare provision is not in place in Scotland as of 2018. The SCTT remains focussed on a number of initiatives to further the scale-up and implementation of telecare services across Scotland. These include:

• Service improvement through telecare data collection and analysis

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[49] Scottish Centre for Telehealth and Telecare & Joint Improvement Team (2012) *A National Telehealth and Telecare Delivery Plan for Scotland to 2015: Driving Improvement, Integration and Innovation*. Available at: http://www.gov.scot/Publications/2012/12/7791/downloads (accessed during 2014 phase of research). p.30

- Embedding telecare within Care Pathway Redesign programmes for dementia, falls and overnight support services

- Analogue to digital telecare programme

- Undertaking a feasibility study to explore options for telecare expansion

- Development of an on-line telecare Self-Check & Signposting Tool to support awareness raising and expansion[50]

Since 2010, official data has been compiled on the numbers of clients for whom a community alarm or telecare service has been provided by each local authority and as of 2018, there are 160,000 telecare users in Scotland.[51]

### 5.1.1.3 The Scottish Centre for Telehealth and Telecare (SCTT)

The SCTT has a remit to support and guide the development of telehealth and telecare in Scotland.[52] The organisation does this by working with key stakeholders (industry, academia, partnerships, NHS Boards and the voluntary and private sectors) and using recognised models to inform the redesign of health and care services.

More specifically, the SCTT has been tasked with

- disseminating best practice

- providing both clinical and technical practical support

- co-ordinating the evaluation of projects

- evaluating the impact of telehealth and telecare on service redesign, and

- developing interoperable standards and protocols.

The National Telehealth and Telecare Delivery Plan to 2015[53] published by the Scottish Government in 2012 provides a useful indication of how the themes of

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[50] Scottish Centre for Telehealth and Telecare (2018) *Telecare*. Available at: https://sctt.org.uk/programmes/telecare/ (accessed June 2018).

[51] Scottish Centre for Telehealth and Telecare (2018) *Telecare*. Available at: https://sctt.org.uk/programmes/telecare/ (accessed June 2018).

[52] Scottish Centre for Telehealth and Telecare (2016) *SCTT Business Plan 2017-2022*. Available at: https://sctt.org.uk/wp-content/uploads/2017/03/SCTT-BUSINESS-PLAN-2017-22.pdf (accessed June 2018).

[53] Scottish Centre for Telehealth and Telecare & Joint Improvement Team (2012) *A National Telehealth and Telecare Delivery Plan for Scotland to 2015: Driving Improvement, Integration and Innovation*. Available at: http://www.gov.scot/Publications/2012/12/7791/downloads (accessed during 2014 phase of research).

telecare and telehealth are being addressed and how they link with wider healthcare system components and objectives.

Objective 2.2 of the plan was about supporting people to actively participate in the design and delivery of their 'technology-enabled services'.  A priority activity under this objective was co-design and co-production of telehealth and telecare solutions which provide information, support, products and services in collaboration with users, patients and carers.

There was also a recognition of the 'crucial' role of unpaid carers and the need to develop solutions to meet their needs and support wellbeing. The SCTT work with carer organisations to develop and implement a carers' support/telehealthcare annual work plan each year.

National policy in complementary areas has also underlined the importance of developing TH/TC in Scotland. Reshaping Care: A Programme for Change 2011-2021[54] draws particular attention to the role of TH/TC in supporting elder care, supporting carers, and independent living. It states:

All older people over 75 years will be offered a Telecare package in accordance with their assessed needs. There is clear evidence of the benefits of Telecare for both older people and their carers. Telecare should be seen as a core support that can assist people to optimise their independence and wellbeing.

## 5.2 How does the Community Alarm telecare system work?

The main focus in Scotland in general has been on the safety and risk management functionalities of telecare. Community Alarms and more advanced telecare services are now regularly provided as a component of the social care and housing services across Scotland. There is extensive usage by older people and also by other groups that can benefit.  This includes people living in ordinary (dispersed) housing in the community and people living in sheltered housing arrangements. Given the relatively systematic approach adopted to the development of telecare services in Scotland, substantial data on uptake and impact are available.

An important distinction is made in the data set between people in receipt of a technology package which

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[54] Scottish Government (2010) *Reshaping Care for Older People: A Programme for Change 2011-2021*. Available at: http://www.gov.scot/Resource/0039/00398295.pdf (accessed during 2014 phase of research).

1. consists of a communication hub with a button/pull chords/pendant that transfers an alert/alarm/data to a monitoring centre or individual responder (Community Alarm), and

2. people receiving a technology package which includes other sensors or monitoring equipment such as linked pill dispensers; linked smoke detectors; linked key safes; bogus caller buttons and door entry systems; property exit sensors, extreme temperature, flood, falls, movement detectors (Telecare).

A standalone device is not considered to be part of a telecare package if it is only capable of alerting or providing information to a monitoring centre or individual responder.

### 5.2.1 Who is responsible for Community Alarms / Telecare services?
Community alarms and telecare are somewhat embedded in social care and housing services at local authority level and the most common form of service provision is through local arrangements rather than through nation-wide service providers.

Call centres and, where offered, responder services are mostly organised and provided by public sector services or non-governmental organisations (primarily in the housing sector), and sometimes through outsourcing to private telecare provider companies. In some cases, a local authority may arrange to have the services operated via another authority's service and in a few cases a more distant call-handling centre is used. Table 2 provides an overview of the variety of arrangements across partnerships in Scotland.

There is considerable variation in the extent and nature of responder service provision across the partnerships in Scotland.[55][56] The majority of authorities provide at least some level of formal responder service, sometimes as the main response mode and in other cases restricted to a subset of clients with particular needs. Collaborations with voluntary sector organisations to utilise volunteer responders are also in place in some cases.[57]

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[55] Sergeant, E. (2010) *Summary of telecare services in Scotland*. Edinburgh: Joint Improvement Team.

[56] Watson, D. and O'Sullivan, T. (2012) *Alarm Monitoring and Response Services in Scotland*. Edinburgh: Joint Improvement Team.

[57] Sergeant, E. (2010) *Summary of telecare services in Scotland*. Edinburgh: Joint Improvement Team.

In Renfrewshire, the Responder Service employs 30 staff. The bulk of needs addressed were frail elderly and those prone to falling. However, responding to toileting needs has been reported to be on the increase. Responders complete a written report (standard form) for every response visit made. These are scanned and copied to Care Managers who can use the reports to monitor clients over time and to reassess/review their needs.

### 5.2.1.1 Referral to Community Alarms / Telecare services

Despite the level of coverage and activity evident in Scotland, no standardized approach to referral, individual needs assessment and specification of appropriate telecare solutions has emerged.  Documentation on the TDP provides some information on these processes in each local authority for purposes of that programme.[58]  In many cases, initial referral arose through trigger questions on the Single Shared Assessment (SSA)[59] procedure.  In practice, however, the evidence is somewhat mixed in relation to the quality of approaches to telecare assessment in the context of the Single Shared Assessment (SSA) process.

Other referral sources included various health and social services as well as self-referral.  More specific telecare needs assessments are made by frontline professionals, sometimes with the support of dedicated internal telecare functions where these are in place. A telecare prompt has been included in the National Minimum Information Standards that guide assessment and care planning for all adults in Scotland (Joint Improvement Team, 2010).

#### Table 2 Call handling and Responder Provision Arrangements in a selection of Community Alarm and Telecare Services

| Local Authority | Call Handling Provision | Responder Provision |
| --- | --- | --- |
| Aberdeen City | In-house provision through Aberdeen Regional Communication Centre (ARCC) | Most users have informal contacts as main responders. The Community Alarm Service (CAS) operates a responder scheme for approximately 100 dispersed alarm service |

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[58] Sergeant, E. (2010) *Summary of telecare services in Scotland*.  Edinburgh: Joint Improvement Team.

[59] Scottish Government (2005) *Single Shared Assessment - Indicator of Relative Need - Operational Guidance Resource Pack*. Available at: http://www.gov.scot/Publications/2005/02/19542/39298 (accessed during 2014 phase of research).

| | | users – 3 Community Alarm Assistants act as responders between 8am and 6 pm and mobile wardens cover from 6pm to 8 am. There is ongoing discussion with British Red Cross regarding an expansion of this service utilising volunteers as 1st Responders. |
|---|---|---|
| Angus | In-house combined calls handling and responder provision. | Consists of 4 Teams with staff operating in pairs, providing 24/7 services. The teams work across the Angus area aiming to provide a response within 20 minutes, accessing specially equipped vans, enabling access to hoists etc. The calls handling and response provision is provided by Social Care Officers who are trained to SVQ Level 2. |
| Argyll & Bute | Contract with Hanover Telecare | Most clients are asked to name their own key holders who are known to them. Red Cross volunteers also respond in some areas where clients do not have nominated key holders. During working hours local homecare staff are available to respond in absence of nominated key holders. Carr-Gomm provide an overnight response (11pm to 7am) within eight areas and gain access via a keysafe |

| Clackmann-anshire | Contract with Stirling Council in-house provision. | In-house Mobile Emergency Care Service (MECS) which provides a 24/7 responder service and related support, having access to an equipped van. Staff carry out reviews, battery checks and recommissioning/ decommissioning as required. Staff are trained to a minimum of SVQ Level 2 and additional appropriate training. Keysafes are being increasingly used to enable access of responders. |
|---|---|---|
| East Lothian | In-house service which supports all Council call handling provision | 24 hours service - EL Emergency Care Service (ECS) - now available. It provides a response service including "falls pick-up" and a crisis care service as required. Referrers for community alarms/telecare are encouraged to provide two informal local contacts/key holders where at all possible but ECS will be available to them and can be recorded as the only or second responder for clients who have one or no informal local contact.  A Falls Care Pathway has also been set up with healthcare; where a resident without a community alarm/telecare calls NHS24 or GP Surgery with uninjured fall, health services can access ECS to |

| | | |
|---|---|---|
| | | request a staff visit to assist |
| Midlothian | Contract with East Lothian | Two Carers from the Rapid response Team are on call to respond to Telecare activations 247. They back up service users who have their own responder/key holders but who may to be available at that particular time as well as covering service users who have no personal responders. Also respond to uninjured fallers for both groups. |
| Moray | Contract with ARCC | Reliance on named key holders. Some additional informal provision was previously provided by Red Cross but contract terminated in 2011 due to lack of available volunteers. An Intermediate Care Team has recently been set up via Change Funding which will offer a limited overnight response service for community alarm / telecare users. |
| North Lanarkshire | In-house service dedicated to community alarm service | 1st responder may be a relative or informal carer. Responder service is available, based with Community Alarm Team on 24/7 basis, for vulnerable users. |
| Renfrewshire | Contract with Hanover Telecare | Renfrewshire 24 provide 24/7 responder provision which is integrated with rapid response, overnight |

| | | homecare and out of hours homecare management support (including assessment and care planning processes). This service employs 30 staff. |
|---|---|---|
| South Ayrshire | In-house provision through South Ayrshire Monitoring Station (SAMS) | Integral response provision with SAMS. 14 Staff cover a 24/7 responder service, with the service being managed through Homecare. Mobile Attendants also complete installations and carry out service reviews. All staff receives training from Tunstall and some have and some are, working towards SVQ Level 2, in care. |
| Stirling | In-house calls handling provision, which provides for all of Stirling Council's call's handling services | An established Mobile Emergency Care Service (MECS) has been built upon to provide a responder provision across Stirlingshire and sits within Intermediate Care services |

## 5.2.2 Who can access the service?

The Scottish Government estimated that, in March 2012, there were just over 110,000 clients receiving community alarm and telecare services (Scottish Government, 2012) and in 2018, this figure was estimated to be 160,000[60]. As in the other countries reviewed for this study, community alarms in Scotland have been mainly targeted towards older people.

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[60] Scottish Centre for Telehealth and Telecare (2018) *Telecare*. Available at: https://sctt.org.uk/programmes/telecare/ (accessed June 2018).

Table 3 shows the breakdown of service users from the Scottish Government's 2012 report, with the vast majority being Community Alarm users over the age of 65. That said, 14.1% are younger than 65 and tend to be more frequent users of telecare only or telecare-and-community-alarms groups, as opposed to users of community alarms only. The coverage index rate in Scotland ranges from 12 – 19% which places Scotland near to or at the top end of the scale internationally in terms of overall provision/usage of telecare.

Figure 6 presents overall levels of usage by age group across the partnerships in Scotland.

The Scottish data also provides an insight into the provision of community alarms and/or telecare to clients receiving home care services - disaggregated from statistics on all users of community alarms and telecare (Table 4).  About 54% (33,937) of community alarm or telecare services were delivered to home care clients.

### Table 3 Local Authority clients receiving Community Alarms and Telecare in Scotland (2012)

|  | Community Alarm only | | Another telecare service only | | Both services | | Total | |
|---|---|---|---|---|---|---|---|---|
|  | Users | % | Users | % | Users | % | Users | % |
| Under 65 | 11,295 | 12.5 | 1,014 | 26.9 | 3,168 | 19.5 | 15,477 | 14.1 |
| 65 plus | 77,501 | 86.1 | 2,747 | 72.1 | 13,044 | 80.3 | 93,292 | 84.7 |
| Unknown | 1,269 | 1.4 | 8 | 0.2 | 42 | 0.3 | 1,319 | 1.2 |
| Total | 90,065 | 100.0 | 3,769 | 100.0 | 16,254 | 100.0 | 110,088 | 100.0 |

## Rate of Community Alarm and Telecare use per 1,000 population
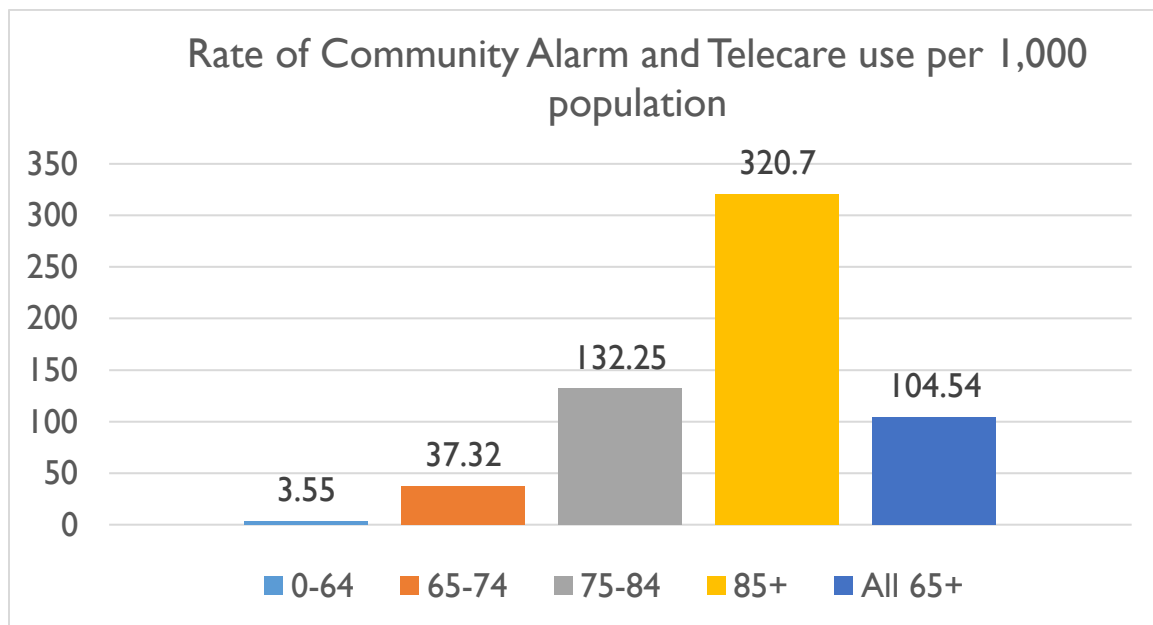


**Figure 6 Local Authority clients using Community Alarms and Telecare in Scotland**

The highest levels of provision of community alarms and telecare are provided to home care clients receiving services because of physical disability (61.4%), infirmity due to old age (58.3%) and people with dementia (51.6%).

**Table 4 Clients receiving Home Care and a Community Alarm and/or Telecare by client group (Scottish Government, 2012)**

| Client group | Home care clients | Home care clients provided with community alarms/telecare | | | | | | | |
| | | Community Alarm only | | Another telecare service only | | Both services | | Total community alarms/ telecare | |
| | | Users | % | Users | % | Users | % | Users | % |
| Infirmity due to age | 31,416 | 15,125 | 48.1 | 639 | 2.0 | 2,540 | 8.1 | 18,304 | 58.3 |

| Client group | Home care clients | Home care clients provided with community alarms/telecare | | | | | | | |
| | | Community Alarm only | | Another telecare service only | | Both services | | Total community alarms/ telecare | |
| | | Users | % | Users | % | Users | % | Users | % |
|---|---|---|---|---|---|---|---|---|---|
| People with dementia | 3,284 | 1,116 | 34.0 | 85 | 2.6 | 492 | 15.0 | 1,693 | 51.6 |
| Mental health | 2,777 | 603 | 21.7 | 85 | 3.1 | 197 | 7.1 | 885 | 31.9 |
| Learning disability | 4,588 | 617 | 13.4 | 114 | 2.5 | 224 | 4.9 | 955 | 20.8 |
| Physical disability | 17,526 | 8,429 | 48.1 | 397 | 2.3 | 1,934 | 11.0 | 10,760 | 61.4 |
| Other | 2,086 | 516 | 24.7 | 36 | 1.7 | 328 | 15.7 | 880 | 42.2 |
| Not known | 1,155 | 424 | 36.7 | 13 | 1.1 | 23 | 2.0 | 460 | 39.8 |
| Total | 62,832 | 26,830 | 42.7 | 1,369 | 2.2 | 5,738 | 9.1 | 33,937 | 54.0 |

It is likely that most of the people with dementia and many of the people with physical disabilities are in the older age group.  Nevertheless, a substantial proportion of people in other client groups receiving home care are benefitting from community alarms/telecare services. These include people with mental health problems (31.9%) and people with learning disabilities (20.8%).  The proportion of people with dementia, learning disability and mental health problems receiving advanced telecare of some form seems to be higher than overall usage.

The TDP assessment report (Joint Improvement Team, 2010) noted that the main reason for offering a community alarm or telecare service to new clients was meeting a (relatively) low level of client need rather than reducing specific resource utilisation. The allocation also provided peace of mind and respite for carers. Reasons linked to specific resource utilisation included the prevention or lessening of risk of hospital admission, prevention of care home admission and facilitation of hospital discharge.

### 5.2.3 Costs

Call-handling and responder services in Scotland are primarily funded through the mainstream social work budgets of the partnerships. In some areas this funding arrangement has been identified as unsustainable and user charging is being considered as a way to address funding shortfalls.

Available data for March 2010 indicated a range of charges from zero up to £6.75 per week. The most common fee was between £1 and £2 per week (Joint Improvement Team, 2010). In some partnerships this can be billed to users annually, or arranged for payment in instalments.

There is variation in terms of whether or not means testing is undertaken to establish service user ability to pay a charge. Telecare services additional to the basic community alarm service were, in 2010 and with a few exceptions, generally not subject to additional charges.

An example of costs related to community alarms in the Renfrewshire area, where the call handling and monitoring part of the service is outsourced, shows that the partnership pays by the number of connections supported each week. The cost per connection per week to the service provider is reported to be approximately £0.50.

### 5.2.4 Quality Assurance

Over the period of the TDP programme, a number of lines of activity addressed standards for telecare service.[61] The initial effort focused on encouraging partnerships to seek accreditation under a recognised framework such as that provided by the Telecare Services Association (TSA) in England. Quite a number of the partnerships are now members of TSA and some have achieved accreditation while others are formally working towards it.

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[61] Dementia Services Development Centre and Joint Improvement Team (2010a) *Telecare and Dementia: Using telecare effectively in the support of people with dementia*. Edinburgh: Dementia Services Development Centre / Joint Improvement Team.

The TSA developed the Quality Standards Framework (QSF) for the Technology Enabled Care industry (TEC). QSF is available to all organisations in the sector - service providers, suppliers, associations, emergency response services and third sector organisations, whether TSA members or not.[62] The framework is run by TEC Quality, who provide independent audit and accreditation against the standards of the QSF.[63] There are 10 standards modules and 3 service delivery models.[64]

**Standards Modules**

1. User and Carer Experience

2. User Safety

3. Effectiveness of Care

4. Information Governance

5. Partnership Working and Integrated Care

6. The Workforce

7. Business Continuity

8. Ethics

9. Performance and Contract Management

10. Continuous Improvement and Innovation

**Service Delivery Models**:

1. Telecare Monitoring

2. Assessment of and Installation of TEC

3. Response Services

Another set of activities focused on linking telecare standards to mainstream social care standards activities and processes.  This involved the Care Commission, Social Work Inspection Agency and the Scottish Social Services

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[62] TSA (2018) *An Introduction to QSF*. Available at: https://www.tsa-voice.org.uk/an-introduction-to-qsf (accessed June 2018).

[63] TSA (2018) *Who is TEC Quality?* Available at: https://www.tsa-voice.org.uk/who-is-tec-quality (accessed June 2018).

[64] TSA (2018) *QSF Modules.* Available at: https://www.tsa-voice.org.uk/qsf-modules (accessed June 2018).

Council in relation to service inspection and training and registration requirements for staff working in telecare services.  Work was also initiated to explore a common approach to standards and regulation for telehealth in cooperation with the (then) Scottish Centre for Telehealth.

Adhering to quality and compliance under these various bodies are considered good practice, rather than mandatory.

### 5.2.5 Outcomes

£8 million was disbursed during the first phase of TDP (2006-2008).  In 2010, an evaluation of the 2006-2010 period[65], found that:

- More than 29,000 people began a telecare service through TDP funding over the period 2006-2010. Over the whole period around 7,300 subsequently stopped receiving a service[66]

- Over 2,000 people that received a TDP-funded service are known to have dementia, but the true figure is likely to be significantly higher

- By 31st March 2010, local partnerships had spent £10.4 million of TDP funding and another £2.6 million as match funding

- Around 1,500 hospital discharges were expedited due to TDP funding against an initial business case expectation of about 1,800

- Around 6,600 unplanned hospital admissions were avoided against an expectation in the initial TDP business case of around 3,800 unplanned hospital admissions

- Over 2,650 care home admissions were avoided against an initial business case expectation of 3,025

By achieving the above outcomes, partnerships saved around:

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[65] Joint Improvement Team (2010) *An assessment of the development of telecare in Scotland: 2006-2010*. Available at: http://www.gov.scot/Resource/Doc/328586/0106225.pdf (accessed June 2018).

[66] NOTE: The reasons given for the turnover were not outlined fully in the evaluation. "Over time the turnover rate (defined as the number of people that stop using a TDP funded telecare service within a year as a proportion of the gross number of new clients within that year) has been increasing. This is perhaps not surprising; as time has passed, increasing numbers of initial beneficiaries of TDP funded telecare would be expected to not require it for a number of reasons." (p.7) However, other jurisdictions would highlight mortality and moving into residential services as reasons for withdrawing from telecare.

- 346,000 care home bed days (against an expected 188,000 outlined in the initial business case for TDP)

- 65,000 hospital bed days through facilitated discharges and unplanned admissions avoided (against an expected 80,000 in the initial business case for TDP)

- 35,000 nights of sleepover/wakened night care (against an expected 55,000 in the initial business case for TDP)

- 411,000 home check visits were less than anticipated (against an expected 615,000 in the initial business case for TDP)

Overall, the gross value of TDP funded efficiencies over the period 2006-10 is approximately £48.4 million at 2016 prices. The financial value of gross benefits achieved was close to expectations, given the uncertainties involved in business planning. Much of the focus of the telecare strategy in the 2008 -2010 period was about providing guidance and support to care partnerships, and developing the 'infrastructure' necessary to deliver effective telecare services.

The TDP case in Scotland showed that installation of telecare and telemonitoring devices had a significant impact on the employment situation of informal carers. Knowing that they would be informed immediately if any problems occurred made it easier to leave the patient temporarily, enabling the carer to continue or restart employment.[67] As with other jurisdictions, telehealthcare may indirectly offer cost benefits to the wider economy.

Where responder services have been in place, similar to Spain, they have shown that they can facilitate cost savings in areas such as falls management and reduce the need for formal health and residential care services. For example, equipping responder teams with lifting cushions has been reported to have avoided the need for ambulance call outs in a substantial number of cases.

However, the evaluation also highlighted that the TDP telecare services still had ground to make up before being mainstreamed into services (Table 5). Partnerships were asked to rate the extent to which telecare services had been embedded, where 1 represented 'not started' and 10 represented 'completed'.

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[67] Dobrev, A., Meyer, I., Müller, S., Kubitschke, L., Hammerschmidt, R., Korte, W.B., Hüsing, T., van Kleef, T., Otto, S., Heywood, J. and Wrede, M. (2013) *Coping with an ageing population – Learning from good eHealth and telecare practices. The eCare Benchmarking study* (Contract Number: 30-CE-0358386/00-54). Bonn: European Commission, DG Information Society & Media Contract Number. p.65

**Table 5 Extent to which telecare had been embedded in services by partnerships[68]**

| | Mainstream Assessment Process | Care management and review processes | Care at home service | Community equipment service | Approach to managing long-term care and dementia | Budget setting processes |
|---|---|---|---|---|---|---|
| 1 | 0% | 0% | 0% | 22% | 6% | 9% |
| 2 | 6% | 6% | 3% | 0% | 9% | 16% |
| 3 | 9% | 3% | 9% | 16% | 13% | 19% |
| 4 | 6% | 16% | 9% | 13% | 25% | 3% |
| 5 | 6% | 9% | 19% | 3% | 6% | 13% |
| 6 | 13% | 13% | 16% | 6% | 16% | 13% |
| 7 | 9% | 22% | 6% | 6% | 6% | 3% |
| 8 | 25% | 13% | 13% | 13% | 6% | 6% |
| 9 | 6% | 3% | 9% | 3% | 0% | 9% |
| 10 | 16% | 13% | 9% | 6% | 6% | 6% |
| No response | 3% | 3% | 6% | 12% | 6% | 3% |
| Total | 100% | 100% | 100% | 100% | 100% | 100% |

## 5.3 Telehealth Initiatives in Scotland

A number of trials, pilots and small-scale telehealth projects have taken place in Scotland. As of 2018, they have not reached mainstream roll-out and the mechanisms of each have not been described in depth. However, together they give a flavour of the direction in which telehealth in Scotland is moving.[69]

### 5.3.1 Telescot programme

The Telescot programme[70] is based in Lothian and is a collaboration between NHS Lothian, Edinburgh University, Edinburgh Napier University, SCTT, Chest Heart & Stroke Scotland, The Scottish Chief Scientist's Office and others. It is

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[68] Joint Improvement Team (2010) *An assessment of the development of telecare in Scotland: 2006-2010*. Available at: http://www.gov.scot/Resource/Doc/328586/0106225.pdf (accessed June 2018). p.24

[69] Watson, D. and O'Sullivan, T. (2012) *Alarm Monitoring and Response Services in Scotland*. Edinburgh: Joint Improvement Team.

[70] This was reported on in the 2014 phase of National Disability Authority research

primarily an academic research project involving a series of randomised controlled trials aimed at supporting people with a range of long-term chronic conditions including COPD, congestive heart failure, diabetes, and hypertension. It also involves a small telehealth trial with stoke/TIA patients. The programme aims to assess the potential role of technology in early intervention and examines clinical outcomes, cost efficiency and user experience.

### 5.3.1.1 Hypertension Trial

As of 2014, this was the only Telescot trial that had been completed and reached report stage. It investigated whether changing NHS services to support self-care helped to reduce blood pressure for hypertensive patients, whether it improved patient knowledge and sense of empowerment around blood pressure control, and what users thought of the service.  Over a six-month trial period, supported telemonitoring was found to be more effective than usual care at reducing blood pressure. However, it was also more costly.

The report concluded that these additional costs would probably be balanced by reduced costs of future cardiovascular events, assuming that clinical gains were sustained. It recommended more long-term modelling of costs and outcomes to fully examine the cost-effectiveness implications.[71] With regard to patient and staff experiences, the study found that although patients became more engaged in the clinical management of their condition, telemonitoring challenged the existing roles and work practices of professionals and increased their workload.[72]

### 5.3.1.2 Other trials

Telescot have also run (or are running) the following:

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[71] Stoddart, A., Hanley, J., Wild, S., Pagliari, C., Paterson, M., Lewis, S., Sheikh, A., Kirshan, A., Padfield, P. and McKinstry, B. (2013) 'Telemonitoring-based service redesign for the management of uncontrolled hypertension (HITS): cost and cost-effectiveness analysis of a randomised controlled trial'.  *BMJ Open*; **3**(5). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3657667/ (accessed during 2014 phase of research).

[72] Stoddart, A., Hanley, J., Wild, S., Pagliari, C., Paterson, M., Lewis, S., Sheikh, A., Kirshan, A., Padfield, P. and McKinstry, B. (2013) 'Telemonitoring-based service redesign for the management of uncontrolled hypertension (HITS): cost and cost-effectiveness analysis of a randomised controlled trial'.  *BMJ Open*; **3**(5). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3657667/ (accessed during 2014 phase of research).

- The COPD Trial[73]: 55 patients in Edinburgh, all stable and not at risk of hospitalisation were issued with a 'Simple Telehealth' system. Patients were provided with pulse oximeters (to self-test their blood oxygen saturation levels) and personalised health management plans but they are not monitored remotely. Evaluation of the programme showed that in quantitative terms, the system did not reduce hospital admissions when compared with usual care. It increased workload in primary care and was not cost-effective. There was no evidence of impact on quality of life, anxiety, condition knowledge or self-efficacy. Interestingly though, the qualitative results showed that the intervention was very popular with patients who felt well cared for, and with those clinicians who used the system who felt that care and patient self-management had improved as a result.[74] Based on the results, it was not recommended that the project by scaled up.

- The Congestive Heart Failure Trial[75]: this aims to determine if telemonitoring services deployed by NHS Lothian are acceptable to patients with congestive heart failure and their clinical staff and if such services increase or reduce workload for the NHS.

- The Diabetes Trial[76]: this trial is assessing whether a telemonitoring system can help reduce the blood glucose, blood pressure and weight of people with Type II diabetes who have poor control of their symptoms.  It also aims to assess if telemonitoring can help improve the quality of life of diabetics, and save patients and their clinicians' time.

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[73] Source: http://www.telescot.org/copd.html (accessed on 24/08/2013). This website is not active anymore but further details of current Telescot programmes can be found here: University of Edinburgh (2018) *Usher Institute of Population Health Sciences and Informatics – TELESCOT*. Available at: https://www.ed.ac.uk/usher/telescot (accessed June 2018).

[74] University of Edinburgh (2018) *Usher Institute of Population Health Sciences and Informatics – TELESCOT: COPD*. Available at: https://www.ed.ac.uk/usher/telescot/projects/completed-projects/copd (accessed June 2018).

[75] Source: http://www.telescot.org/heart-failure.html (Accessed on 24/08/2013) This website is not active anymore but further details of Telescot programmes can by found here: University of Edinburgh (2018) *Usher Institute of Population Health Sciences and Informatics –TELESCOT*. Available at: https://www.ed.ac.uk/usher/telescot (accessed June 2018).

[76] Source: http://www.telescot.org/diabetes.html (Accessed 24/08/2013) This website is not active anymore but further details of Telescot programmes can by found here: University of Edinburgh (2018) *Usher Institute of Population Health Sciences and Informatics –TELESCOT*. Available at: https://www.ed.ac.uk/usher/telescot (accessed June 2018).

### 5.3.2 United4Health[77]

Scotland has also participated in a number of pan-European telehealth projects. Scotland (through NHS24) coordinated United4Health which trialled telehealth services in 14 regions across the EU and involved the telemonitoring and treatment of patients with COPD, congestive heart failure and diabetes. The aim of the project was to promote self-care and assess the effectiveness of telemonitoring in the management of these conditions.

The United4Health COPD trial involved short term follow-up post hospital discharge. Patients were monitored intensively for first 10 days using home telemonitoring, telephone and video support. This was then stepped down to home telemonitoring (not including spirometry), and then further stepped down to a lighter touch with people reporting verbally. Figure 7 shows how integrating telehealth changes the nature of the care service model.

### 5.3.2.1 Delivering Assisted Living Lifestyles at Scale (DALLAS)

Another initiative was the 'Living it Up' programme which was Scotland's element of the wider UK DALLAS programme. Living it Up was a three-year programme involving five local partnerships across Scotland and its objective were to enable people to improve their health and well-being. The programme aimed to deliver integrated health, care and wellbeing services, and information and products via familiar technologies such as TVs, mobile phones, games consoles, computers and tablets.

NHS 24 was responsible for providing overall leadership, coordination, programme management and financial governance for the project. The programme was funded through the Technology Strategy Board and 3,000 people had been recruited as of 2014. The aim was for 55,000 people to be recruited by the end May 2015 with 50% having long term conditions. A key element of the Living it Up programme was co-production in the design of the system. This is discussed in more depth in Section 7.3.4.1.

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[77] United4Health (2016) *Telehealth in Practice Care Delivery Models from 14 Regions in Europe*. Glasgow: United4Health. Available at: http://united4health.eu/wp-content/uploads/2016/01/U4H-Brochurev1.0.pdf (accessed June 2018).
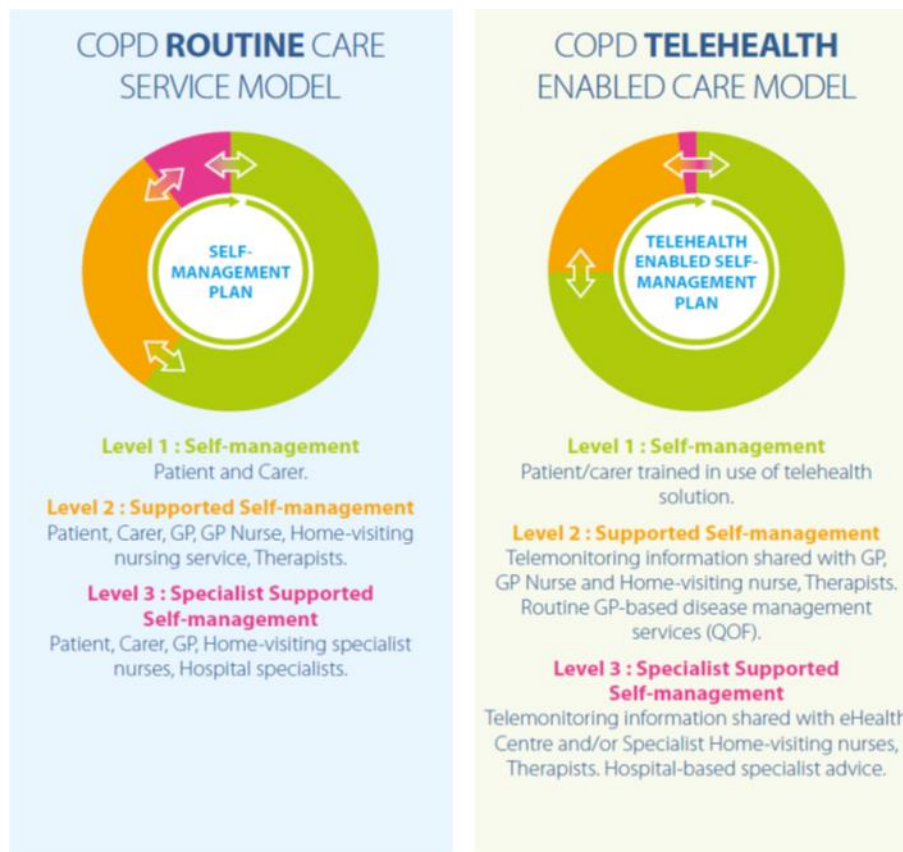
**Figure 7 United4Health COPD Project Scotland - Effects of telehealth on care models**

## 5.4 Key learning points

Scotland has a relatively developed system of telecare in place, using both traditional alarms and more advanced devices. Coverage rates are comparatively high (12-19%) though target groups have been predominantly older users (65 plus). As with other jurisdictions, there is some variability in the mechanisms of delivery – partnerships may have embedded telecare to varying extents, different processes and service models. However, health and social services are administered by the same agencies (as with all territories in the UK) and it allows for telecare initiatives to be integrated into social and healthcare responses.

There are a number of strengths in the Scottish TH/TC system that Ireland can learn from. First, the establishment of the Scottish Centre for Telehealth and Telecare (SCTT) and the National Telehealth and Telecare Delivery Plan to 2015 are evidence that a national system framework is in place that will drive the development of TH/TC in Scotland. The country explicitly set out to become

internationally recognised for TH/TC. Strategically, Scotland has integrated the vision for telecare and telehealth and linked in with existing services, e.g. NHS24 (tele-helpline), Scotland Excel (procurement) and SWAN (ICT network), to deliver initiatives.

A second aspect is that quality is attended to in TH/TC through the TEC Quality Standards Framework. Though not mandatory, providers are encouraged to comply with these standards and gain accreditation. As a result, good practice guidance and staff development are most highly developed in Scotland where a series of guides were produced in relation to telecare services for people with a range of conditions including dementia and various disabilities. These guides also address ethical issues that can arise with regard to various conditions. In addition, staff training was addressed and a model for an induction training programme was developed.

A third positive is the inclusion of co-production as a key process in the development of TH/TC initiatives (discussed more in Chapter 7). Co-production is a practise that aids in the universal design of products and services. If done well, this should allow for design flaws and opportunities to be realised and ironed out in the design phase of services. Links to complementary organisations and strategies provide practical ways for users to be included in the design of TH/TC, e.g. the Scottish Co-Production Network, and the National Standards for Community Engagement. An additional element to this has been the efforts to share good practice within the social and healthcare system, e.g. through learning forums.

Telehealth has been prioritised for development although to date, initiatives remain at the pilot/trial phase. Most initiatives have concentrated on telemonitoring and to a lesser extent, telerehabilitation. Perhaps a knock-on effect of the strong policy-driven national agenda for TH/TC and the growth in pilot/trial projects has been that outcomes and cost efficiencies have been well mapped and data are available, e.g. the business case for the TDP could be measured against later actual outcomes. As national roll-out of telehealth is within the remit of the SCTT, there is a drive to systematically find initiatives that work.

# 6.0 Spain - 'Teleasistencia Domiciliaria' (TD)

The Spanish approach to the deployment of basic telecare and social support can provide useful guidance about how legislation, regulation, quality assurance and procurement standards can be put in place. Telehealth remains unestablished and as result, this national review focusses on the provision of telecare through the *Teleasistencia Domiciliaria* (TD) service.

## 6.1 Overview

Spain has had a top-down development of telecare since the 1990s. TD is included as part of the social care provisions for older people and other appropriate groups in Spain, and is firmly embedded within the system of social care services and supports.

Public telecare services are provided by a mix of private and non-governmental telecare providers. There are also a number of private telecare service providers (both commercial and non-profit organisations, such as the Red Cross) that offer various forms of more advanced telecare for private subscription.

In general, public telecare provision focusses on the traditional home unit and pendant for service users. In addition to responding to calls initiated by the user through their home unit, the telecare service includes proactive calls and other services initiated from the call centre. There can be a social element to these calls, for instance, on national holidays or the user's birthday. More advanced telecare (involving environmental and movement sensors) is also becoming more available through TD, though in low volume.

The objectives of the TD service[78] are to:

- enable the person to remain living in their normal way of life and social environment,

- ensure immediate intervention in the event of crisis, and

- make a substantial contribution to preventing unnecessary admissions to residential care.

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[78] IMSERSO-FEMP (1999) *Normas Generales del Servicio de Teleasistencia Domiciliaria*. Available at: http://www.todossc.es/repositorio/20120924102815_normasteleasistencia.pdf (accessed June 2018).

## 6.1.1 Key Policy Developments

In 1992, the development of *Teleasistencia Domiciliaria* as a national programme for telecare was initiated by the National Institute for Elderly and Social Services (IMSERSO), an agency of the national Health and Social Policy Ministry, located within the General Secretariat for Social Services and Equality. The initiative was deployed through an agreement between IMSERSO and the Spanish Federation of Municipalities and Provinces (FEMP) in 1993.

> **Key Policies, Standards and Laws**
>
> Normas Generales Del Servicio De Teleasistencia Domiciliaria (1999)
>
> UNE 158401 (2007)
>
> Law 39/2006 on Promotion of Personal Autonomy and Care of those in Dependent Situations (Dependency Law)

IMSERSO and FEMP developed and implemented guidance/standards for TD (**Normas Generales Del Servicio De Teleasistencia Domiciliaria**) to be implemented by provinces and municipalities, who are in receipt of central funding, setting up a service in their area (IMSERSO-FEMP, 1999). The guidance has an emphasis **on operational elements**, such as:

- the characteristics of the home telecare (TD) service

- procurement procedures

- user target groups (and exclusion criteria) and

- various service quality issues[79]

    - requirements for the public authority that is contracting the service and the interworking between the authority and the contracted telecare provider

    - requirements for the telecare provider to

        - have a dedicated focus on telecare or other social care services

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[79] IMSERSO-FEMP (1999) *Normas Generales del Servicio de Teleasistencia Domiciliaria*. Available at: http://www.todossc.es/repositorio/20120924102815_normasteleasistencia.pdf (accessed June 2018).

- (if also engaged in other fields, such as security) have a telecare department or unit totally separate from these other activities

- have their own call centre and staff dedicated to the service

- have a system of quality assurance in accordance with UNE / EN / ISO 9002, and

- have an appropriately staffed office in the area served, although the call centre might be located outside the area served as long as the cost of calls is not higher than a local call.

Requirements on the user terminal are also specified and are discussed in more detail in *Chapter 7*.

In 2007, the requirements for providers and minimum service levels were set out in the Spanish standard for telecare service management - **UNE 158401**. This is the main reference document used in public-private contracts for telecare, and service specification in public tenders for telecare services. Where *Normas Generales* gives overarching guidance, UNE 158401 emphasises matters of **day-to-day service operation**.

The standard aims to promote personal autonomy and care to persons in situations of dependency. The aims of the service include supporting the person to remain in their everyday environment; ensuring their safety and confidence in times of personal, social or health crises; and promoting contact with their social and family environment.

The standard specifies minimum requirements in various areas, including:

- Provision of the telecare service in terms of service access conditions, information provided, data collection, contractual relations, etc.

- Human resources, training and  qualifications

- Physical resource specifications for the call centre, mobile units, user equipment, etc.

- Service protocols for call handling, e.g. incoming/outgoing, emergency, social and reminder calls

- Service protocols for setting up new users, house key custody (if applicable), communication with public administrations, preventive and corrective protocols, etc., and

- Quality systems and procedures, verification and validation of quality indicators.

In January 2007, Law 39/2006 on *Promotion of Personal Autonomy and Care of those in Dependent Situations* (**Dependency Law**) entered into force[80]. The TD service was listed as one of the basic services to which people in a dependent situation are entitled to in terms of social care provision.

This provision therefore placed obligations on the provinces and municipalities, which have responsibility for the promotion of personal autonomy and care of those in dependent situations, to ensure access to telecare for these groups under their remit.

The Dependency Law is implemented through the System for Autonomy and Support of Dependency (SAAD). This is a set of assistive mechanisms and financial supports.

The SAAD procedures can involve a mix of public services provided at regional and local levels, third sector providers, and private for-profit providers.  Funding for services is derived from a combination of General State Administration funds, FEMP funds and user contributions towards costs of services.

## 6.2 How does Telasistencia Domiciliaria work?

The TD service outlined under the IMSERSO-FEMP agreement provides the following services:

- Immediate support via the telephone line to calls coming from the user (this may be related to general needs for help, anxiety, loneliness, as well as domestic accidents, falls, etc.)

- Mobilization of resources in response to emergencies (health, home situation or social)

- Ongoing monitoring from the service centre through periodic phone calls

- An agenda service, to remind the user about things they needs to do such as taking medication or attending scheduled appointments for services/activities.

There are two main modes of telecare delivery. One mode is a phone-based service provided from a call centre (no responder service); the other mode is

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[80] Government of Spain (2006) *Law 39/2006, of December 14, on the Promotion of Personal Autonomy and Care for people in situations of dependency*. Madrid: Agencia Estatal Boletín Oficial del Estado. Available at: https://www.boe.es/buscar/doc.php?id=BOE-A-2006-21990 (accessed June 2018).

where the call centre service is complemented with (formal) mobile response units to provide relevant home interventions.

The phone-based service provides for linking the user with informal responders (e.g. family) and pro-active calls.

Mobile response units can go to the user's home, providing basic supports such as first aid, help in getting up from a fall where there is no injury, fixing minor problems, or other relevant interventions.  The telecare service mobile responder may also call the medical emergency services to the home if this is required, and can brief them on the nature of the problem so that they can be better prepared when they arrive.

A disadvantage of the service in many areas is the reliance on landlines to set up and use the system.

### 6.2.1 Who can access the service?

The Dependency Law defined dependent situations as people in need of care due to illness, disability or age.[81]  The *Normas Generales* set out a number of user exclusion criteria - for example, service users who have (cognitive) difficulty understanding, e.g. those with dementia, and people with severe speech and language impairments. Otherwise, TD is targeted at the following groups

- older people and people with disabilities

  - living alone permanently or for much of the day, or

  - living only with other people in similar circumstances

- people at risk of fear or anxiety because of geographical or social isolation

- risk arising from old age, disability or illness, and

- those with low income.

Telecare in Spain is generally targeted towards older people and/or those who are deemed dependent under the provisions of the Dependency Law and SAAD. All dependent people (apart from those receiving an assisted residential service) have the right to access a telecare service when it is specified in their personal assistive programme following assessment.

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[81] Eurofound (2009) *Law to support care of dependent people, Spain*. Available at: https://www.eurofound.europa.eu/data/tackling-undeclared-work-in-europe/database/law-to-support-care-of-dependent-people-spain (accessed during 2014 phase of research).

In 2011, it was reported that more than 690,000 people were using the TD service nationwide. There has been sustained growth in the **median coverage index**, from 1.13% in 2000 to 8.4% in 2011. The main published statistics on the user population tend to refer only to older people, with typically more than one-half of the users across the regions being more than 80 years of age (IMSERSO, 2012).

### 6.2.2 Who is responsible for telecare?
Telecare is administered through the autonomous administrative provinces and municipalities (FEMP). Despite TD being an overall national service model, there are some variations in the mechanisms of implementation as a result of regional variations and the methods of delivery. Two models have emerged:

- Each province/municipality procures the service from telecare providers (for-profit companies or third sector organisations like the Red Cross) through public tendering – overwhelmingly the most common practice (e.g. in the Municipality of Madrid)

- Provision of telecare services directly by the province's public services (in the province of Andalucía only).

The IMSERSO website lists more than 40 public telecare services that were in operation at regional, provincial or local levels in 2009.  At the end of 2012, the central funding stream from IMSERSO to provinces and municipalities for telecare was withdrawn.[82]  This has led to some consolidation of public service provision, with smaller provincial and municipality services stopping and/or being amalgamated into larger ones, sometimes operating at regional level (e.g. in Andalucía).

### 6.2.2.1 At the operational level
Madrid's system of TD shows one model of responsibility at the operational level that takes in user engagement, municipal actors and private providers (see Figure 8). *Servicios de Teleasistencia S.A.* (ST) won the contract to provide telecare services in the Municipality. An individual (or their family) who wishes to apply for the TD service can either call the Municipality's Citizen's Information telephone number or go to any of the Municipality's Citizen Information Offices or Social Services Centres - **self-referral to TD is possible**.

A form is filled out and may be accompanied by additional documentation, e.g. Disability or Dependency Certificates (for persons under 65 years of age).

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[82] NOTE: The typical agreement for provincial and municipality services did include a funding rate of 65% by IMSERSO with the rest covered by the local authority's funds and user charges

Persons over 65 who live alone and who present the completed application form in the Citizen Information Offices do not have to submit any additional documents.

The Social Services department assess the application form, and decide if the person is eligible and whether the installation is urgent or not. Social Services contact ST and pass on all the necessary personal information (name, address, telephone number, and so on)[83] and the type of client it is.

An interesting feature of this system is that from the point of installation on, the staff interacting with the user (e.g. assessing, responding, training) are all primarily ST staff rather than, say, public health / social care staff. However, all contact with the user is made in the name of the "Municipality of Madrid" – from telephone greetings to forms to staff uniforms.

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[83] NOTE: When the original research phases in 2014, 2016 and 2017 were in development, GDRP regulations had not yet been implemented. It is unknown how the new regulatory environment has affected operational details like this. Likewise, private operators hold sensitive health information and other demographics on the user-base and it is unclear if this can be repurposed for commercial use.
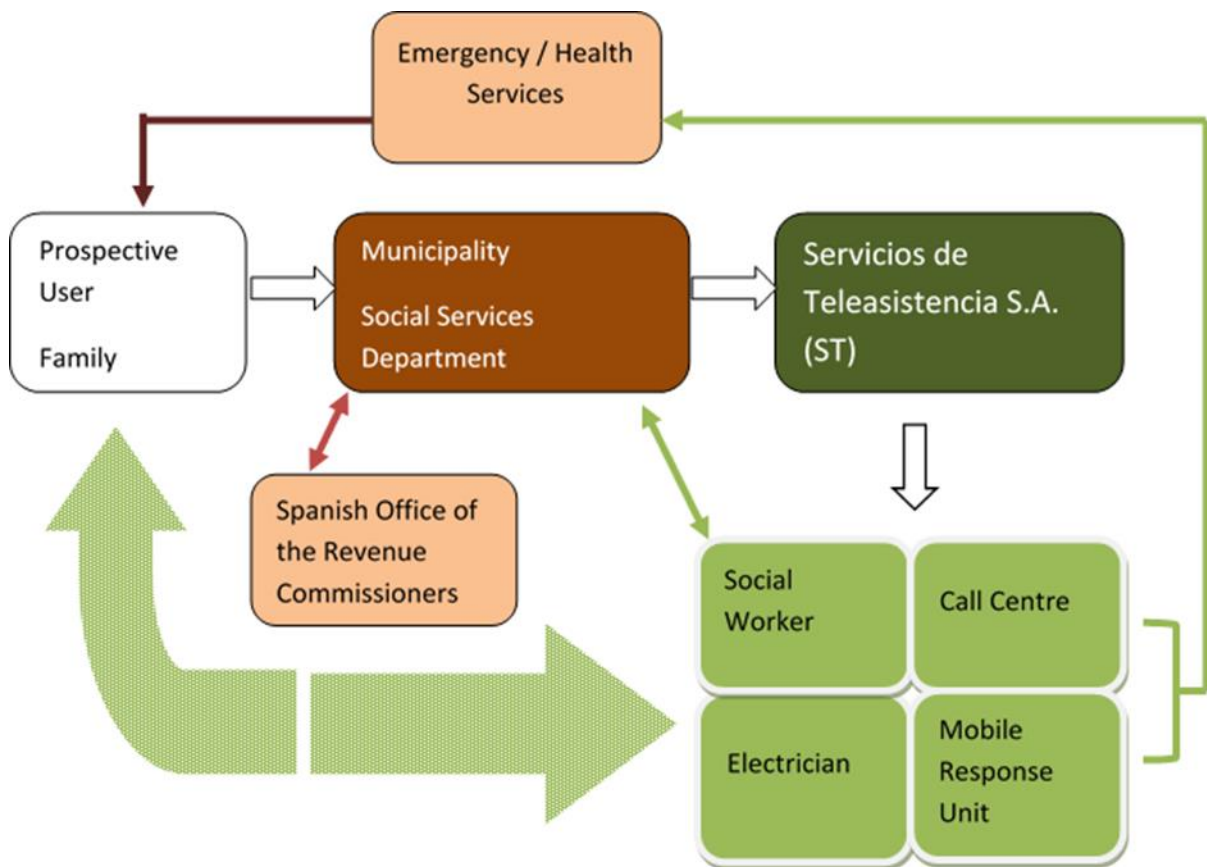
**Figure 8 Relationship between actors in the Madrid TD system**

The service provider employs social workers who have a number of roles within the system:

- Attend initial consultation – gather information on the individual/family/household, user's health, emergency contacts, etc.

- Assess the functional status of the user using the Barthel, Barber and Lawton tests (this information is used as a baseline for future visits)

- Train the user to use the system, demonstrate the functions

- Annually assess the user, or sooner, if a deterioration in their condition has been reported, and

- Act as a liaison between the Municipality's Social Services department and the service provider, sending regular reports on the number of incidents, calls, etc.

A different model of responsibilities and relationships can be seen in the region of Andalucía. *Andalucian Tele-Assistance Service* (SAT) was created in 2002 and is reported to be the largest such service in Europe with almost 180,000 users as of 2014.  SAT is provided by the Andalucian Agency for Social Services and Dependency (ASSDA), which operates under the Regional Ministry of Health and Social Welfare.

This service operates as a telephone-based model, rather than a system of response being provided. Users can call, and are called, regularly through the system.

### 6.2.3 Costs

An overall figure for the national spend on the TD system is unavailable. The services are funded from a variety of possible sources – public funds, investment/grants and user contributions.

An example of service finances is Andalucía's SATS service, which is the only region in Spain to deliver TD directly. The TD service has two call centres, one in Seville and the other in Malaga, with a total of more than 180 call posts. SATS has more than 500 staff of its own. There are also more than 100 staff at a social insertion company[84] to which the home installation part of the service has been outsourced.

Overall financing of the service in 2012 amounted to just over €29.7 million.

This comprised €23 million from the regional government, €2.9 million from the service's own income (e.g. through user contributions) and €3.9 million from investment (through regional government funds).

In Spain, the principle of user contribution is a feature of *Teleasistencia Domiciliaria*.  The levels of user charging are determined at regional and local level, where a basic unsubsidised charge is set and then substantially (or even completely) discounted for many users based on income, needs and other factors.

Social Services  work out the corresponding monthly cost-sharing amount that the service provider will collect and likewise, that the client may pay. Costs to the user are allocated based on the household's average monthly per capita income. In order to accurately make this decision, the Social Services department

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[84] NOTE: These are a type of company operating in Spain's social economy. They provide employment to disadvantaged or excluded groups.

can access the individual's tax information through the Spanish Office of the Revenue Commissioners.

An example of user contributions in Madrid is described in Table 6.

**Table 6 User contribution per average monthly household income**

| Average monthly per capita income (per household) 2013 (€) | MONTHLY FEE (€) |
|---|---|
| Up to 460.29 | 0 |
| 460.30 to 614.29 | 3 |
| 614.30 to 768.30 | 6 |
| 768.31 to 999.32 | 9 |
| 999.33 or more | 12 |

Each province/municipality determines the basic (user) monthly price of the TD service.  Table 7 presents some of the variations in prices between regions. Annual fees range from a low of €110.37 in Navarra, to a high of €576.34 in Catabria (mean across regions is €287.25).

Since the economic crisis, and the withdrawal of central funding from IMSERSO, it is reported that public telecare services have begun to consider increasing co-payments and extending them to additional user populations in order to help finance the services provided.

Population density affects the design and cost-effectiveness of services, for example, it is cost efficient to enable mobile response units in an urban area like Madrid but less so when users are dispersed across a wide region.

## Table 7 Telecare user prices (2011)[85]

| Province/Municipality | Euro per year | Euro per month |
|---|---|---|
| Asturias | 274.00 | 22.83 |
| Illes Balears | 357.00 | 29.75 |
| Canarias | 288.00 | 24.00 |
| Cantabria | 576.34 | 48.03 |
| Castilla y León | 195.00 | 16.25 |
| Castilla-La Mancha | 153.81 | 12.82 |
| C. Valenciana | 254.40 | 21.20 |
| Extremadura | 264.00 | 22.00 |
| Galicia | 239.63 | 19.97 |
| C. de Madrid | 300.00 | 25.00 |
| R. de Murcia | 288.00 | 24.00 |
| C.F. de Navarra | 110.37 | 9.20 |
| País Vasco | 202.00 | 16.83 |
| La Rioja | 518.90 | 43.24 |
| España | 287.25 | 23.94 |

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[85] IMSERSO (2014) *INFORME 2012: Las Personas Mayores en España Datos Estadísticos Estatales y por Comunidades Autónomas*. Madrid: Administración General del Estado. Available at: http://www.imserso.es/InterPresent1/groups/imserso/documents/binario/infoppmm2012.pdf (accessed July 2018). p.208

## 6.2.4 Quality Assurance

Spain has well-developed standards and regulations to govern quality across telecare services, though there are some variations between regions based on service providers and contractual obligations.

In the Municipality of Madrid, the interplay of state regulatory bodies, municipal actors, and service providers are evident in how compliance is achieved. Service providers monitor key performance indicators related to the number of calls, response times, repair work, etc. The Municipality conduct annual audits which include spot checking call recordings and checking the entire process from installation to operation for a number of random cases. Yearly compliance audits of the UNE 158401 are also undertaken by the Spanish Association of Standardization and Certification (AENOR) which includes a review of the service provider's processes, its protocols and its redundancy and safety measures.

## 6.2.5 Outcomes

Users are surveyed on their satisfaction with the services received though clear evidence on the cost effectiveness or cost benefits of TD was not forthcoming in the reports reviewed.

In Andalucía, various user surveys are conducted with the results reported on the web.[86] Levels of user satisfaction are reported to have been continually increasing over the years, with a score of 9.8 (on a scale of 0 to 10) achieved in in 2012.

The vast majority of users would recommend the service to their relatives and friends and high ratings were given to various aspects of the service, including

- treatment by telecare staff

- ease of use

- contact frequency

- efficiency in solving requests, and

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[86] Source: Junta de Andalucía:
http://www.juntadeandalucia.es/organismos/saludybienestarsocial/actualidad/noticias/detalle/76976.html (accessed during 2014 phase of research). This website does not contain information currently however as of July 2018, information on the Andalucían telecare service can be found here:
https://www.juntadeandalucia.es/agenciadeserviciossocialesydependencia/en/canales_en/C_SAT_en/wfchannel_view_pub

- time from application to installation.

Another survey specifically addressed experiences of those who made emergency calls (by pressing the button on the home unit or pendant) and also found high levels of satisfaction with their experiences of this, including the care provided by staff during the emergency and monitoring provided after this.

In addition, 18% of those who had made such a call said that they would not have been able to contact the emergency services by phone in the situation; another 64% believed that they could have raised the alert by telephone but that this would have been more complicated.

A survey of family carers was also conducted in 2012. This found high levels of satisfaction with the operation of the services. Benefits such as peace of mind were reported by almost all carers, as well as many carers reporting benefits in terms of helping them to work outside the home and/or giving them more free time.

A survey of 700 users of the Madrid telecare services (ST) was commissioned by the municipality in 2012 (*Area de Gobierno de Familia y Servicios Sociales*, 2012). Some of the key findings are outlined in Table 8.

**Table 8 Survey responses from service users - % of respondents who strongly agreed with the following statements**

| User felt calmer | 93.7% |
|---|---|
| User's family had benefited | 92.1% |
| User felt more secure | 91.3% |
| User felt more accompanied | 90.0% |
| User had improved mood | 82.9% |
| User had improved autonomy and independence | 81.6% |
| User was more satisfied with life in general | 81.4% |
| User had improved general health | 74.6% |
| Helped to relate better to others | 71.6% |

Other positives about the service included:

- it enabled users to stay living at home under better conditions (94.7%)

- without the service users would have had to stop living in their home and look for other options (69.3%)

- high levels of overall satisfaction with the service (97.4%)

- almost all users agreed that they would request it again (99.0%) and recommend it to someone else (99.3%), and

- strong satisfaction was also indicated for specific parameters of the service

  - service personnel (98.0%)

  - functioning of the equipment (93.9%)

  - speed alarms were answered (87.0%)

  - speed at which the mobile unit arrived (80.7%).

Though difficult to quantify, indirect cost benefits of any TH/TC system should be considered. For example, services that assist informal carers to work outside the home or negate the need to pay for residential solutions to care (such as nursing homes) have a bearing. These workers can earn an income, contribute to the tax base and economy, while earnings lost through time spent caring have a cumulative effect nationally.[87]

## 6.3 Key learning points

*Teleasistencia Domiciliaria* is a traditional telecare model, stressing social rather than health factors. In many ways it is reminiscent of Ireland's Seniors Alert Scheme. A key aim of the service is to assist people to continue living independently in their homes.

Telecare provision is included in dependency legislation which requires that people meeting the eligibility criteria are provided with an appropriate service. This includes not only older people but people under the age of 65 years who are vulnerable. While enshrining telecare in Irish legislation may be premature, the concept of a strong national framework and the elements that should be included in this are worthy of consideration.

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[87] NOTE: This point was made during a presentation by Dominic Trepel at the ABI Research Seminar 2018 held in Dublin on 18 May 2018. Details available here: https://www.abiireland.ie/wp-content/uploads/2018/03/current-trends-and-future-horizons-Draft-programme.pdf

The broader social care model which has been integrated into telecare provision has the potential to provide not only risk management support but also emotional support and reassurance to address the community needs of users and to support them in living independently. The inclusion of a social component in an Irish telecare strategy should be considered.

It is not clear from reviewing the reports the depth to which health services link (if at all) with telecare providers other than assisting in responding to emergencies. Much like Ireland, telehealth is not well established in Spain. However, telecare has the potential to positively impact on health services. For example, Mobile Response Units are a feature of many telecare services in Spain. Though not always economically viable when the population is dispersed geographically, the inclusion of a mobile response component in an Irish telecare strategy could reduce reliance on already stretched emergency health services.

Though in some ways a small aspect, the ability of Social Services to check the income of prospective users by accessing their Revenue information is a useful process in assessing user contributions. Yet in the Irish system, the sharing of information between government agencies may be a thornier issue – for instance, public concern over the use of the Public Services Card to obtain passports or driver licenses; or, Irish Water holding/obtaining PPS numbers. Though user charging is not currently part of the Irish telecare system, it is likely that a system needs to be considered as an element of an Irish telecare strategy.

The key strength of the Spanish system of telecare is the regulatory environment and Ireland can benefit from studying this model more closely. *Normas Generales* and UNE 158401 offer detailed guidance on service levels, procurement matters, operational expectations, user groups, and design of devices, among other areas. Having these centrally mandated elements allows for regional flexibility in how services are set up and run, while not compromising on quality. These systematic approaches to procurement and monitoring could offer a template for designing a public-private strategy for delivery.

# 7.0 Universal Design in TH/TC

Universal Design (UD) is the design and composition of an environment, including any building, product, system or service in that environment so that all people, regardless of their age, size, ability or disability, can access, understand and use it.[88]

The seven principles of UD, if applied to TH/TC designs, can inform the design process and educate both designers and consumers about the characteristics of more usable products. The principles are as follows:

1.  Equitable Use

2.  Flexibility in Use

3.  Simple and Intuitive Use

4.  Perceptible Information

5.  Tolerance for Error

6.  Low Physical Effort

7.  Size and Space for Approach and Use

The Centre for Excellence in Universal Design (CEUD) within the National Disability Authority produces reports and guidelines and holds conferences/workshops on UD. In 2015, the CEUD produced Universal Design Guidelines for dementia friendly dwellings for people with dementia, their families and carers. This report addressed safety and technology systems, including assistive technology, telecare and telehealth.

Often, products are designed for exclusive categories of people – the able-bodied or the disabled. The reality is that capability varies widely and universal design includes those who might previously have been excluded from product use, as well as improving the product experience for others. Universal design places the responsibility on *product designers*, not users, to ensure the product can be used.[89]

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[88] Centre for Excellence in Universal Design (2018) *What is Universal Design?* Available at: http://universaldesign.ie/What-is-Universal-Design/ (accessed March 2018).

[89] Clarkson, J. (2007) 'Designing a More Inclusive World'. *Universal Design for the 21st Century: Irish & International Perspectives,* Dublin, 16 October. Available at: http://universaldesign.ie/What-is-Universal-Design/Conference-Proceedings/Universal-Design-for-the-21st-Century-Irish-International-Perspectives/Designing-a-more-Inclusive-World/Designing-a-more-Inclusive-World.html (accessed during 2016 phase of research).

Most people who use TH/TC initiatives and devices are not ICT specialists. It makes sense that the industry, developers and service providers take a user-centred and universal design approach to design and delivery. Though much TH/TC is aimed at older adults, improving usability benefits all age groups.

By designing technologies and devices with the principles of UD in mind, the broadest possible group of people can use TH/TC services in the most efficient, elegant way possible.

## 7.1 Issues and Barriers – Evidence from the literature

In terms of implementing TH/TC, a lot of attention is given to policy and funding. However, if the main focus is on cost-efficiency, usability may take a back seat. UD issues in the development and delivery of TH/TC have not received much attention in the research literature and manufacturers / service providers are not generally attuned to UD concepts and applications.

The TH/TC service concept is not seen as being very complex and, superficially at least, the home equipment involved appears to be simple and straightforward to use.  Research focuses on user-related issues mainly - such as appropriate use, stigma, reluctance to use social alarms[90] and alarms being used for social contact rather than emergency contact. The link between design, user needs and preferences, and user-related issues is not often made.

Bentley et al.[91] identified a number of issues and barriers around design and suitability.

- **Look and feel is important.** The design of a piece of technology influences if and how it will be used. For example, where the iPad embodies modernity and status, some TC alarms can signify dependence and loss of youth. Fisk noted the stigma that older users feel about having and wearing social alarms.[92]

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[90] Fisk, M. (2003) *Social Alarms to Telecare: Older Peoples Services in Transition*. University of Bristol: The Policy Press.

[91] Bentley, C.L., Powell, L.A., Orrell, A. and Mountain, G.A. (2014) 'Addressing design and suitability barriers to Telecare: Has anything changed?' *Technology and Disability*, **26**, 221-235.

[92] Fisk, M. (2003) *Social Alarms to Telecare: Older Peoples Services in Transition*. University of Bristol: The Policy Press.

- It's important to **challenge stereotypes**. Older adults are not passive users. They are interested, mostly positive about the role of technology, and pro-actively seek solutions to restrictions and impairments.

- **Older designs remain in use**. Pendant alarms remain in common use, despite the availability of wrist and brooch designs. The high volume of accidental triggering (and intrusion) that occurs with pendants can lead to the user abandoning the technology.

- **Design needs to move with the times**. Technological advances should be continuously exploited to improve wellbeing and allow choice and independence.

Buckle et al.[93] stressed the importance of co-operative, participative design involving collaboration between designers and end-users to improve outcomes. He reported a range of specific design concerns, errors and failures:

- Physical equipment, e.g. battery design, uncomfortable to wear, difficult to put on;

- The end user's fear of using the device arising from poor design and understanding, e.g. interface design, complexity, insufficient demonstrations of how to use the equipment;

- False alarms and triggering, and the consequences of same;

- Design of reminders and alarm checking, e.g. overly complicated medication reminders, not being able to switch alarms off;

- Design that is unsuitable for those with impairments, e.g. those with hearing impairments not being able to hear an audio alarm, or those with physical impairments who cannot press the button

In addition to these issues, Buckle also highlighted procurement-related problems. Those purchasing equipment may lack the appropriate knowledge to make wise choices. Inappropriate equipment can also be recommended – users may not be able to afford what is proposed, while training may be insufficient for proper use. He also pointed to practical maintenance and installation issues associated with equipment that can be problematic.

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[93] Buckle, P. (2014) *Human Factors that influence the performance of the Telecare System*. London: Technology Strategy Board. Available at:  http://circle.leeds.ac.uk/files/2014/05/AKTIVE-PAPER-7.pdf (accessed during the 2016 phase of research).

Greenhalg et al.[94]  carried out research in the homes of 40 people aged 60-98. They found that

- Installed Assistive Technology met very few older people's needs, with some devices being abandoned and others deliberately disabled

- Successful technology arrangements often involved pragmatic customisation by the participant or someone who knew and cared about them, combining new with legacy devices (bricolage), and

- With few exceptions, the current generation of so-called 'assistive living technologies' did not assist older people in their lives.

Some useful contributions on UD issues in relation to home telehealth have appeared in the research literature.[95][96]

Bitterman[97] emphasised the unique and complex nature of these devices from a human-environment-machine perspective, given the

> changeable unpredictable behaviour of users, the unknown, amorphous home environment and the intricacy of tasks performed by patients having various diseases and disabilities.[98]

[94] Greenhalgh, T., Wherton, J., Sugarhood, P., Hinder, S., Procter, R. and Stones, R. (2013) 'What matters to older people with assisted living needs? A phenomenological analysis of the use and non-use of telehealth and telecare'. *Social Science and Medicine*, **93**, 86-94.

[95] Bitterman, N. (2010) 'Complexity in Home Medical Equipment Design'. *Design Research Society 2010: Design and Complexity*. Montreal, 7-9 July. Available at: http://www.drs2010.umontreal.ca/data/PDF/012.pdf (accessed July 2018).

[96] Singh, J., Lutteroth, C. and Wünsche, B. (2010) 'Taxonomy of Usability Requirements for Home Telehealth Systems'. *11th International Conference of the NZ Chapter of the ACM Special Interest Group on Human-Computer Interaction*. Auckland, 8-9 July. Available at: http://www.academia.edu/825994/Taxonomy_of_usability_requirements_for_home_telehealth_systems (accessed during 2014 research phase).

[97] Bitterman, N. (2010) 'Complexity in Home Medical Equipment Design'.  Design Research Society 2010: Design and Complexity. Montreal, 7-9 July. Available at: http://www.drs2010.umontreal.ca/data/PDF/012.pdf (accessed July 2018).

[98] Bitterman, N. (2010) 'Complexity in Home Medical Equipment Design'.  Design Research Society 2010: Design and Complexity. Montreal, 7-9 July. Available at: http://www.drs2010.umontreal.ca/data/PDF/012.pdf (accessed July 2018). p.1

The design must therefore take account of the needs of a very broad spectrum of users with differing needs, and diverse home environments within which the devices are to be used, following inclusive design principles.

Bitterman's analysis and discussion covered a number of different categories of medical equipment for the home. These included:

- **Monitoring and diagnostic devices:** from simple universal devices (such as thermometers and weighing scales) to specific devices such as blood pressure meters, glucometers, INR meters (for anti-coagulant therapy), pulse oximeters, peak flow meters, ECG devices, pulse meters, etc.

- **Disease prevention, treatment and alleviation devices:** from simple equipment such as inhalers and wound healing equipment to advanced equipment such as sleep apnoea masks, liquid oxygen tanks, oxygen generators, catheters, infusion pumps, pain relief and analgesia devices, home dialysis machines

- **Rehabilitation home equipment:** from home exercise systems to more complex, purpose-built rehabilitation equipment.

He noted that users may include the patient as well as other family members and carers, and may be of any age. Many are older people because of the steep rise in prevalence of chronic disease with age. Common diseases and disabilities may impair a user's ability to operate the equipment, unless their needs are anticipated in the design and operating phases. For example:

- motor restriction may make it difficult to perform manipulations required by equipment

- visual impairments may affect the ability to read results of tests

- hearing impairment may affect following of sound indicators, such as when a procedure has finished, and

- cognitive deterioration may affect various aspects of equipment usage as well as managing the general process of using the equipment and services effectively.

The side effects of medications can also present difficulties, including visual changes (e.g. anti-cholinergic drugs), hearing (streptomycin), alertness (anti-allergenic drugs), tactile sensation (chemotherapy), perception, cognition and information processing abilities (psychoactive medications). In addition, anxiety, fatigue, loss of sleep and depression can contribute to decreased attention and performance by the patient or family members.

In the case of people with multiple chronic conditions or older people, the challenges may be even more complex.  Each home is unique in terms of physical features as well as the composition of occupants, lifestyle patterns and so on. Factors that need to be considered include the positioning of devices in the home; physical environment factors that may affect use (lighting, noise etc); and the activity patterns and lifestyles of the occupants. Issues of equipment aesthetics are also of central importance, including designs that are compatible with the home décor and fashions that avoid stigma.

Brennan and Barker[99] discussed UD issues specifically in relation to telerehabilitation systems. In addition to the types of design consideration discussed by Bitterman[100], the authors noted that the home is an unsupervised setting with assistance only generally available from a family caregiver (if there is one).  The importance of providing adequate training for family carers was therefore emphasized.

## 7.2 Solving design issues with Universal Design

### 7.2.1 Co-production and co-design

UD emphasises the important role played by user communities in achieving universally designed products and services. Co-production refers to the collaboration of users in the production process. The engagement of users is a pre-requisite to creating more user-friendly and usable artefacts, however co-production goes further than the design and development of new systems. User engagement should be sought in the "visioning and re-thinking of the context into which such systems and devices are to be procured and deployed".[101]

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[99] Brennan, D. and Barker, L. (2008) 'Human factors in the development and implementation of telerehabilitation systems'. *Journal of Telemedicine and Telecare*; **14**(2) 55-8.

[100] Bitterman, N. (2010) 'Complexity in Home Medical Equipment Design'.  *Design Research Society 2010: Design and Complexity*. Montreal, 7-9 July. Available at: http://www.drs2010.umontreal.ca/data/PDF/012.pdf (accessed July 2018).

[101] Wilson, R., Maniatopoulos, G., Martin, M., McLoughlin, I (2012) Innovating relationships: taking a co-productive approach to the shaping of Telecare services for older people Information, Communication & Society Vol. 15 ( 7) p 1136 –1163. p.1138.

The authors of the ATHENE project (Assistive Technologies for Health Living in Elders: Needs Assessment by Ethnography)[102] proposed a number of procedures to underpin the co-production process.

- **Facilitate communication**. Allow formal and informal carers to work together and support customisation of technologies and services by using diverse communication methods and channels, e.g. text, voice, video.

- **Commit to user-centred methods of device and service design**, especially important for service stakeholders.

- **Repeated cycles of co-production**. User needs should be assessed based on in-depth home visits and cultural probes, as well as continuous monitoring and evaluation of how devices and services are being used in practice.

- **User experience should feed the evolving process of design**, and should be taken into account by technology suppliers and services configurating their offerings.

An example of co-design can be seen in the Sus-IT project which examined ways of helping older people to engage and stay engaged with new ICTs as they age[103]. Older users were involved in the research and design of associated technologies and products. Starting concepts were outlined to focus groups for critical feedback while sub-groups considered what elements should be changed, lost or introduced to refine an individual concept. Through constructive discussion, key insights were gained in the values and assumptions underpinning the design process.

Participatory design is related to co-production and sees participants as 'partners' rather than 'subjects' in the process of technology development.[104] The process again encourages design workshops which develop concepts, engage interested parties, combine different people's ideas and produce design artefacts.[105]

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[102] Procter, R., Greenhalgh, T., Wherton, J., Sugarhood, P., Rouncefield, M., Hinder, S (2014) The Day-to-Day Co-Production of Ageing in Place Computer Supported Cooperative Work, 23, 245–267

[103] Sus-IT (N.D.) *Sus-IT Briefing Paper*. Available at: http://sus-it.lboro.ac.uk/SusITBriefingDocs.pdf (accessed June 2018).

[104] Sanders, E. and Stappers, P.J. (2008) 'Co-creation and the new landscapes of design'. *CoDesign*, **4**(1), 5-18.

[105] Frohlich, D.M., Lim, C.S., Ahmed, A. (2014) 'Keep, lose, change: Prompts for the re-design of product concepts in a focus group'. *CoDesign: International Journal of Co-Creation in Design and the Arts*, **10**(2), 80-95.

The European Commission-funded OLDES project (Older People@Home) attempted to nurture a co-production design approach to the design of telecare services for older people. The project developed a user-friendly and home-based entertainment, health and social care platform for older people. The user-centred design approach adopted was based on ISO 13407 standard for human-centred design processes for interactive systems. The authors documented ground rules for designers who engage in user-centred design and co-production:

- Recognise that self-report feedback from users can be positive even when activity logs indicate that the technology is not actually being used

- Engage users in visioning and re-thinking not only the devices and systems but also the context within which they need to be procured and deployed

- Escape from the rigid distinction between design and use

- Leave behind the notion that devices once designed are largely fixed in their characteristics

- Utilise user communities as proactive partners during the design process to achieve a greater emphasis on participation in system development and design

- Acknowledge the risk that specific user involvement in preparatory technology design can result in the specification of systems and technologies for a narrow range of users and hinder generalisation to other seemingly similar contexts

- Broaden the span of involvement beyond design to include implementation and use within context and operate on the basis that innovation does not cease when devices are produced by the supply process.

### 7.2.2 Involving all TH/TC stakeholders in developing systems
TH/TC, delivered over a distance, will always span more than one organisation. The many stakeholders involved in designing, implementing, delivering and maintaining telecare and telehealth systems present both opportunities and challenges.

Buckle et al.[106] illustrated the complexity of the system through mapping the multiple stakeholders involved (Figure 9). They highlight that each stakeholder may hold important information for the provision and efficacy of TH/TC services

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[106] NOTE: Researchers conducted the mapping in the two study locations of Leeds and Oxford. This diagram is copied from that research. See Buckle, P (2014) *Human Factors that influence the performance of the Telecare System*. London: Technology Strategy Board. Available at: http://circle.leeds.ac.uk/files/2014/05/AKTIVE-PAPER-7.pdf (accessed during the 2016 phase of research).

and there are potential failures at each link in the chain - for example, a poor assessment of needs may result in the provision of an inappropriate device. The root cause of the failure may be attributed to an 'end-user' issue. However, it might relate more to an earlier failure in the process – the assessor wasn't trained adequately.
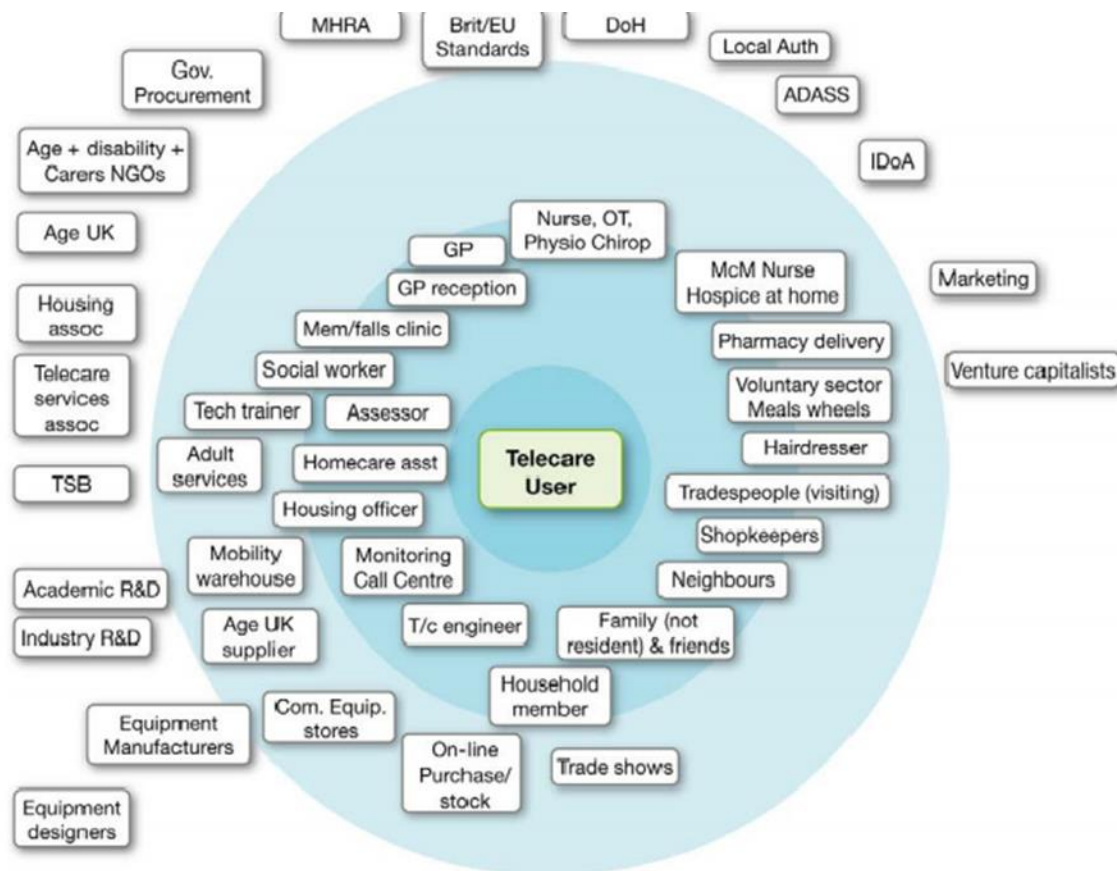


**Figure 9 Mapping of stakeholders in the development and delivery of Telecare in England (Oxfordshire and Leeds)[107]**

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[107] Buckle, P. (2014) *Human Factors that influence the performance of the Telecare System*. London: Technology Strategy Board. Available at: http://circle.leeds.ac.uk/files/2014/05/AKTIVE-PAPER-7.pdf (accessed during the 2016 phase of research).

The researchers suggest a number of solutions to performance difficulties, errors and failures and many of these reflect universal design principles as well as pitching these at a variety of stakeholders. Several of these examples are shown in Table 9.

**Table 9 Examples of UD solutions to TH/TC implementation issues[108]**

| Performance difficulties, errors, failures | Why would this happen? | What might the solutions be? |
|---|---|---|
| Device incorrectly installed | Deficiencies in design and operating documentation. | • The quality of the documentation should be designed inclusively.<br><br>• Those with visual impairments need to be considered.<br><br>• Experts in inclusive design (e.g. equipment, instructions) should be consulted. |
| Cannot use equipment | Fail to check user can operate equipment and / or that training / instructions given are understood / users are compliant | • Installers and assessors must be aware that the technology may not be fully inclusive of all intended users.<br><br>• Ensuring that the users can operate it before it is left with is |

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108 Buckle, P. (2014) *Human Factors that influence the performance of the Telecare System*. London: Technology Strategy Board. Available at:  http://circle.leeds.ac.uk/files/2014/05/AKTIVE-PAPER-7.pdf (accessed during the 2016 phase of research).

| | | |
|---|---|---|
| | | essential (e.g. location of the base unit may result sin user being unable to hear or respond to the alarms).<br><br>• The need for a more resilient system, perhaps with additional sound units should be explored. |
| Does not understand the equipment | Too complicated design | • Industry to work more closely with inclusive designers, human factors experts and HCI specialists.<br><br>• There is good ergonomics advice on how to design equipment that facilitates ease of use |

Broens et al. also investigated why it is difficult to implement TH/TC services and what goes wrong.[109] Like Buckle et al., the researchers postulated that different factors impact at different points of the implementation lifecycle.

Based on their findings they developed a Layered Implementation Model which details four implementation phases and determinants of success (Table 10). The phases are variously focussed on the technological and structural feasibility of proposed TH/TC services and as the focus shifts, different stakeholders are required.

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[109] Broens, TH., Vollenbroek-Hutten, MM., Hermens, HJ., van Halteren, AT., Nieuwenhuis, LJ., (2007) 'Determinants of successful telemedicine implementations: A literature study'. *Journal of Telemedicine and Telecare*, **13**, 303–309.

**Table 10 Layered Implementation Model**

| Phases of Implementation | Determinants of Success |
|---|---|
| Prototype | The extent to which users and society accept the technology |
| Small-scale pilots | |
| Large-scale pilots | Organisational and financial issues, e.g. change management, standards and protocols |
| Fully operational | Policy and legislation |

Greenhalg et al.[110] undertook a discourse analysis of the telehealth and telecare literature and found that different stakeholders understood telehealth and telecare in very different ways. They concluded that if investments in TH/TC are to bear effective results, inter-stakeholder dialogue is essential to establish an organising vision that accommodates competing discourses.

## 7.2.3 Questioning myths around older people using ICT

A literature review (2003-2013) listed facilitators and barriers to TH/TC usability in older adults[111].  As numbers of older people continue to increase, they are likely to be one of the large consumer groups of TH/TC. Foster and Sethares's list (2014) includes many practical elements that could be easily remedied with good design.

Factors that made TH/TC more acceptable included:

• Devices that use fewer buttons

• Automatic transmission of information

• Utilising low-tech platforms such as telephone and TV

• Devices that generate reminders or alerts

• Providing both visual and audio guidance

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[110] Greenhalgh, T., Procter, R., Wherton, J., Sugarhood, P. and Shaw, S. (2012) 'The organising vision for telehealth and telecare: discourse analysis'. *BMJ Open*; **2:**e001574. Availalable at: doi: 10.1136/bmjopen-2012-001574 (accessed during 2016 phase of research).

[111] Foster, MV., Sethares, KA (2014) Facilitators and barriers to the adoption of TH in older adults: an integrative review. *Computers, informatics, nursing*, **32** (11), 523-533.

- Appropriate user-friendly images

Barriers to TC/TH usability identified included:

- Font size, unusual characters that are difficult to read

- Poor colour contrast and bland graphics

- Using devices with widgets that are difficult for people who lack poor fine motor, eye-hand coordination

- Use of a computer mouse that is difficult for those with arthritis

- Unskilled on the use of a smart phone or computer

- Multiple screen transitions to complete a task

- Menu bars that contain several layers

- Inappropriate size of a smart-phone – too big or too small – frail persons who have diminished grip strength may have problems handling the device

- Delays in responses, lack of feedback, and technical problems can all lead to frustration and reduce motivation for people to continue self-monitoring

- TH/TC can also represent a cultural change for some older people

Older adults are not averse to new technology, providing that it is useful, practical and appropriately introduced.   It is very important to understand what might motivate older people to use technology.  TH/TC developers need to bear in mind the visual-spatial, auditory, physical and cognitive changes that come with increasing age. This must be understood along with the technical skills and design devices that accommodate for these changes so that people can use the technology.

Developers can design devices to deliver information in small increments so that people can process the information adequately. The use of TH/TC should enhance a person's quality of life, not impede it. Akin to this is the theme emerging from co-production consultations that TH/TC should put people first, before technology.

As older people are key target groups for lots of TH/TC initiatives, it is important to be aware of (and question) common attitudes around the use of ICT by older people. Wandke, Sengpiel and Sönksen[112] discuss six myths about

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[112] Wandke, H., Sengpiel, M. & Sönksen, M. (2012) 'Myths About Older People's Use of Information and Communication Technology'. *Gerontology,* **58**, 564–570.

older people's use of ICT and human computer interaction (HCI), noting the impact they can have on the value that designers and other stakeholders put on universal design:

> **(1) Just wait and see**. Future generations of older people will use computers without problems. The problems older people have with HCI are only a temporary phenomenon. The next generation entering the 'older person' stage will possess the knowledge and skills necessary to use HCI.

In actual fact, technology is constantly changing to the extent that even someone expert in computers in the 1980s may struggle to cope with today's usability. Terminology, hardware, software and UX design (user experience interfacing) will continue to evolve so everyone will need to learn to adapt to new kinds of technology. As perceptive, motor and cognitive skills decline with old age, this adaptability may prove challenging but communal inaction and avoidance while hoping user difficulty will 'age out' is not the solution.

> **(2) Older people are not interested in using computers**. They are unaware of computer capabilities. It is not a problem of design; older people are simply not interested in using computers and completely unaware of computer capabilities. So, why bother?

Evidence from the literature is mixed, with early studies showing a disinterest and later studies showing that older adults were more positive about computers than younger adults. "The reality appears to be far more complex than the myth suggests. Older people are especially interested in Internet applications but are discouraged when sophisticated computerized devices replace simpler ones which were easier to use."[113]

> **(3) Older people consider computers useless and unnecessary**. Older people may be aware of ICT but consider computers to be useless and unnecessary for their personal lives.

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[113] Wandke, H., Sengpiel, M. & Sönksen, M. (2012) 'Myths About Older People's Use of Information and Communication Technology'. *Gerontology,* **58**, 564–570. p.567

"The main reason for older people deciding to use a computer system is its perceived usefulness… The main reason for non-use is not the lack of perceived usefulness but rather the lack of perceived (and real) usability."[114]

(4) **Older people lack the physical capabilities to use ICT**. The problem of HCI and older people is mainly one of size (e.g. text fonts and buttons), contrast, brightness and other physical features. This problem can be solved by designing user interfaces specifically for older people.

It may be true for some that visual acuity and motor function becomes more limited with age. However, these limitations can be overcome with good universal design that benefits all user groups. The advent of touchscreen technology over the mouse demonstrates this.

(5) **Older people simply cannot understand interactive computing technology**. Older people lack the basic knowledge required for HCI. There is a special language used to describe computer objects and functions which is foreign to older people. The meanings of words such as 'file', 'browser', 'link', 'desktop', 'download', 'site', 'scrollbar' and 'cursor', among others, are unknown. For this reason, older people are simply unable to understand how computers work.

Often, when faced with ICT, older people seem to have trouble understanding the function, common interaction patterns, computer icons and terms. Some decline in cognitive abilities, for instance the general slowing of processing speed, decreasing ability to discriminate between relevant and irrelevant stimuli, and the increased vulnerability to stereotype threat, which further decreases memory performance can lead to difficulties comprehending ICT. However, "most older people would be very capable of using ICT if it were not designed by younger people *for* younger people… ICT which cannot be understood by older people could just as well be considered as being flawed in design."[115]

(6) **You can't teach an old dog new tricks.** The problem of HCI for older people is that these individuals do not learn to use new technologies and interaction techniques. They are unmotivated and not cognitively able to learn how to interact with computers.

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[114] Wandke, H., Sengpiel, M. & Sönksen, M. (2012) 'Myths About Older People's Use of Information and Communication Technology'. *Gerontology,* **58**, 564–570. p.568

[115] Wandke, H., Sengpiel, M. & Sönksen, M. (2012) 'Myths About Older People's Use of Information and Communication Technology'. *Gerontology,* **58**, 564–570. p.569

"If (older ICT users) fail when they try to use an interactive program or device for the first time, the negative experience can result in avoidance strategies. Consequently, a vicious cycle can develop. People become less and less interested in exploring new technology, while the use of new technology simultaneously becomes increasingly difficult for them… the effects of these processes on the use of technology by older people should not be overgeneralized, nor should they be used as an excuse to neglect design efforts on behalf of older adults."[116]

The researchers further note elements which could be important for the training of TH/TC clients to use devices – all training should begin with a success, and a clear case for the usefulness of the device or software should be made.

### 7.2.4 A quality framework and principles for TH/TC
Building on their research with people with multiple morbidity, assisted-living needs technology suppliers, and co-design workshops, Greenhalg et al.[117] formulated the ARCHIE framework for designing, installing and supporting telehealth and telecare products and services.

The framework comprises six quality principles (ARCHIE) and the researchers put forward recommendations on each principle (Table 11).

### Table 11 ARCHIE Quality Principles[118]

| Principle | Description | Recommendations |
| --- | --- | --- |
|  |  |  |

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[116] Wandke, H., Sengpiel, M. & Sönksen, M. (2012) 'Myths About Older People's Use of Information and Communication Technology'. Gerontology, 58, 564–570. p.569

[117] Greenhalgh, T., Procter, R., Wherton, J., Sugarhood, P., Hinder, S., Rouncefield, M. (2015) What is quality in assisted living technology? The ARCHIE framework for effective telehealth and telecare services BMC Medicine  13:91 doi:10.1186/s12916-015-0279-6 Available at: www.biomedcentral.com/1741-7015/13/91 (accessed during 2016 phase of research).

[118] Greenhalgh, T., Procter, R., Wherton, J., Sugarhood, P., Hinder, S., Rouncefield, M. (2015) What is quality in assisted living technology? The ARCHIE framework for effective telehealth and telecare services BMC Medicine  13:91 doi:10.1186/s12916-015-0279-6 Available at: www.biomedcentral.com/1741-7015/13/91 (accessed during 2016 phase of research).

| 1 Anchored | Design and development should be ANCHORED in a shared understanding of what matters to the patient or client | All involved should understand and share 'What matters to the person'.<br><br>Spend time with the individual to find out what activities and functions are personally meaningful and important to them, e.g. related to family or community roles, or religious practices.<br><br>Ensure the client's needs and goals remain central, possibly by providing advocacy. |
|---|---|---|
| 2 Realistic | The technology solution and care package should be REALISTIC about the natural history of illness and the progressive impairments it may bring | Effective solutions are realistic about what the technology can do and the capability of the user.<br><br>Assistive technologies cannot cure disease or age-related conditions.<br><br>Non-specific impairments (e.g. chronic tiredness, dulling of cognitive capacity) may interfere with a person's ability and motivation to use a technology designed to alleviate impairments. |
| 3 Co-creative | Solutions should be CONTINUOUSLY CO-CREATED along with users and carers, using practical reasoning and common sense | Stakeholders should see personalisation of solutions as a continual process that never ends, rather than as part of a standardised, one-off assessment.<br><br>Formal and informal care networks require capacity to track and review the solution while in use, recognising that further customisation and innovation are likely.<br><br>Creativity is needed to deal with diverse and abnormal situations, including 'outside the box' thinking and practical reasoning, rather than sticking rigidly to standard protocols and procedures. |

| 4

Human | HUMAN elements such as personal relationships and social networks will make or break a TH or TC solution | Frequent inter-personal interactions with users and their carers (as informal as possible) will build their familiarity with the service and promote trust, a sense of being cared for and confidence to take the initiative if problems arise.

Interactions will also develop providers' knowledge about key contextual factors that may have a bearing on delivery of effective and dependable support.

Stakeholders need to align technology with both formal and informal social support that can bridge the design-reality gap in ways that are sometimes very subtle.

It is important to consider the available human resources within the intended user's care network and how members of the network might connect with the technology and service to support its' use and customisation. |
| --- | --- | --- |
| 5

Integrated | The service must be INTEGRATED by maximising mutual awareness, co-ordination and mobilisation of knowledge and expertise | Everyone involved (both lay and professional) must be clear about the client's changing needs and capabilities and about the technical and social supports in place.

They must have an ongoing sense of what other stakeholders are doing and how this fits with their activity towards the common goal of supporting the person.

It is crucial to mobilise the different knowledge and expertise within the network – both formal (e.g. through data on records) and informal e.g. through storytelling, inter-disciplinary case-based discussion and informal interactions). |

| | | |
|---|---|---|
| **6**<br><br>**Evaluated** | EVALUATION and monitoring is essential to inform system learning | Technology designers and services need to<br><br>• monitor use and experience of technology solutions,<br><br>• workarounds developed for them, and<br><br>• the repurposing of the technology and service<br><br>to inform ongoing innovation and improvements for both individual clients and the wider system. |

To implement the ARCHIE principles changes are required of the sector:

- A shift in *focus* from product ('assistive technologies') to performance ('supporting technologies-in-use')
- A shift in the *commissioning model* from standardised to personalised home care contracts
- A shift in the *design model* from 'walled garden', branded products to inter-operable components that can be combined and used flexibly across devices and platforms

## 7.3 Evidence from Jurisdictions

In reviewing the systems across various jurisdictions, there are valuable lessons and practices that can be extracted. In the main, the focus appears to be on clinician/health worker usability, rather than significant evidence arising from user experience. The learning most relevant for the universal design perspective is outlined below.

### 7.3.1 Ireland – Pendant Alarm Users

Hermann et al.[119] studied 30 Irish users of a personal alarm system.  A majority of users felt positive, seeing the alarms as an aid to independent living. Though they understood the basic activation function of the pendant alarm, participants experienced a variety of usability issues, for example:

- difficulties pressing the activation button

- lack of clarity about the functions and use of buttons

- not understanding the sequence of events initiated by activating the alert button

- interpreting the feedback provided by devices

- the location of the base system

- the length of the pendant chain

- the size of the device, and

- the lack of initial training in its use.

A number of design suggestions were made to address these issues, in particular, for designers to use design surveys as a tool to improve prototypes and the design process, and to allow user feedback to link universal design with product features.

### 7.3.2 Israel - MOMA programme

Maccabi, one of four Health Management Organisations (HMO) in Israel implemented the MOMA initiative in 2012 in collaboration with the Gertner Institute. It offers an example of an e-Health system integrated with routine care and illustrates good design by involving stakeholders in the early phases.

By way of introduction, MOMA is a 24/7 advanced technology, multi-disciplinary call centre[120] for the treatment of various chronic illnesses. The centre integrates

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[119] Hermann, S., Soraghan, C. and Boyle, G. (2012) Universal Design and Technology for Older People: A survey tool for assessing technology design for older people in-situ, in an Irish context.  Report for the National Disability Authority. Available at: http://universaldesign.ie/Web-Content-/Technology-for-Older-People.pdf (accessed during 2014 research phase).

[120] Peinado, I., Villalba, E., Mansoa, F. and Sánchez, A. (2015) 'MOMA and Maccabi Healthcare Services (Israel) Case Study Report'. *Strategic Intelligence Monitor on Personal Health Systems Phase 3 (SIMPHS3)*, Report EUR 27261 EN. Luxembourg: Publications Office of the European Union. Available at: http://is.jrc.ec.europa.eu/pages/TFS/documents/lfna27261enn.pdf (accessed during 2016 phase of research).

different services like long-term care, pharmacy, home and hospital care, which are coordinated with the patient's primary care physician and other community-based resources. The integration of MOMA has enhanced vertical coordination as it involves professionals in different tiers of the healthcare service, from nurses to primary care to secondary care and home care services.

The programme utilises technology that was adopted by Maccabi in the 1980s, namely:

- an organisation-wide electronic health record
- computerised services and computerisation of each health transaction with the patient
- patient access to their health records, and
- telemedicine.

MOMA has served more than 11,500 patients from 2012 to 2016, specifically patients who require special care for illnesses which affect their quality of life significantly - for example, age-related chronic illnesses (e.g. chronic heart failure, COPD, frailty and diabetes) and other chronic illnesses (e.g. stoma, chronic wounds, and oncology patients). These illnesses can also contribute to psychological impacts like depression. Patients with these range of illnesses tend to be the most costly in the health system as they require special disease management processes and frequent hospitalisations.

Maccabi analysed the data of four long-term cohorts, comparing the costs before MOMA began (2011) and after one year of the programme (2013). Though baseline costs were higher for MOMA patients (which may be attributable to the high burden of care for these type of chronic illnesses), Maccabi estimate that MOMA has led to a 4% saving when compared with other scheme members, and a 48% saving when compared with chronically ill patients not using MOMA.[121]

The success of MOMA was contributed to in two notable ways. First the Gertner Institute, an independent research institute for the study of epidemiology and health policy, championed the development of TH/TC – both conceptually and financially. It had the idea and collaborated actively with Maccabi to turn MOMA

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[121] Peinado, I., Villalba, E., Mansoa, F. and Sánchez, A. (2015) 'MOMA and Maccabi Healthcare Services (Israel) Case Study Report'. *Strategic Intelligence Monitor on Personal Health Systems Phase 3 (SIMPHS3)*, Report EUR 27261 EN. Luxembourg: Publications Office of the European Union. Available at: http://is.jrc.ec.europa.eu/pages/TFS/documents/lfna27261enn.pdf (accessed during 2016 phase of research).

into a reality. Maccabi and the Gertner Institute are also collaborating with other HMOs in Israel to promote the implementation of similar initiatives to MOMA.

A second element in the success of MOMA has been the maturity of the ICT infrastructure in Maccabi. The organisation has been a pioneer in the development of ICT solutions, deploying a functional Electronic Health Record (EHR) as early as 1994.

A key lesson in design is offered by MOMA's transition to the common use of the EHR. This was a gradual process. First, some doctors volunteered to participate in a pilot, in order to ensure the usability, accessibility and other non-functional parameters, such as security and scalability of the system; some years later, all new doctors hired by Maccabi were obliged to use the EHR in their daily practice. This gradual implementation allowed usability and accessibility issues to be identified and ironed out and the system to be designed based on users' reality.

Maccabi has also developed ICT solutions for patients. Patients have access to their own medical history, can contact their doctors via telephone or teleconferencing and can receive, if they request it, electronic messaging with advice on healthy lifestyle or self-care. This technological maturity has helped to create a culture where technology is a desirable tool, not an obstacle and is reflective of a culture that is comfortable with using technology – from patient, health care provider, carer and organisation.

For Ireland, a journey will be needed to develop a similar technological culture.

### 7.3.3 Northern Ireland - Telemonitoring NI
A number of pilot projects were conducted and evaluated in the development of the Telemonitoring NI service. A number of key recommendations and conclusions arising from the evaluation of the pilot projects were made that should inform the implementation of a mainstream telemonitoring service.[122] Most relevant from the UD perspective were

- The need to introduce a mechanism to gather and share feedback from clinicians around the difficulties they encounter and the solutions they identify in relation to telemonitoring

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[122] O'Brien, Dr M. (2008) *Remote Telemonitoring: A Preliminary Review of Current Evidence*. Belfast: European Centre for Connected Health.

- The need to ensure that peripheral products selected for use in tele-monitoring offer flexibility to meet the needs of the wide variety of patient characteristics and illnesses.

The first point speaks to the need for TH/TC systems to incorporate feedback loops, allowing for co-created solutions to issues arising that can be used to develop the system as a whole. This happens through well-designed monitoring and evaluation structures that allow stakeholder experience to inform services. The second point critically refers to flexibility of use whereby products chosen can accommodate a wide variety of users. From a procurement point of view, this may also offer cost-efficiencies as bespoke or specialised devices are not as needed.

From a policy perspective, the DHSSPS began work with Northern Ireland's economic development agency, Invest NI, to develop a joint Connected Health and Prosperity agenda. The aim was to contribute to improved health and well-being and patient care, while also supporting the economic development strategy. Similarly, in June 2018, Health Innovation Hub Ireland launched a call for start-up businesses with innovative TH/TC solutions to apply for support on the road towards commercialisation of products. Both initiatives offer a valuable collaboration space between prospective designers and healthcare professionals and incentives to develop useful TH/TC products.

Tunstall Healthcare, one of the Telemonitoring NI consortium members carried out a case study outlining lessons learned from the programme.[123] Among these were many that align with ARCHIE Principles and ATHENE project recommendations. They include:

- Focus on understanding the patient journey through the service

- Invest effort in the service design phase – if you haven't explicitly defined it and designed it, problems will arise

- Do not expect informal processes and practices built up in delivering a pilot to directly translate into processes for large-scale service delivery. Large-scale, mainstream services need to be designed

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[123] Tunstall Healthcare (N.D.) *Designing and delivering scalable telemonitoring and telecare through partnership*. Available at: http://tunstall.com/media/1204/northern-ireland-case-study-new.pdf (accessed June 2018).

- Commence clinical engagement as early as possible in the service design process. Do not underestimate the time it takes to engage and achieve consensus on the clinical care pathway design

- Establish mechanisms to support clinical collaboration and encourage clinicians to champion their telemonitoring success stories and disseminate good practice. Hold clinical forums to enable this

- Plan for ongoing clinical engagement following operational service commencement - a time for bedding in and evaluating effectiveness is required to accommodate local experiences as they accumulate.

Design consideration has been given to the usability of the telehealth equipment installed in service users' homes. As part of the Telemonitoring NI procurement process, devices from competing providers were demonstrated to health professionals who were asked to evaluate them in a number of areas, including usability.

In a practical sense, the equipment deployed in the telemonitoring service utilises Bluetooth technology, which means that users do not have to plug devices in and out, however landlines (as opposed to mobile) are required. Users with visual impairments are provided with voice output devices which guide them in taking and uploading their readings.  In addition, the service has recently had its first hub device translated into another language (Lithuanian).

### 7.3.4 Scotland – Co-production in TH/TC development
'A National Telehealth and Telecare Delivery Plan for Scotland to 2015' specifically named co-production of services in the national strategy, viewing it as an important element of TH/TC development.

According to SCTT & JIT (2012)

> Co-production recognises that people have 'assets' such as knowledge, skills, characteristics, experience, friends, family, colleagues and communities. These assets can be brought to bear to support their health and wellbeing

and the national delivery plan for telehealth and telecare includes a work stream to

> Co-design and co-produce telehealth and telecare solutions with users, patients and carers which enable access to information, support, products and services.[124]

The Living It Up programme involved five local partnerships across Scotland and its objective was to enable people to improve their health and well-being. The programme used

> co-production to shape the way that new technologies facilitate services, products, and information to support people to manage their Long Term Conditions and wellbeing. Community engagement work, led by Glasgow School of Art, the Health and Social Care Alliance and Carers Scotland brings together all partners to 'co-design' solutions by sharing their experience, skills and different perspectives. Partners include individuals, carers, local communities, third sector organisations, industry, enterprise and health, housing and care practitioners. [125]

The Joint Improvement Team produced a review of good practice on co-production in Scotland and further afield particularly related to health and wellbeing.[126]

Loeffler and Bovaird (2012) note that co-production is a growing theme in public service delivery around the world and advocate for co-production to be adopted to change traditional service delivery.

They highlight that quality in healthcare is not simply evaluated by service users on the basis of outcomes, but also on the process of service delivery (e.g. friendliness, responsiveness, how comfortable they felt using a service). As a result, including users in the design of services not only has a positive impact on

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[124] Scottish Centre for Telehealth and Telecare & Joint Improvement Team (2012) A National Telehealth and Telecare Delivery Plan for Scotland to 2015: Driving Improvement, Integration and Innovation. Available at: http://www.gov.scot/Publications/2012/12/7791/downloads (accessed during 2014 phase of research).

[125] Scottish Centre for Telehealth and Telecare & Joint Improvement Team (2012) A National Telehealth and Telecare Delivery Plan for Scotland to 2015: Driving Improvement, Integration and Innovation. Available at: http://www.gov.scot/Publications/2012/12/7791/downloads (accessed during 2014 phase of research). p. 17

[126] Loeffler,E. Power,G., Bovaird, T. & Hine-Hughes, F. (Eds) (2012) *Co-Production of Health and Wellbeing in Scotland*. Available at: http://www.govint.org/fileadmin/user_upload/publications/Co-Production_of_Health_and_Wellbeing_in_Scotland.pdf (Accessed June 2018).

quality, choice and responsiveness, but it can also reduce costs as the users do more for themselves.

Though TH/TC provision is often discussed within the context of ageing populations, Loeffler and Bovaird view this as an opportunity for co-production. Older people are generally more engaged in improving public outcomes and services than younger people.

### 7.3.4.1 Co-production in action
Scotland has a dedicated organisation to provide a space for co-production initiatives (Scottish Co-Production Network).[127] One of the co-production projects facilitated through this was ALLIANCE's 'Our GP' – digitally enabled GP services.[128] This began with two surveys – one for citizens and one for healthcare practitioners – which identified a range of issues in using telehealth in this way. In particular, healthcare practitioners highlighted a number of challenges for them using telehealth solutions:

- Digital innovations have been technology driven without the involvement of practitioners

- Reluctance to engage with and recommend digital technologies when they have concerns about safety and risk

- It's hard to keep up with the pace of change in digital innovation, and

- Lack of connectivity between digital technologies and electronic patient records is a significant barrier for adoption.

Following the surveys, a series of workshops with citizens and healthcare professionals brought up a number of recurring themes (Table 12). From the information gathered in these workshops, four prototype tools were then developed (Table 13).

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[127] Note: The Scottish Co-production network was formed as an informal network in 2010, co-facilitated and chaired by Scottish Community Development Centre and NHS Tayside on a voluntary basis. It came into being as a result of contact established between the New Economics Foundation (NEF) and NHS Tayside as part of their work around the Health Equity Strategy: Communities in Control and through the Meeting the Shared Challenge programme led by Scottish Community Development Centre.  More details here: http://www.coproductionscotland.org.uk/about/about/ -

[128] Alliance – Health and Social Care Alliance Scotland (2017) *OurGP Story: Co-designing the future for digitally enabled GP services*. Available at: https://www.alliance-scotland.org.uk/digital/wp-content/uploads/2018/01/DIGITAL-OurGP_PhaseThree_Report_Final_Version3.pdf (accessed June 2018).

### Table 12 Themes emerging from stakeholder workshops[129]

| |
|---|
| Optimising the use of practice space during citizens' visits to practices was a priority but requires further co-design activity to develop ideas. |
| There was a significant gap between the enthusiasm and actual infrastructure available at the current time in practices and also the confidence to use tools in practice. |
| Digital tools still require potential for paper-based options and/or download options to overcome connectivity and digital confidence issues. |
| There was universal enthusiasm for more use of digital technologies across GP practice services. |
| Connectivity with new tools and existing digital assets was a recurring theme. |
| Citizens wanted highly personalised tools which they retained control over but which were also connected in useful ways to their GPs systems. |

### Table 13 Four prototypes of digital GP services developed after workshops[130]

| | |
|---|---|
| **Personal profile** - a tool for patients to share nonclinical information about them and their lives with their GP. This is simple profile to help GPs get to know their patients. Written by the patient, and displayed in a user friendly format, the profile enables practice staff to quickly understand their | **Digital image triage** - a digital tool that allows patients to photograph their minor injury, or non-acute skin condition, and securely send the image to clinical staff for advice.

Conditions could include rashes, skin redness, minor injuries such as a |

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[129] Alliance – Health and Social Care Alliance Scotland (2017) *OurGP Story: Co-designing the future for digitally enabled GP services*. Available at: https://www.alliance-scotland.org.uk/digital/wp-content/uploads/2018/01/DIGITAL-OurGP_PhaseThree_Report_Final_Version3.pdf (accessed June 2018). p.8

[130] Alliance – Health and Social Care Alliance Scotland (2017) *OurGP Story: Co-designing the future for digitally enabled GP services*. Available at: https://www.alliance-scotland.org.uk/digital/wp-content/uploads/2018/01/DIGITAL-OurGP_PhaseThree_Report_Final_Version3.pdf (accessed June 2018). pgs. 11-14

| | |
|---|---|
| preferences, needs and goals. The profile uses icons and infographics that can be understood at a glance and clicked on for more information. | sprained ankle or infected cut. The patient enters their mobile phone number and receives a text telling them when they can expect a response. The patient then receives a further text which may ask them to make an appointment with the practice nurse or GP. A link to the online booking system is sent to the patient |
| **Information and advice** - a digital tool, prescribed by the GP, following a new diagnosis or significant change in treatment.<br><br>The tool will enable patients to record information during consultations so that they can digest it after the appointment.<br><br>It will also give them access to relevant, trusted information about their condition(s) at intervals after their diagnosis. This will enable patients to digest bite-sized information at a time when they feel ready. It will help them avoid feeling overwhelmed. | **Remote education** - a package of online education seminars incorporating rewards for positive change. The education seminars are delivered online on a weekly basis by practice staff on a variety of topics. The group seminars are delivered 'live' and also recorded so they can be accessed afterwards too. |

The prototypes were then presented for stakeholder feedback. This included 11 roadshows throughout Scotland, based in health centres, libraries and other places; stakeholder events and surveys; and, having having a three-minute explainer video and survey online.

This led to the number of prototypes being reduced to three, as participants had a lack of interest in the remote education tool. As of 2018, the prototypes are being discussed with key partners, the Scottish Government Primary Care Digital Services Board, to implement them in reality.

Garven[131] notes a number of barriers to co-production in general. One is engaging the community. A group may be interested in organising local activities (fun runs, lunch co-ops, etc.) or they may be interested in campaigning on local issues (e.g. encouraging education bodies to change policy on school meals). However, she highlights that the type of collaborative engagement needed for co-production may be a less attractive option for communities to engage and

> …would only really work if community awareness and understanding of issues is shared by the Community Health Partnership, Community Planning or any other relevant partnership or agency structure. For these reasons, co-production may be an option only for the most sophisticated and experienced groups. [132]

Garven also notes that co-production activities can be hampered by inequities in compensation for the work. For example, the staff of public bodies will be paid for the time given to co-production activities while individual participants or community activists are usually involved on a voluntary (un-paid) basis.

### 7.3.5 Spain - Teleasistencia Domiciliaria (TD)

Spain's norms and guidelines have paid particular attention to addressing design issues. The *Normas Generales* quality assurance standard gives specific requirements on the user terminal. Apart from the basic, simple activation and hands-free functionality required for the service, the user equipment should have such features as:

- a simple design (without a proliferation of knobs, buttons and indicators)
- conventional telephone functions, with a keypad that has sufficiently sized keys and adequate clearance for usage by people with limited dexterity, good tactile feedback, high visual contrast, tactile point on the 5 key, etc.

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[131] Garven, F. (2012) 'Co-producing with communities in Scotland – the potential and the challenges'. In Loeffler,E. Power,G., Bovaird, T. & Hine-Hughes, F. (Eds) (2012) *Co-Production of Health and Wellbeing in Scotland*. Available at: http://www.govint.org/fileadmin/user_upload/publications/Co-Production_of_Health_and_Wellbeing_in_Scotland.pdf (Accessed June 2018).

[132] Garven, F. (2012) 'Co-producing with communities in Scotland – the potential and the challenges'. In Loeffler,E. Power,G., Bovaird, T. & Hine-Hughes, F. (Eds) (2012) *Co-Production of Health and Wellbeing in Scotland*. Available at: http://www.govint.org/fileadmin/user_upload/publications/Co-Production_of_Health_and_Wellbeing_in_Scotland.pdf (Accessed June 2018). p.116

- all elements to be labelled in appropriate languages (always Castilian, but other official languages optional as well) and symbols/codes for easy understanding

- anti-strangulation mechanism to be included in the case of neck-worn pendants

- a certificate of acceptance of the equipment should be gained from the State centre for Personal Autonomy and Technical Aids (CEAPAT).

The CENTAC Foundation (National Centre for Technology Access) has also been addressing the issue of how telecare can meet the diversity of users that have specific accessibility needs and what technological advances are being incorporated to improve such accessibility.[133]

Across Spain in general, the home equipment of base unit and pendant have microphones and loudspeakers to enable hands-free operation. A high number of erroneous calls were being recorded by call centres. Base units have a number of buttons intended for use in particular situations - 'family' (for initiating contact with family); 'emergency' (for alerting when immediate help is needed, e.g. for medical reasons); 'failures' (for making contact about problems with home equipment); and 'information' (for getting information needed, such as the name and address of a doctor).

Ojel-Jaramillo and Canas[134] examined this issue of erroneous calls and found that the  inclusion of graphical icon,s as well as text labelling of the buttons, could help to reduce the number of mistakes made in selecting the correct button to initiate the desired type of call.

There have been some initiatives in Spain to address accessibility barriers to telecare for people who are deaf or have speech impairments.  One system in place is Smartcom, developed by the Neat Group, which uses a touchscreen

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[133] Source: http://www.lateleasistencia.es/search?q=centac&x=-1080&y=-238 (accessed during 2014 phase of research). This website no longer contains information however, as of July 2018, information on the telecare service can be found here: https://lateleasistencia.es/.

[134] Ojel-Jaramillo, J. and Canas, J. (2006) 'Enhancing the usability of telecare devices'. *Human technology,* **2**(1), April, 103-118.

mobile device allowing people with hearing or speech difficulties to communicate effectively with the Telecare Service Centre.[135]

In Catalonia, the CNSE Foundation and the organisation for deaf people *Federacio de Persones Sordes de Catalunya* (FESOCA) have signed a collaboration agreement for the implementation of the SVisual telecare service for deaf people, which allows communication through sign language[136].  In Castilla-La Mancha, it has been announced that the telecare service will be extended to people with severe or profound deafness in the near future.[137] A requirement for telecare terminals to be accessible to persons with hearing impairment is one of the conditions included in the tender for the new contract for telecare management.

Different types of equipment are available, such as terminals that emit louder sounds or lights attached to the terminal, depending on the degree of hearing impairment. New terminals that do not cause interference with hearing aids were also being trialed as of 2014.

However the sophistication of these initiatives varies across the provinces and municipalities and national roll-out of devices inclusive to those who have hearing or speech impairments is not apparent. In Andalucía, the SAT service equipment and protocols are not necessarily adapted for people with a hearing or speech impairment. In many ways, the practices for responding to users with these impairments are quite rudimentary, unreflective of equitable use and possibly stigmatising.

For example, service protocols for the users with hearing impairments are much the same as for hearing users. The rationale is that the person in trouble is still able to communicate and the course of action is based on that information provided, therefore, the service can function even if the user is unable to hear what is happening / how it is being handled. However, on an intuitive level and in a crisis situation, potentially not being able to hear if responders have understood

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135 Source: http://www.gruponeat.com/index.php?ids=914&lang=es (accessed during 2014 phase of research). This website no longer contains information however, as of July 2018, information on the telecare service can be found here:  https://www.neat-group.com/es/

136 Source: http://www.lateleasistencia.es/2013/02/teleasistencia-para-personas-sordas.html (accessed during 2014 phase of research). This website no longer contains information however, as of July 2018, information on the telecare service can be found here: https://lateleasistencia.es/.

137 Source: http://www.lateleasistencia.es/2013/02/las-personas-sordas-de-castilla-la.html (accessed during 2014 phase of research). This website no longer contains information however, as of July 2018, information on the telecare service can be found here: https://lateleasistencia.es/.

the needs and are responding may at least lead to confusion, if not additional stress.

Another example is the approach to catering for users with speech impairments. Personnel at the call centre are trained to respond to users through non-verbal means such as the person making a clapping or other sound to represent certain situations if they need help, family or assistance. Speech recognition technology is being trialled in Andalucía but has not been introduced to the regular telecare package.

As with other jurisdictions (e.g. Northern Ireland), there are limitations on users with cognitive of physical impairments using telecare services. In Madrid, persons who have comprehension or other intellectual/cognitive difficulties and who cannot understand how the device functions, or persons who have physical or sensory disabilities that prevent them from using the device, are eligible only if they live with persons who can activate the alarm on their behalf. Likewise, in Andalucía, should the prospective user have cognitive and/or physical impairments (such as in the case of the requesting party having Alzheimer's Syndrome or any other aged-related dementia) the possibility of use is based on having a person responsible for their care using the system.

The ARCHIE principles emphasise the need to be realistic about the nature of the person's condition, and utilise existing human resources (like informal carers, family and co-habitants for assistance using the system). Though simple changes (like the use of infographics on base units) may further assist in designing the system for a broader user base, service fees and client categories that take into account other users is a strength in the context of these principles. For example in Madrid, there are three categories of user which reflect that others may be assisting a primary user to engage with the system:[138]

1. **Type 01: Principal Client** has the main device and pendant

2. **Type 10: Client with Additional Pendant** is a person that lives with a Principal Client, but has his/her own pendant, separate from the one that the Principal Client has. When an alarm is emitted from this pendant, it

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[138] Dirreción General de Mayores y Atención Social (2013) *Memoria de Actividades: Ejercicio 2012*. Madrid: Dirreción General de Mayores y Atención Social. Available at: https://www.madrid.es/UnidadesDescentralizadas/ServSocialesYAtencionDependencia/Publicaciones/MEMORIA%202012/Memoria%20DG%20Mayores%202012.pdf (accessed June 2018). p.51

sends its own signal, and is received in the call-centre as an individual entity, although identified as living with the Principal Client

3. **Type 20: Client without an Additional Pendant** is a person who lives with a Principal Client but is unable to use the technology to ask for help. It is therefore the Principal Client who presses the pendant for help in case this person has an emergency. An example would be persons with severe physical, intellectual/cognitive or sensory disabilities living with others.

Charges for the service are calculated by household income (as opposed to the number of users in the abode) and this facilitates others to assist users who may have impairments preventing them from using the telecare system directly. That said, the model of reliance on another person to operate devices should not be the primary solution. Universal Design, fully realised, would allow the individual to use much of the existing devices.

# 8.0 Challenges to TH/TC adoption

## 8.1 The nature of innovation and implementation

Van Dyk[139] points out that one can recognize Rogers' categories of innovation adoption in TH/TC – this is essentially the way that people adopt new technologies. Adoption of innovation flows from the initial innovators, to early adopters, early majority, late minority and finally, laggards (Figure 10).
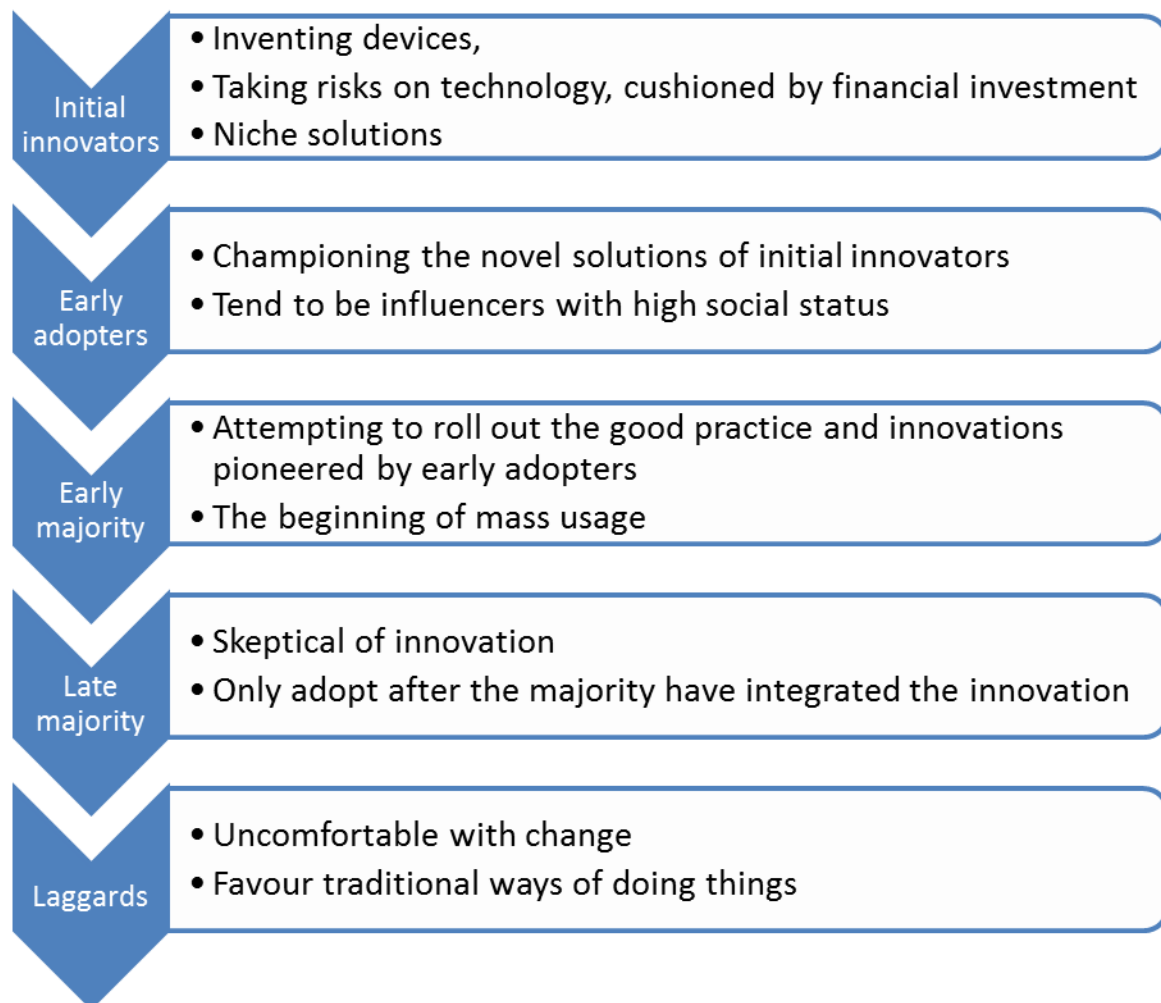
**Initial innovators**
- Inventing devices,
- Taking risks on technology, cushioned by financial investment
- Niche solutions

**Early adopters**
- Championing the novel solutions of initial innovators
- Tend to be influencers with high social status

**Early majority**
- Attempting to roll out the good practice and innovations pioneered by early adopters
- The beginning of mass usage

**Late majority**
- Skeptical of innovation
- Only adopt after the majority have integrated the innovation

**Laggards**
- Uncomfortable with change
- Favour traditional ways of doing things

**Figure 10 Rogers' categories of innovation adopters**

Van Dyk argues that we are in the 'early majority' phase as attempts are being made to mainstream TH/TC in healthcare services. This way of conceptualising

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[139] Van Dyk, L. (2014) 'A Review of Telehealth Service Implementation Frameworks'. *International Journal of Environmental Research and Public Health*, **11**(2), 1279-1298.

makes sense on a practical level, when looking at innovations and initiatives across jurisdictions and seeing a wide range of pilot and trial projects but less nationally-implemented programmes.

Berridge et al.[140] developed a conceptual framework for how innovation functions within health and social services. They built this framework on four conditions operating within the cultural contexts of each country (Figure 11). Their hypothesis is that successful innovation in independent living services occurs when these essential four conditions are present together:

- **Consumers identified need**: compelling societal/consumer/user need is identified and attracts attention and resources
- **Service Providers:** a technology-enabled innovation solution is available
- **Payer Environment:** a viable business model with appropriate payer(s) is in place
- **Regulators:** supportive regulatory systems exist, or are introduced, to reduce barriers to implementation

Cultural context, and the kind of health and social care operating in the country, is important. This includes the home care models that have been adopted. Berridge et al. examined a number of countries and found that each one had taken action toward innovation and mainstreaming technologies for independent living. Specific cultural contexts, policy subsystems, health care services, and business models shape the diverse approaches across countries.

This is borne out in the examination of different systems operating in the jurisdictions reviewed. For example, in both Spain and Scotland telecare systems have grown out of needs identified in the housing sector to receive national support through health and social care systems / funding / policies. In Ireland, we have a very similar first-generation telecare system in the Seniors Alert Scheme. However, the context is different – the SAS focusses on rural and lone-living, and supporting vulnerable older adults to live in the community. As a result, it is managed under the Department of Rural and Community Development.

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[140] Berridge, C., Furseth, Pl., Cuthbertson, R., Demello, S. (2014) 'Technology-based innovation for independent living: policy and innovation in the United Kingdom, Scandinavia, and the United States'. *Journal of Aging and Social Policy*, **25**, 213-228.
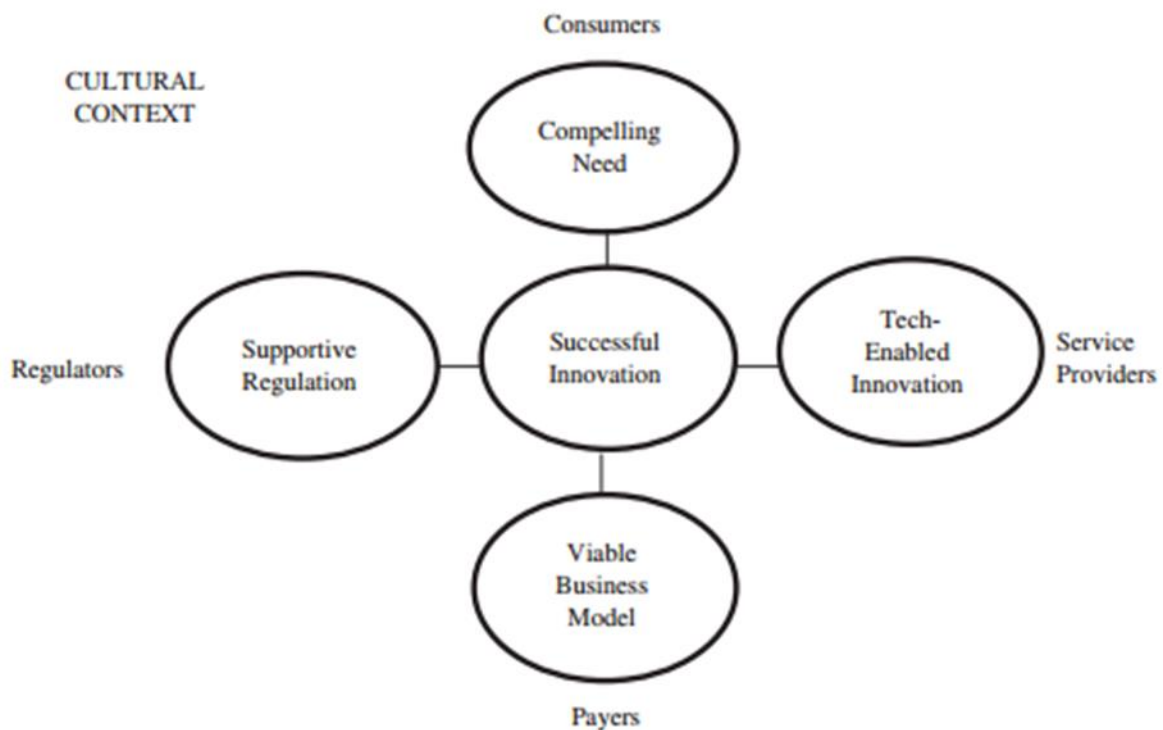
**Figure 11 Berridge et al.'s Integrated Core Model of Innovation[141]**

On one level, this is an unusual situation for a telecare system (e.g. in comparison to the jurisdictions reviewed which had integrated telecare to health and/or social care services) and might make it harder to integrate with health and social care services. However, Berridge argues that cultural context is not the enemy of innovation, it just needs to be considered:

> Given the new opportunities technology provides and the range of business models at play, no simple model will enable successful innovation across countries. For the purpose of future research, we suggest that priority is placed on gaining a more precise understanding of where responsibility for paying for technology-

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[141] Berridge, C., Furseth, Pl., Cuthbertson, R., Demello, S. (2014) 'Technology-based innovation for independent living: policy and innovation in the United Kingdom, Scandinavia, and the United States'. *Journal of Aging and Social Policy*, **25**, 213-228.

based services might appropriately lie within each cultural context.[142]

## 8.2 Barriers to the implementation of TH/TC

Tanriverdi and Iacono[143] drew on Attewells' work on innovation[144], proposing four barriers for the diffusion of TH/TC:

- Technical barrier: It is imperative that the appropriate technology is available, as well as knowledge about it

- Behavioural barrier: This involves change management, especially with respect to resistance to change, power and politics around TH/TC

- Economic barrier: Reimburse healthcare workers for TH/TC consultations and open up new patient markets

- Organizational barrier: Integrate TH/TC services into existing organizational structures and provide institutional support to execute these services

These categories resonate with the barriers the European Innovation Partnership on Active and Healthy Aging[145] highlight around full deployment of interoperable, independent-living, ICT solutions for older people to assist healthy aging. In reality, there are many overlaps and addressing challenges of implementation requires both a top-down and bottom-up approach.

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[142] Berridge, C., Furseth, Pl., Cuthbertson, R., Demello, S. (2014) 'Technology-based innovation for independent living: policy and innovation in the United Kingdom, Scandinavia, and the United States'. *Journal of Aging and Social Policy*, **25**, 213-228. p. 226

[143] Tanriverdi, H., Iacono, CS. (1998) 'Knowledge Barriers to Diffusion of Telemedicine'. *International Conference of the Association for Information Systems*, Helsinki, Finland, 14–16 August, pp. 39–50. As cited by Van Dyk, L. (2014), A Review of Telehealth Service Implementation Frameworks International Journal of Environmental Research and Public Health, **11**(2), 1279-1298.

[144] Attewell, P. (1992) Technology diffusion and organizational learning: The case of business computing, Organ. Sci., 3, 1–19 as cited by Van Dyk, L. (2014) 'A Review of Telehealth Service Implementation Frameworks'. *International Journal of Environmental Research and Public Health*, **11**(2), 1279-1298.

[145] European Innovation Partnership on Active and Healthy Ageing (N.D.) *Full deployment of interoperable independent living solutions for older people*. Available at: https://ec.europa.eu/eip/ageing/sites/eipaha/files/library/54ecab52bd3fa_C2%20corrected.pdf (accessed during 2017 phase of research).

## 8.2.1 Addressing implementation from the top down

As evidenced by the jurisdictions, driving TH/TC from the top down gives impetus to the integration of these solutions into existing health and social care systems.

- Northern Ireland - the Centre for Connected Health and Social Care tendered for telemonitoring services in response to the country's aging population. The eHealth and Care Strategy 2016 has key objectives for furthering TH/TC.

- Scotland – the government has the political will to position the country as an internationally recognised site of TH/TC products and services. The Scottish Centre for Telehealth and Telecare (SCTT) brings together stakeholders from industry, academia, local authorities (partnerships), NHS Boards and voluntary and the private sectors to inform the redesign of health and care services and implement TH/TC initiatives.

- Spain - telecare provision is included in dependency legislation which requires that people meeting the eligibility criteria are provided with an appropriate service. Quality standards and compliance for services are outlined in *Normas Generales* and UNE 158401.

There is evidence that countries are developing strategies and undertaking infrastructural work to progress TH/TC. What is also evident from looking at the various jurisdictions is that standards and quality are approached very differently. Spain was the only country reviewed which featured a strong regulatory environment, providing clear guidance to stakeholders in implementing and operating a telecare system. In comparison, Scotland has some standards but they are more opt-in, where a TH/TC provider undertakes to become accredited.

At European level, the European Telecommunications Standards Institute (ETSI) has given some attention to this field and prepared some guidance documentation (ETSI, 2008).  This covers a broad range of human factors and user experience issues of relevance to telecare and home telehealth. Its main focus is upon ways to ensure that users have access to the outputs of devices, are capable of generating appropriate inputs and find it easy to locate service elements. It covers electronic assistive technology services; home safety and security monitoring services; information, communication and educational services; personal monitoring services; and user-centred integration of elements. It provides examples and scenarios in each of these areas which illustrate how human factors can interact with devices and services. While it is not specific about UD, many of the examples are related to the seven UD principles.

An important resource, which is primarily targeted at standards developers, is the ISO/IEC Guide 71:2014 (CEN/CENELEC Guide 6) guidelines to address the needs of older persons and persons with disabilities. This ISO guide provides tools to assist in the identification of factors that will affect the use of a product, service or environment. Sensory, physical and cognitive functioning are addressed in relation to a number of design features the most relevant of which are information, labelling, instructions and warnings; materials; and installation

In the current context, the country studies revealed a number of instances where potential users were prevented from benefitting from telecare or telehealth service because of sensory impairments or cognitive difficulties.  A UD approach to design would have eliminated the need for special treatment for these users by building in accessibility and usability features from the beginning.  Apart from a small number of initiatives in designing services to overcome these challenges there was little evidence of a focus on the intersection between the domains of telecare and telehealth and UD. Country strategies for eHealth provide vision and drive development but without standards, UD may not be embedded at all levels.

With the ratification of UNCRPD[146], the absence of standards may become more problematic as matters of inclusivity and access (for which TH/TC and assistive technologies are being heralded as solutions) must be attended to. For instance,

> Persons with disabilities must be able to live independently, to be included in the community, to choose where and with whom to live and to have access to in-home, residential and community support services (Article 19). Personal mobility and independence are to be fostered by facilitating affordable personal mobility, training in mobility skills and access to mobility aids, devices, assistive technologies and live assistance (Article 20).

Particularly in relation to the use of aids, devices and assistive technologies, agreed standards will allow for quality (and compliant) approaches to be taken by stakeholders.

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[146] UN General Assembly (2007) *Convention on the Rights of Persons with Disabilities : A/RES/61/106.* Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/the-convention-in-brief.html (accessed June 2018).

## 8.2.1.1 What role for TH/TC technologies?

There is a broader, more philosophical question to be asked around how TH/TC is being developed currently. Looking at the developments in policy, it is clear that the impetus on developing TH/TC has emerged from demographic changes. In particular, trends of ageing populations and the likely increased numbers of persons with disabilities, or increased numbers of people requiring assistance due to their impairments.

As a result, older people (in particular) have been a key target group for TH/TC across the jurisdictions reviewed, as well as in Ireland. The development of services, technologies and devices has been driven by health agendas as *solutions* to combat rising healthcare costs and pressures on health systems that will come from increased need.

This model of TH/TC – as a solution to medical problems – downplays one of the core advantages of using this technology. That is, the greater inclusion of persons with disabilities and older persons within our societies. For the full potential of TH/TC technologies to be realised, a shift may be needed towards using these technologies as a pro-active means of inclusion rather than reactive medical solutions.

The learning on Universal Design in TH/TC, for instance the ARCHIE principles, position good design as a tool to enable the TH/TC solutions to work – good design and technology are being prescribed for medical diagnoses. However, universally designing products and services have a much more prized potential - inclusivity. TH/TC development, especially when driven by top-down policy or organisations, needs to be mindful that innovations are not being pursued purely within the medical model.

This also makes long-term economic sense. One of the structural fears is that an ageing population impacts pension costs and necessitates workers to stay working longer.[147] These fears around the demographics drive TH/TC development and yet by viewing the wider use of assistive technologies in terms of inclusion, it is precisely this demographic group that could be facilitated to adapt and continue in the workforce.

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[147] Scientific Foresight Unit (STOA) (2018) *Assistive technologies for people with disabilities*. Brussels: European Parliamentary Research Service. Available at: http://www.europarl.europa.eu/RegData/etudes/IDAN/2018/603218/EPRS_IDA(2018)603218_EN.pdf (accessed June 2018).

## 8.2.1.2 Benefits of top-down development

Top-down development of TH/TC does have the advantage and scope to implement health infrastructure that supports TH/TC. One example of this is the adoption of electronic health records (EHRs), seen as crucial to the success of many services.

EHR systems create, update and share patient health records. They remove the risk of errors posed by paper-based records and reduce duplication and contradictory information. The use of these systems can result in improved patient care, resource efficiencies and improved decision-making. Implementing them, however, can be complex in relation to getting critical mass use, data protection and interoperability of systems. [148]

Again, top-down policy at the European level can address many of these challenges. The EU reviewed the laws of EU countries on EHRs and made recommendations to facilitate patients' rights to cross-border healthcare[149].

The e-Health Network facilitates cooperation between European e-Health systems. It is developing a series of guidelines to facilitate cross-border transferability of medical data, taking into account EU data protection rules. The European Commission (EC) 2012-2020 action plan proposes a series of measures and expresses the commitment of the EC to remove existing barriers to "a fully mature and interoperable e-Health system in Europe".[150]

To date, Ireland has poorly developed electronic medical records. There are examples of EHRs operating in some general practices, but not to any uniform system. EHR use in hospital practice is much less developed. A number of pilot projects are underway between primary care/general practice and hospital

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[148] Kenny, G., Connolly, R (2016) 'Drivers of Health Information Privacy Concern: A Comparison Study'. Americas Conference on Information Systems, San Diego, 11-14 Aug. Available at: https://pdfs.semanticscholar.org/6601/30f524abb267a5cdb1a162ae7d0c1383efb0.pdf (accessed during 2017 phase of research).

[149] e-Health Stakeholder Group (2013) Report of the e-Health Stakeholder Group: Patient access to the Electronic Health Records. Brussels: BEUC – The European Consumer Organisation. Available at: file:///H:/Downloads/PatientaccesstoEHRreportEHSG.pdf (accessed during 2017 phase of research).

[150] Health Programme of the European Union (2013) *Overview of the national laws on electronic health records in the EU Member States and their interaction with the provision of cross-border e-Health services: Final report and recommendations*. Brussels: Milieu Ltd. Available at: http://ec.europa.eu/health/ehealth/docs/laws_report_recommendations_en.pdf (accessed during 2017 phase of research).

services as well as between hospitals. There is an understanding that each person should have a unique health identifier. Many hospitals have introduced the (PACS) radiology communication system.[151]

The strategic approach being taken by eHealth Ireland speaks to the absence of nationwide, centralised ICT systems being used in healthcare. They have identified several 'must-haves', namely, the Individual Health Identifier (IHI) and a national system of EHRs.

Establishing a comprehensive system of EHRs is a key strategic priority, and is considered a cornerstone of the eHealth Strategy for Ireland. In May 2016, eHealth Ireland finalised a Business Case for the use of EHRs which is under consideration by the Department of Health in the context of the Programme for Government with a view to the work having budgetary establishment by 2018.[152]

The learning from Israel's MOMA programme has shown that having an independent, evidenced-based policy organisation driving innovation and funding initiatives in TH/TC is another critical element to successful TH/TC implementation. Israel's Gertner Institute, an independent research institute for the study of epidemiology and health policy, championed the development of TH/TC – both conceptually and financially.

The creation of eHealth Ireland may fulfil some of the functions illustrated by the organisations across the various jurisdictions. It will provide a strategic vision, sufficient power to view (and influence) the system as a whole, and direct TH/TC implementation in Ireland. However, the 'must have' top-down infrastructural projects, though very important solutions in themselves, will not be sufficient to drive TH/TC use in Ireland and attention must also be given to bottom-up drivers.

A cultural shift must encompass patients, carers and clinicians - getting buy-in from these primary user groups. Policy alone cannot drive implementation – the average user of TH/TC systems must be motivated by compelling needs and

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[151] e-Health Stakeholder Group (2013) Report of the e-Health Stakeholder Group: Patient access to the Electronic Health Records. Brussels: BEUC – The European Consumer Organisation. Available at: file:///H:/Downloads/PatientaccesstoEHRreportEHSG.pdf (accessed during 2017 phase of research).

[152] Department of Health (Ireland) (2013) *eHealth Strategy for Ireland*. Available at: http://www.ehealthireland.ie/Knowledge-Information-Plan/eHealth-Strategy-for-Ireland.pdf (accessed July 2017).

viable technological solutions, while services will need to fit into appropriate business models for ease and sustainability.

## 8.2.2 Changing the culture

The lessons from MOMA in Israel have shown that technological maturity, a culture where ICT use is viewed as an integral tool of healthcare, and the comfort of users across all stakeholder groups has contributed to its success. This success has not been replicated nationally, nor even in other organisations within Israel and a principal barrier has been the technological immaturity elsewhere in the system.

For TH/TC initiatives to succeed on a wider level in Ireland, there has to be a cultural shift towards the use of technology as a tool in healthcare. To this end, the creation of the Chief Information Officer role within the HSE in 2014 was a welcome development though it must be recognised that Ireland is only beginning to build this culture. We remain technologically immature.

An element of creating this culture is how integral ICT use is for individuals. A global issue around TC/TH and ICT is the question of digital literacy and overcoming the digital divide. As of 2015, approximately 58 million Europeans had never used the internet.[153]

The PIAAC 2012[154] survey looked at the proficiency of adults' problem-solving in technology-rich environments by assessing respondent's ability to use a number of common computer applications to complete various tasks (e.g. email, spreadsheets, word processing, internet browsing). It is a good indicator of digital literacy. A significant percentage of Irish adults score in the lowest level of proficiency (Figure 12), at 42% (29.5% at Level 1, 12.6% below Level 1). Higher-level proficiency is lower than the international average (25% of Irish adults are at Levels 2 or 3 compared to the international average of 34%).

Examination of 'age' and 'principal economic status' variables in the PIAAC survey further complicates the issue of proficiency. Participants aged 60-65 have the lowest levels of digital literacy and mean proficiency declines as age increases

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[153] Members' Research Service (2015) *Bridging the digital divide in the EU*. Brussels: European Parliamentary Research Service. Available at: http://www.europarl.europa.eu/RegData/etudes/BRIE/2015/573884/EPRS_BRI(2015)573884_EN.pdf (accessed June 2018).

[154] CSO (2012) PIAAC 2012 Survey Results for Ireland from the OECD's Programme for the International Assessment of Adult Competencies. Dublin: Stationary Office. Available at: http://www.oecd.org/skills/piaac/Ireland.pdf (accessed March 2018).

across the groups (65 was the oldest age group surveyed). Participants who reported having a 'permanent disability' recorded the lowest mean scores amongst the categories of principal economic status. However, low sample sizes / disclosure of disability status, and large standard error and standard deviations make for imprecise estimates and point to a wide variation in proficiency amongst persons with disabilities.

To address the challenge of technical barriers, ICT capacities need to be built at tertiary education and vocational training levels. Healthcare professionals including doctors must come to understand digital technologies as part of their core toolkit for diagnosis, treatment, prevention, communication, research, and service innovation. European medical school curricula do not typically reflect this need.  Similarly, nursing and other healthcare professionals need to train their students in digital technologies.

The integration of interdisciplinary e-health training at all levels in the academic curricula of health and care education is necessary. Ultimately, eHealth should enter core curricula and qualifying national board examinations. This becomes particularly important if the model of service delivery includes health service clinicians assessing / recommending / training patients to use TH/TC systems, for instance was the case in Northern Ireland. To ensure pro-active and innovative TH/TC solutions, those implementing the care technology at the coal face must have adequate expertise and time to develop knowledge.

In a very general sense, addressing this challenge also requires a commitment to lifelong learning, as the pace of technology results in frequent changes to methods and tools. This commitment needs to be at the individual level (for all users of the health system) and matched by learning opportunities and training that are available to TH/TC users in order to upskill, e.g. Age Action Ireland's 'Getting Started in Computers' programme for over 55s.[155]

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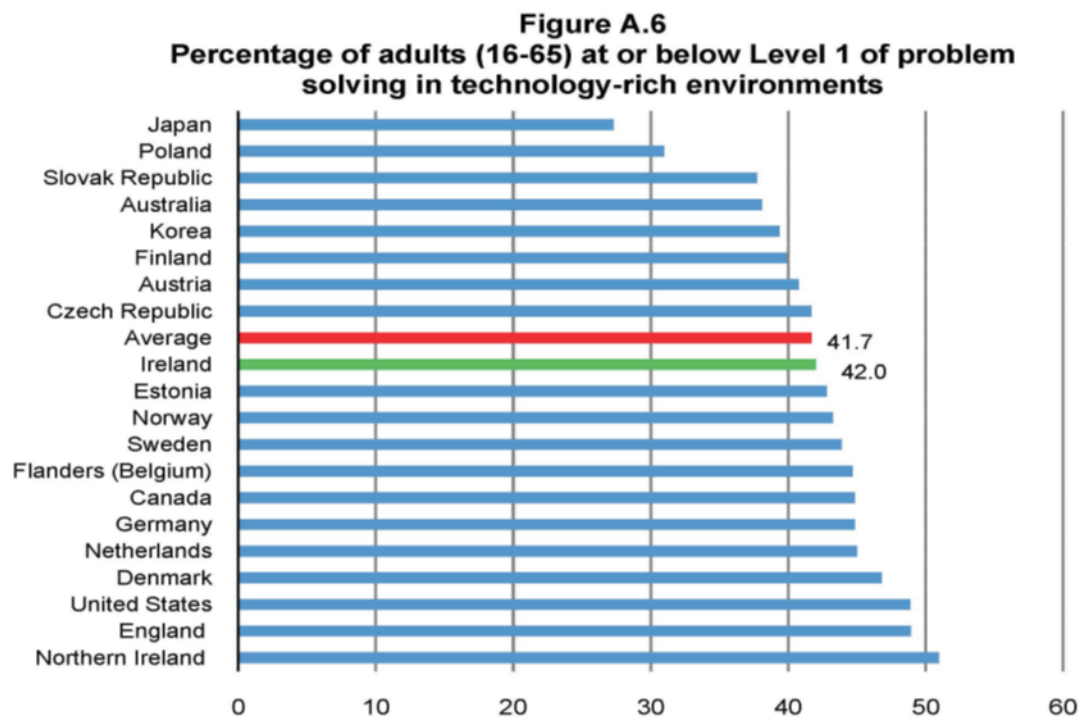[155] Age Action (2018) *Getting Started Computer Training*. Available at: https://www.ageaction.ie/how-we-can-help/getting-started-computer-training (accessed March 2018).

**Figure A.6**
**Percentage of adults (16-65) at or below Level 1 of problem solving in technology-rich environments**

| Country | Value |
|---|---|
| Japan | |
| Poland | |
| Slovak Republic | |
| Australia | |
| Korea | |
| Finland | |
| Austria | |
| Czech Republic | |
| Average | 41.7 |
| Ireland | 42.0 |
| Estonia | |
| Norway | |
| Sweden | |
| Flanders (Belgium) | |
| Canada | |
| Germany | |
| Netherlands | |
| Denmark | |
| United States | |
| England | |
| Northern Ireland | |

**Figure 12 Ireland's technological literacy score in comparison with other OECD countries[156]**

Van Dyk highlighted some of the challenges in implementing innovative TH/TC solutions and in particular, managing change can be a sticking point.[157] Where prospective users are sceptical of the service offered, or simply favour traditional ways of working, it might be difficult to progress.

In the Irish context, where telecare initiatives are managed almost independently from health and social care (e.g. through private providers or the Seniors Alert Scheme), a cultural – as well as policy – shift may be required to further innovation and implementation. Another learning from the MOMA programme was the need to have clear role delineation so that the responsibilities of each professional in an integrated TH/TC system are evident and workable. Again, where TH/TC initiatives are not centrally coordinated, these delineations would

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[156] CSO (2012) PIAAC 2012 Survey Results for Ireland from the OECD's Programme for the International Assessment of Adult Competencies. Dublin: Stationary Office. Available at: http://www.oecd.org/skills/piaac/Ireland.pdf (accessed March 2018). p.6

[157] Van Dyk, L. (2014) 'A Review of Telehealth Service Implementation Frameworks'. *International Journal of Environmental Research and Public Health*, **11**(2), 1279-1298.

need to be carefully negotiated and adhered to (which top-down policy/legislation/standards can impact).

Sanders et al.[158] explored the barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial using a qualitative research design. They identified key themes challenging the adoption of telehealth and telecare as:

- requirements for technical competence and operation of equipment

- threats to identity, independence and self-care

- expectations and experiences of disruption to services.

Respondents held concerns that special skills were needed to operate equipment but these were often based on misunderstandings. Participants were reluctant to risk potentially disruptive changes to existing services that were often highly valued. These findings crystallised why engagement with service users to understand how they feel about the service development is a significant critical success factor.

The joint research centre in the European Commission published guidelines for ICT-supported Integrated Care in 2015.[159] Some of their recommendations directly address the issue of user roles and managing change:

- Regarding professionals – involve professionals from various sectors in the development and implementation strategy of the TH/TC solution from the start and appoint champions to advocate the initiative, monitor change management and define new roles for care professionals where required to implement change and coordinate new care processes

- Regarding users – involve target users from the start in the development of the TH/TC tools and the implementation strategy to address their specific needs and adapt the solutions to their capacities. Offer training and support

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[158] Sanders, C., Rogers, A., Bowen,R., Bower, P., Hirani, S., Cartwright, M., Fitzpatrick, R., Knapp, M., Barlow, J., Hendy, J., Chrysanthaki, T., Bardsley, M. and Newman. S. (2012) 'Exploring barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial: a qualitative study'. *BMC Health Services* Research, **12**. Available at. https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-12-220 (accessed September 2017)

[159] Graafmans, W. and Abadie, F. (2015) *SIMPHS3 Guidelines for ICT-supported Integrated Care*. Brussels: Joint Research Centre. Available at: http://is.jrc.ec.europa.eu/pages/TFS/SIMPHS3WS20150519/SIMPHS3%20WS%20Guidelines.pdf (accessed during 2017 phase of research).

to patients/citizens and other users so they can acquire the necessary skills and solve problems

- Regarding functionality – make sure that the solution is a good answer to a clearly defined user need and that it focuses on, for example, care professionals and/or patients/citizens or other stakeholders. In addition, design and plan awareness actions to make sure targeted users are engaged and know about the benefits of the system

- Plan and organise training within the organisation affected by the new technology so as to allow for adjustment to new roles and processes, and

- Initiate cultural change in organisations to promote the adoption of innovation and to stimulate communication, co-creation and cooperation between organisations.

### 8.2.3 Technological advances and issues

Beyond individual users, there are also challenges that need to be addressed around the structure of technology and ICT implementation. It has been stated that in the next 10 years, data science and software will do more for medicine than all the biological sciences together.[160] eHealth generates a vast amount of data and there is a significant amount of work required to enhance understanding and knowledge of handling, storing and utilising this data.  For example how will it be kept secure, how will it inform clinical decision making, and who owns the data?

The EU Data Protection Regulation (GDPR) is one of the most important changes in data privacy regulation in the last 20 years and has direct relevance to the questions that big eHealth data throws up.[161]

Big Data in Health refers to large routinely or automatically collected datasets, which are electronically captured and stored. It is reusable in the sense of multipurpose data and comprises the fusion and connection of existing databases

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[160] Lardinois, F. (2013) 'Vinod Khosla: In The Next 10 Years, Data Science Will Do More For Medicine Than All Biological Sciences Combined'. *Tech Crunch*, 11 September..Available at: https://techcrunch.com/2013/09/11/vinod-khosla-in-the-next-10-years-data-science-will-do-more-for-medicine-than-all-biological-sciences-combined/ (accessed October 2017).

[161] Data Protection Commission (2018) *General Data Protection Regulation*. Available at https://www.dataprotection.ie/docs/GDPR/1623.htm (accessed October 2017).

for the purpose of improving health and health system performance. It does not refer to data collected for a specific study.[162]

Data for eHealth purposes may be prospectively gathered or retrospectively analysed with the purpose of increasing the effectiveness and quality of treatments, preventing disease, improving patient safety, prediction of outcomes, understanding demographic challenges and knowledge dissemination.

The World Health Organisation (2016)[163] recognises that the ability to capture data through sensors, monitors and wearable devices has expanded the sources of data beyond traditional health and public care records. Furthermore they recognise that new analytical methods allow us to link to other, dissimilar data such as environmental, geospatial, lifestyle and behavioural data (conceptualised in Figure 13).

Firouzi et al.[164] highlight that the Internet of Things (IoT) and Big Data are important emerging fields for smarter healthcare as people adopt wearable biosensors and new applications for individualised eHealth. The IoT is the phrase coined to articulate the networking of billions and trillions of smart objects connected to the internet.  The main goal of the IoT is to create a better world for human beings where the objects around us know what we like, what we want and what we need without explicit instructions.[165]

Data is not a barrier to TH/TC adoption, however knowing what to do with the sheer mass of information may add an element of confusion. If interrogated correctly (and creatively), the data gathered will give great insight to the health of individuals and society as a whole. However, without the requisite structures, procedures, vision and human resource skills there are possibilities that, at best,

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162 Gesundheit Österreich (2016) *Study on Big Data in Public Health, Telemedicine and Healthcare*. Brussels: European Commission.  Available at https://ec.europa.eu/health/sites/health/files/ehealth/docs/bigdata_report_en.pdf (accessed October 2017).

163 World Health Organisation (2016). *Evolving Health Data Ecosystem*. Available at http://www.who.int/ehealth/resources/ecosystem.pdf?ua=1 (accessed October 2017).

164 Firouzi, F. Rahmani, A.M. Mankodiya,K. Badaroglu, M. Merrett, G.V. Wong, P. Bahar, F. (2018) 'Internet of Things and big data for smarter healthcare: From device to architecture applications and analytics'. *Future Generation of Computer Systems*, **78** (2) 583-586.

165 Patrono,L. Brizzi, P.Petracca, M. Radic, J. 2016. RFID Technologies and the Internet of Things. Journal Of Communications Software and Systems. 12(1)1-3.

the potential in the data will not be realised while at worst, the system could drown in data.

One of the leading research projects in this area is MIDAS – Meaningful Integration of Data, Analytics and Services which is funded for €4.5M under the EC's H2020 SCI1-PM-18 2016 call for Big Data Supporting Public Health Policies[166]. MIDAS is a 40 month project designed to harness the power of big data to better inform public policy making and improve health and wellbeing outcomes across Europe. The MIDAS project is developing a pioneering big data digital platform for healthcare policy makers with a view to allowing these decision-makers to utilise multiple sources of unstructured and unconnected healthcare data.

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[166] MIDAS (2017) *About.* Availlable at http://www.midasproject.eu/about/ (accessed October 2017).

## Evolving health data ecosystem
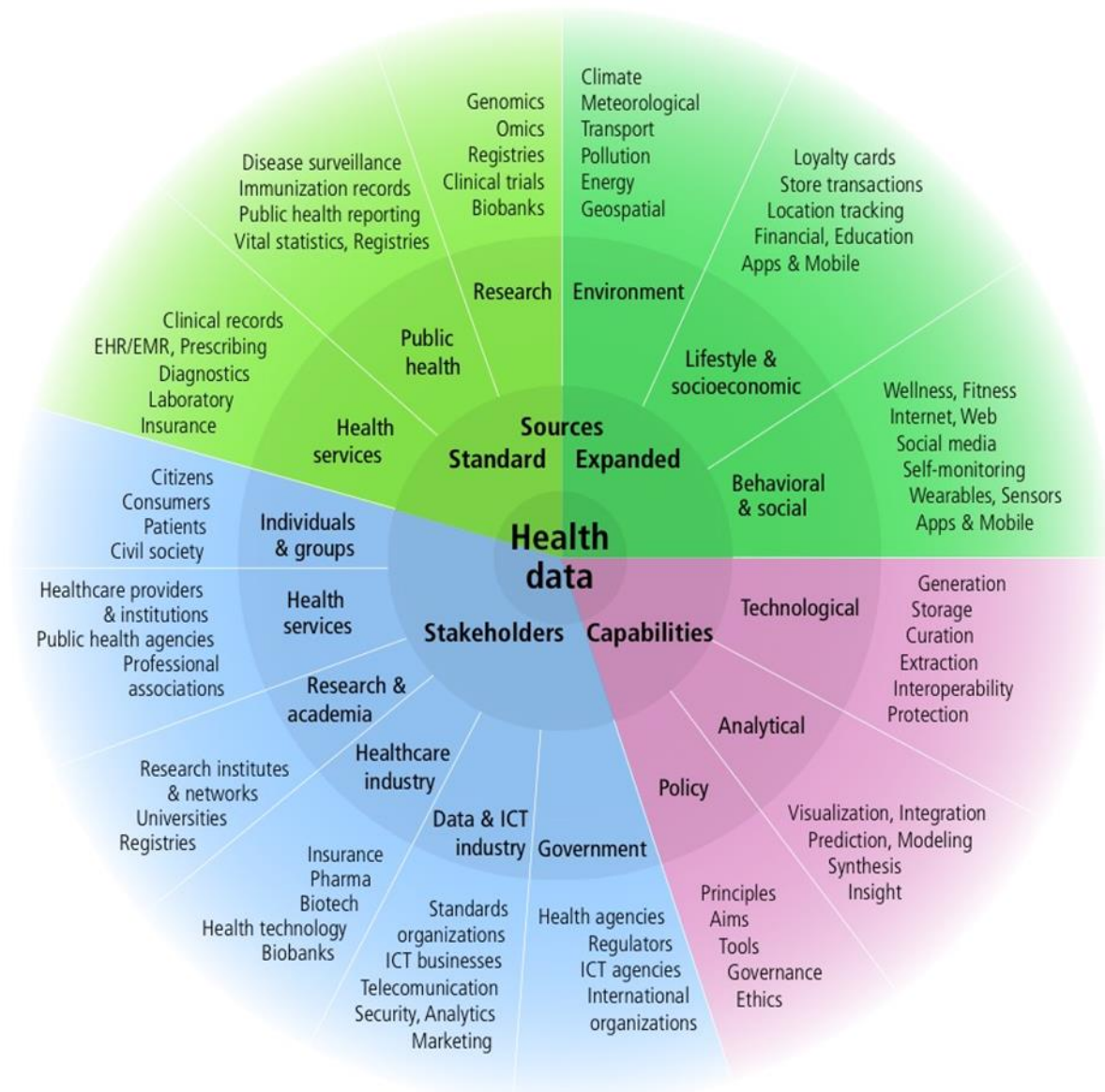


E. Vayena, J. Dzenowagis, M. Langfeld, 2016

**Figure 13 World Health Organisation Health Data Ecosystem[167]**

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[167] World Health Organisation (2016). *Evolving Health Data Ecosystem*. Available at http://www.who.int/ehealth/resources/ecosystem.pdf?ua=1 (accessed October 2017).

The MIDAS consortium is also investigating connecting patient data from European health authorities with individual data collected from apps, sensors and social media. It is hoped that the resulting insights will better inform policymakers to design evidence-based preventative strategies and implement policies that address specific health and social care challenges, whilst also reducing costs - ultimately improving the health and wellbeing of the population.

Taking the learning again from the MOMA programme in Israel, the issue of **scalability** of technology is demonstrated. The system works well and a sophisticated ICT model is in use, however, it is only applicable to one system. So a second ICT barrier is software and procedures that can be afforded, adopted, linkable and useful to various organisations.

### 8.2.4 Social and ethical issues

There is a fear that TH/TC could replace human interaction in favour of human-computer interaction[168], thus increasing the potential for social isolation of users. For example, where self-management of chronic illness replaces the social connection with caregivers and healthcare providers, is this a positive development?

The welfare of the user, cost-efficiencies in healthcare, access to care (especially for more remote or mobility impaired users), convenience and peace of mind for informal caregivers may well all benefit from the implementation of TH/TC services. However, these wins must be balanced against the social and ethical issues that come with these services.

The British Social Care Institute for Excellence's (SCIE) reports refer to the ways in which the commissioning and provision of telecare can compromise ethical principles. SCIE (2010) summarises the ethical issues as follows:[169]

- Telecare has the potential to threaten individual users' privacy, autonomy and control

- Social care and health professionals need to consider a range of ethical issues when supporting an individual in deciding whether to use telecare. These

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[168] Berridge, C., Furseth, PI., Cuthbertson, R., Demello, S. (2014) 'Technology-based innovation for independent living: policy and innovation in the United Kingdom, Scandinavia, and the United States'. *Journal of Aging and Social Policy*, **25**, 213-228.

[169] Perry, J., Beyer, S., Francis, J. and Holmes, P. (2010) *Ethical issues in the use of telecare*. London: The Social Care Institute for Excellence.

issues need to be considered before, during and after the installation of a telecare service

- Commissioners must ensure that people who are self-funders or personal budget holders have access to relevant information so they can decide what type of telecare service would best suit their needs

- Local priorities and commissioning strategies may affect telecare services, including what kind is provided and who receives and pays for it

- Service providers must have robust systems and agreements for collection, storage and sharing of data

- Proper support for telecare users will have training implications for practitioners

- Equipment manufacturers are urged to improve the sophistication of technology to reduce the potentially stigmatising effect of certain types of telecare. They are also urged to improve flexibility in the means of communication between monitoring centres and telecare users

- Telecare offers potential benefits for individual users including safety and independence. It also has the potential to reduce social care costs, allowing the more efficient deployment of direct care staff.

Researchers at the Welsh Centre for Learning Disabilities identified ethical issues in the use of telecare through the 'Delphi' method.[170] Researchers adopted an 'ethical framework' to illustrate the potential problems associated with the use of telecare. This framework consists of the following four principles:

- Autonomy – the ability of an individual to make choices.

  This is related to independence and choice in everyday life that is often taken for granted. When people rely on professionals or family carers for their care or for safety monitoring, the introduction of a telecare service can promote or restrict autonomy

- Beneficence – the principle of working for the benefit of the individual.

  Telecare has the potential to benefit people. It can provide assurance and confidence and can reduce unwanted dependence on professional staff or family carers. It can also increase comfort through environmental sensors and controls

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[170] Perry, J., Beyer, S., Francis, J. and Holmes, P. (2010) *Ethical issues in the use of telecare*. London: The Social Care Institute for Excellence.

- Non-maleficence – the principle of doing no harm.

  While telecare can benefit an individual, it also has the potential to expose people to risk. A balance must be achieved between ensuring safety and invading privacy. The potentially stigmatising effect of telecare should be recognised and minimised

- Justice – the moral obligation to act on a fair adjudication between conflicting claims.

  In the interests of justice, resources for telecare services should be allocated so as to balance the needs of the individual with those of the wider community

The most familiar example of telecare equipment that raises concern is the use of GPS monitoring systems for people living with dementia. Though they provide practical benefits in the area of risk management, the practice can also be considered an infringement of human rights.

The Mental Welfare Commission for Scotland (2015)[171] has issued principles and guidance on good practice when considering the use of use of telecare and assistive technology for people with dementia, learning disability and related disorders. They are very clear that some technologies have the potential for abuse if not used within a proper legal framework with guidance to good practice (again, the importance of robust standards and quality is illustrated here).

The Commission also considers that telecare and assistive technology have the potential to stigmatise and be degrading for the user, with potential for these services to place limits on the personal freedom of the individual if not used discreetly. This is why they believe a rights-based approach to decision making is required.

In addition the Commission stresses that those considering the use of telecare and assistive technologies clearly have to be aware of the potential for harm that their actions have[172] and to take this into account in their decision making. This includes those who are not employed to do so, but also those who care for

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[171] Mental Welfare Commission for Scotland (2015) *Decisions about technology*. Available at: http://www.mwcscot.org.uk/media/241012/decisions_about_technology.pdf (accessed November 2017).

[172] NOTE: The Commission highlight rights infringement, stigma, the potential for users and carers to perceive the technology as intrusive and demeaning, and the potential for the technology to be used as restraint (p.3-4)

someone living in their own private home. Perry et al.[173] outline a pragmatic approach to an ethics of telecare to include both the pre- and post-installation phases.

Much of the ethical considerations have thus far focussed on telecare initiatives. Obviously telehealth data has the potential to be damaging if sensitive personal data is exposed. However, further than this, as devices get more sophisticated in the future, an ethical issue may arise between technology that offers assistance and technology that offers enhancement.[174] For example, technologies that enhance the user, whether they have a disability or not, challenge the notion of bodily 'normality'. Should the use of assistive technology become widespread, then those who may be unwilling or unable to use such technology may suffer discrimination or face barriers, e.g. in finding employment.

### 8.2.5 Economic opportunities and barriers

The management of chronic illness is costly to the exchequer and most telehealth and telecare activities have catered directly for these patients. Over one third (38%) of the Irish population report that they have a chronic illness. This increases with age – 62% of persons aged 65 years and over report having a chronic illness. In 2016, approximately 542,400 people aged 65 years and over, had at least one chronic condition. By 2022 it is projected that there would be a further 96,670 additional people with at least one chronic condition (Health Service Executive 2017).[175] With the population ageing, it is estimated that these costs will keep increasing.

In terms of costs, Wren et al. [176] reported that stroke costs in Ireland were estimated to have been between €489 and €805 million in the year 2007, with

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[173] Perry, J., Beyer, S., Francis, J. and Holmes, P. (2010) *Ethical issues in the use of telecare*. London: The Social Care Institute for Excellence.

[174] Scientific Foresight Unit (STOA) (2018) *Assistive technologies for people with disabilities*. Brussels: European Parliamentary Research Service. Available at: http://www.europarl.europa.eu/RegData/etudes/IDAN/2018/603218/EPRS_IDA(2018)603218_EN.pdf (accessed June 2018).

[175] Health Service Executive (2017) *Planning for Health 2017*. Available at: http://www.hse.ie/eng/services/news/newsfeatures/Planning-for-Health/ (accessed September 2017).

[176] Wren, M.A., Gillespie, P., Smith, S., Kearns, K. and Wolfe, C. (2014) *Towards Earlier Discharge, Better Outcomes, Lower Costs: Stroke rehabilitation in Ireland*. Available at: http://epubs.rcsi.ie/cgi/viewcontent.cgi?article=1001&context=sphysiorep (accessed September 2017).

nursing home care needs and indirect costs accounting for the largest proportion of costs.

In 2008, a meta-analysis of home monitoring studies globally found TH/TC to be a cost-effective alternative to traditional provision in 21 of 23 studies, the majority of which focused on chronic disease care.[177] The main benefits were decreased hospital utilisation, improved patient compliance with treatment plans, improved patient satisfaction with health services, and improved quality of life.

Multiple studies have found savings associated with the application of telehealth for home monitoring when applied to heart failure patients. A set of recent studies that compared telehealth to traditional outpatient care recorded savings estimates ranging from 17% to 75%.[178]

In the USA, the Veterans' Health Administration developed a national model of telehealth focussed on the provision of routine, non-institutional care. The service targets patients with

- complex chronic conditions at risk of long-term institutional care
- high-resource usage patients with chronic disease management needs (related to diabetes, heart failure, PTSD and depression, and so on), and (increasingly),
- primary prevention of chronic conditions through programmes such as obesity management.

Care objectives include improving clinical outcomes while reducing complications, hospitalization and clinic or emergency room visits.

The VHA has a particularly strong practice of data analysis and evaluation, both to inform care and track outcomes. Substantial reductions in hospitalisations

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[177] Zanaboni P, Wootton R. (2012) 'Adoption of telemedicine: from pilot stage to routine delivery'. *BMC Medical Informatics and Decision Making* **12**(1), 1-9.

[178] NOTE: See 7 references cited in Dinesen, B et al (2016) 'Personalized Telehealth in the Future: A Global Research Agenda'. *Journal of Medical Internet Research*, **18**(3):e53. Available at: http://www.jmir.org/2016/3/e53/ (accessed during 2016 phase of research).

were reported – savings were estimated per patient per annum of between $1,238 and $1,999.[179] Additional advantages[180] of the programme include:

- Reduced admissions (down 20% in 2010)

- Decreased resource utilisation - patients with diabetes (-20%), heart failure (-30%) and depression (-56%) and,

- High patient satisfaction - remaining above 86%.

Along with savings for the overall system, there are also savings to the individual,[181] for example resources such as travel, time and accommodation. These costs, incurred directly by older chronically impaired patients or by informal carers, can be significant since these patients are frequenting hospitals more often than the average population. A reduction in the use of these resources leads to monetary savings.

Additionally, though difficult to quantify, indirect cost benefits of any TH/TC system should be considered. For example, services that assist informal carers to work outside the home or negate the need to pay for residential solutions to care (such as nursing homes) have a bearing. These workers can earn an income, contribute to the tax base and economy, while earnings lost through time spent caring have a cumulative effect nationally.[182]

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[179] Darkins, A. (N.D.) Telehealth Services in the Department of Veterans Affairs (VA). Washington D.C.: Veterans Health Care. Available at: https://www.graham-center.org/content/dam/rgc/documents/press-events/primary-care-forum/AdamDarkins-Telehealth.pdf (accessed during 2016 research phase).

[180] Dinesen, B et al (2016) 'Personalized Telehealth in the Future: A Global Research Agenda'. *Journal of Medical Internet Research*, **18**(3):e53. Available at: http://www.jmir.org/2016/3/e53/ (accessed during 2016 phase of research).

[181] Dobrev, A., Meyer, I., Müller, S., Kubitschke, L., Hammerschmidt, R., Korte, W.B., Hüsing, T., van Kleef, T., Otto, S., Heywood, J. and Wrede, M. (2013) *Coping with an ageing population – Learning from good eHealth and telecare practices. The eCare Benchmarking study* (Contract Number: 30-CE-0358386/00-54). Bonn: European Commission, DG Information Society & Media Contract Number.

[182] NOTE: This point was made during a presentation by Dominic Trepel at the ABI Research Seminar 2018 held in Dublin on 18 May 2018. Details available here: https://www.abiireland.ie/wp-content/uploads/2018/03/current-trends-and-future-horizons-Draft-programme.pdf

Likewise, by using assistive technology for the purpose of inclusion rather than solution, it may assist users to remain working and thus contribute to these indirect cost benefits.

Despite some evidence of cost efficiencies, the European Innovation Partnership on Active and Healthy Aging[183] highlighted economic barriers to independent-living and ICT solutions for older people. These include the limited availability of affordable and commercially viable solutions, fast technological evolution and difficult business models.

Evidence from the three phases of National Disability Authority research on TH/TC detail the need to have adequate funding to scale-up initiatives, and to have properly sustainable service models. For instance, Spain's linkage of user costs to monthly household income, and the Northern Irish financial incentive for telecare through the Community Care Grant.

In understanding the cost for services and sustainability, care must be taken to include the cost of implementing best practice. For example, adequate training for all users of TH/TC is necessary and needs to be focussed at different levels of depth.

Taking the Northern Ireland referral pathway as an example, the need to attend to the additional, more subtle costs is evident. Healthcare practitioners assessed the prospective telehealth user and detailed the equipment that was to be used. This was then forwarded to the telehealth provider.

In order to achieve the best use of technology, as well as a system that is workable for healthcare practitioners, staff operating in such a model will need proper training and time in their roles to foster continuous expertise in TH/TC. It has been found that many health, social and housing care workers have little understanding of telecare and telehealth so building this knowledge will need consideration.[184] This has knock-on effects for costs, for instance, the initial and constant upskilling, or the need to redistribute work to other human resources to accommodate the TH/TC requirements of their role.

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[183] European Innovation Partnership on Active and Healthy Ageing (N.D.) *Full deployment of interoperable independent living solutions for older people*. Available at: https://ec.europa.eu/eip/ageing/sites/eipaha/files/library/54ecab52bd3fa_C2%20corrected.pdf (accessed during 2017 phase of research).
[184] European Commission (2013) Study on business and financing models related to ICT for ageing well http://www.healthyageing.eu/sites/www.healthyageing.eu/files/resources/HA-technolage_d8_final%20study%20report_vfinal.pdf

It is interesting to note that Northern Ireland has coupled TH/TC to the prosperity agenda. Invest NI is offering support and resources to businesses in Northern Ireland that have innovative products and services to scale-up, and which can create jobs for the wider economy.

# 9.0 Conclusions

Given the policy impetus to tackle increased needs (and costs) from an increasingly ageing population, it is likely that TH/TC services will take a more central role in social and healthcare provision. The implementation and monitoring of such systems in Ireland would benefit from significant consideration, resources and planning being put into several areas.

## 9.1 Philosophy of Development

There is a danger that the approach to TH/TC as a reactive solution to medical issues and problems of independent living could embody the medical model. TH/TC should be part of wider approaches to assist people to live independently and inclusively.

Broadening strategy, initiatives and services to look beyond the context of the ageing population and consider all user groups is important (i.e. not just older persons, persons with disabilities and those managing chronic illness). eHealth technologies should not necessarily be 'for' one group. They should allow benefits for many users.

Having a strong emphasis on Universal Design in TH/TC allows for inclusiveness, with possible bonus benefits – the wider the application of technologies, the more likely commercial viability can be reached. For example, teleconsultations with healthcare professionals might especially benefit persons with mobility impairments but they are also convenient, useful and in-demand from all groups in society.

Cultural change will be needed to fully exploit the benefits of TH/TC – an explicit social model approach to TH/TC, the employment of Universal Design and even just on a basic level, the role the average user sees ICT playing in health and social care. The latter point applies to the average health and social care professional as much as it does to service users. Ireland is only beginning to develop into ICT maturity but this is a key determinant of TH/TC success in other jurisdictions.

TH/TC also throws up ethical questions and attendance to these should underpin thinking around implementation and monitoring. An ethical balance needs to be achieved between the need for cost efficiencies and the user's privacy, opportunity for social contact and independence. Though this review centred on ethics in telecare, as technology progresses it will likely begin to straddle the line between assistance and enhancement. Being clear about the ethics should feed policy development, standard setting and coal-face implementation.

## 9.2 Policy

The development of Ireland's eHealth strategy is welcome and as evident in Northern Ireland and Scotland, national policy is a driver for TH/TC implementation. A national approach is also essential for developing central, interoperable systems that facilitate the mainstream use of TH/TC. For example, an electronic health record system has been essential to the success of programmes in other jurisdictions and is under development in Ireland.

The HSE and the Department of Health have introduced a wide programme of infrastructure development in the area of eHealth. It is interesting to note that these top-down initiatives have focussed on improving systems before moving to roll out specific TH/TC interventions or guidance. As such, the approach has been linear rather than integrated. Action is needed in parallel with these infrastructural projects and in a range of areas, not least the development of standards, staff up-skilling and expertise, and broader cultural change within the health and social care system.

The structure of implementation should encompass a wide range of actors – it is not sufficient to design the technology and strategize its use from the top down. User input is essential to a workable system that creatively addresses compelling needs.

Aligning the development of TH/TC with national investment programmes has the capacity to generate investment and jobs. Innovative services for users could also be developed by supporting designers, and technology and product developers. Scotland and Northern Ireland are pursuing links with business and offering incentives to developments in TH/TC. It makes sense to draw these two strands together, especially as sufficient funding to implement sustainable initiatives is important and much needed in early product development.

However if these incentives focus too much on the traditional target users, the full range of innovative and universally designed products may not emerge. For example, calling for products to specifically address the needs of older persons may invite a narrowing of design and scope or simply play into bad design excuses seen in the myths associated with older ICT users (why bother, older people don't want to use ICT).

By switching the focus to support and incentivise universally designed assistive technology, a wider scope of products might emerge which will benefit the target groups in turn.

## 9.3 Finance

Cost-effectiveness is difficult to ascertain for large-scale TH/TC projects as often data are not available. The stage of development for centralised TH/TC initiatives in Ireland is almost in a pre-implementation phase while the focus is put on improving the ICT architecture to allow for future large-scale initiatives.

As a consequence, data on outcomes and financial dis/incentives are centred around smaller-scale pilot and trial schemes – we see this in the range of telehealth initiatives being funded in Scotland. The variability in approaches makes it difficult to assess results and generalise. That said, individual projects (more often than not funded or supported by national actors, e.g. governments) are demonstrating outcomes and cost-effectiveness, even if the evidence is piecemeal.

In understanding cost-benefits to TH/TC more than the cost of the device or service delivery must be taken into account. In particular, the indirect costs incurred and gained. Staff training and the mainstreaming of TH/TC as core expertise in health and social care roles will require significant investment. Likewise, where telecare has shown that informal carers have been enabled to return to work (or work more), their earning goes back into the economy. Most importantly of all, where universally designed products and services (including in the TH/TC sphere) enable the person themselves to participate in the workplace, the cost-benefit of this must be taken into account.

Understanding costs also firmly relates to the capacity of any system to monitor its inputs and outputs against outcomes. Good data practices will be needed. A particular strength of the Veterans' Health Association is its capacity to use reflexive data analysis to understand and anticipate how users engage with telehealth. The data are then used to inform care. It was interesting that the VHA was one of the few sources that could give an estimate on savings per annum, per patient and arguably, this is down to how they monitor their systems.

The jurisdictions reviewed had a mix of TH/TC service models but often these were publicly funded and privately delivered. The importance of standards and guidance on service level expectations is illustrated by Spain. The country has national standards and guidance - from setting up a service to day-to-day operations to device design requirements. Getting this national guidance right then allows flexibility across small actors' implementation of TH/TC, while quality assurance and service levels are consistent nationally. Ireland should seriously consider developing and implementing such standards and guidance, particularly with the ratification of UNCRPD and the role of assistive technologies.

The method of procurement embarked on by Northern Ireland also offers an interesting blueprint for Ireland. It is fair to hypothesise that at this stage of TH/TC development nationally, private players will continue to provide services into the future. Competitive dialogue allows a flexible, workable service model to evolve – ideal for an immature market like Ireland.

To facilitate TH/TC being integrated into health and social care (and even housing), the funding streams and mechanisms must allow for services to be joined up. For example, the current system of funding Ireland's Seniors Alert Scheme through the Department of Rural and Community Development might make it hard for such a telecare scheme to be integrated with health and social care, coming with different administration and different budgetary provision. That said, eHealth should be considered a strand of assistive technology development across many different sectors so developments and learning should not be siloed either.

## 9.4 Human Resources

Depending on the model of implementation, the average health and social care professional may need to become expert in TH/TC. At a minimum, they will need to be au fait with the options as part of their day-to-day work with patients. In Northern Ireland, healthcare professionals assessed and recommended specific equipment for users but this requires a wealth of knowledge. It also requires this knowledge to be constantly updated apace with technology.

For this to happen, considerable time, consideration and financial resources will need to be embedded into job descriptions, role delineations and workloads. Given this, there is a decision to be made around the depth of expertise needed. For example, if the implementation model includes a specialised role or unit to look after assessment / training / user set-up, then it might be reasonable to expect that the average health and social care staff needs to have enough knowledge to refer a prospective user but not necessarily in-depth expertise on the latest developments. If the model of implementation is that the healthcare professionals themselves will need to recommend TH/TC for their patients, then the burden of knowledge and learning will be considerable.

Another aspect of expertise that will be needed is staff skilled in data analytics. As mentioned above, understanding the data will greatly assist in evidencing what works, why and how much it costs. But beyond this, TH/TC is going to generate a lot of health data. If interrogated creatively, innovatively and expertly it will inform services, anticipate needs and highlight opportunities for development of TH/TC. As such, this key role will need to become a core member of TH/TC implementation teams/providers.

## 9.5 ICT and Products

This paper was based on three phases of research that were conducted pre-GDPR. eHealth generates an enormous amount of personal and health data and any system of implementation and monitoring needs to take privacy to the heart of structural design. That said, big eHealth data offers opportunity to analyse public health and social care, and understanding and using this data is part of an integral feedback loop for TH/TC services. Implementation systems therefore need to protect data but know when and how to use it.

Products, devices and services should be flexible enough to cater for individual needs. For example much work has been done on telemonitoring for diabetes but should the illness be co-morbid with other impairments, the design of TH/TC services should be able to address these additional, unique combination of needs.

TH/TC implementation with users may also benefit from alignment with learning and training opportunities for ICT use in general. Digital literacy is a barrier to TH/TC use and therefore training and up-skilling should not just be for health and social care professionals, but users and patients also.

The approach to TH/TC services should include personalised programmes beyond the standard packages. In order to do this, procurement should accommodate a mix-and-match approach (or the ability to 'add on' applications) and staff assessing and deciding on which technologies to employ should have sufficient expertise to build these individual programmes.

To build TH/TC products and services, it is imperative that consideration be given for bottom-up development. To this end, including users in the design and production of devices, technology, products and service is essential for understanding what the needs are and how the system can work well, as well as identifying problems in the early stage that can be rectified at the minimum of cost (i.e. pre roll out).

Finally, as so many TH/TC services rely on broadband and Wifi capabilities in the home, the provision of reliable high-speed networks (particularly in rural areas) will need to be progressed for the potential of TH/TC to be fully realised.

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