

Prepared for: Northern Ireland Housing Executive (NIHE)

Environmental Control Systems (ECS): Scoping Review

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FINAL

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- Lead occupational therapists in Belfast HSCT, Northern HSCT, Southern HSCT, South Eastern HSCT and Western HSCT;
- Commercial suppliers Odel Mobility, Ideal Technology, Jameison Electrical Technologies, and Safe Care Technologies;
- Stakeholders from the health and housing sector, and charity / non-profit organisations;
- Case studies participants.

Notes on terminology

ECS is used to stand for Environmental Control Systems.



1. EXECUTIVE SUMMARY

Background

RF Associates, in association with Professor Suzanne Martin of Ulster University, were appointed to undertake a scoping study of Environmental Control Systems (ECS) for the Northern Ireland Housing Executive in January 2017.

The study set out to review current service provision and help determine how co-ordinated Health and Social Care (HSC) / Housing service provision of home environmental control technology can support independent living of disabled people (both under and over 18) within Northern Ireland. The work focuses specifically on ECS that enable co-ordinated control of the home environment by a person living with a physical disability. This includes a defined range of electronic assistive technologies described as environmental control systems which enable control over the home environment for example opening doors, windows and turning on lights.

Our methodology involved: an academic systematic literature review complemented with a narrative scoping review of policy, legislation, practice papers and grey literature aiming to understand the existing evidence base around the theme of environmental controls. In addition, analysis of data collected from the five Health and Social Care (HSC) Trusts in Northern Ireland on environmental control technology provision was cross referenced with, data sets held by HSC Business Services Organisation (BSO) and commercial providers of technology. Interviews with stakeholders across the health and social care spectrum considering the procurement and use of environmental control systems; the development of case studies with users of environmental control technology to aid understanding of the application of the technologies; and a final summative workshop to agree key recommendations from the project

Key Findings

The provision and implementation of ECS into health and social care is complex. In total the legislation and policy of five departments directly influence and shape the provision of ECS through a housing and health prism. Relevant policy documents highlight a role for technology in supporting independent living, supporting user focused approaches and ensuring inclusivity, as well as helping to address the housing and health needs of an increasingly aged population. Given this policy context our project has presented the opportunity to more fully understand the supply of a specific category of technology (ECS) for a specific group of users (those with a physical disability).

ECS are one of a number of categories of assistive technology which cover a broad spectrum of devices, that overtime have been evolving as technological developments have enabled. Our review suggests that one of the dominant benefits of such devices is that they enable the autonomy and independence of individuals, facilitating control of their environments for example their heating, lighting, security, entertainment etc, and in acting as an enabler of independence ECS have an important impact on overall well-being.

Access to ECS for people with physical disability is achieved predominantly through Community Occupational Therapy Services. However, the approach from assessment through to provision and maintenance differs by HSC Trust area. Our stakeholder engagement and data analysis highlights that there are a number of issues in terms of services processes that require review.



Historically ECS have been prescribed within the HSC system. In recent times innovation in technology has both evolved some of the legacy systems and pushed useable software routinely onto mainstream devices for example smart tablets and phones. The opportunities for increased functionality has emerged within affordable parameters. Interoperability of systems, and single platform consolidation all create significant opportunities for application into everyday life for people living with disability. The range and functionality of ECS currently available is increasing with adaptability inbuilt to personalise systems and minimise complexity. The pace of technology development means that new systems, and devices, are constantly evolving and emerging in the market place. It is now possible to create a home ECS that incorporates established ECS devices alongside other new and evolving technologies. Further systems and devices are also increasingly available through mainstream high street sources, as they are no longer solely accessible through specialist providers. As a result, it is difficult to gather a full picture of all the ECS technologies and devices that might be available to those with physical disabilities. Complexities also sit at the heart of the use of some of this new technology for example navigating providing access to software and hardware. For example, how does the HSC Trust navigate the provision of software (such as an app) to a device that is owned by an individual (such as their phone) and how are any issues with maintenance / break down navigated.

Within the HSC Trusts Occupational Therapists are the primary prescribers of ECS, working with a small number of commercial suppliers who make technology-based recommendations. Occupational therapists themselves however have limited knowledge of the evolving technologies and are advised by a handful of providers, who may also be less aware of suitable options purchasable through the high street.

Individuals with physical disabilities at the same time, unless extremely tech savvy, find that there is limited information to help them feed into any discussion around technology.

Further the reliance by individual HSC Trusts on their own procurement practices means that relatively few devices are procured on an annual basis, meaning that occupational therapists are provided limited opportunity to develop their learning around this area and are fully reliant on the technology recommendations of a handful of suppliers. They are not necessarily enabled to be intelligent purchasers of systems and devices.

Further, the approach by each HSC Trust to assessment, procurement and maintenance of these systems differs and appears piecemeal with limited resources being available to manage for example on-going maintenance and repairs. Complexities also arise for example when equipment becomes obsolete with it sometimes returning to the commercial provider for provision to another user on a later date.

Users of ECS that are provided by the HSC Trusts seem anecdotally most frustrated by easy access to maintenance and repair, so it seems only right to suggest that these elements be handled more effectively and efficiently.

As a result, we recommend:



Recommendation 1 – The development of a centralised single procurement framework for the whole of Northern Ireland that offers access to a wide range of suppliers and provides for purchase and on-going maintenance of ECS. This does not necessarily have to mean the development of a separate framework for Northern Ireland – there may be existing frameworks it is possible to be part of / there may be opportunities to work across the UK and Ireland. It is assumed that such an approach would better provide value for money to the public purse, as well as better meet the needs of service users and support the development of relevant expertise. It is likely that such a framework might make most economic sense if it were focused in the area of assistive technology more widely rather than solely re ECS.

Recommendation 2 – There should be the development of a service that is equitable and ensures ease of access to users for support with faults, repairs and maintenance across each of the five trusts.

Recommendation 3 – The development of an independent public point of information and expertise on the use and application of ECS technology within health and social care and specifically within a person's own home.

Recommendation 4 – Training and support to help occupational therapists to improve their knowledge of ECS technologies (that can be procured by HSC Trusts or purchased by the client themselves or the development of Occupational Therapists who specialise in the application and use of ECS.

One further possibility might be to centralise some expertise and resource alongside the communication and wheelchair specialisms at Musgrave Park Hospital. This development of more detailed expertise may also provide more clarity around an appropriate diagnostic approach more specific to relevant recommendations i.e. matching the right technology and specific device with the health need.

Recommendation 5 – There should be much greater clarity and transparency around HSC Trust processes/criteria for the awarding of ECS to ensure consistency across Northern Ireland.

Recommendation 6 – Exploration of how to enable the use of personal devices within healthcare to maximise the opportunities afforded by what are now everyday technologies (smart phones and tablets etc). This includes an exploration of how funding might work for example in relation to own devices. Further a discussion around, what level of support it is the role of the state to provide and what should be borne by the private citizen, is needed.

Whilst there are issues with the data collected from the HSC Trusts, suppliers and BSO HSCT, the number of people making use of ECS as a result of funding from Health and Social Care Trusts seems to be somewhere in the region of 100 to 120. We speculate that this falls far short of the number of people who may benefit from these systems – that said we do not know the size of the private market. We are also aware that in some HSC Trusts budgetary constraints mean that it is simply not possible to offer access to these technologies. As a result, we recommend:



Recommendation 7 – Further analysis work to understand the numbers of people with physical disabilities who would benefit from the use of ECS technology.

Recommendation 8 – Increased resources for the procurement of ECS. This may be best considered as a cumulative budget rather than a year on year cost to allow for unpredictability across years.

ECS by their very nature can include some components that relate specifically to safety, so it would seem appropriate that Occupational Therapists might alert the Fire Service to where individuals would be particularly vulnerable to fire risk. It would seem sensible to suggest that some process of recommendation from Occupational Therapists to the NI Fire Service might take place to ensure that those with physical disability have a Full Fire Safety Check. As a result, we recommend:

Recommendation 9 – Sharing of information between Occupational Therapy departments and the fire service to ensure people with physical disabilities are given full access to fire safety provision.

Our research project involved substantial effort to access data on the use of ECS in Northern Ireland, with HSC Trusts having to return to in the main hard copy patient files to create the dataset. Therefore, we recommend:

Recommendation 10 – The development of an appropriate IT System which would include an integrated IT case management system with access by all stakeholders, which would help reduce delays in the process from assessment to technology being in place and would enable improved day to day maintenance and management of systems.

Detailed work has been undertaken by an organisation called CECOPS developing an international code of practice for the planning, commissioning and providing of technology enabled care services. We suggest that this code is reviewed in the design and development of any new approaches as it sets out in detail outcomes-based standards for those planning and commissioning services as well as those providing services. (CECOPS is the only standards body representing all assistive technology services including, for example, community equipment, wheelchair and seating services, telecare, telehealth and communication aids. CECOPS is also unique in that it covers commissioning, provision and clinical aspects of services. CECOPS is formally approved by regulators and professional bodies including the Care Quality Commission (England), Health and Safety Executive and the Association of Directors of Adult Social Services, to name but a few.)

Recommendation 11 – Refer to the International Code of Practice for Planning, Commissioning and Providing Technology Enabled Care Services, developed by CECOPS (The Community Equipment Code of Practice Scheme), in the development of new approaches to the planning,



commissioning and development of new ECS services.

To build on all this work it is our final recommendation, recommendation 12, that an action plan is developed based on the 11 recommendations, which would allow this research work to progress into an agreed regional strategy with specific objectives.



2. BACKGROUND & METHODOLOGY

2.1 Background

RF Associates, in association with Professor Suzanne Martin of Ulster University, were appointed to undertake a scoping study of Environmental Control Systems (ECS) for the Northern Ireland Housing Executive in January 2017. This work set out to review current provision and help determine how co-ordinated Health and Social Care (HSC) / Housing service provision of home environmental control technology can support independent living of disabled people (both under and over 18) within Northern Ireland.

The project focuses specifically on ECS that enable co-ordinated control of the home environment by a person living with a physical disability. This includes a defined range of electronic assistive technologies described as environmental controls such as:

- Full integrated environmental control systems
- Door entry systems
- Automatic door opening technology
- Automatic window and ventilation controls
- Automated control of heating, light and power
- Specialist control or communications equipment required to control any of the facilities above.

The study includes a number of elements:

- 1. An academic literature / desktop review to understand the existing evidence base around the theme of environmental controls.
- Analysis of data collected from the five HSC Trusts in Northern Ireland around the environmental control technology currently in place, alongside data collected from HSC Business Services Organisation (BSO) and private providers. There was also consideration of how this health data can be augmented / tracked across to link to any further data related to installation of environmental control technology through the housing sector.
- 3. Thirty-three interviews with stakeholders across the health and social care spectrum considering the procurement and use of environmental control systems.
- 4. Eight case studies with users of environmental control technology to aid understanding of the application of the technologies.
- 5. A final summative workshop to agree key recommendations from the project.



A Project Advisory Group was set up to oversee the project, it included the following members:

Member	Organisation
Paul Armstrong	NIFHA
Adrian Blythe	NIHE Asset Management
Dwyer Campbell	NIHE Research
Donal Diffin	HSC Board
Gerry Doherty	NIHE
Shane Elliott	HSC
Carolyn Fenning	DPG, NIHE
Lawrence Fisher	NIHE Grants
Ruth Flood	RF Associates
Andy Frew	NIHE Asset Management
Karly Greene	NIHE
Jennifer Hawthorne	NIHE
Soo Hun	Centre for Connected Health & Social Care
Orla McCann	Disability Action
Shauna McCrea	HSC Board
Joe McWilliams	NIHE
Suzanne Martin	Ulster University
Maureen Mawhinney	NIHE
John Montgomery	NIHE
Paraig O'Brien	NIHE
Heather Porter	NIHE
Polona Rogina	RF Associates
Philip Scott	NIHE
Geraldine Teague	РНА

Table 1 – Project Advisory Group Members



2.2 Methodology

To address the project specification a mixed methods approach was used, which featured:

- i. A review of existing evidence
- ii. Sourcing and analysis of data
- iii. Stakeholders interviews
- iv. Case studies
- v. Workshop

i. A review of existing evidence

Legal Review

This section reviewed the legislation in Northern Ireland that refers to social welfare and housing of people in relation to adaptations. NIHE provided direction and discussion around the relevant legislation; this was then accessed from government websites and considered in more detail.

Policy Review

This section considers policy informing the implementation of ECS in Northern Ireland. ECS fall across two broad areas; health and housing. We have drawn on policy materials from a range of government departments and related organisations. This summary review considers the following key policy documents, and associated analysis:

Title	Year	Produced by
The Housing Association Guide	2017	DfC
Sustainable Rural Communities: Rural Strategy & Strategic Plan	2016	NIHE
(2016-2020)		
Care Act Statutory Guidance	2016	DoH
Adaptation Guide	2016	DfC
Inter-Departmental Review of Housing Adaptations Services: Final	2016	DfC/ DoH (Formerly known as
Report and Action Plan 2016		DSD/DHSSPS)
Systems Not Structures: Changing Health and Social Care	2016	DoH
Supporting People Review	2015	DfC (Formerly known as DSD)
Home Accident Prevention Strategy 2015 - 2025	2015	DoH (Formerly known as
		DHSSPS)
Housing and Communities' Inequalities in Northern Ireland	2015	Alison Wallace
Inter-Departmental Review of Housing Adaptations Services:		DfC/ DoH (Formerly known as
Adaptations Design Communications Toolkit 2014		DSD/DHSSPS)
Making Life Better 2013 – 2023		DoH (Formerly known as
		DHSSPS)
Inter-Departmental Review of Housing Adaptations Services-	2013	NIHE
Evidence Base Report		
Transforming Your Care: A Review of Health and Social care in	2013	HSCB
Northern Ireland		
Physical and Sensory Disability Strategy and Action Plan 2012 –	2012	DoH (Formerly known as
2015/17		DHSSPS)
Facing the Future: The Housing Strategy for Northern Ireland	2012	DfC (Formerly known as DSD)
2012-2017		

Table 2 – Policy Documents Reviewed



Strategy to Improve the Lives of Disabled People 2012 -2015	2012	NI Executive
Northern Ireland Supporting People Guidance 2012	2012	NIHE
Improving Dementia Services in Northern Ireland: A Regional	2011	DoH (Formerly known as
Strategy		DHSSPS)
UN Convention on the Rights of Persons with Disability	2010	UN (DSPDD)
Living Fuller Lives. The Bamford Review of Mental health and	2007	DfH
Learning Disabilities		
Caring for Carers – Recognising, Valuing and Supporting the	2006	DoH (Formerly known as
Caring Role		DHSSPS)
Inclusive Design through Home Adaptations: A Good Practice	2004	NIHE
Guide		
Barriers to Independent Living	2003	Disability Rights Commission
UN Principles for Older Persons 1991	1991	UN

Desk-top Literature Review

We undertook a search for relevant grey literature published by HSC Trusts, research organisations and charitable organisations who are advocating for people living with different disabilities. This material covers themes such as:

- What is the general understanding of ECS?
- How are ECS defined?
- Who are the most common users of ECS?
- What are the main benefits that ECS bring to their users?
- What is the potential scale of need for ECS?

The list of material sourced and reviewed is included at Appendix 2.

Academic Literature Review

A systematic literature review was designed and completed. A protocol was developed to ensure a focus on the research topic with a pragmatic approach to literature searching and data retrieval. Inclusion and exclusion criteria were applied to the research papers. The protocol can be found at appendix 4. An electronic search was conducted on 15th February 2017 for relevant information up to this time in the Embase, CINAHL and Medline databases. The search produced 4169 citations, with 745 being duplicates, therefore the total search found 3424 citations. The remaining titles and abstracts were screened against the inclusion and exclusion criteria of the protocol. Following this only two of the 3424 citations were found to meet the inclusion criteria (M. Myburg et al., 2015 and M. R. Tomita, et al., 2007). The paper by M. Myburg et al, was used to help source other useful material by following up relevant citations and the bibliography which led us to another 13 relevant studies.

ii. Sourcing and analysis of data

Given that no data was in the public domain in relation to the usage of ECS in Northern Ireland, we set about requesting data from a range of sources whom it was considered could help us to compile a useful dataset around the types of ECS in place and whom they are being used by. We approached the following organisations:

- Five Health and Social Care (HSC) Trusts
- Four commercial suppliers
- Housing Executive
- Business Services Organisation (BSO)
- Department of Health



The requested information had to relate to people who currently have ECS installed. A template for data collection from the HSC Trusts was piloted with South Eastern HSCT. After feedback and adjustments, we shared the tool with the remaining four HCS Trusts. Data from four commercial suppliers who were suggested by lead occupational therapists was also requested; three suppliers returned data.

We have tried to compare the data provided by the HSC Trusts and the commercial suppliers. However due to the limited availability of information in some sections / and the variability of the information itself we have been unable to match the data case by case. We did, however, compare the same variables from the two data sets (Trusts and Commercial) and our findings can be found within this report.

Data was also requested from NI Housing Executive Private Grants (The Private Sector Improvement Service) and from NIHE Property Adaptations Department. Only data from Private Grants was returned, as no relevant data is collected by the NIHE Property Adaptations Department. Our understanding is that NIHE only fund some elements of ECS, such as automatic door openers, and does not fund whole environmental control systems. Therefore, the data we received was limited.

BSO exists to provide support for a broad range of regional businesses, including specialist professional services to the health and social care sector in Northern Ireland. The first time we requested data from BSO, we were informed that they did not hold any data in relation to ECS. However, after discussion in the Project Advisory Group we were directed to a contact within BSO who helped supply data when we provided the names of the commercial suppliers known to us. BSO provided data based on more than 600 cases from their Purchase Order (PO) System – however it is not always clear if the elements included fall under the heading of ECS as we have termed it for the rest of the project.

We also received data from the Department of Health on the information they hold on ECS installations and the number of cases in HSCTs; this is data that is supplied to the DoH from the HSCTs direct.

iii. Stakeholder interviews

Stakeholder interviews were conducted across six different groupings – occupational therapy, other health areas, housing, commercial suppliers, charity / non-profit organisations, and education. More detail is provided on these groupings below. These interviews provide useful contextual information concerning ECS, such as:

- General awareness of ECS
- Procurement activities and pathways of the five HSC Trusts
- Awareness and practice of occupational therapy / health departments in relation to the complexities and processes around specific 'equipment' / 'technology' decisions;
- Commercial supplier point of view;
- Awareness and activities by charity / non-profit organisations in relation to ECS.

The Project Advisory Group was asked to suggest individuals for interview to be added to a list compiled by RF Associates – this gave us a sample of 44 individuals across the groupings. In total, we conducted 34 interviews.

• The charity / non-profit grouping included organisations providing support to people living with physical disabilities and also with learning disabilities and sensory



impairments. Six people from the charity / non-profit organisations opted out or could not contribute anything to the study due to their lack of time or because they had no knowledge / experience of ECS.

- In the health grouping, we interviewed 13 individuals from within for example the HSC Trusts, HSC Boards, PHA, and CECOPS.
- Discussions in the occupational grouping were with the lead Occupational Therapist in each HSC Trust.
- We identified four commercial suppliers of ECS, two based in Northern Ireland (Odel Mobility, Jamieson Electrical Technologies) and two based in the South of Ireland (Ideal Technology, Safe Care Technology). They provided a perspective on ECS and the procurement systems across the HSC Trusts.
- In the housing grouping, we interviewed NIHE staff who deal with grants and adaptations for private housing and NIHE properties.
- There were three stakeholders from other sectors interviewed. One interviewee from an educational/training perspective, one from fire and safety services and one from the Department for Communities.

Category	Total number of interviewees on sample list	Interviews completed
Charity / non-profit	15	9
Health	13	10
Occupational Therapy	5	5
Suppliers	4	4
Housing	4	3
Other	3	3
TOTAL	44	34

Table 3: Number of interviews within categories

iv. Case Studies

Eight face-to-face / telephone qualitative interviews were conducted to generate case studies around the use of ECS, highlighting the varying provision pathways, and the issues and challenges in providing the benefits of this technology for people. As far as possible these case studies seek to explore personal experience, covering the range of pathways to provision (through NIHE, Housing Associations and HSCTs if in private accommodation), distil the range of conditions where prescription is recommended (physical disability, brain injury, spinal injury, older people), the range of locations and range, types and scale of the technology being deployed.

The interviewees for case study were identified by the lead occupational therapists in each of the HSC Trusts who checked with the service user if they would be willing to participate and if agreement and consent was given they passed to RFA the details of people who were willing to participate in the research. Each study participant was appropriately informed about the project including what was expected of them, and they were assured of confidentiality and appropriate governance of data. Housing Executive also suggested a service user representative for interview who has been involved with previous relevant projects.



Gender	Age range	Condition	HSC Trust	Housing tenure	Research interview with
Male	50-60	Multiple sclerosis	Northern	Private	Person living with disability
Male	30-40	Spinal injury	Northern	Private	Person living with disability
Female	16-20	Cerebral palsy	Northern	Private	Guardian of the person living with disability
Female	60-70	Multiple sclerosis	Belfast	Housing association	Person living with disability
Female	40-50	Multiple sclerosis	Belfast	Housing Executive	Person living with disability
Male	40-50	Quadriplegia	Belfast	Housing Executive	Person living with disability
Male	60-70	Muscular dystrophy	South Eastern	Housing association	Person living with disability
Male	60-70	Multiple sclerosis	Western	Private	Person living with disability

Table 4: Profile of individuals involved in case studies

The case studies are dispersed through the report with fictional names and without any information that might help identify the individuals involved.



v. Workshop

Having completed all the stages of research highlighted above, we compiled a summary report of the project and delivered a workshop with project stakeholders / project advisory group to discuss the way forward. The workshop offered the opportunity to discuss the research findings in some detail and consider areas for development and change going forward.



3. REVIEW OF EXISTING EVIDENCE

This section is split into two areas of work:

3.1. Policy Review

Table 2 above outlines the breadth of policy review completed concerning health and social care provision, housing and disability in Northern Ireland in order to understand the policy/legal context informing practice concerning ECS. This section begins with a brief overview of the relevant legislation.

3.2 Literature Review (Combined Desktop and Academic)

For the purposes of achieving a comprehensive overview of the topic, and its overall context, we have conducted a review of both academic literature (sourced through academic electronic databases) and key grey literature concerning ECS and their provision across the UK. It is particularly striking that much of the academic work reviewed draws from the 1990's to early 2000's and that there seems to less more recent work in this field.



3.1 Policy Review

3.1.1 Northern Ireland Legislation

Legislation relevant to ECS falls across two sectors; health and housing. The table below highlights the relevant sections of the legislation. What is clear from a basic review of this material is that the legislation is open to interpretation, that it is overlapping in terms of responsibilities and does not make an explicit mention of technology or ECS.

Tablo 5	l ogiclation	rolovant to	nrovicion	ofECS
	Legislation		provision	

Legislation	
Health and	No. 1265 (N.I. 14) PART II, Article 15
Personal	General social welfare
Social Services (Northern Ireland) Order 1972	15. (1) In the exercise of its functions under Article 4(b) the Ministry shall make available advice, guidance and assistance, to such extent as it considers necessary, and for that purpose shall make such arrangements and provide or secure the provision of such facilities (including the provision or arranging for the provision of residential or other accommodation, home
	help and laundry facilities) as it considers suitable and adequate.
	Co-operation between Health and Social Services Boards, district councils, etc.
	67. In exercising their respective functions, Health and Social Services Boards, HSS trusts, special agencies, district councils, Education and Library Boards, the Northern Ireland Library Authority, and the Northern Ireland Housing Executive shall co-operate with one another in order to secure and advance the health and social welfare of the people of Northern Ireland.
Chronically	Chapter 53
Sick and	1. Information as to need for and existence of social welfare services.
Disabled	(1) The Department of Health and Social Services for Northern Ireland shall inform itself of the number of and so far as reasonably practicable, the
(Northern	identity of persons who are blind, deaf or dumb, and other persons who are
Ireland) Act	substantially handicapped by illness, injury or congenital deformity and
1978	whose handicap is of a permanent or lasting nature or are suffering from a
	mental disorder within the meaning of the Mental Health (Northern Ireland)
	Order 1986, and of the need for the making by that Department of
	arrangements for promoting the social Welfare of such persons under social Care (Peferm) Act (Northern
	Ireland) 2009 and Article 15 of the Health and Personal Social Services
	(Northern Ireland) Order 1972.
	(2) The Department of Health and Social Services for Northern Ireland—
	(a) shall cause to be published from time to time at such times and in such
	manner as that Department considers appropriate general information as to
	the services provided under such arrangements which are for the time being available under section 2(1)(b) of the Health and Social Care
	(Reform) Act (Northern Ireland) 2009 and Article 15 of the Health and
	Personal Social Services (Northern Ireland) Order 1972 and
	(h) shall ensure that any such person as aforesaid who uses any of those



	services is informed of any other services provided under the Health and Personal Social Services (Northern Ireland) Order 1972 and of services provided by other government departments, public bodies and voluntary organisations which in the opinion of the Department are relevant to his needs.
	 2. Provision of social welfare services. Where the Department of Health and Social Services for Northern Ireland is satisfied in the case of any person to whom section 1 above applies that it is necessary in order to meet the needs of that person for that Department to make arrangements under section 2(1)(b) of the Health and Social Services (Reform) Act (Northern Ireland) 2009 and Article 15 of the Health and Personal Social Services (Northern Ireland) Order 1972 for all or any of the following matters namely— (a) the provision of practical assistance for that person in his home; (b) the provision for that person of, or assistance to that person in obtaining, wireless, television, library or similar recreational facilities; (c) the provision for that person of lectures, games, outings or other recreational facilities outside his home or assistance to that person in taking advantage of educational facilities available to him; (e) the provision of assistance for that person in arranging for the carrying out of any works of adaptation in his home or the provision of any additional facilities designed to secure his greater safety, comfort or convenience; (h) the provision for that person of, or assistance to that person in obtaining, a telephone and any special equipment necessary to enable him to use a telephone.
	3 Duties of Housing Executive. The Northern Ireland Housing Executive when considering the needs of any district with respect to the provision of further housing accommodation shall have regard to the special needs of chronically sick and disabled persons; and any proposals for the provision of new housing shall distinguish any houses which the Executive proposes to provide which make special provision for the needs of those persons.
The Housing (Northern Ireland) Order 2003	The Housing (Northern Ireland) Order 2003 No. 412 (N.I. 2) PART III CHAPTER II Disabled facilities grants, Article 54 (1) The purposes for which an application for a disabled facilities grant must be approved, subject to the provisions of this Chapter, are the following— (a) facilitating access by the disabled occupant to and from the dwelling or the building in which the dwelling or, as the case may be, flat is situated; (b) making the dwelling or building safe for the disabled occupant and other persons residing with him; (c) facilitating access by the disabled occupant to a room used or usable as the principal family room; (h) facilitating the preparation and cooking of food by the disabled occupant; (i) improving any heating system in the dwelling to meet the needs of the disabled accupant or if there is no evicting heating outer in the dwelling



or any such system is unsuitable for use by the disabled occupant,
providing a heating system suitable to meet his needs;
(j) facilitating the use by the disabled occupant of a source of power, light or
heat by altering the position of one or more means of access to or control of
that source or by providing additional means of control;
(k) facilitating access and movement by the disabled occupant around the
dwelling in order to enable him to care for a person who is normally
resident in the dwelling and is in need of such care.

3.1.2 Policy



The policy work of five departments potentially influences the adoption and use of ECS (DoH, DfC, OFMDFM, DEFRA, DOF)

Home adaptations, associated technologies and technology enabled healthcare like eHealth are placed as central to the policy framework informing health and social care. (There are examples of this within Transforming Your Care¹ and the Bengoa Report².) Previous research has indicated, that while the primary responsibilities for housing adaptations lie with DfC/ DoH (Formerly known as DSD/DHSSPS), the legislation and policies of other Northern Ireland Executive Departments and their agencies are influential at both strategic and operational levels.³ This includes OFMDFM equality legislation in relation to older and disabled people, DEFRA (formerly known as DOE) planning policy and DOF (formerly known as DFP) building regulations and procurement policy. In total, the legislation and policy of five departments directly influence and shape the housing adaptations service.

Safety is a key consideration

The Home Accident Prevention strategy⁴ states its vision is *"to minimise injuries and deaths caused by home accidents, particularly for those who are most at risk."* Older people and people living with disabilities are among the groups most at risk. The strategy points out that the majority of deaths or serious injuries in house fires are the result of exposure to smoke and toxic gases produced by the fire, rather than exposure to heat and flames. For people with poor mobility, sensory impairment, poor sense of smell and a reduced tolerance, smoke and burns contribute to fatalities. Cookers, smoking materials, electric fires and heaters, candles and open fires are major sources of ignition. ⁵ Therefore, one important aspect of housing adaptation is that very basic environmental controls can help prevent these accidents at home.

The Adaptations Design Communications Toolkit⁶ is a very practical and specific resource to guide Occupational Therapists in recommendations for both minor and major home adaptations for people with physical disabilities. It gives practical instructions for social housing providers for a consistent range where minor housing adaptations are needed, (which do not require HSC Trust Occupational Therapy assessment) and also for major adaptations (where the assessment from HSC Trust is needed.) It also gives occupational therapy recommendations and associated specifications, so they are carried out in a consistent, robust format; containing enough information to justify higher cost adaptations and to support the design process but without compromising client confidentiality. The toolkit is very technical on

¹ HSCB, *Transforming Your Care: A Review of Health and Social care in Northern Ireland*, 2013, Accessed at: http://www.transformingyourcare.hscni.net/wp-content/uploads/2013/03/Transforming-Your-Care-Vision-to-Action-Post-Consultation-Report.pdf

² DHSSPS, *Systems Not Structures: Changing Health and Social Care*, 2016, Accessed at: https://www.healthni.gov.uk/sites/default/files/publications/health/expert-panel-full-report.pdf

³ NIHE. *Inter-Departmental Review of Housing Adaptations Services-Evidence Base Report*, 2013, Accessed at: http://www.nihe.gov.uk/interdepartmental_review_housing_adaptations.pdf

⁴ DHSSPS, Home Accident Prevention Strategy 2015 – 2025, 2015, Accessed at: https://www.health-

ni.gov.uk/sites/default/files/publications/dhssps/home-accident-prevention-strategy-

^{2015.}pdfhttp://www.legislation.gov.uk/nisr/2008/67/signature/made

⁵ Ibid.

⁶ DSD/DHSSPS, Inter-Departmental Review of Housing Adaptations Services: Adaptations Design Communications Toolkit 2014, Accessed at:

https://www.nihe.gov.uk/adaptations_design_communications_toolkit.pdf



home adaptations, however ECS is only mentioned in passing in relation to the major home adaptations.

Northern Ireland Fire and Rescue Service (NIFRS) are very much aware of accidental fire fatalities in dwellings. In 2016 they introduced an updated People at Risk Strategy (2016-2021)⁷ with a targeted approach towards people living in the communities that are most at risk of accidental fire such as people aged 60 or older, people living with a disability or impaired mobility and people who are referred to NIFRS by a partnership agency. NIFRS have currently 73 partnerships with different agencies across NI. Their overall methodology and ethos is to target people at risk as opposed to areas, too help with this NIFRS have calculated and identified 20 areas using demographic indicators to highlight areas where extra resources may be utilized to engage with people at risk and maximise community engagement and education. NIFRS run a free Home Fire Safety Check (HFSC) programme for People at Risk. Under the HFSC programme NIFRS fit free smoke alarms within dwellings where operational crews attend an incident and it is identified that no smoke alarms are present or that the smoke alarms are not working. Since the start of April 2016, when the People at Risk Strategy was introduced, up until the end of January 2018 NIRS have completed 6,759 Home Fire Safety Checks across NI, out of these checks 2,643 occupants have been completed with people living with impaired mobility or disability. In the same period, they have fitted smoke alarms to 4,754 properties.

Changes in health and social care policy

The impact of policy discourse on health and social care, and hence those living with disabilities came into focus recently, when the *Bengoa Report* was published by the then Health Minister Michelle O'Neill.⁸ It outlined a proposed 10-year plan to rejuvenate health and social care in Northern Ireland. It has 18 time-specific action points, which are based on 14 recommendations from a government-appointed panel. The Report reflects many of the themes that are pertinent to legislation and policy on health and social care in Northern Ireland, with a primary focus on those who deliver care. When implemented this will have ramifications for a wide variety of health and social care issues. The Bengoa report recommends that the HSC should continue its positive work to invest in and develop three key areas of workforce, eHealth and integration. It recommends, 'as a key enabler of Accountable Care Systems, the HSC should continue to invest in e-health to support improved self-management, care at home and use of information to drive better population health outcomes'.

In England and Wales, the Care Act 2014 came into effect from April 2015 replacing most previous law regarding carers and people being cared for. This may be important, as it could influence changes in Northern Ireland, especially for carers where law is lacking. The Act outlines to local councils' a new duty to promote people's wellbeing, which will now apply not just to users of services, but also to carers; local authorities should carry out needs assessments and also carer's assessments; how local authorities should determine who is eligible for support; how local authorities should charge for both residential care and community care; and places new obligations on local authorities. The Care Act 2014 statutory guidelines⁹ in section 24 of the Act include what it means to 'meet needs', and what to take into

⁷ Northern Ireland Fire and Rescue Service, *People at Risk Strategy (2016–21)*, 2016, Accessed

at: https://www.nifrs.org/wp-content/uploads/2016/03/NIFRS-People-at-Risk-Strategy-2016-2021.pdf

⁸ DHSSPS, Systems Not Structures: Changing Health and Social Care, 2016

⁹ Department for Health, *Care Act statutory guidance*, 2016, Accessed at:

https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance



considerations when doing so. The guidelines state: "Where the local authority provides or arranges for care and support, the type of support may itself take many forms. These may include more traditional 'service' options, such as care homes or homecare, but may also include other types of support such as assistive technology in the home or equipment/adaptations, and approaches to meeting needs should be inclusive of less intensive or service-focused options."

In Northern Ireland People living with disabilities are legally entitled to ensure that their living conditions are suitable, safe and fit for purpose (as prior legal section highlights). It has been previously noted that when a person living with disabilities begins undertaking major adaptations to their home, they will require the support of a range of skilled professionals and agencies working collaboratively within different legislative and policy frameworks. ¹⁰ It is therefore necessary that stakeholders work closely on the wide policy interfaces, which should support the ultimate aim of ensuring people with disabilities are supported to live independently in their homes.

In focusing on policy relevant to housing adaptation and the needs of those living with disabilities, it is possible to identify four common themes in the policy literature:

- 1. Independent living;
- 2. User focused approaches;
- 3. Inclusive and cohesive approaches; and
- 4. Future planning.

i. Independent living is a key area of focus

Independent living is a key focus of many of the relevant policies relating to the area of concern. The Disability Rights Commission identified it as:

"...all disabled people having the same choice, control and freedom as any other citizen at home, at work and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves' but that any practical assistance people need should be based on their own choices and aspirations."¹¹

*Transforming Your Care*¹² particularly emphasised this in relation to older people. The following point encompasses the policy's commitment to innovative approaches to ensuring independent living amongst older people, with a focus on technology:

"Promote the wider use of technology in the form of telehealth and telecare for remote health monitoring and support with activities of daily living. Providing individuals and families with security and communication options to support people in their own homes. This will help to identify potential problems or the deterioration of a condition much more effectively and allow action to be taken sooner."

This suggests that there is the potential to ensure independent living in relation to the treatment and monitoring of specific conditions through home adaptation and the use of technology. This

¹⁰ DSD/DHSSPS Inter-Departmental Review of Housing Adaptations Services: Final Report and Action Plan 2016, Accessed at: http://www.nihe.gov.uk/housing_adaptations_review_final_report_2016.pdf

¹¹ Disability Rights Commission. *Barriers to Independent Living.* 2003, Accessed at:

http://disability-studies.leeds.ac.uk/files/library/morris-independent-living-scoping-paper-final-edit.pdf.pdf

¹² HSCB, Transforming Your Care: A Review of Health and Social care in Northern Ireland, 2013. pg 28



approach is also identified in relation to long-term conditions. The Report also makes the point that specific approaches are required for those living with physical disabilities and/or sensory impairment. It states the need to develop *"more appropriate living options for people with disabilities with community support and through maximising the use of technology to assist people in their day-to-day lives"*.¹³ Essentially *Transforming Your Care* places the home at the centre of social care delivery. However, some research has suggested that limited home adaptations may serve to undermine the delivery of social care in the home.¹⁴ This reinforces the need to ensure policy interventions are responsive to the lived reality of those people with disabilities.

The *Northern Ireland Supporting People Guidance 2012*¹⁵ also addresses the issue of independent living in stating that:

"The term 'own home' should be understood in terms of its common usage, which implies the principles of control and autonomy for the individual."

Strategy to Improve the Lives of Disabled people 2012-2015¹⁶ in their strategic priority 8 focuses on independent living, choice and control – "Increase the level of choice, control and freedom that people with disabilities have in their daily lives". The Northern Ireland Executive is committed to ensure that people who are living with disabilities have access to systems, resources and appropriate support for independent living.

The strategy *Improving Dementia Services in Northern Ireland*¹⁷ recognises the need for support for people to be able to remain, for as long as possible, in their own home and maintain their independence. The strategy touches on assistive technology and home adaptations, which can help a person with dementia to remain in their home. It also suggests the need for training for formal and informal carers in the effective use of assistive technology.

The *Supported People Programme* is also aiming for better quality of life for vulnerable people to allow them to live more independently and to remain in their tenancies. The Supported People Review¹⁸ reported that the evaluation of Accommodation-Based Services found that this core aim was being achieved and indicated benefits to people's economic, social, psychological, and physical well being. Outcome 13 (point C) in the *Making Life Better* strategy¹⁹ also refers to the Supported People Programme and the delivery of practical support for people who are living with physical disabilities, learning disabilities or older people to live independently.

¹³ Ibid. pg 41

¹⁴Alison Wallace, *Housing and Communities' Inequalities in Northern Ireland*, 2015, Accessed at:

http://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/HousingInequalities-FullReport.pdf

¹⁵ NIHE, Northern Ireland Supporting People Guidance 2012, Accessed at:

http://www.nihe.gov.uk/supporting_people_guidelines_2012.pdf

¹⁶ NI Executive, *Strategy to Improve the Lives of Disables people 2012-2015*, Accessed at:

https://www.executiveoffice-ni.gov.uk/sites/default/files/publications/ofmdfm/disability-strategy-report-2013-2014.pdf

 ¹⁷ DHSSPS, Improving Dementia Services in Northern Ireland: A Regional Strategy, 2011, Accessed at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/improving-dementia-services-2011.pdf
 ¹⁸ DSD, Supporting people review, 2015, Accessed at: https://www.communities-

ni.gov.uk/sites/default/files/publications/dsd/review-of-supporting-people-report.PDF

¹⁹ DHSSPS, Making Life Better 2013 – 2023, Accessed at: https://www.health-

ni.gov.uk/sites/default/files/publications/dhssps/making-life-better-strategic-framework-2013-2023_0.pdf



The Inter-Departmental Review of Housing Adaptations Services-Evidence Base Report²⁰ espouses independent living as central to their entire approach with regard to housing adaptations, stating: *"Housing adaptations are necessary to make the home of a person with a disability suitable for his/her needs and to promote independent living"*. The Report positions independent living as a key consideration in dealing with the growth in demand for adaptations in homes. This is necessary due to the changing demographics of the region (i.e. an ageing population, with increasingly complex needs).²¹

The *Physical and Sensory Disability Strategy and Action Plan 2012-2015/17²²* identified "personalisation" as a key area for improving services to support and promote independent living. This was focused on the following areas:

- choice and control;
- family/person-centred planning; and
- self-directed support.

In centralising "personalisation", the Physical and Sensory Disability Strategy and Action Plan ensures that there is due regard for the particular circumstances of each person. This focus on autonomy goes to the heart of what is means to live independently. There has also been an emphasis on the role of carers in this context and how they can be enabled and empowered to ensure individuals are living as independently as possible, while ensuring suitable and sufficient care is in place. The DHSSPS' strategy *Caring for Carers - Recognising, Valuing and Supporting the Caring Role* acknowledges the need to assess carers' needs, as well as drawing on their experience to enable people to live independent lives.²³ It states:

*"It is essential that we act positively to protect the interests of carers and to foster a climate where they can continue to care for as long as they wish and are able to do so, without jeopardising their own health and well-being, financial security, or reducing their expectations of a reasonable quality of life. We want to enable carers to make more choices for themselves and to have more control over their lives."*²⁴

These policies, focused on Northern Ireland, reflect a wider international focus on the importance of independent living. For example, *the United Nations Principles for Older Persons* 1991²⁵ explicitly references "independence" in relation to older people, and that "Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities".

ii. User focused approaches are expected

 ²² DHSŠPS, *Physical and Sensory Disability Strategy and Action Plan 2012 – 2015/17*, Accessed at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/disability-strategy-2012-2015.pdf
 ²³ DHSSPS, *Caring for Carers - Recognising, Valuing and Supporting the Caring Role,* 2006, Accessed at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/caring-for-carers.pdf
 ²⁴ Ibid. pg 6.

²⁰ NIHE, Inter-Departmental Review of Housing Adaptations Services-Evidence Base Report, 2013, Pg 9 ²¹ We are aware that NIHE has made recent efforts to improve the time taken for assessments in relation to some areas of adaptations. Housing assessments now take from 3.5 to 9.6 days, homeless assessments from 6.2 to 12.6 days and disabled facilities grant assessment an average of 250 days.

²⁵ United Nations, United Nations Principles for Older Persons 1991, Accessed at:

http://www.un.org/documents/ga/res/46/a46r091.htm



Policy and legislation emphasises the need to tailor services to the individual circumstances of people living with disabilities. The current legislative and policy framework supports the improved involvement of people living with disability with associated services. However, it is important to be mindful of the wider international frameworks, which are also user focused in their approach and are relevant to housing adaptation. Article 9 of the *UN Convention on the Rights of Persons with Disability²⁶* is focused on "accessibility". It states:

"The countries will eliminate barriers that people with disabilities face in buildings, the outdoors, transport, information, communication and services, in both cities and the countryside. This way people with disabilities can live independently and fully live their lives."

The *Bamford Review Living Fuller Lives*²⁷ recommends the promotion of user centred approaches that are focused on long-term care options for people with dementia, that they should include options such as specialist home care, supported housing options, assistive technology and dementia design specific care homes.

This user-focused accessibility is reflected at the local level here in Northern Ireland, where the Northern Ireland Housing Executive (NIHE) has produced a good practice guide entitled *Inclusive Design Through Home Adaptations.*²⁸ It identifies the following "Principles of Good Adaptation Design":

- incorporates the views of the user and other family members (A User Centred Design approach);
- uses fully inclusive communication involving the disabled person, occupational therapist, designer, and housing providers;
- gives clear specification to meet the needs of the user;
- promotes independence, privacy and safety through good environmental design;
- offers options through innovative design, within financial constraints; and efficiency and effectiveness – the design should have a positive outcome for the user and be achieved rapidly and cost effectively.²⁹

All the above points are focused on the specific contexts and experiences of people living with disability and ensuring that design and adaptation is user focused.

iii. Inclusive approach

Policies informing the nature of adaptations also emphasise an inclusive approach, as well as being part of a wider policy focus on social cohesion. Previous research has identified the combined strategies in - the DfC *Housing Association Guide*³⁰ for building Lifetime Homes (within General Needs Housing) and Wheelchair Housing; *Adaptations Guide*³¹; Part R Building

²⁶ UN (DSPDD), UN Convention on The Rights of Persons with Disabilities and Optional Protocol, 2010, Accessed at:

http://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/UNCRPDOptionalProtocolPlainla nguage.pdf

²⁷ DfH, *Living Fuller Lives. The Bamford Review of Mental health and Learning Disabilities*, 2007, Accessed at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/Living%20Fuller%20Lives_3.pdf

²⁸ NIHE, *Inclusive Design Through Home Adaptations*, 2004, Accessed at:

http://www.nihe.gov.uk/inclusive_design-home_adaptations.pdf

²⁹ Ibid. pg 15

³⁰ DSD, *The Housing Association Guide*, 2017, Accessed at: https://www.communities-ni.gov.uk/design-standards

³¹ DfC, Adaptation Guide, Accessed at: https://www.communities-ni.gov.uk/adaptations-guide



Regulations for accessibility; planning policies such as Creating Places and the creation of more accessible public buildings and retail outlets as a result of the Disability Discrimination Act - are helping to build a more inclusive and sustainable society. These policies are practical in how they view housing adaptation as playing a role in the engagement of those living with disability in wider society. This means in practice *"that people can leave their own homes when they want to, visit family and friends, access essential community services, and have more options for enjoyable living"*.³²

In reviewing policy on inclusive approaches to home adaptation for those living with disabilities, it becomes apparent that they are complex and inter-related. For example, the urban/rural divide is an area that requires attention in this context. The NIHE evidence this in their *Sustainable Rural Communities: Rural Strategy & Strategic Plan (2016-2020)* ³³ which considers inclusivity at policy level in Action 25 which aims to:

"Enable cross-representation between the Rural Residents Forum and the Disability Forum to ensure that the particular challenges facing people with disabilities in rural areas are considered when scrutinising new policies and services."

This is underpinned in the document with a commitment to creating rural communities who are *"active, inclusive, well run, and fair for everyone"* with teams dedicated to: community cohesion; community safety; and community involvement.³⁴ Housing adaptation has the capacity to ensure that the rural nature of some areas is not a socially limiting factor for people living with disability, and hence feeds into a wider policy focus of social inclusion.

iv. Future planning

Given the policy focus on housing adaptation to meet the challenges for those living with disabilities, as well as an emphasis on technology in this regard, it is clear that there is an awareness of the potential challenges in both policy and practical contexts. In meeting the future challenges of a rapidly ageing society and in addressing any potential care gap that could arise, housing and associated assistive technologies such as home environmental controls will have an important contribution to make in complementing personal care. *The Review of Health and Social care in Northern Ireland*³⁵ identified 12 principles for change to shape the future model for health and social care in Northern Ireland. One of the principles is 'Maximising the use of technology' which refers mostly to telehealth and assistive technology for promoting independence and personalisation.

The DSD recently published their *Facing the Future: The Housing Strategy for Northern Ireland* 2012-2017.³⁶ It states that two of its central aims are:

- Providing support for individuals and families to access housing, particularly the most vulnerable in society; and
- Promoting equality of opportunity in housing and promoting good relations

³²DSD/DHSSPS Inter-Departmental Review of Housing Adaptations Services: Final Report and Action Plan 2016, pg 6

³³ NIHE, *Sustainable Rural Communities: Rural Strategy & Strategic Plan (2016-2020)*, pg 24, Accessed at: http://www.nihe.gov.uk/rural_action_plan_2016_2020.pdf

³⁴ Ibid. pg 25

³⁵ DHSSPS, Transforming Your Care: A Review of Health and Social care in Northern Ireland, 2013

³⁶ DSD, *Facing the Future: The Housing Strategy for Northern Ireland 2012-2017*, Accessed at: https://www.communities-ni.gov.uk/sites/default/files/publications/dsd/facing-the-future-housing-strategy.pdf



Consultation on Inter-Departmental Review of Housing Adaptations Services³⁷ has already recommended that there should be a more collaborative approach such as a 'One stop shop' that would be a jointly funded single body capable of providing a turnkey adaptation service. This would include an integrated IT case management system with access by all stakeholders, which would help reduce delays in the process. This would also enhance transparency and accountability among agencies, with the applicant having visibility of their case from end to end. There was also a suggestion for the development of common standards of customer services across all housing tenures and HSC Trusts as there is the need for definitive documentation to ensure consistency of approach and equitable service standards across all housing tenancies. Another suggestion under the collaborative work recommendation is for dedicated Housing Occupational Therapists to work in partnership with housing colleagues in an extended role, e.g. development of the accessible housing register, planning new build schemes, assessing complex case work, and assisting with complex allocation/adaptations.

Further, the Northern Ireland Housing Executive identified that there is a potential care gap that could arise due to a rapidly ageing society, where housing and associated assistive technologies such as home environmental controls will have an important contribution to make in complementing personal care. They feel that there is also an increasing understanding and awareness of a need for future housing and health and social care research into the impact of the design of the environment on human behaviour ("design for the mind"), which the Northern Ireland Housing Executive has identified would contribute to the Autism and Dementia Strategies.³⁸

The draft programme for government outcomes framework under the overarching purpose 'Improving well-being for all – by tackling disadvantage and driving economic growth' has one outcome area focused on 'we care for others and we help those in need'. The indicator of relevance to people with physical disabilities intends to consider 'Average life satisfaction score of people with disabilities' and yet the draft delivery plan associated with this makes no mention of ECS nor the potential application of technology more generally.

Conclusion

In summary, policy discourse refers only in passing to the potential of technology in general (and not ECS technology specifically) to help address and support the desired rise in independent/personalised living, and more user led, inclusive approaches to care.

³⁷ NIHE, Inter-Departmental Review of Housing Adaptations Service: A Summary of Consultation Responses, 2013, Accessed at:

 $http://www.nihe.gov.uk/summary_of_consultation_responses_to_the_interdepartmental_review_of_housing_adapt ations_services.pdf$

³⁸ NIHE, Inter-Departmental Review of Housing Adaptations Service: Final Report and Action Plan 2016, Pg 7



3.2 Desk-top Literature Review

i. Definitions and understanding of ECS

ECS are one of a number of categories of Assistive Technology (AT), which covers a broad spectrum of devices. The World Health Organisation³⁹ defines assistive technology as *"any item, piece of equipment or product system whether acquired commercially, modified or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities".*

Through our review of the literature we would suggest that some of the domains of assistive technology are:

- Aids for Daily Living (ADL)
- Devices to mitigate against:
 - o Blindness and Visual Impairment (VI)
 - o Cognition and Learning Disabilities
 - o Deafness and Hearing Impairment (HI)
- Communication Aids (Augmentative and Alternative Communication (AAC)
- Computer Access
- Environmental Controls (EC)
- Mobility equipment
- Prosthetics and Orthotics
- Recreation and Leisure devices (or else take this out as it isn't a device)
- Seating and Positioning systems
- Smart Home Technology (SHT)
- Sensors and networks to create Telecare, Telehealth, telemonitoring and pervasive homes
- Vehicle Modifications⁴⁰

However clearly this list is not exhaustive, and these domains also can overlap. For example, Environmental Controls (EC), which are electronic in nature, overlap with Smart Home Technology (SHT) and Aids for Daily Living (ADL), specifically when these are electronic (EADL). Augmentative and Alternative Communication (AAC) are complementary to ECS and may be presented on a single platform (for example tablet device) or sometimes integrated in one software.

Assistive Technology includes Electronic Assistive Technology (EAT), which has been referenced, to "enhance the independence and autonomy of disabled people".⁴¹ It is a broad term and refers to:

...a broad range of devices for example environmental control systems to enable a physically disabled person have more control over the home environment (CSIP 2006) or the social alarm/alert which a frail elderly person can use to summon help when

³⁹ World health Organisation and The World Bank, World Report on Disability, 2011, p.101

⁴⁰ These have been modified from the *Assistive Technology Guide*, 2016 to represent out thoughts on the categories.

⁴¹ Martin, S, et al. Smart home technologies for health and social care support. (Protocol). *Cochrane Database of Systematic Reviews 2007*, Issue 1, p.1



required (Tele- care 2006). All EAT use information and communication technology as a core component.⁴²

At its core, ECS enable people with limitations or disabilities to live more independently through control of the immediate physical (structural) environment. NHS England define environmental controls as equipment that:

"enables the user control of functions or appliances primarily within the residential environment, but may also be used in other locations, such as school, college or workplace. The functions can include summoning help in an emergency, control door entry, make and receive telephone calls, operate electrical appliances and access computer technologies."⁴³

Age UK Factsheet 42 states:

*"Environmental Control Systems help maintain and improve your independence and security if you have a severe physical disability and poor manual dexterity. The ability to control everyday equipment such as the phone, TV and lighting is provided via a central control unit and a single switch. It can be used to control access into the home and summon emergency help".*⁴⁴

A report⁴⁵ from Trailblazers in 2015, a campaign group of disabled people and part of Muscular Dystrophy UK, acknowledges the importance of ECS. They report that ECS are being rapidly absorbed into mainstream use, which means that you can use *"your smartphone to control your heating, turn on your washing machine and even find out what's in your fridge! They also help people who lack full mobility to open doors, answer telephones and intercoms, and operate a host of electronic devices, from lamps and televisions, to motorised chairs and beds."*

The Enable Ireland Report⁴⁶ echoes this: *"On top of that there is a growing range of mainstream mobile solutions available via apps on smartphones and tablet devices, which can support everything from personal navigation to personal organisation and memory aids."*

Initially developed in the 1960s, ECS are about control of the immediate environment by application of equipment, as Judge et al. explain:

*"Environmental Control refers to the technology and equipment that enables people with disabilities to control home adaptations (also school and work adaptations) and electrical appliances from a single controller or computer-based systems, configured with appropriate access method (input device) for the user."*⁴⁷

"Environmental Control Systems are defined as assistive technologies that provide a person with a disability the opportunity to access and operate

47 Ibid.

⁴² Ibid.

⁴³ NHS England, *NHS Standard Contract for complex disability equipment: Environmental Controls (all ages)*, 2013

⁴⁴ Age UK, Factsheet 42 Disability equipment and home adaptations, 2011, p.16

⁴⁵ Trailblazers Muscular Dystrophy UK, Switched On, 2015, p. 8

⁴⁶ Enable Ireland, Assistive technology for people with disabilities and older people, 2016, p.12



multiple electronic and electrical powered devices in their environment. An ECS generally consists of an input switch interface that can be customised to the user needs, and a control unit that includes an integrated feedback system, which sends an output signal to a target device.^{#48}

"Electronic aids to daily living (EADL), also known as environmental control units, allow people with severe physical disabilities to control aspects of their home, school or work environment. These aids provide alternative access to devices such as telephones, personal entertainment centres, computers, home security systems, lights and thermostats by means of single switches, voice, or serial input through a computer."⁴⁹

From the literature reviewed, it is clear that what constitutes ECS has evolved with technology, while retaining the core elements of control of the environment in order to allow greater autonomy.

ii. How EC systems work

There are three main parts to ECS:

- input devices (the user interface that accepts inputs from the user such as remotecontrol style devices and switches)
- the processor (the unit that sends signals to control the electronic devices)
- outputs (the devices to be controlled such as thermostat, fans, television, radio etc.).⁵⁰

In addition to these three elements a networking component is required between different processors that communicate through different signals for example infra-red, Bluetooth, wifi or cable.

It is important to note that ECS tend to combine a range of devices that can differ in how they 'talk' to each other. These technologies operate through different types of signals such as Bluetooth, infrared or Wi-Fi signals. X-10 is one type of technology that sends the signal through the existing home electrical wiring by using a controller to turn devices on and off such as lights or any other electrical appliance. This system can receive radio frequency signals from the wireless controllers, transmitted into X-10 signal and sent through the electrical wiring. Another similar technology to X-10 is Insteon, which receives radio frequency and infrared signals, translates them and sends them to the wiring.⁵¹

There are also more developed systems such as Imperium 200H⁵² that can communicate between X-10, Insteon, general infrared devices, telephones and other similar devices. The main differences between systems are the signals through which they are controlled.

The systems generally offer flexibility in how a person with a physical disability operates the control. This can range from a push button or switch, to voice activation, head-pointed devices,

⁴⁸ M. Verdonck et al., Experiences of using an Environmental Control System (ECS) for persons with high cervical spinal cord injury: the interplay between hassle and engagement, *Disability and Rehabilitation Assistive Technology*, 2014, 9(1) p.70

⁴⁹ P. Rigby et al., Impact of Electronic Aids to Daily Living on the Lives of Persons with Cervical Spinal Cord Injuries, *Assistive Technology*, 2005, p.85

⁵⁰ K. Harrington et al., Environmental Control for Persons with Disabilities, Worcester Polytechnic Institute, 2007 ⁵¹ Ibid

⁵² Ibid



sip-puff switches, tongue switch or other specialised switches. This enables personalisation of systems according to a person's ability.⁵³

One systematic review⁵⁴ looked at eleven ECS and Smart Home Technology studies where one area of focus was the types of technology and associated functionalities. The most commonly used technologies assessed in studies were:

- lighting control, remote opening / closing doors;
- operation of telephones;
- home entertainment equipment control; and
- presence of security alarms.

In the other four to six studies that reviewed, the systems and devices most commonly mentioned were controlled door opening, lighting, heating, ventilation, specialised telephones and voice activated ECS.

iii. Users of ECS (including potential scale of users in NI)

ECS are for people who have complex physical disabilities (for example, multiple sclerosis, motor neurone disease, cerebral palsy, paralysis and muscular dystrophy), are unable to operate standard handsets (e.g. TV remote control, telephone), but are cognitively and physically able to operate the EC system provided, as well as motivated to use it.⁵⁵ The systems can be personalised to adapt to altered cognitive ability.

In most grey and academic literature, the main users of ECS are people living with a physical disability. However, we know that usage is wider. For example, the Thomas Pocklington Trust has published a guide⁵⁶ for people with sight loss on assistive home technology. Older people are also not always specifically mentioned in ECS related literature, however there are ways they can benefit from electronic assistive technology as it can incorporate a wide range of devices (stand alone or networked) that create services like telecare or telehealth, as well as devices that relate to the control of the home environment.⁵⁷ Standalone door release systems are popular with and useful to older people. Elements of ECS can also assist people with dementia as assistive technology placed ubiquitously within the home can detect temperature, smoke and carbon monoxide. This can be linked with a number of devices that enable gas or electricity supplies to be shut off automatically, or power operated windows to be opened.⁵⁸ These sorts of systems are prevalent within Northern Ireland, both in home and within cluster housing provision. In short ECS can be tailored to fit particular context and circumstance, with additional sensors to amalgamate other services.

⁵³ Ibid. p.3-5

⁵⁴ A. Brandt et al., Activity and participation, quality of life and user satisfaction outcomes of environmental control systems and smart home technology: a systematic review, *Disability and Rehabilitation: Assistive Technology*, 2011, 6(3), p.193

⁵⁵ Oxford University Hospitals, NHS Foundation Trust, *Environmental Control Service, Information for patients*, 2015

⁵⁶ Thomas Pocklington Trust, Assistive and Inclusive Home Technology: A guide for people with sight loss, p. 6

⁵⁷ Age UK, Technology and Older People Evidence Review, 2011

⁵⁸ Alzheimer's Society, Assistive technology,

https://www.alzheimers.org.uk/info/20091/what_we_think/85/assistive_technology



Based on broad definitions and understanding of ECS in previous sections it is clear people with various forms of disability could benefit from having ECS in their home. However, the criteria for ECS from NHS England narrows this to individuals with:

- "Profound and potentially complex physical disability, such that they are unable to operate standard controls for functioning independently in the home.
- Where simpler and cheaper non-customised solutions are not suitable or appropriate.
- Cognitively and physically able to operate EC equipment consistently.
- Able to demonstrate sustained motivation to use the EC equipment.
- Individuals requiring multiple control functions integrated into a single means of access as multiple devices are inappropriate (including also potential for integrating functions for communication, computer access and/or powered wheelchair control."⁵⁹

The research papers reviewed primarily involved participants with disabilities (very likely to be considered as 'profound and potentially complex physical disability') such as: tetraplegia; quadriplegia; cervical spinal cord injuries; spinal cord injuries; cerebral palsy; muscular atrophy; multiple sclerosis; amyotrophic lateral sclerosis; acquired and traumatic brain damage; and degenerative neuromuscular conditions.

If we want to understand the potential scale of use in Northern Ireland, we need to find some data proxies that will help create some sense of this. If we assume that ECS are more likely to be provided to those with physical disabilities who are often wheelchair users, we can get some sense of the scale of need in Northern Ireland. However, this is of course not a perfect approach.

With the help of NIHE we have received data from the Regional Wheelchair Services at Musgrave Park Hospital for 2018 for users classed as long-term wheelchair users. This data shows that in 2018 there were approximately 22,000 people in Northern Ireland who were registered on the Regional Wheelchair Services database as long-term wheelchair users. (Note this database undergoes periodic data cleansing to reflect attrition in this population.)

From the data collected from our survey of the five HSC Trusts we found there are currently 107 people overall who have ECS installed in their homes. However, according to the databases supplied by the three commercial suppliers, 114 people have ECS in their home. Further discussion of this information can be found in section 4.7.

For a broader picture, and again some sense of the potential market for the breadth of ECS, the European Commission state that an estimated 2.6 million people in Europe have mobility problems affecting their upper limbs, with around 1.3 million of them require assistive technologies or the help of human carers, to be able to perform everyday tasks.⁶⁰ Forbes reported that The World Health Organization (WHO) estimate that 70 million people need a wheelchair worldwide.⁶¹

These figures only take into account the wheelchair users, however people with sensory loss can benefit from these technologies also, therefore the need for assistive technologies is even greater.

⁵⁹ NHS England, *NHS Standard Contract for complex disability equipment: Environmental Controls (all ages)*, 2013, p.6

⁶⁰ European Commission, Adaptive assistive technologies for people with disabilities, 2013

⁶¹ McCue, TJ, Elderly And Disabled Assistive Technology Market To Surpass \$26 Billion By 2024, 2017



iv. Quality of life: Definitions, measurement and challenges to measurement.

The intention of deploying an ECS is primarily to bring greater autonomy to the user, thereby improving their quality of life. Before considering how ECS promote autonomy to users, it is first helpful to examine how 'quality of life' is being defined.

In the research reviewed, this is described in various terms. The World Health Organisation defines quality of life as *"individual's perceptions of their position in life and in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"*.⁶² Quality of life is also defined as a person's state of wellbeing, encompassing aspects of life that contribute to the person's degree of comfort, independence, enjoyment, choices, etc.⁶³ Quality of life therefore could be construed as a personal, subjective perception based on external and internal factors.

Measuring the outcomes of assistive technology interventions poses numerous challenges to therapists and rehabilitation researchers alike. Rigby (2010) mentions a study of Lenker and colleagues, who examined 82 assistive technology devices (ATD) outcome studies published from 1980 to 2001 and found that most of the measures used in these studies had been developed specifically for that study and lacked evidence of validity and reliability. The samples included in these studies were heterogeneous with respect to age, disabling conditions and type of ATD used. This hampered the interpretation of outcomes and diminished the validity of the study results. Furthermore, they found very few studies that considered AT outcomes for children and caregivers of children with disabilities.

In our review, we found only one study⁶⁴ which specifically measured the quality of life with a tool called "Quality of Life Profile: Physical Disability" (QOLP-PD), which is suitable for people with a variety of physical disabilities. Other papers measured quality of life more indirectly through AT outcome measurement tools; two of the most utilised are the 'Quebec User Evaluation of Satisfaction with Assistive Technology' (QUEST) and the Psychological Impact of Assistive Devices Scale (PIADS). Other recognised measurement methods used were the Functional Independence Measure (FIM instrument), Canadian Occupational Performance Measure (COPM), Life Habits (LIFE-H), The Functional Autonomy Measuring Scale (SMAF), Lincoln Outcome Measures for Environmental Controls and Audit of Installation Quality (LOMEC) and Measurement of Control using Electronic Aids to Daily Living (MCEADL).

iv. Literature on the benefits of ECS, and impact on quality of life

Academic studies

Craig et al ⁶⁵ (2005) concluded that the benefits of ECS technology had not been widely examined. However, much has changed since then, and so we considered reports commenting on people's quality of life (QOL), namely, what increased their independence in their home

⁶² A. Brandit et al., Activity and participation, quality of life and user satisfaction outcomes of environmental control systems and smart home technology: a systematic review, *Disability and Rehabilitation: Assistive Technology*, May 2011; 6(3) p.190 (accessed 10 May 2017)

⁶³ A. Craig et al. The efficacy and benefits of environmental control system for the severely disabled, *Med Sci Monit*, 2004, 11(1)

⁶⁴ P. Rigby et al., Electronic aids to daily living and quality of life for persons with tetraplegia, *University of Toronto Press*, 2010

⁶⁵ Craig et al., The efficacy and benefits of environmental control systems for severely disabled, *Med Sci Monit*, 11(1), 2005



environment, as well as their self-esteem? We also considered the possibility of other secondary benefits, such as a decreased work load of a carer.

P. Rigby et al (2010)⁶⁶ considered 36 adults with spinal cord injury (SCI) and compared users and nonusers of electronic aids to daily living (EADL) and their QOL. The users were defined as persons with tetraplegia from SCI who were able to activate more than two appliances in their home (home entertainment system, door opener, computer, security system). QOL was measured with Quality of life Profile-Physical Disability (QOLP-PD) as it was felt to be the most appropriate for people with SCI. This subjective measure has three main domains; being, belonging and becoming. Each of the domains has three sub-domains. The study showed that EADL users were significantly more satisfied with their QOL than non-users, specifically in the sub-domains 'physical being', 'practical becoming', 'leisure becoming' and 'growth becoming⁶⁷'.

A Canadian study⁶⁸ compared 20 users and 20 non-users of EADL with people who had degenerative neuromuscular condition. They conducted two interviews with each participant, six months apart. They used Functional Independence Measure (FIM instrument), QUEST and the participant's personal profiles. The EADL devices related to security, safety, and communication. 70 per cent of users were living on their own or with their partner / friend but only 25% of non-EADL users were living similarly, suggesting that EADL allow people with severe disabilities to live more independently in the community. Almost 80 per cent of users overall were quite satisfied or very satisfied with their technology. The element they were not very satisfied with was the cost of the EADL.

An American experimental study⁶⁹ was conducted with 11 people who had acquired brain damage. The participants were asked to stay one week in s purposely designed training apartment with EADL. The apartment simulated a home environment, with space of 90 square metres. A computer was placed in the living room, which was connected to an alarm system and personalised for each participant. With remote or voice control, participants were able to control doors, window shades, telephone, TV and the stereo equipment. There was a "good night" button in the bedroom by the bed, which participants could use to lock the door and switch off the stove or the oven. The initial feelings of participants moving in were fear, stress, frustration, and loneliness but at the same time also curiosity, excitement and expectation. After this phase the participants started to feel more comfortable with the technology and able to handle it. At the end of the week the participants felt that they had improved their competence to perform daily activities and felt during the one-week period in the apartment.

An Irish qualitative study, ⁷⁰ used focus groups for data collection from 15 people with tetraplegia. Some of the people in groups were using EADL and some were not, however the themes were similar in both user and non-user groups. The main themes from focus groups

⁶⁶ P. Rigby et al., Electronic aids to daily living and quality of life for persons with tetraplegia, *University of Toronto Press*, 2010, p.119

⁶⁷ lbid. 'physical being' – being physically able to get around my neighbourhood; 'practical becoming' – helping family, friends or neighbours in practical ways; 'leisure becoming' – visiting or socialising with friends or neighbours; 'growth becoming' – trying things I haven't tried.

⁶⁸ M. S. Stickel et al., Toward a comprehensive evaluation of the impact of electronic aids to daily living: evaluation of consumer satisfaction, *Disability and Rehabilitation*, 2002, 24:1-3

⁶⁹ A. Erikson et al., A Training Apartment With Electronic Aids To Daily Living: Lived Experience of Persons With Brain Damage, *The American Journal of Occupational Therapy*, 2004, 58, 261–271

⁷⁰ Verdonck et al., Electronic aids to daily living: be able to do what you want, *Disability and Rehabilitation: Assistive Technology*, 2011, 6(3), p.268-281



with EADL users and non-users were around the 'desired features of EADL', 'use and utility of EADL' and 'meaning of EADL'. Three other subthemes were recognised from these themes:

- Relationships: Due to EADL caregivers don't need to be constantly present, which changes the relationships. Otherwise users and non-users feel they are being babysat all the time.
- Autonomy: For users the main things were to be able to do something yourself and to do what they want without relying on a carer. Non-users were predicting that autonomy could be a result of having EADL.
- Time alone: Users are pleased to be able to spend some time alone, and this was discussed as a possible valuable experience of non-users.

The study found the dominant value of having ECS was autonomy – being able to do something yourself. The same study concluded that ECS provide people with severe and significant disability, an ability to be free from carers, have time alone, do things for themselves, feel safe and have independent relationships. They suggested that the provision of ECS should be a fundamental human right.⁷¹

As far back as 2003, the Kuopio University Hospital Device Centre in Finland financed environmental control units for 31 people with disabilities. The centre also sent out a questionnaire afterwards as part of their quality assurance programme about the benefits and usability of the devices. Almost 80% of users returned the questionnaires. The results highlighted that the devices were used every day, with door opening most frequently used. Other commands mentioned by users were window opening, door intercom, lights, phone, domestic appliances and helper-alarm. Users reported that door opening gives them a greater level of independence and more opportunity to engage in social relationships.⁷²

Another U.S. study highlights the usefulness of ECS to frail older people. This project⁷³ involved a 2-year randomised controlled trial, which was conducted to test the feasibility and effectiveness of the X10 product with frail elders (60 years of age or over) who live at home. Forty-six people were in the treatment group and 67 in the control group. The X10 ActiveHome kit was utilised for the study to control lamps and appliances with additional stand-alone products such as door, window and motion sensors. They used five different measurement instruments – Functional Independence Measure (FIM) for ADL, the Duke Older Americans Resources and Services Procedures (OARS IADL, Mobility subsection of Dysfunction section of Sickness Impact Profile (SIP), Craig Handicap Assessment and Reporting Technique (CHART) Mobility for handicap measure, and Mini-Mental State Examination (MMSE). By the end of the study 80.4% of the treatment group participants were still living in their own home, in comparison to 65.7% of the participants from the control group. The majority of participants in the treatment group recommended the smart home technology and almost all of the participants found it beneficial.

Grey Literature

⁷¹ Ibid. p.297

 ⁷² A. Kanto-Ronkaneng et al., The benefits of Environmental Control Units in everyday life, view of users and helpers, *Craddock MG, Assistive Technology – Shaping the Future, ISO Press*, 2003, p.596–600
 ⁷³ M. R. Tomita, et al, Use of Currently Available Smart Home Technology by Frail Elders, *Topics of Geriatric Rehabilitation*, 2007, 23 (1) p. 24-34


In 2006, a Housing Executive wheelchair housing study⁷⁴ found out that customised ECS have a valuable role to play when people are living alone and do not have control over essential aspects of the home environment. Attention to design detail is vital to ensure that controls can be reached and used easily, and back-up systems should be considered in the event of power failure. One of the recommendations (based on their literature evidence and from interviews conducted during the course of the study) was for further development and deployment of controls that promote security and independent living.

In 2013 in Melbourne, Australia, Residential Independence Pty Ltd (RIPL) opened small-scale living environments for people who sustain neurotrauma, specifically severe traumatic brain and spinal cord injury. These new environments were intended to offer a model of shared support, combining the design of the environment and assistive technology to enable greater independence for residents who require almost 24-hour care. The system operates using a smartphone or tablet (Android or iOS), which can run via a wireless network or over the internet. The assistive technology includes home automation and customised environmental control functions that allow the programming of frequently-used scenarios, such as the control of lighting and heating / cooling, and adjustment of blinds or opening of doors on arrival. ⁷⁵

The evaluation of the first phase (RIPL Project One) showed that the integrated smart home technology was working successfully and creating independence, but that the evaluation participants had a limited awareness of certain features offered by the system and some confusion regarding the user interface (linked to the intuitive use of the technology, and the cognitive ability of the user.)⁷⁶

Where previously a user may have needed one remote device to open a door, one to turn on a light and another to operate a motorised bed, evolution in technology has now made it possible to operate all these devices through a smartphone. The Trailblazers Report particularly noted this development, and that change will continue as this technology becomes more accessible, and more of the home environment can be controlled with greater ease.⁷⁷

Alzheimer's Society acknowledges that there are many benefits of ECS for people with dementia such as increased independence and autonomy, staying longer in their own home, improving confidence and quality of life, and help manage potential risks in their home. However, they warn that technology also has its difficulties. Assistive technology can never replace human contact and interaction and it should never be used for this purpose, which is an important point not only for people with dementia but for any other users as well. It is also important to be aware that assistive technology can limit, but not eliminate risk. It can only assist people in improving their safety and wellbeing, not provide perfect solutions.⁷⁸

⁷⁴ Housing Executive, Wheelchair User – Housing Study – An evaluation of users' experience and the evolution of design standards, 2006

⁷⁵ Tregloan K, Callaway K et al., *RIPL Project One: Post-occupancy built and technology design evaluation*, 2014, Monash University

⁷⁶ Ibid.

⁷⁷ Trailblazers Muscular Dystrophy UK, *Switched On*, 2015, p.9

⁷⁸ Alzheimer's Society, Assistive technology – devices to help with everyday living, 2015



4. FINDINGS FROM PRIMARY RESEARCH

4.1 Service landscape

The assessment, prescription, provision and maintenance of ECS within Northern Ireland has it seems never been well defined and from a services user perspective reflected random chance likelihood rather than assured equity of opportunity. Prior to the establishment of the HSC Trusts regional funding was held within the Eastern Board, with coordination supported by the then Consultant in Rehabilitation Medicine Dr Michael Swallow. Occupational Therapists who identified appropriate clients could liaise with Dr Swallow or progress with the provision of the ECS. Funding for the ECS and recurrent maintenance funding was then secured from the regional budget. Advice and guidance was available from an Occupational Therapist within the Regional Disablement Services (RDS) at Musgrave Park Hospital with input from commercial vendors. On establishment of the HSC Trusts responsibility for funding and provision was devolved down to local level. The RDS at Musgrave Park Hospital has also been dissolved.

A number of different organisations are currently involved with the delivery of ECS:

i. Community occupational therapy services through HSC Trusts

The Community Occupational Therapy Service in each HSC Trust supports individuals assisting them to live as safely and independently as possible within their own home environment or within a Residential or Nursing home. The process involves a functional home assessment of the individual's needs, from which the Occupational Therapist may devise an intervention. This could include providing advice, issuing equipment or making recommendations for minor or major adaptations to the home environment. The service operates on an open referral system and accepts referrals from service users, carers, GPs, other health care staff and agencies such as the Northern Ireland Housing Executive. Community Occupational Therapists are members of integrated teams which also include social workers and district nurses.

Highlighted in the table below are the broad stages that occur in the process to receiving ECS – with detail regarding the different approaches across the five HSC Trusts. This diagram following lays out the broad general process:

Table 6 – Approach by HSC Trusts to assessment and procurement

Assessment	A combination of approaches is taken by the different HSC Trusts to the			
	assessment process for ECS. For some the occupational therapist			
	completes an assessment on their own to identify need, for others this			
	assessment involves a commercial supplier who then is asked to provide a			
	quotation. Some HSC Trusts use either of these processes depending on the			
	context. Occupational therapists commented that it can be very difficult to			
	have a discussion with commercial suppliers in front of the client in their			
	home but that this is sometimes the case. In some HSC Trusts need has to			
	be verified by a Panel before progressing to the seeking of quotations.			
	One HSC Trust found it difficult to talk about the process as no assessments			
	have been made in recent years.			



	One HSC Trust commented that they have very specific eligibility criteria and that it is this that provides the framework for discussion around need and eligibility for access to technology.
	Two HSCT Trusts mentioned existence of regional eligibility guidance ⁷⁹ , where one is not using it as they have their own eligibility criteria, the other continues to use it but considers that it needs to be updated.
	One trust commented that in general systems are rarely declined for people provided there is an assessed need under the regional eligibility guidance.
Quotations	Supplier/s are asked to send quotations for the proposed technology they think is most suitable for the client. In some cases, suppliers send out quotations after only receiving a description and requirements, without an assessment visit. However sometimes there is a visit as outlined above.
	Occupational therapists mention trying to achieve three quotations from commercial suppliers but comment that this is often difficult.
	Trusts have different approaches to agreeing the spend / signing of the technology at this next stage. In some HSC Trusts the material is presented to a Panel, which includes senior clinical staff, and the panel makes the decision as to whether to go ahead. In other HSC Trusts sign of seems to happen through the lead occupational therapist depending on its complexity, but should it be complex it is passed to a Panel for discussion.
Budget	Only one HSC Trust has a designated budget for ECS (£30,000 per financial year). The rest have no specific budget, and one has no budget at all.
Installation	After the deciding on the type of system, and when the financial resources are available, the order is sent to the chosen supplier. The supplier orders the ECS and arranges the installation.
	The process from the assessment to the installation can take from a few weeks up to a year, depending on the available resources. All HSC Trusts said that the time it takes is variable.
Maintenance	Three of the HSC Trusts have maintenance contracts in place but two do not.
	One commercial supplier commented that they carry out maintenance checks on a twice -yearly basis.
Repairs	Some HSC Trusts have made provision for repair as part of their maintenance contracts with repair services being provided even if that company did not supply the original technology. At least one trust has a repairs contract only.

⁷⁹ Health and Social Care and Ulster University, 2011, *Electronic Assistive Technology A Practice Guide for Occupational Therapists in Community Practice*



	One trust commented that their systems rarely break down. A commercial supplier commented that they are called out to do repairs about once a month.
Reuse / Recycling	The arrangements in some HSC Trusts allow commercial suppliers to hold equipment that has gone out of use by one client, for use by another client should this technology be deemed appropriate for another client. Occupational therapists were generally uncomfortable with this approach as it relies on the commercial supplier to consider if it is appropriate in another setting as those arise, also the technology being held can overtime become obsolete in any case. (Though this is not necessarily something that occupational therapists commented on occurring a lot)

Diagram of procurement process





ii. Regional Wheelchair Service (Musgrave Park Hospital)

The Regional Wheelchair Service based at Musgrave Park Hospital in Belfast is the primary provider of wheelchairs in Northern Ireland. It works with wheelchair users from across Northern Ireland and a network of regional Occupational Therapists to determine a persons' needs and prescribes appropriate wheelchair equipment. It is part of The Regional Rehabilitation Engineering Centre. The staff provide support to the Regional Rehabilitation Engineering Service, the Regional Special Seating Service, the Regional Wheelchair Service and the Communication Advice Centre. The Principal Bioengineer, Clinical Engineer and Rehabilitation Engineers work closely with the Service Users and Therapists to achieve the best possible outcome for them. Very often they will be working with more than one of these Services for the same Service User at the same time. Services of the centre are accessed through referral from individual HSC Trusts. In some cases, they are providing the technical structures to secure and sometimes integrate the ECS into the wheelchair for clients. This centre is focused on the provision of increasingly technical wheelchairs and hence is staffed by clinical scientists and technicians.

iii. Communication Advice Centre (Musgrave Park Hospital)

The Communication Advice Centre is also a regional service for adults and children, relating to speech and language. They work with adults and children across Northern Ireland with complex communication difficulties (Cerebral Palsy, MS, MND, Parkinson's, Autism). They have a wide range of Augmentative and Alternative Communication (AAC) systems in their loan bank of equipment, which are used for assessment only. They do not provide equipment for individuals on a longer-term basis, but they work closely with the HSC Trusts where the individual is resident around recommendations for funding.

The Communication Advice Centre is integrated with Speech and Language Therapy services across NI. All referrals must come via the client's Speech and Language Therapist. The client and their multidisciplinary team are fully involved in any intervention. The Communication Advice Centre staff work with the local team who know the client well; assessment would be a joined approach to consider the possible benefit of an alternative communication aid and other technology to help with communication. In many cases, however, they recommend very low-tech devices. Their job is to assess and make recommendations for the appropriate communication system, to allow it to then be purchased by the relevant HSC Trust.

Occasionally they come across a client who already has an EC system in place (or they are getting an EC system put in place), and they collaborate with the Occupational Therapist to provide advice on compatible communication aids / or how limited physical movement may be used to move between facilitating the door opening and communicating. The major trend they have observed over time is that some of the technology people have purchased was inspired by smart home technology and a rush to prepare for the future but that eventually patients don't necessarily use it due to a change in their condition. For example, the purchasing of lots of door openers and security features in the early stages of a progressive condition in preparation for the future, when in reality the future means they will not be living so independently and the technology is not required. Whilst the Centre are directly involved in prescribing ACA systems available from those specified on contract – they don't get involved in the tender process or specifying what is on the contract.



iv. Community Social Work through HSC Trusts

In theory, recommendations for ECS can come from social workers, where users are not accessing occupational therapy services, for example in cases where people are blind or partially sighted. However, it does not seem to be the case that referrals for ECS are currently being made through these channels.

v. BSO HSC

The Business Services Organisation (BSO) has been established to provide a broad range of regional business support functions, and specialist professional services, to the health and social care sector in Northern Ireland. The Procurement and Logistics Service (PaLS) is a Centre of Procurement Expertise delivering value-for-money contracting, procurement and logistics services for the circa £656million annual HSC spend on goods and services in Northern Ireland. Procurement is split into two main functions. One function lets and manages circa 2,500 contracts across a wide range of HSC goods and services. Contracts are arranged to optimize value for money for goods and services within the HSCNI, to ensure probity and to minimise resources used in the contracting process. Procurement and Logistics Service is required to comply with the Public Contract Regulations 2015 for contracts over a designated monetary threshold. The second function provides localised support to HSC organisations, providing advice and guidance as well as processing of circa 0.25m manual transactions for all HSC organisations. BSO HSC were approached to provide data on the procurement of ECS across the health service.



4.2 Understanding of ECS

The majority of the stakeholders that we spoke to are aware of ECS and mostly understand them as 'technology that helps people to live more independently'.

"Systems that allow people to have a control of certain functions within their home, in their home environment. Primary focus is around electrical systems such as lights, TV, doors, windows." [Occupational therapy]

"About supporting individuals in the community ... for supporting people with functionalities in their own home and broadening the interface to manage their day-to-day life. Having the environment set up with timers, and reminders, switches for heating, lights, windows, etc." [Charity / non-profit]

Awareness of ECS exists in a general sense rather than individuals having very detailed knowledge. Even occupational therapists admit that they don't know the full landscape of what is possible in terms of technology.

A couple of the stakeholders from the charity / non-profit sector were aware of whole systems that can be controlled through a tablet or smart phone app, but they were not aware of the commercial names. Four people from charity / non-profit sector had come across automatic door / window openers and lamp control technology, and one also was aware of automatic door openers due to their organisational funding scheme for their clients. The rest of the stakeholders in the charity / non-profit grouping had a general awareness rather than knowledge of specific technology.

Two stakeholders from the health sector commented that they are more aware of telecare systems but not at all about ECS.

"Anything that makes life easier for people living with disabilities. From heating to lightning, door opening etc." [Charity / non-profit]

"I know of technology that is available where you can control your whole home environment with a phone or a tablet, but I haven't seen anything like that here in NI. The most of ECS that are in people's homes here are automatic door openers and lamp control." [Charity / non-profit]

In summary, relatively little is known in detail about the potential use and application of this type of technology. While there is relative clarity over what ECS is in definition terms, there is no evidence of detailed knowledge of the wide range of devices that could be deployed, nor detailed familiarity with what is a constantly evolving field.



4.3 Views on the benefits of ECS to users

Not everyone who was asked about the benefits of ECS to users was able to provide an answer. From the nine stakeholders who did give feedback, seven comments were positive. Two stakeholders from the health sector stated that is hard to say as there is a lack of evidence. Stakeholders from charity / non-profit group have very little exposure to the clients with ECS so they mostly assume that it works well. Two stakeholders (one charity / non-profit and one health) did mention that abandonment of the technology is common.

Lead occupational therapists who perhaps have the most actual practical experience consider that ECS technology generally works well and clients are generally delighted with what they receive. Two occupational therapists did mention that it is hard to say for definite the benefits as there is very little follow up after the systems are installed.

"I think it works well for people who use it but I'm not really sure, I don't know much about it to be honest." [Charity / non-profit]

"From my experience, the technology works well. The main issue is abandonment of the technology - staff or carers would use it instead of individuals with the disability. [Charity / non-profit]

"[ECS] generally work well, the systems are reliable and they don't break down very often. However, we need to review people more frequently for how the systems work." [Occupational therapy]



Olivia

Environmental Controls Systems installed:

Olivia currently has an environmental control system called "Evoassist", which is a programme installed on her iPad. This was described as operating remotely, with a central signal in the house. There is an operating screen on the iPad that includes symbols to specific controllable devices such as:

- Television/DVD player
- A lamp in her bedroom
- Automated blinds
- An alarm buzzer to contact family members.

This system was provided by the HSC Trust approximately six years ago.

Other communication systems / telecare / additional technology in place:

Olivia's room has additional automated blinds and easy to use light/door switches. They were installed when her parents were designing their house with a view to "future proofing" the residence:

"We recognised that you change as a person growing up and that someday she may want to live there independently and may be not with us. We viewed technology as linking in to "future proofing" it [the house]."

Experience of any other ECS:

Olivia's guardian did a lot of research a number of years ago into the type of ECS, which may be of benefit to her. They viewed other systems that performed similar functions as the ECS they currently have installed (Evoassist). However, she felt that other systems were less centralised and had too many components. She did not feel she received sufficient information from the HSC Trust at that time in relation to the ECS but considers that the HSC Trusts are now starting to come around to understanding the variety of types of ECS available.

Benefits:

Olivia's guardian described the ECS as enabling her to increase her independence. She related this as important to supporting a more holistic view of Olivia's health; including her emotional and mental wellbeing:

"There are very few times where she can feel independent. There are huge pay offs in so many ways for it [ECS]. It's about choices and being in your own space."

Olivia adapted to the ECS straight away and was able to decipher what her guardian termed "the layers" of the programme that enabled her to instruct others in how to use it. It also has safety benefits in the form of a "night buddy" system, which is linked in with the ECS. This is a buzzer and it means Olivia can alert others of any problems, instantly.

Challenges:

In the early stages of having the Evoassist programme installed on the iPad there were some issues with signals from the system. Also, while not an issue for Olivia, the set up required a



significant amount of engagement in terms of her specific need. Olivia's guardian believed that this could prove more difficult for other clients.

Olivia's guardian raised the issue of maintenance. She stated that there was a lack of clarity around the process in terms of maintenance contracts; if they exist; and who you should approach should there be an issue with the system. She knew that the person who installed the system (a private business) was best placed to maintain it if/when there are issues. However, as the HSC Trust does not have a maintenance contract with them, it takes an increased period of time to organise maintenance.

Suggestions for improvements:

Olivia's guardian suggested the following areas for improvement:

- A centralised, regional HSC Trust point of contact in relation to ECS. This would focus on providing individuals and families with a range of complex needs with advice on ECS.
- The process of procurement needs to be addressed. This should be client centred rather than solely cost-focused as the client/family are best placed to know what would genuinely support an individual. The client's mother gave the example of an add-on to their wheelchair that would have increased the cost of it by £100 but would have huge added benefit to the client in terms of safety and independence.
- The whole approach to ECS should be viewed as an integral part of a wider person centred / holistic model to people living with disabilities.

Olivia's guardian also commended the HSC Trust on their provision of Evoassist, given the expense, and commented on the positive benefits if has achieved for them as a family.

"It has enabled us as a family to live in a better way. She [the client] has been future-proofed in terms of her independent living."



Case Study 2 - James

James

Environmental Controls Systems installed:

James has a Samsung tablet-based system called HouseMate which is managed through a suck and blow system and controls the following in his room:

- Television
- Telephone
- Lighting
- Doors
- Curtains

Other communication systems / telecare / additional technology in place: He has no other forms of technology.

Experience of any other ECS:

James was first introduced to environmental control systems in 1995 with a "Possum" system, which he had put in place. He had variations of this system up until mid-2017. He liked the original system, which he described as being able to store over one hundred telephone numbers.

Benefits:

The system allows him to control various areas in his room in terms of lighting/doors/curtains, and it also ensures he retains good communication through a phone and intercom facility which is also facilitated through the tablet.

Challenges:

James believes that the replacement Samsung tablet system is slower than his previous Possum version. He also indicated that he can now only store twenty numbers on the system, in comparison with the over one hundred he could store on the previous system. He wanted and requested a Possum replacement, but was told these were no longer available:

"There was no other option, I find it a bit strange that this system seems less able [than my previous] – I thought technology was developing not going backwards."

He also stated that the system does not have an emergency button facility on it, which he believes is an important feature of a system for his needs.

Suggestions for improvements:

James suggested the following areas for improvement:

- More options in terms of the technology available. He feels that he was presented with only the one option in terms of the ECS available to him.
- The option of an emergency button for his system, as at present he believes the process to alert someone is too cumbersome.
- He described a process in which his OT had little engagement with him on identifying new forms of technology/ECS which may be able to support him.

"A person from [company name] came out and told me about the system – I'd go to them if I needed any information, but the OT didn't tell me anything".



4.4 Views from commercial suppliers

Commercial providers were asked to give a rough approximation of the percentage of their activity that is in the HSC Trust market versus the private sector. For the two suppliers contacted in Northern Ireland it is clear that their main market for ECS is the HSC Trusts - with less than five percent of ECS activity being in the private sector for one of the suppliers and the other supplier's activities in relation to ECS are solely with HSC Trusts.

Clarity of procurement process

We spoke to four commercial suppliers to understand their perspective on the procurement process and about ECS in general. These four were approached as they were the main companies mentioned in the discussions around the project. (The BSO HSC data suggests a further two additional suppliers who were not approached as part of this project.)

In summary, the suppliers themselves seemed unclear about how exactly the procurement system works in each HSC Trust.

Two of the commercial suppliers are based in Northern Ireland and two suppliers are based in the Republic of Ireland. From the interviews, it appears that only one supplier works across all five HSC Trusts. One supplier works only in the Southern, South Eastern and Western Trusts. Another supplier works in Northern, Southern and Belfast Trust and another one provides services to South Eastern, Belfast and Western Trusts. All suppliers described the process similarly and all mentioned that every HSC Trust works slightly differently.

One commercial supplier commented that they see a mix of things happening across procurement, that often times OT's are making decisions to achieve the easiest and cheapest solution, but also that sometimes there is over-specification of devices beyond patient needs.

Assessment and providing quotations

The suppliers said that they are always initially contacted directly by the occupational therapists. All suppliers mentioned that some HSC Trusts just approach one supplier who then joins the occupational therapist at the needs assessment. Suppliers said that HSC Trusts then sometimes ask for quotations from one other supplier, to compare. Only one supplier assumed that the second supplier then does a visit and an assessment; the other three said that they have all been sent only the specification and requirements and they have had to prepare the quotations on the basis of that, without a visit. Quotations are then supplied and some suppliers consider that the supplier who has attended the visit is the one most likely to be awarded the contract.

"Trusts contact us, sometimes only us, some need two quotations so they may go to another company." [Supplier]

"You are chosen based on the "preferential selection" of OTs. Sometimes they ask for quotations even if you didn't go to do an assessment, but you usually don't win the contract because they don't give sufficient information." [Supplier]

Installation

All four suppliers are aware of the lack of resources that HSC Trusts are facing. They are also aware that the awarding process can take some time - one supplier said that it usually takes about one year from the assessment to the installation. Other suppliers said that the time



period varies. All the suppliers were confident to say that as soon as the order comes through from the HSC Trust they get on with providing the system and installation as quickly as they can.

"It usually takes a couple of months from assessment, quotation to installation, but it can also take from 6-8 months." [Supplier]

"When the contract is signed we install the technology within 3-4 weeks." [Supplier]

Maintenance and repair

Each supplier takes a different approach to maintenance and repair. One supplier said that they already have the maintenance cost included in their contract cost. Another supplier said that they have a repairs contract with one HSC Trust. Another supplier mentioned that there is a major issue with this, as most HSC Trusts don't have a rolling service contract and there is no follow up with the client from their end. They said that some HSC Trusts do contact them, in these cases they go out and do repairs, but it is not a rolling contract.

One of the complications that it is important to articulate in relation to maintenance is that some commercial providers are installing proprietary products which only they can maintain. This creates complications if an on-going maintenance/repairs contract is awarded to one provider.

A maintenance issues highlighted by one of the contractors was that they sometimes see devices installed without the required 'battery back-up' to allow the device to operate in the case of a power cut. Generally, they commented on the variability of suppliers providing services to the HSC Trusts.

How the systems work for clients

All the suppliers consider that ECS work very well with clients. One commented that they generally think that it works well, however they can't tell for sure as they don't do any follow up, servicing or maintenance. One of the suppliers commented that from their experience the technology generally works well if chosen appropriately, and if people don't have their expectations set too high compared to the ability of the user. Another supplier also commented that it works well when the technology chosen is appropriate for the client – but that sometimes the technology that is put in place is the cheapest not the most appropriate.

"Systems work if the assessment is done properly and appropriate technology is put in place. It happens that technology that is procured is usually the cheapest not the most appropriate." [Supplier]

John

Environmental Controls Systems installed:

John currently has the environmental control system, "Possum" installed which is a blow/suck activated device and does the following in his room:

- Controls lighting
- Allows him to answer telephone calls
- Controls television/ SKY TV/e-book/DVD player/music
- Controls the intercom
- Controls the door

This system was purchased by the HSC Trust approximately six years ago. In that period, he has had approximately three variations of the same system installed. He found one version too slow and another too fast. He states that he is happy with the current system he has in place.

Other communication systems / telecare / additional technology in place:

John refereed to other technology in his home, such as his wheelchair, and bed.

Experience of any other ECS:

John has had visits from what he described as "private companies", demonstrating different forms of ECS, however, he stated he had no interest in them as they did all the things he can do with his current system.

"At the start I didn't know what the craic was with the different forms of systems. Once I saw them, I realised they all did standard things. Four or five different people have visited me from companies, but I want to stick with this [his current ECS]."

He also discussed trialling a pair of glasses which could perform controls via eye movement, but he found this unsuitable due to uncomfortable positioning:

"I had a pair of glasses with an infrared spot, that allowed me do things with eye movement, but it wasn't comfortable and I went back to this [his current ECS]. I think it's best I stick with what I know."

John said that if he wanted to learn about other available ECS he would do an internet search or simply call the person who maintains his existing system.

Benefits:

John finds the system easy to use and described the range of uses of the system. He described it as making his living environment more manageable. His family members don't have to intervene to support him in his room as much, as he is able to undertake tasks himself.

"It controls everything I need it to here in my room. I don't need to keep calling others to help with these things [TV/DVD/lighting/telephone]. It's like having a remote control in my hand"

Challenges:



John views the main challenges with his current ECS as being with regard to the maintenance of the system in terms of faults. He views the composition of the unit as having loose wiring, which is easily "knocked out" if moved too quickly by a family member, or carer. He described a situation where it was difficult to get the appropriate person out to fix the unit in these circumstances. The process was frustrating as it took a lot time, as he has to contact his occupational therapist, who then contacted a maintenance company. John viewed the time this took as being excessive and the process as being overly complicated.

Suggestions for improvements:

John suggested the following areas for improvement:

- He described experience of lengthy processes in relation to the maintenance of his system. This he felt should be streamlined and done quickly.
- He believes that some of the private companies who have visited him had more of an interest in selling rather than his specific needs. He would rather only have these visits when a very different system is being detailed and explained.
- He would like a clear, more direct line of communication in terms of who to contact when there are issues with his system.



4.5 Barriers to accessing ECS

Lack of funding

Nearly all of the stakeholders from the charity / non-profit sector responded that the biggest barrier is lack of funding for ECS. Occupational therapists likewise raised this issue. For example, one HSC Trust hasn't procured anything in the past few years due to no resources being available at all for ECS.

"There is very little that gets procured due to low budgets." [Charity / non-profit]

"The issues they are facing when it comes to technology are that the products are there but there are very limited resources, so only the most urgent things get funded." [Charity / nonprofit]

Technology awareness

A smaller number (two) of stakeholders from the charity / non-profit sector mentioned that awareness of technology is perhaps the most significant barrier as people do not know what is possible.

"People don't know what is available." [Charity / non-profit]

"They often are not aware of what is available to them. This can be due to not having accessible information in their language i.e. British or Irish Sign language." [Charity / non-profit]

Lack of knowledge of occupational therapists

This limited awareness of technology also applies to occupational therapists. The lead occupational therapists themselves agree that in most cases community occupational therapists don't know enough about the range and type of technology that is available. One therapist even questioned whether it is possible for a generalist occupational therapist to know all about the technology – and that the case should be made for this becoming an area that occupational therapists could specialise in, like other areas of the profession.

"We don't know the technology, they don't know products, should we as OTs even need to know about the technology, I don't know. Is it for an OT to know this stuff?" [Occupational therapy]

Limited number of commercial suppliers

Two lead occupational therapists also mentioned that there is a very limited number of commercial suppliers in Northern Ireland, and that in some cases some technology is really only available from one supplier, and that, to a degree, they can therefore set the price.

Length of time taken to receive ECS

A number of occupational therapists commented on the length of time it can take to put some of the ECS technologies in place. One occupational therapist commented that a client with a life limiting condition had passed away before the system which they had been assessed for could actually be installed, due to the assessment and procurement process taking some time.



Case Study 4 - Sharon

Sharon

Environmental Controls Systems installed:

Sharon has a "housemate" installed. This is a unit connected to a button which is controlled by the movement of her head pressing on it. It is then connected to her phone which allows her to control:

- her phone
- her television
- a buzzer to alert her family

Other communication systems / telecare / additional technology in place: She has no other forms of technology.

Experience of any other ECS:

The "housemate" is the first system Sharon has used over an extended period of time. She explained that she has experimented with a "suck and blow" mechanism, as well as one which was placed on her forehead. However, she felt that they were unsuitable as they were not as "controllable" as the button attached to the back of her head with a velcro-strap.

"It was trial and error getting the system in the first place. A couple of companies introduced systems, which just didn't work for me."

Benefits:

The system allows her to text, call and stay in contact with her friends and family and is a key part of her being able to socialise and remain in contact with people. She has a keen interest in current affairs and the mechanism enables her to control her television to watch programmes related to this area.

"it's been such a good thing for me, in so many ways - anything you can do with your hands on your phone, I can do with it."

Challenges:

Sharon says it took her about two weeks to get used to using the device, but after that period it was very easy to use. However, in ensuring that the system was easy to use, she feels that the technician who installed it set the system to function at a very slow rate, which she feels could be sped up to make it more suitable for her.

Sharon also feels that OTs do not communicate with her in regard to her ECS and if she is to find out any information she has to contact the ECS companies herself.

Suggestions for improvements:

Sharon suggested the following areas for improvement:

- OTs should prioritise the introduction and suitability of ECSs to and for users and ensure that individuals are kept informed.
- Systems may need to be adapted during their period of installation, further reinforcing the need for OTs to maintain contact with users.





4.6 Views on possible improvements and developments

Across the interviews a number of improvements were suggested, predominantly relating to changes to the procurement process, addressing issues with funding and knowledge levels of occupational therapists about the technology itself.

Improvement 1 – The development of a procurement process for the whole of Northern Ireland Lead occupational therapists all feel that there needs to be a more effective procurement process. They consider that one contract for ECS across Northern Ireland would be much better for clients and the HSC Trusts themselves, similar to the procurement of lifts and wheelchairs. Suppliers likewise requested a regional process of at least more clarity across the HSC Trusts in their approach to procurement. It was also commented that a centralised process might help reduce waiting times, which in some cases seem to be lengthy.

"If there was a tendering process and NI wide contract in place it would be more effective." [Occupational therapist]

"Getting three quotes has proven very difficult, due to the lack of available companies and a lack of responses."

"There needs to be a collective approach. One Trust seems to do one thing, another Trust seems to do another thing and some Trusts are not doing anything. And the Trusts who don't do anything, why are they not doing anything? Is it because they don't have the knowledge, do they feel that this is not something they want to do? I feel that there needs to be some centralised system put in place that people can get the knowledge, that people can get the assistance they need and then in conjunction with the service provides like ourselves who provide the equipment, get the expertise for the end users." [Supplier]

Improvement 2 – Develop an independent point of expertise on the development and application of ECS technology

A couple of stakeholders, one from the charity / non-profit sector and one from the health sector think that it would be useful to have a "one stop shop" or a "go-to person", where occupational therapists or clients could get information on available technology instead of relying on information from suppliers. One stakeholder (charity / non-profit) has worked previously as an occupational therapist for a HSC Trust in England where there is a specific service run by NHS England for ECS that provides information about the funding available, the process of applying for funding, the range of available technology and eligibility criteria.

"There should be one stop shop for ECS where you can see what is available, what are the updates." [Charity / non-profit]

Improvement 3 – Increased resources for procuring ECS

There is a desire from all groups to see more funding for this type of technology and support, however organisations and individuals are aware that resources are limited.

Improvement 4 – Training and support to help occupational therapists to improve their knowledge of ECS technologies (that can be procured by HSC Trusts or purchased by the client themselves)



Occupational therapists consider that they rely too much on suppliers' knowledge of technology options due to their limited technology knowledge. One lead occupational therapist commented that they are aware that there are alternative systems available and that the community occupational therapists should receive some training in relation to alternative technology to suggest to clients when the funding is not available. One stakeholder from the health sector commented that because of the relatively small number of cases where ECS gets procured on a Trust by Trust basis, then there is a lack of experience with it, and no one is really focusing on building up this expertise. Another theme that comes through in this discussion is the understanding of the efficacy of the technology and what it delivers for users; more understanding of this would be welcomed.

"Training for therapists/staff - they need more knowledge." [Occupational therapy]

"We need to reflect on outcomes of this provision - to have a framework of what technology brings to clients - at the moment they don't have anything specific. But it needs to be a shared approach across all the Trusts." [Occupational therapy]

"There might be a training need in terms of what is out there on the market to manage the alternative." [Occupational therapy]

"A clinically led pathway for the Trust would be a way forward and having enough experience with ECS and keeping the clinical needs at the forefront." [Health]

"OTs don't know the technology and what is available so there is an issue when a supplier goes to do an assessment, they propose something but at the end they will usually go for what is cheaper, but not what is appropriate, and it might not necessarily benefit clients." [Supplier]

"OTs don't have the knowledge, some have absolutely no knowledge, but some might know a bit. They rely on suppliers or they don't bring anyone at all to the assessment." [Supplier]

Improvement 5 – The development of clear criteria around what the role of the health care provider is, what they can provide and what they cannot provide

This was raised by a small number of occupational therapists – a request to help manage public expectations around what it is possible to provide, in which circumstances, to help provide clarity given the changing pace of technology and what are considered to be increasing public expectations.





Darren

Environmental Controls Systems installed:

Darren has a "Possum" installed which is controlled by buttons on his wheelchair. It controls:

- doors
- lighting
- the positioning of the bed
- telephone
- television

Other communication systems / telecare / additional technology in place: He has no other forms of technology.

Experience of any other ECS:

He has had no other experience of ECS.

Benefits:

The possum system allows him to control all the aspects of his home that he feels he currently needs. It also increases his independence from carers, by allowing him to reposition himself in his bed, for example. He is able to keep in touch with people with ease, and this facilitates him in maintaining a social life and keeping up to date with his areas of interest such as sport.

"It [ECS] has worked out really well. It's opened up my life. It's nice to get up in the morning and be able to control things."

Challenges:

Darren states that the stand the system is installed on is not sufficiently robust as it is moved around by his carers a number of times per day. As such, he believes it would be better to install two separate stands, which would make it easier for the carers. He also envisages a time when the current systems will not be suitable and will require adaptation, for example if he loses control of his hand and/or neck. However, he believes his OT and those who maintain the system will be able to provide for his needs:

"They're [ECS] are all very adaptable, and the people putting them in know their stuff."

Suggestions for improvements:

Darren suggested the following areas for improvement:

- He believes that other people living with disabilities are not aware of ECS. He gave the example of a group he meets, which includes other people with similar conditions, and he feels that many are not kept informed by their OTs.

"If you don't enquire yourself, you'll never find out [about ECS]. People are living without it and it could be a God send for them."

The maintenance of the system is an issue as Darren felt there was no clear line of contact, and that the whole process is too bureaucratic.



Peter

Environmental Controls Systems installed:

Peter received a Possum Primo device through the HSC Trusts after his accident a few years ago. The system is button operated and allows him to control his bed and television.

He also has automatic door openers around the house which operate through proximity sensors, and the doors to outside open with a specific magnetic card that is attached to his wheelchair. The automatic door opening system was also purchased by the HSCT Trust.

Other communication systems / telecare / additional technology in place:

Peter has personally financed other technology around his house.

- Amazon Echo / Dot: This is a voice control device with multiple functions. It works through Wi-Fi signals. He has two devices one in the living room, which can turn on/off the side lamps, and communicate with 'Harmony' (a Logitech device, which controls the TV through the infrared signals) to turn on/off the television and change channels. (See diagram below.) The second amazon echo device is located in his own bedroom. It controls the main room lights, the side lamp, a fan and the movement of the bed up and down. The bed and the fan are connected to the Amazon echo through a Broadlink RM Pro Smart Home Hub. There is also intention to link smart blinds in to the system.
- *Glassouse UK*: These are glasses with a biting device that work as a mouse to allow the control of a laptop or desk top computer or an android tablet, or phone. (The system does not work with an iPad/iPhone). With the help of these glasses Peter can also control a drone that he uses.
- Sesame Enable phone: This is a hands-free smartphone that is controlled by head movement.



Benefits:

All the technology in the house enables Peter to have a lot of independence especially from a social perspective. He can communicate ably with his family and friends – and he also uses the drone as part of his business to edit video material for clients.



Challenges:

Peter did mention that there was some thinking necessary in relation to how to link all the devices together.

Below we highlight the devices that the individual has purchased themselves to augment what is provided by the HSC Trust:



Glassouse Uk http://glassouse.uk/ £275

echodot

Amazon Echo Dot www.amazon.co.uk/ echodot £40-£50



Amazon Echo www.amazon.co.uk/echo £120-£150

Does the same as the Dot, just has a bigger speaker



Search "Logitech Harmony" on amazon.co.uk £99-£270 depending on remote

Logitech Harmony

TP-link Wifi plug

on amazon.co.uk

£20-ish

This connects Alexa to the tv. The hub alone costs £99 and will work via an app, but I think it's handier to have the remote too

Works with Laptops, Computers,

Doesn't work with ipad / iPhone

Android tablets and phones.

Other brands available at about £15. These seem to be the best / most reliable. Controlled directly by Alexa.



Broadlink RM Pro Smart Home Hub Search "Broadlink RM Pro" on amazon.co.uk £29

Alexa does not have infra-red so this hub provides this and also RF Connected to Alexa via an Android device (phone/tablet) that has to be on the same network. This hub learns the codes from the controller that can then be voice activated via Alexa



Soma Smartshades uk.somasmarthome.com 299

This system allows the blinds to be controlled via an app.



ol Smart Shades

amazon alexa S Apple H

SOMA Connect blinds control for Amazon Alexa uk.somasmarthome.com £79

This allows the blinds to be voice controlled by Alexa

Search "TP-link Wifi plug"



4.7 Actual number of ECS in place in Northern Ireland

i. Limitation of data sources

There is very little market research data available on the development of the ECS market in Northern Ireland. An early audit of the provision of ECS, which was undertaken between 1992 and 1997, identified 49 users as receiving services from Steeper and Possum, two of the suppliers still on the market.⁸⁰

A recent study provides some more up to date but very basic information. Guide Dogs NI have recently put out a survey⁸¹ to their service users, where 32% (19) of participants have some form of environmental control within their home. (They defined environmental controls as types of electronic assistive technology that allow users to remotely access equipment within their home, so they can complete daily tasks.) These environmental control systems included Alexa, Amazon Echo, HEAT or INSPIRE home automation to help complete tasks within the home. Twenty-six respondents also identified other forms of assistive technology in their home. Seventeen of these participants had voiceover technology on their phones or computers and 9 users had items from the RNIB shop such as level indicators, colour indicators and talking book machines.

The data collected from the five HSC Trusts through this study finds that there are 107 people overall who have ECS installed in their homes. According to the databases supplied by the three commercial suppliers, 114 people have ECS in their home. (As noted in the methodology section despite both being given the same guidance we are not able to 'match' the data provided by the HSC Trusts and commercial suppliers as they look more different than similar. We can only speculate that this is due to differences / inaccuracies in record keeping and or different interpretations of the data requested. Also, perhaps the HSC Trusts have more up to date / precise data as to the installations that are currently live, rather than no longer in place.

The data received from Housing Executive is very limited and was not added to our dataset. It only features four cases with individual system elements rather than any fully integrated systems, which is the focus of our dataset.

BSO returned data based on their Purchase Order (PO) system with 652 purchases very broadly relating to ECS from December 2012 until end of October 2017. It is difficult to interrogate the data as there is limited information provided on the items purchased and it has been sourced by searching for the companies who provide ECS and by names of technology rather than through an active identifier of ECS. It is therefore likely that it includes a significant number of elements outside the scope of this study.

Data from the Department of Health is also limited as it only provides the number of ECS for each HSC Trust per year for quarters of 2016 and 2017.

⁸⁰ SM Maguire, JP McCann and M Swallow, An audit of the provision of environmental control systems in Northern Ireland, 1992–1997, Clinical Rehabilitation, 2001, 15, 320–323

⁸¹ This data comes from a recent study conducted by Guide Dogs. Sixty individuals living with sight loss and who currently receive services from Guide Dogs were contacted and completed a telephone questionnaire.



ii. How do the number of ECS in place in Northern Ireland compare to the number of wheel chair users?

As table 7 below shows we have considered the number of ECS in each HSC Trust area alongside the overall population and the number of long-term wheel chair users. Whilst this comparison is crude, as we are unclear how many wheel chair users might be eligible for ECS technologies, it does suggest that their use is very limited. More work needs to be completed to understand the full scale of need for ECS technologies.

HSC Trust	Estimate Population*	No. of ECS (according to HSC Trust data)	% of ECS of Popln	No. of powered wheel chair users**	% of powered wheel chair users of Popln
NHSCT	436,000	22	0.005	313	0.072
SHSCT	365,712	32	0.009	608	0.166
SEHSCT	345,000	26	0.008	434	0.126
BHSCT	340,000	13	0.004	430	0.126
WHSCT	300,000	14	0.005	390	0.13

Table 7: % of ECS and % of powered wheel chair users per HSC Trust

* Population numbers are approximate and are based on the information provided on HSC Trusts' websites.

**All users are classed as long-term wheelchair users and not those who will only require wheelchair use for a short period of time. The number of wheelchair users in each HSC Trust was provided by Regional Wheelchair Services.



Diagram 1: HSC Trust boundaries



iii. How are ECS distributed across Northern Ireland?

Chart 1 below shows how many people in each HSC Trust have ECS installed in their home. Based on the received data, Belfast HSC Trust has the smallest number of people with ECS, only 13. However, this information did not match with the data provided from the commercial suppliers, which suggested that Belfast HSC Trust has the second highest number of ECS installed. Southern has the most cases where people have got ECS based on the data from the HSCT (32). Based on suppliers' data Northern HSCT has the most ECS installed (31). According to both datasets the Western HSC Trust has the least number of ECS installed.



Diagram 2 below shows in more detail the distribution of ECS across Northern Ireland based on first part of the postcode taken from the HSCT data. It shows very clearly a concentration in the South of Southern HSC Trust and in Belfast.

Diagram 2: Postcode distribution across NI (Legend on diagram represents the number of ECS in place in a postcode area)





Data received from suppliers' records many more cases across Belfast HSCT (represented with the very dark purple on the Diagram 3.) Northern HSCT is geographically larger therefore representation is spread across the HSC Trust.





The data that

was provided from the Department of Health (DoH) is very limited, as it is based on the number of ECS cases that the HSC Trusts report to DoH. For year 2016 DoH holds only data from Southern and Northern Trust on the total number of ECS in use at the start of each quarter. Chart 2 shows that in Southern Trust the number of ECS in use stayed the same for the first and second quarter of 2016. However, in Northern Trust there were three new installations in the first quarter of 2016.



Chart 2: Number of ECS in use for first and second quarter of 2016⁸²



NB. The DoH where approached to explain what the term NA means but we have not had a response.

For 2017 there is only data available from the Northern HSCT. Nothing has changed in the third and fourth quarter of 2016 as the number for the first quarter of 2017 stays the same -28 ECS in use, the same as it was in the second quarter of 2016. However, there is one new installation in the first quarter, which shows the change in the second quarter -29 cases of ECS in use.



Chart 3: Number of ECS in use for first and second quarter of 2017⁸³



⁸² Information supplied by DoH

⁸³ Information supplied by DoH



iv. Can we see any trends in installations of ECS over time?

Trusts and suppliers were requested to give data only about ECS that are currently live. It seems that only four ECS installed before 2000 are still in use, or at least this is all that the HSC Trusts and suppliers were able to find in their records when their data is combined.

There were 34 installations between 2000 and 2010 according to the data from HSC Trusts, however supplier data suggests 34 ECS installed between 2006 and 2010.

After 2010 according to the HSC Trusts there were 29 installations by 2015 and another 26 after 2016. Based on the HSC Trust data there would seem to be an upward trend in the number of systems being installed with the numbers for after 2016 already being half what they were in the preceding four years. However, data from suppliers shows a decline in ECS installations.



Chart 4: Number of ECS by the year of installation



Data received from BSO only starts in December 2012, which is the reason for such a small number of purchases in 2012. As with the data from HSC Trusts and suppliers, we can see an upward trend in purchase numbers. However, BSO data includes purchases of technology itself as well as maintenance and repairs – and therefore seems to be more comprehensive.



Chart 5: Number of ECS by the year of the installation based on BSO data



v. How much money has been spent on purchasing ECS?

There was information on budget spend for only 47 cases out of the 107 provided overall from the five HSC Trusts. Suppliers provided this information for 82 out of 114 cases. BSO provided information for 652 purchases, however as noted above these are not individual cases, some seem to be duplicates as their database includes all the purchases, maintenance and repairs costs. Therefore, we have not compared BSO data directly with the data from HSC Trusts and suppliers.

Budgets vary from between £370, which is the lowest amount in the dataset from a HSC Trust and £15,849 the highest from a HSC Trust – see table 8 below. The mean amount of spending from the HSC Trust data is £5,061.25. Data from suppliers showed that the most cases (27) cost between £2,001 and £3,000. The budget on the suppliers' data set varies between £405 and £13,215. The mean amount for the procured ECS is £3,785.99 (table 8).



Table 8: Minimum,	maximum	and mean	of ECS	spending

	Base	Minimum	Maximum	Mean
Budget HSCT	47	£370	£15,849	£5,061.25
Budget Suppliers	82	£405	£13,215	£2,785.99

As the number of cases that expenditure data was provided on varies it is difficult to understand the true picture in terms of costs. Belfast HSC Trust provided information on the cost for only one case, and the other Trusts likewise were not able to provide cost data on all cases. South Eastern Trust appears to have spent the most, by some distance (Chart 7).



Chart 7: Total spending on ECS based on HSCT data



According to the data from BSO and their Purchase Order (PO) system, there were in total 652 purchases related to ECS from 2012 onwards. (BSO only have data available from 2012.) The most cases are recorded from the Northern HSC Trust, which also reflects the largest expenditure. For the Southern HSC Trust, the least purchases are recorded and therefore their total expenditure is by far the lowest. Since 2012 the total cost for ECS based on the PO system is £562,091. In addition to the PO system at BSO there is also data from the FPM system that may relate to ECS. However again it is difficult to discern what elements recorded on here might relate to ECS, therefore the numbers gathered through the BSO data recorded here are likely to be an underestimation according to BSO.



Chart 8: Expenditures on ECS by HSCT based on BSO data from 2012 to end October 2017



Further to the cost of ECS more work needs to be undertaken to understand the contribution ECS makes to health outcomes by supporting people to live in their own homes rather than in more supported facilities.

vi. How much is spent on the maintenance of ECS?

We asked lead occupational therapists from all five HSC Trusts, and the commercial suppliers, to provide an approximate up to date total annual charge for maintenance for each case for the most recent year possible. HSC Trusts were able to provide this cost for only 23 cases out of 107 and suppliers provided this cost for 48 cases. It should perhaps be of some concern that this information is not up to date and accessible. Maintenance cost data from the two sources varies in some places with most similarity around the cases stating a cost of £660 per year.







vii. Who is funding ECS?

Information provided by the HSC Trusts in relation to funding showed that in 65 cases out of 68, the ECS were funded through HSC Trust budgets. In just two cases the budget was provided through another organisation (on one occasion a housing association, and another through a Disabled Facilities Grant, which is provided by Northern Ireland Housing Executive.)

Suppliers' data concurs that HSC Trusts are the dominant source of funding for ECS – as in 95 out of 99 cases it stated that funding came through HSC Trusts. There were three cases were ECS was part funded by a housing association and a HSC Trust, and only one case solely funded by a housing association.



Chart 10: Source of funding for environmental control systems



viii. Who are the suppliers of ECS technology?

Data from HSC Trusts on who supplied the technology was available in 95 cases. In 62 cases Odel Mobility provided the technology and as a result they seem to be the biggest player in the market here in Northern Ireland. The rest of the suppliers mentioned were IDEAL Technology (in 12 cases), Jamieson Electrical Technologies (in 11 cases), Care Assist (in 4 cases), and Safe Care Technologies (in 3 cases). In one case, it seems that Odel and Jamieson Electrical each provided part of the technology.



Suppliers provided information on which HSC Trust they supplied the technology to. One supplier is quite dominant across all the HSC Trusts. However, it is important to note that the overall base on the supplier database is higher than the HSC Trust database.



Chart 12: Suppliers data on their customer base



ix. Who are the people who have ECS installed?

Gender

Overall, there are more men than women who have ECS installed in their home, 67 men compare to 40 women according to the HSC Trust data. There is a similar split suggested by the supplier data.





Age

The data suggests that ECS are more often accessed by older people. In the data received from HSC Trusts there is only one child under 16 years of age recorded in the dataset and even the number of users under 30 who have ECS is only twelve. There are 47 people across Northern Ireland that have ECS installed who are between the ages of 31 and 55 years old and 43 people that are 56 or older. The largest individual group of people, 15 out of 103, who have ECS are between 61 and 65 years of age.

In the dataset from suppliers there is no one under 16 years of age. Their data had fewer cases with known age. Only six people were under 30 years old. The largest individual group of people according to the supplier data who have ECS are between 66 and 70 years old – 17. On suppliers' data, there are 40 people who are 56 or older.




Chart 14b: Grouped age range



Medical conditions

Multiple sclerosis and spinal injury are the most common conditions found in the data from HSC Trusts and the commercial suppliers. HSCT listed 19 other conditions that are listed in the table 9 below. HSC Trusts were unaware of only seven conditions out of all 107 cases. Suppliers were only aware of the condition for 63 cases.



Chart 15: Type of conditions



Table 9:	List of	other	conditions
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*Other conditions	Number of conditions
Quadriplegia	3
Spinal Atrophy	3
Tetraplegia	2
Amputee	1
Ankylosing Spondylitis	1
Arthritis	1
Arthrogryposis Multiplex	1
Chromosomal Abnormality	1
Complex Epilepsy	1
Downs Syndrome	1
Missing Limb Deficit	1
Primary Cerebellar Syndrome	1
Spinal Lesion	1
Syringomyelia	1



Housing Tenure

Chart 16 shows data supplied by HSC Trusts. The majority of people (71 out of 96) who have ECS in their home, live in a privately-owned property. Sixteen people who have ECS live in a property that is owned by a housing association and seven are in a Northern Ireland Housing Executive property. (None of the commercial suppliers provided this information.)



x. What are the referral pathways to people accessing ECS?

Data from HSC Trusts suggests that the majority of people were referred through adult physical disability services (62 out of 105) to occupational therapy services – this suggests that the majority of people with ECS are living with a physical disability. Thirty people were referred through older people services. Interestingly there so not seem to be any cases that are based on 'self-referral'.

From the suppliers' data, for all the cases (base: 101) the suppliers stated, 'Physical Disability'.



Chart 17: Referral Pathway



xi. What ECS technology is in place?

As in other areas the data on the exact technologies in place does not neatly match across the two data sources – the HSC Trusts and the suppliers. In most cases, commercial suppliers provided the name of the technology installed, however in the HSC Trust data there were more descriptions of what the technology controls rather than the name of the system (which is what we asked for, being aware that occupational therapists have less awareness of the specific technology). 'Possum Primo' was the most mentioned technology by suppliers, whilst 'auto door opening system' was the most mentioned technology in the HSC Trust data. (Please note we were keen with this project to focus on more complex technology rather than individual door openers.) There were other systems mentioned in the datasets, which can be seen below in tables 10 and 11.



Chart 18: Types of technology in place

Table 10.	Other technol	a mu frama tha a	latabaaa UCCT data
	Uther technol	logy from the d	latabase – HSCT data

HSCT Other Technology	Count
TV, Radio / telephone, Doors and Lights	6
Care Assist Pager & PIR	3
Info pager, Door sensors, Door alert system	3
Fox	2
Grid 2	2
Possum Compact	2
TV and Telephone	2
Butler voice control system	1
Door intercom and Lights	1
Door Release and Intercom System	1
Duocom room system	1
ECS	1
Eye Mobile Mini software	1



Reflector Beam and alarm/floor alert sensor	1
SRS-LITE	1
Telephone, lights	1
Tobii I	1
TV, Lights, Computer, Intercom, Door entry	1
TV, Telephone, Intercom and Door Release	1
Video intercom system	1
Window opening devices	1

Table 11: Other technology from the database – Commercial Suppliers data

Suppliers Other Technology	Count
Senior Pilot	3
Sicare Light	3
Fox	2
Possum Compact	2
Gewa 111	1
Gewa MEDI MULTI	1
PICO 16	1
PICO 4	1
PICO 8	1
Possum Companion	1
Possum Info	1
SRS Lite	1
Window openers and curtain controllers	1



Given the range of products and their overlapping nature it has been very difficult to analyse this part of the dataset. In an effort to understand the technology in more detail we have spoken with one of the commercial suppliers at some length. One of the ways to group and discuss the technology seems to relate to the way they operate. The diagram below seeks to provide some sense of how the products compare. We have tried to use some crude categories to map the different types of technology, arranging them from more basic functionality through to more advanced and according to how they function.



Diagram 4: Mapping of ECS Technology



To see if this sheds any light on who has access to specific technologies we have completed further analysis. Chart 19 below shows the number of types of these devices in each grouping.



Chart 19: Technology groupings

NB. Doors refers to automatic door openers / Doors+ refers to automatic door openers plus control of another combination of elements such as windows or television etc. Other relates to anything that we could not categorise into the other categories

We considered the technology groupings by condition but it still very hard to see any trends. (see table 12 below)

			Infrared	d / Radio	Smart pho	one / Tablet								
	Obsolet	e / Basic	Sig	nals	Ba	sed	Do	ors	Do	ors+	Ot	her	To	tal
	HSCT	Suppliers	HSCT	Suppliers	HSCT	Suppliers	HSCT	Suppliers	HSCT	Suppliers	HSCT	Suppliers	HSCT Base: 88	Suppliers Base: 61
Multiple Sclerosis	1	7	6	9	3	0	3	0	1	0	10	3	25	22
Spinal Injury	4	8	3	7	3	3	0	0	1	0	2	3	15	23
Cerebral Palsy	3	1	2	0	0	1	1	0	2	0	1	0	10	2
Muscular Dystrophy	1	5	1	0	2	0	0	0	1	0	4	3	10	8
Brain Injury	0	0	3	0	1	1	1	0	0	0	2	0	7	1
Learning Disability	0	0	0	0	0	0	1	0	0	0	6	0	7	0
Motor Neurone Disease	0	2	0	1	1	2	1	0	0	0	2	0	6	5
Quadriplegia	0	0	2	0	0	0	0	0	1	0	0	0	3	0
Spinal Atrophy	1	0	1	0	0	0	1	0	0	0	0	0	3	0
Tetraplegia	0	0	0	0	0	0	1	0	0	0	1	0	2	0

Table 12: Technology groupings by conditions (with more than 1 case)



We then considered the technology groupings by age and it is possible to perhaps suggest that smart phone and tablet-based devices are more likely to be accessed by younger people. It is very difficult to see patterns according to age and condition and type of technology. This underlines on our view the complexity of matching technology to the specific health and mobility needs.



Chart 20a: Technology groupings by age (HSCT Data)







We also considered the technology groupings by spend to see if newer technologies are being charged at the same cost as the technologies which are now more basic but it is difficult to see any clear trends in the data.

Technology Grouping	Cost £1,000 - £3,000	Cost £4,000 - £6,000	Cost £7,000 - £9,000	Cost £10K +	Total
Other	12	1	3	3	19
Infrared / Radio Signals	1	5	2	1	9
Obselete / Basic	0	2	3	1	6
Smart phone / Tablet Based	0	5	0	1	6
Doors+	2	1	1	1	5
Doors	0	2	0	0	2
Total	15	16	9	7	47

Table 13: Technology groupings by Cost (Trust Data)

Table 14: Technology groupings by Cost (Supplier Data)

Technology Grouping	Cost £1,000 - £3,000	Cost £4,000 - £6,000	Cost £7,000 - £9,000	Cost £10K +	Total
Other	6	5	2	0	13
Infrared / Radio Signals	11	11	2	1	25
Obselete / Basic	14	11	3	1	29
Smart phone / Tablet Based	5	6	0	1	12
Doors+	1	1	0	0	2
Doors	1	0	0	0	1
Total	38	34	7	3	82



Claire

Environmental Controls Systems installed:

Claire currently has an environmental control system called "Possum" which is activated by a single large button placed close to her hand (she refers to it as "the dot" given its appearance). It allows her to:

- control the lighting within the room
- control the television/DVD player
- answer the phone
- open and close doors in the house.

This system was purchased by the HSC Trust approximately 7/8 years ago. She was advised by her occupational therapist that this was available and that it would support her in living more independently. Her family and carers all understand how it works.

"They [family and carers] know I rely on it and I'm very used to using it."

Other communication systems / telecare / additional technology in place:

Claire lives in a purpose-built home for her needs. It was built to her specific requirements and includes added benefits of systems such as a hoist. As a result of her home, the client believes she has less need for any other communication systems/telecare/additional technology.

"Since I moved into this house I don't need as much [technological assistance, in general]. It was purpose built. I haven't looked for anything else since getting this [the Possum]."

Experience of any other ECS:

Claire is not aware of any other ECS as she does not feel she currently has a need for it. If she wanted to explore other forms of ECS, she would ask her occupational therapist.

Benefits:

Claire uses her ECS "at least twice a day" and has found it practically useful on a day-to-day basis in helping her live independently, it enables her to for example self-select a television shows or turn the lighting on or off in her room. She prioritises the use of the telephone as part of her ECS.

She described a situation when the system helped her in a medical emergency:

"I probably value the use of the phone on it [the ECS] the most. Last year I had a health emergency, I woke up and I just couldn't breathe, and I was able to call my son without any trouble and let him know. If I hadn't had it [the ECS] I would've been in big trouble."

Claire described how this gives her a sense of security, as she knows it has worked when she needed it most.



Challenges:

There have been some minor challenges with regard to maintenance of the system and Claire is not sure whom to contact to deal with this beyond her occupational therapist. She did not feel that this had been too much of a problem to date, as her occupational therapist has put the processes in place to ensure that when there is an issue that it is dealt with quickly.

Suggestions for improvements:

Claire had no suggestions for how her experience of ECS could be improved other than to praise the work of the HSC Trust.

"A lot of people complain about the Trust, but they do everything they can for me."



xii. Do ECS occur with other technologies?

We wanted to understand if people who have ECS in their home, are likely to have other technologies as well. We asked HSC Trusts and suppliers to let us know in each case if there was a telecare system or additional communication systems in place.

For the majority of cases there is not also a telecare system. There are only three cases that the HSC Trust knows of where people have telecare as well. The data from the commercial suppliers reported that there were 18 cases where people also had a telecare system.



Chart 21: Presence of a telecare system

In relation to any additional communication systems, the HSC Trusts were only aware of four cases out of 68 and did not know for 30 cases. Suppliers were aware of only one person who has an additional communication system in place as well.









4.8 Summative reflections from user/case study discussions

This section highlights the main pertinent themes from discussions with users of ECS through the case study discussions and a short group discussion with a group of visually impaired people facilitated by Guide Dogs NI (seven people attended the group discussion).

1. ECS play a key role in supporting and enabling independence and autonomy which has an impact on general health and well-being

All users were very clear of the important role that the technology plays in enabling them to have as much independence as possible and to live their daily lives.

"Echo Dot has become my main form of communication aid ... it has revolutionised my life!"

2. Users generally find it hard to gather information about technology options and are not necessarily presented with a range of options at procurement stage

From the group from Guide Dogs UK users it was clear that users mostly found out about relevant devices through other sight-impaired people as well as through other fully sighted friends. Television advertising was also mentioned, as was 'In Touch'. 'In Touch' is a specialist radio programme, available live or through podcasts, which provides direction on useful products. RNIB Northern Ireland also promotes their products through their podcast called 'Craic On'.

Generally knowing what technology is actually available on the market and how it works is difficult. Word of mouth was commented on as the most common way of finding out about different device. The Guide Dogs UK groups commented that there is no one stop place that has all the up to date information.

"There are organisations whether its community organisations, charities, businesses all want to have their slice of the pie, someone out there needs to pull everything together and it needs to be in one place."

Those whom we conducted the case studies with were on the whole very dependent on their occupational therapist and the HSC Trust to provide information on technology options. However they did not feel that OTs were necessarily able to provide all the required information and support.

When trusts are procuring technology not all users are provided a range of options in relation to the technology that might work best for them and they seem to have limited engagement in the decision-making process.

3. Repair and maintenance of devices and technology is the area that causes most difficulties and frustration

Users are not always clear whom to address should they have a problem with the technology.

4. Users, who are tech savvy, are able to add substantially to systems provided by HSC Trusts

Tech savvy users see the emergence of a plethora of software and devices that may provide even greater independence to them – and are actively seeking information on how these devices might support them and how they might work with their existing technology.



5. Costs of devices / technology can be a key issue

Cost was also highlighted particularly by the Guide Dogs UK group who were conscious of trying to find appropriate every day devices e.g. in relation to basic appliances for example kitchen appliances - these increasingly have LCD control panels (rather than buttons and knobs) which can make it hard to use them, and talking appliances are very expensive.

"LCD control panels are a nightmare."











Sam

Environmental Controls Systems installed:

Sam currently has an environmental control system called "Butler" which is voice activated and does the following in his home:

- opens three doors (front, hall and back door)
- opens the window in the kitchen area
- controls the heating in the property
- controls the curtains in the kitchen area
- controls lighting within the property
- controls movement of the leg section of his wheelchair

This system was purchased by the HSC Trust approximately ten years ago. He is aware that there have been some updates to the Butler system, but none of these have been offered to him since the system was installed.

Other communication systems / telecare / additional technology in place:

Sam has personally financed two extra systems to support himself in his living environment. These are the Apple system "Siri" through his iPhone 6 and a computer, which are both voice activated. They have the added benefit of enabling communication, and as a result, relying on one particular system does not compromise his personal safety. Sam also described the added benefit of mobile technologies as not being hard-wired, and therefore not relying on an electricity supply, for example.

He also referred to other technology in his home, such as his wheelchair, bed and hoist. However, these are all button controlled and require support workers to operate them.

Experience of any other ECS:

Prior to the installation of the "Butler" system, Sam had a "Possum" environment control system installed. However, due to the reduced movement in his hands, this became unsuitable (it is a touch activated system). He has also trialled other systems, including a "blow/suck" system, which was described as being unsuitable due to the positioning of the device in relation to Sam's lack of mobility (he described a situation where it dropped to the floor and he was unable to reposition the device).

Benefits:

Sam has tailored his use of his particular ECS to his specific needs. In his own words, it allows his living space to be both his home, and a working space for carers. This was particularly the case for example with respect to lighting. He did not want his home lighting system to resemble office lighting, but he understood the need to have lighting in the environment that facilitated work by his carers.

Sam spoke about the empowering aspect of this level of self-determination in relation to conditions in his own environment, and how this has profoundly and positively impacted his perception of his living space.

The additional systems he has personally been involved with installing and has been using,



have increased his ability to communicate more easily via telephone/email/text message.

"I keep up to date with developments in technology in this area. I look at what is being used by other people and I know that my needs are being met, as I'm computer savvy. I know how to self-advocate."

Challenges:

Sam described a situation whereby technology is moving faster than medical and support professionals can keep up with. This means that many individuals living with complex disabilities are having to self-advocate for the procurement and installation of appropriate ECS. According to Sam, this means that many individuals may not have access to the most suitable/advanced ECS systems for their needs. Also, he has found there to be challenges in terms of temporary or agency staff understanding the technology – he gave an example of an agency worker calling and not understanding he needed time to activate the door mechanisms with his voice.

"OTs are over-laden with duties and the procurement processes are lengthy and confusing for people.

Suggestions for improvements:

Sam suggested the following areas for improvement:

- It is time consuming for occupational therapists, when they are already under pressure with existing workloads to consider ECSs and emerging technologies. A dedicated team member within HSC Trusts would benefit service users, and the teams themselves, in delivering targeted and suitable ECSs for people living with disabilities.
- Sam described experiences of lengthy processes of procurement by HSC Trusts. Sam found this to be confusing and sees it as having the potential to "put people off" seeking ECSs. The procurement process needs to be as streamlined and transparent as possible.
- There needs to be an assurance, and systems put in place, that the repairs/maintenance of existing ECSs be done quickly and effectively.
- The area of more accessible/affordable technology such as iPhones to support ECSs needs to be explored and developed by HSC Trusts.

"Trusts need to look at things like iPhones and Siri as they're much more accessible and affordable. It will help people be more comfortable and secure."



5. HOW ARE ECS SERVICES STRUCTURED OUTSIDE OF NI?

While it has not been within the specific remit of this research to consider best practice in the structuring and development of ECS services, we have tried to seek any easily accessible material in relation to how to improve the delivery of ECS. This section highlights two possibly useful approaches:

i. The specification from NHS England for the commissioning of environmental controls, it is not clear how far this specification is followed in practice.

ii. The components of the International Code of Practice for Planning, Commissioning & Providing Technology Enabled Care Services by CECOPS

i. NHS England Specification for the commissioning of Environmental Controls

It is suggested there should be different elements to this service. NHS England has a general commissioning group - The Clinical Reference Group (CRG), which covers complex rehabilitation and complex disability services. 'Complex disability' includes specialised prosthetics services, environmental controls and Augmentative and Alternative Communication (AAC) technologies.

Aims of the service

The aims of the service are stated as:

- To provide relevant EC equipment to adults and children with complex physical and other disabilities due to a variety of medical conditions in order to improve their independence, quality of life, safety and participation.
- To participate with the provision of other EAT such as communication aids, powered wheelchair controls and other equipment of daily living, where this is appropriate.
- To collaborate with other clinical services and social agencies to optimise patients' wellbeing.
- To ensure that patients and carers are well informed on the use of the equipment that has been loaned to them.
- To adapt equipment provision to meet the changing needs of the patient.
- To provide the service in an independent, unbiased, cost effective and accountable way.
- To ensure all staff within the service are trained to an adequate and relevant level of competency, including awareness of technological developments
- To promote the development and application of EC and other relevant EAT products.
- To promote equitable provision of service across the population and diagnostic groups.
- To support primary and secondary care staff by offering them specialist professional advice and training.
- To collaborate with national initiatives to develop and improve service provision.

Staffing of the service

The assessment and provision of EC equipment is carried out by a multi-disciplinary team consisting of experienced professionals from a clinical / Allied Health Professional (AHP) background to ensure appropriateness and independence of prescription. All EC provider services employ, or have reliable access to, properly accredited and experienced clinical scientists, rehabilitation physicians, clinical technologists, occupational therapists and speech



and language therapists. The service has as Clinical Lead an established clinician with relevant, proven competences who is well versed in service organisation, innovation and research.

The service ensures that they offer training packages, seminars and symposia to inform professionals (especially community occupational therapists, social workers, speech and language therapists) and voluntary sector personnel within its catchment. This ensures that patients who could benefit from EC provision are referred to the service. EC and other EAT services across the country collaborate to ensure equity of standards in prescription.

Care Pathway for EC service delivery

- Referrals will be accepted from health and social care professionals, charity support workers.
- When treating children, the service will additionally follow the standards and criteria outlined in the Specification for Children's Services.
- Additional information to the referral may be required from other sources and primarily the patient's General Practitioner (GP), who is responsible for the care of the patient in the community and is to be informed about the referral and its outcome.
- All referrals will be acknowledged within 10 days of receipt by the service, and it be stated if there is reason to delay the assessment or referral acceptance, such as insufficient referral information.
- The service will assess the EC needs of all patients fulfilling the acceptance criteria.
- Patients will be assessed at their home, place of residence, hospital, school, or workplace as appropriate, by competent, experienced personnel and in collaboration with other services where necessary.
- Referral will be made to other services, such as other EAT services where appropriate.
- The assessment recommendations shall be confirmed in writing to the patient, referrer, GP and other stakeholders as appropriate.
- Opportunity for a temporary trial of suitable sample equipment shall be recommended and made available when indicated, such as when there is doubt over the patient's motivation or ability to use the equipment.
- When equipment provision is recommended at the assessment, this will normally be available for use by the patient within 18 weeks of acceptable of the referral. Exceptions to this target may occur due to dependencies on other agencies or when the recommended solution involves custom, bespoke or integrated equipment.
- All patients provided with equipment shall receive adequate training in its use with necessary information in an appropriate format to them. Additional tuition shall be available as required, in consideration of the possible cognitive impairment of some users.
- Patients using the equipment shall receive on-going technical support in case of its malfunction, an annual service maintenance visit including statutory testing of equipment.
- In response to reported malfunctions of the equipment, the service shall ensure that the user is contacted as soon as possible and remedial action for critical functions taken within 48 hours of notification.
- The frequency of user and equipment review shall be determined on a case by case basis by service personnel. Patients with rapidly deteriorating conditions, like Motor Neurone Disease (MND), will require more frequent reviews.
- Adjustments, modifications or change of the equipment provision shall be provided when indicated following review due to change in patient clinical condition, functional impairment or circumstances. A full re- assessment of their needs shall also be available when appropriate.



 Equipment no longer required by users due to change in their circumstances, shall be reclaimed, decontaminated and refurbished to standards agreed with manufacturers prior to becoming available for re-issue. ⁸⁴

ii. International Code of Practice for Planning, Commissioning & Providing Technology Enabled Care Services

The Code of Practice was developed by Brian Donnelly who kindly spoke with the RFA team. Brian has developed this outcomes-based Code of Practice for both commissioning and providing Technology Enabled Care Services. The code is divided into two parts. Part one covers the planning and commissioning of services, and part two covers all aspects of service provision. All the code standard areas are set out in the table below and we would recommend any efforts to reconfigure ECS services use this detailed and internationally accepted code of practice to ensure the best approach is taken.

Planning and Commissioning				
CODE STANDARD 1	Strategic Planning and Preliminary Considerations			
CODE STANDARD 2	Involvement of Stakeholders, Users and Carers			
CODE STANDARD 3	Partnerships, Joint Working and Integration			
CODE STANDARD 4	Governance, Ethics and Risk Management			
CODE STANDARD 5	Business Case Development			
CODE STANDARD 6	Investment and Funding			
CODE STANDARD 7	Procurement			
CODE STANDARD 8	Service Requirements and Specifications			
CODE STANDARD 9	Contractual Arrangements			
CODE STANDARD 10	Eligibility Criteria and Self-funding			
CODE STANDARD 11	Legal & Regulatory Obligations and Standards			
CODE STANDARD 12	Information Technology and Information Management			
CODE STANDARD 13	Marketing and Promotion			
CODE STANDARD 14	Implementation			
CODE STANDARD 15	Performance Management and Continuous Improvement			
CODE STANDARD 16	Measuring and Evaluating Service Impact			
	Service Provision			
CODE STANDARD 17	Governance, Risk and Ethics			
CODE STANDARD 18	Legal & Regulatory Obligations and Compliance with Standards			
CODE STANDARD 19	Managing Referrals and Assessments			
CODE STANDARD 20	Procuring Technologies, Equipment and Services			
CODE STANDARD 21	Implementation of New Technologies and Services			
CODE STANDARD 22	Trialling, Assembling, Installing and Demonstrating Technologies and Equipment			
CODE STANDARD 23	Involving Service Users and Carers in Decision Making			
CODE STANDARD 24	Management of Medical Devices/Technologies			

Table 15: Code Standards

⁸⁴ NHS England, *NHS Standard Contract for Complex Disability Equipment: Environmental Controls (All Ages)*, 2013, Accessed at: <u>https://www.england.nhs.uk/wp-content/uploads/2013/06/d01-com-dis-equ-env-con.pdf</u>



CODE STANDARD 25	Management of Assets and Inventory
CODE STANDARD 26	Monitoring and Alerts
CODE STANDARD 27	Quality Management Systems
CODE STANDARD 28	Health and Safety Management
CODE STANDARD 29	Staff Competence
CODE STANDARD 30	Information Technology, Management and Governance
CODE STANDARD 31	Collaborative Working
CODE STANDARD 32	Third Party Contractors
CODE STANDARD 33	Marketing and Promotion
CODE STANDARD 34	Contract and Performance Management, and Continuous Improvement
CODE STANDARD 35	Measuring and Demonstrating Service Impact



6. RECOMMENDATIONS

Recommendation 1 – The development of a centralised single procurement framework for the whole of Northern Ireland that offers access to a wide range of suppliers and provides for purchase and on-going maintenance of ECS. This does not necessarily have to mean the development of a separate framework for Northern Ireland – there may be existing frameworks it is possible to be part of / there may be opportunities to work across the UK and Ireland. It is assumed that such an approach would better provide value for money to the public purse, as well as better meet the needs of service users and support the development of relevant expertise. It is likely that such a framework might make most economic sense if it were focused in the area of assistive technology more widely rather than solely re ECS.

Recommendation 2 – There should be the development of a service that is equitable and ensures ease of access to users for support with faults, repairs and maintenance across each of the five trusts.

Recommendation 3 – The development of an independent public point of information and expertise on the use and application of ECS technology within health and social care and specifically within a person's own home.

Recommendation 4 – Training and support to help occupational therapists to improve their knowledge of ECS technologies (that can be procured by HSC Trusts or purchased by the client themselves or the development of Occupational Therapists who specialise in the application and use of ECS.

One further possibility might be to centralise some expertise and resource alongside the communication and wheelchair specialisms at Musgrave Park Hospital and consider future partnership arrangements with the Design and Innovation for Assistive Living (DIAL) Centre at the North West Regional College, in consultation with the University of Ulster. This development of more detailed expertise may also provide more clarity around an appropriate diagnostic approach more specific to relevant recommendations i.e. matching the right technology and specific device with the health need.

Recommendation 5 – There should be much greater clarity and transparency around HSC Trust processes/criteria for the awarding of ECS to ensure consistency across Northern Ireland.

Recommendation 6 – Exploration of how to enable the use of personal devices within healthcare to maximise the opportunities afforded by what are now everyday technologies (smart phones and tablets etc). This includes an exploration of how funding might work for example in relation to own devices.

Recommendation 7 – Further analysis work to understand the numbers of people with physical disabilities who would benefit from the use of ECS technology.

Recommendation 8 – Increased resources for the procurement of ECS. This may be best considered as a cumulative budget rather than a year on year cost to allow for unpredictability across years.



Recommendation 9 – Sharing of information between Occupational Therapy departments and the fire service to ensure people with physical disabilities are given full access to fire safety provision.

Recommendation 10 – The development of an appropriate IT System which would include an integrated IT case management system with access by all stakeholders, which would help reduce delays in the process from assessment to technology being in place and would enable improved day to day maintenance and management of systems.

Recommendation 11 – Refer to the International Code of Practice for Planning, Commissioning and Providing Technology Enabled Care Services, developed by CECOPS (The Community Equipment Code of Practice Scheme), in the development of new approaches to the planning, commissioning and development of new ECS services.

To build on all this work it is our final recommendation, recommendation 12, that an action plan is developed based on the 11 recommendations above, which would allow this research work to progress into an agreed regional strategy with specific objectives.



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Appendix 4: Search Protocol

Inclusion criteria

We included studies that met the following criteria: peer reviewed papers; an assistive technology studies; with people living with complex physical disabilities.

Technology devices included were: overall environmental control systems, lightning and heating control, electronic devices to support actives of daily living, smart home technology, automatic door and window openers, communication aids.

Exclusion criteria

We excluded studies related solely to dementia, telecare and telehealth.

Search terms:

- 1 Self-Help Devices/
- 2 (assistive adj (device? or technolog\$)).tw.
- 3 ((smart or automat\$) adj (home\$ or hous\$ or sensor\$ or servic\$)).tw.
- 4 ((smart or assistive or power\$ or automat\$) adj wheelchair?).tw.

5 wearable sensor\$.tw.

6 exp Telemedicine/

7 (telecare or tele-care or telemedicine or tele-medicine).tw.

8 (tele-assistance or tele-rehabilitation or tele-monitor\$ or telemonitor\$).tw.

9 ((health or medical) adj telematic?).tw.

10 Monitoring, Ambulatory/

11 ((personal or home or ambulatory or automat\$ or self) adj health monitor\$).tw.

12 (social adj (alert\$ or alarm?)).tw.

13 ((intelligen\$ or ambient) adj (object? or environment\$)).tw.

14 (remote-control\$ or remote control\$).tw.

15 environment\$ control system\$.tw.

16 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15

17 exp Nervous System Diseases/

18 (nervous adj system adj disease*).tw.

19 dement*.tw.

20 alzheimer*.tw.

21 (lewy* adj bod*).tw.

22 (parapleg* or quadripleg* or tetrapleg*).tw.

23 SCI.tw.

24 (spin* adj2 (fracture* or wound* or trauma* or injur* or damag* or contusion* or laceration*)).tw.

25 (cognitive adj2 impair*).tw.

26 learning disorders/

27 (learn* adj2 disabl*).tw.

28 (mental* adj2 (retard* or disabl* or deficien* or handicap*)).tw.

29 (intellectual* adj2 (impair* or disabl*)).tw.

30 17 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 2192147

31 16 and 30

32 intervention?.ti. or (intervention? adj6 (clinician? or collaborat\$ or community or complex or DESIGN\$ or doctor? or educational or family doctor? or family physician? or family practitioner? or financial or GP or general practice? or hospital? or impact? or improv\$ or



individuali?e? or individuali?ing or interdisciplin\$ or multicomponent or multi-component or multidisciplin\$ or multi-disciplin\$ or multifacet\$ or multi-facet\$ or multi-modal\$ or multi-modal\$ or personali?e? or personali?ing or pharmacies or pharmacist? or pharmacy or physician? or practitioner? or prescrib\$ or prescription? or primary care or professional\$ or provider? or regulatory or regulatory or tailor\$ or target\$ or team\$ or usual care)).ab.

33 (pre-intervention? or preintervention? or "pre intervention?" or post-intervention? or post-intervention?").ti,ab.

34 (hospital\$ or patient?).hw. and (study or studies or care or health\$ or practitioner? or provider? or physician? or nurse? or nursing or doctor?).ti,hw.

35 demonstration project?.ti,ab.

36 (pre-post or "pre test\$" or pretest\$ or posttest\$ or "post test\$" or (pre adj5 post)).ti,ab.

37 (pre-workshop or post-workshop or (before adj3 workshop) or (after adj3 workshop)).ti,ab.

38 trial.ti. or ((study adj3 aim?) or "our study").ab.

39 (before adj10 (after or during)).ti,ab.

40 ("quasi-experiment\$" or quasiexperiment\$ or "quasi random\$" or quasirandom\$ or "quasi control\$" or quasicontrol\$ or ((quasi\$ or experimental) adj3 (method\$ or study or trial or design\$))).ti,ab,hw.

41 ("time series" adj2 interrupt\$).ti,ab,hw.

42 (time points adj3 (over or multiple or three or four or five or six or seven or eight or nine or ten or eleven or twelve or month\$ or hour? or day? or "more than")).ab.

43 pilot.ti.

44 Pilot Projects/

45 (clinical trial or controlled clinical trial or multicenter study).pt.

46 (multicentre or multicenter or multi-centre or multi-center).ti.

47 random\$.ti,ab. or controlled.ti.

48 (control adj3 (area or cohort? or compare? or condition or design or group? or intervention? or participant? or study)).ab. not (controlled clinical trial or randomized controlled trial).pt.

49 (control year? or experimental year? or (control period? or experimental period?)).ti,ab.

50 evaluation studies as topic/ or prospective studies/ or retrospective studies/

51 (utili?ation or programme or programmes).ti.

52 (during adj5 period).ti,ab.

53 ((strategy or strategies) adj2 (improv\$ or education\$)).ti,ab.

54 (purpose adj3 study).ab.

55 "comment on".cm. or review.pt. or (review not "peer review\$").ti. or randomized controlled trial.pt.

56 (rat or rats or cow or cows or chicken? or horse or horses or mice or mouse or bovine or animal?).ti,hw. or veterinar\$.ti,ab,hw.

57 exp animals/ not humans.sh.

58 (or/32-54) not (or/55-57)

59 31 and 58



Appendix 5: Generic Qualitative Discussion Guide

Name of interviewee: Name of organisation:

1. INTRODUCTIONS & BACKGROUND (5mins)

- Introduction to researcher

- Explain background to project
- Ask for brief background on their role and area of expertise
- Ask for specific experience of / involvement with environmental control

- Ask for permission to record – findings are anonymous, recording for note taking purposes only

2. DEFINITIONS (5-10 mins)

- What do you understand as 'Environmental Control Systems'?

- What does it include and exclude, why do you say that?

3. USAGE (10 mins)

- How widespread do you think the usage of environmental controls is?

- Do you think there is potential for this to change – for them to be used more or less?

If more, in what way?

If less, in what way?

4. BARRIERS (15 mins)

- How easy do you think it is to access environmental controls technology?

- Why do you say that?

- Is it easy / difficult for everyone? Why do you say that?

- What are the issues that people living with disabilities have with accessing ECSs? Prompts if necessary:
- Cost? Is it affordable?
- Time? Can it be a lengthy / quick process?
- Access to expertise & advice?

- Where can you get advice on what to purchase and who to purchase it from?

- What do you think are some of the barriers to accessing this type of technology? Why do you say that?

- Are you aware of how the environmental control systems are procured through HSC Trusts? If so, please tell us about what you know

- Do you know anything about the specific technology that is procured?
- Do suppliers work with users? Do they provide on-going technical support?

5. IMPROVEMENTS (15 mins)

 Are there developments / improvements that you would like to see made in this area for people seeking to access environmental control systems?
What could be better and why?
Prompts if necessary:



- Procurement process? Could this be easier or different?
- Installation Could this be easier or different?
- Maintenance Could this be easier or different?
- Cost How affordable are they?

- Knowledge & expertise – is there enough information and expertise available? What might help

- Different technology How fit for purpose is the technology?
- Any other thoughts?

What should stay the same and why?

6. SUMMARY (5 mins)

- Of all the things that we have discussed, if we could only address one key issues to make things better what would you suggest is addressed and why?

7. ANY OTHER COMMENTS (2-3 mins)

- Are there any other comments that you would like to make?

THANK FOR TIME