



Caught in the Web

**Mapping
older people's
information
pathways to
public services**



**older &
bolder**

Support equality for older people



The right to age well at home

This report is published as part of Older & Bolder's campaign **Make Home Work – the right to age well at home** which highlights the obstacles faced by people – older people, people with chronic illnesses, people with disabilities – who want to live well at home and who need support to do so.



Support equality for older people

Older & Bolder is an alliance of eight non-governmental organisations in the age sector in Ireland. The members of the alliance are: Active Retirement Ireland, Age & Opportunity, Alzheimer Society of Ireland, Carers Association, Irish Hospice Foundation, Irish Senior Citizens Parliament, Older Women's Network and Senior Help Line.

Independent Chairman: Mr Tom O'Higgins

Our shared vision is of an Ireland that affirms ageing and the rights of all older people, enabling everyone to live and die with confidence and dignity as equal, respected and involved members of society.

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A research study
prepared by
Olga McDaid

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Foreword

As we age, our dependence on health, social care and other services may increase. As we age, our social networks, which give us so much valuable information about our world and how to navigate it, may not be as strong as they once were. Both phenomena highlight the need to ensure that older people can access the information they need in order to avail of vital public and other services. Yet at a time when information has never been as readily and easily available through information technology, the information needs of many older people are not being met. Isolation, sensory problems, lack of access to the internet, the failure of some service providers to offer adequate or appropriate information about their services – all create barriers between the older person and what they need and are entitled to in order to get the most from their lives.

This research report, commissioned by Older & Bolder, shines a spotlight on these issues and reports the lived experience of many older people as they attempt to find their way through what is often a confused and confusing public service landscape. Those interviewed report a lack of awareness about services that could improve their quality of living. Others are unclear about entitlements or simply don't know how to go about finding out. Some speak of their fear of getting involved with bureaucracy. Many, thankfully, have people in their lives, whether family, local representatives or other contacts, who do help out but others remain isolated and suffer genuine hardship because of a failure to get what they need.

As Ombudsman, I lay heavy stress on the need for public bodies to communicate with those they serve. It is not enough to provide a service; clear and targeted information must be available to ensure that everybody entitled to a service can access it as easily as possible. Greater thought must be given to ensuring that this is done and particularly during an economic downturn when resources are scarce and people are more dependent than ever on getting what they are entitled to. The recent controversy in relation to the Revenue Commissioners and older people, highlights the harm that can be done when public bodies fail to share information or fail adequately to communicate with a more vulnerable section of the community.

I commend this initiative by Older & Bolder. The recommendations, if implemented, will enhance not just the experience of older people with public services but also the population as a whole.

Emily O'Reilly

Ombudsman

January 2012

Researcher's Acknowledgements

This report is based on a research study conducted independently for Older & Bolder. The author would like to thank the staff of Older & Bolder, in particular Diarmaid O'Sullivan for his support and contribution to the research. The author is very grateful for the cooperation of the many gatekeepers who were contacted to source potential participants for the study, many of whom are continuously working to improve services for older people in their local area. To the participants of the study, thank you for giving your time so generously, for welcoming me into your home, for the many cups of coffee and for checking to make sure I had arrived home safely.



1 Introduction

If older people are to age well, remain living independent lives and participating in their community, not only do they require adequate public services, but also they must be enabled to make informed decisions and access the services that are most appropriate to their requirements. Quality information provision and the ability of older people to act on it, has been shown to be critical for maintaining independence and a good quality of life in later life. Sykes et al. (2008) highlighted an important relationship between access to information¹ and access to services; and between access to services and quality of life for older people. Providing accurate public service information efficiently will ensure that older people are supported to make choices, take decisions, secure entitlements, contribute to their community and engage fully in society.

Older people, agencies working with older people and service providers have identified problems in accessing information as a significant barrier to accessing and availing of public services in Ireland. In a report commissioned by The National Council on Ageing and Older People (NCAOP) to investigate the health, social care and welfare information needs of older people, Ruddle et al. (2002) identified this barrier as a serious impediment to equity for older people. The authors contend that older people '*must possess information relating to what services are available to them so that they can make informed decisions and be directed to the service that is most appropriate to their needs*' (Ruddle 2002).

In recognising the importance of effective information provision to the social inclusion of older people in Irish society and their capacity to age well, this research attempts to provide in-depth analysis on the pathways of older people, undergoing pertinent transition times and the obstacles they face in accessing relevant and adequate information. This study is concerned with the public service information needs and seeking experiences of older people in Ireland. This is particularly relevant as older people are regular users of government services. It focuses on the central theme of transition times for older people, exploring the information-seeking experiences of people who have had a recent experience of a transition stage; such older people have been identified by Ruddle et al. (2002) as those with the most need of public services information in later life. For the purpose of this study seven older people were interviewed in depth, assessing their full range of information needs and seeking behaviour with regards to a recent transition time. The study covered a broad spectrum of transition times, including becoming a carer, developing an illness and becoming functionally disabled. The study breaks neatly into two spheres: firstly; an examination of the particular need for public services for those interviewed and secondly; a follow up on their particular information requirements and information seeking experiences in relation to those needs.

¹ For the purpose of this study, 'Information' is defined as the communication of knowledge, facts and ideas.

2 Study Rationale

The impetus to provide quality information for older people in Ireland is rooted in a reorientation of health and social services towards the consumer and a democratic model of consultation (Ruddle 2002). This is in line with international policy on active ageing. The active ageing approach is based on the recognition of the human rights of older people and the United Nation's principles of independence, participation, dignity, care and self-fulfilment. This approach shifts strategic planning away from a 'needs-based' approach to a 'rights-based' approach, which recognises the rights of people to equality of opportunity and treatment in all aspects of life, as they grow older (WHO 2002).

Access to information is essential in supporting older people to make decisions about their lives, participate in a range of activities, and represent their interests (Dunning 2005). There is a significant evidence base highlighting the critical need for information to enable older people to age well and remain socially active (Barrett 2000; Ruddle 2002; Asla 2006; WHO 2007). The World Health Organisation's global age-friendly cities study notes that '*staying connected with events and people and getting timely, practical information to manage life and meet personal needs is vital for active ageing*'. It can be surmised then, that if older people are to age well and participate fully as active citizens in community life they need to be 'informed'.

Irish governmental policy has supported the right of people to remain living independently in their own homes since the publication of *The Years Ahead* in 1998 (Robins 1998). It is well recognised that appropriate and timely information is essential to enable older people to continue living independently in their community. More than a decade later, despite the proliferation of the 'information age', inadequate information provision remains a key challenge and a threat to independence for older people.

In a study of citizens pathways to information Rahaleen (Ralaheen November 2000) stated that information plays a key role in promoting active citizenship by enhancing people's access to their rights and entitlements and that information provision is the process whereby citizens are enabled to identify their needs in the context of existing statutory services. They noted that the majority of information seekers had to employ a variety of pathways when accessing information. Ralaheen (2000) explains the term '*information pathways*' as the journey to satisfying information needs in relation to benefits or entitlements for an individual citizen. This journey depends on a number of factors such as:

- whether the citizen's information need is simple or complex;
- whether the citizen knows where to go to get the required information;
- whether offices or centers delivering the required benefit or service are available and accessible in the locality;
- whether offices or centers delivering the required benefit or service can provide the information required.

They assert that *'the task of information providers is to bridge the gap between citizens who experience needs and problems and the wide and disparate range of government services'*.

While several initiatives have taken place to address the gaps in information provision to older people in Ireland in recent years including the Citizens Information Guidelines for Information Providers (CIB 2007), older people continue to feel the effects of marginalisation from society due to a lack of appropriate access to information and thereby services.

Few studies have comprehensively examined the area of information needs of older people in Ireland. Many studies in this area focus on one particular information need or the information needs of one particular group of older people. The information needs of older people with disabilities (Barrett 2005) and the oldest old (Asla 2006) has been largely neglected in the literature and there is a dearth of literature on the needs of older people faced with significant transition times in later life.

3 Literature Overview

Information Provision to an Ageing Population

When considering the provision of information to older people, it should be acknowledged that older people themselves place a high value on information compared to other demographic groups (Gilroy 2005). Hayden et al (2001) found that 70 percent of respondents in a survey on Better Government for Older People in the UK responded that information on a range of services was either very or quite important to them. Demographic projections suggest a considerable increase in the proportion of older people in the Irish population in future decades. According to the Central Statistic Office (2009), in the next two decades the proportion of people aged 60 years and over will rise to 25 percent, from 11 percent at present. It is also forecasted that the largest increase will be in the 'oldest old', those who are aged 80 years and over. Although retirement age remains the socially constructed definition of 'old' for most official purposes, the average lifespan in developed countries has increased by 20 years over the last half century (United Nations 2003). Therefore significant numbers of people are living well into their eighties and nineties and any examination of phenomena within old age requires further differentiation between younger old and older old. Social gerontologists separate 'older people' into three groups: the 'young old', aged between 60 and 75; the 'old old' aged between 75 and 85; and the 'very old', those aged over 85 years of age. The ageing of the population and especially the increased proportion of oldest old is likely to lead to a significant increase in demand for public services and information on how to access services.

Information Needs

While the information needs of older people may be diverse and context-dependent, there are some priority topics identified by older people themselves. These include health (Tinker 1993; Williamson 1998; Barrett 2000), income and finance (Tinker 1993; Williamson 1995), recreation and leisure (Williamson 1998), services in the home and community (Tinker 1993) and housing and accommodation (Tinker 1993). For older people, access to information is found to be particularly important at transition times (Ruddle 2002). These transition times include:

- 1 reaching retirement age
- 2 becoming functionally disabled
- 3 developing an illness
- 4 needing long-term care
- 5 bereavement
- 6 becoming a carer
- 7 returning to work/education
- 8 experiencing a security breach or other traumatic event
- 9 returning to Ireland from abroad.

Many older people go through later life with little need for information on public services. It has been found that the transition times listed above may be the first prompt for older people to access information on public services. These transition times will directly influence the 'journeys' or 'pathways' that older people embark on when accessing information, namely the types of information required, the information providers that may be used and the best means of presenting the information (Ruddle et al., 2002). The NCAOP's research (Ruddle et al, 2002), found that in particular, four significant transition times in older age require the availability of timely, accessible and accurate information to facilitate adjustment. These are retirement, the onset of illness and disability, moving from home for increased care and bereavement.

Information Pathways

Older people use a variety of channels to access information on services depending on the situation or need (Goodman 1992; Tinker 1993; Williamson 1998). Williamson (1995) found that an older person's information seeking behaviour is shaped by his or her own circumstances and experiences, such as personal characteristics, values, socio-economic circumstances, lifestyles and physical environments. Older people are not a homogeneous group. Their information-seeking behaviour is diverse and their information needs and the response required to serve their information needs effectively is varied. Asla (2006) found that as people grow older they become more selective in the types of information they seek and which information sources² they seek it from. Therefore the range of information channels narrow as people become older and this is an important consideration when targeting information towards older people.

Information presented by formal organisations was not viewed as interesting to the person unless the topic of the information presented was applicable to the individual older person at that particular time (Barrett 2000). It has also been shown that older people value information that is topic based, rather than the agency based information that is more frequently offered (Quinn 2003) for example offering a full suite of information on 'retirement' rather than information from separate agencies on the services they offer. Some research findings are echoed throughout the literature: older people demonstrate poor awareness of information resources available to them; they have a preference for face-to-face information transfer and printed material that is not situation/need specific is relatively ineffective as an information channel, however most agencies rely heavily on this as a method of providing information to older people. Barrett (2005) argues that increasingly, the responsibility rests with older people and their carers to seek practical and financial help and the information and advice they need to manage more easily at home. Being able to stay in their own homes was a fundamental concern for older people and the ability to perform everyday tasks and keep a well-maintained house were vital to a sense of wellbeing, satisfaction with life and feeling part of society (2005).

When it comes to decisions on the best mode of communicating important information to older people, it seems to be dependent on the type of information being conveyed. For more general information, older people themselves suggest television as a good mode of information provision. However it is generally

² Information sources in this study refers to the means by which the data was conveyed such as a printed publication, a person, a place, or a medium or format: verbal or written.

acknowledged that television is not a good mode for conveying complex or sensitive information (Tinker 1993; Barrett 2000). Research clearly shows that older people's preference is to receive complex or sensitive information in person rather than from written material or other modes of communication such as the Internet or television. Friends and family are normally the first port of call for older people accessing information, followed by newspapers and television (Goodman 1992; Wicks 2004). The importance of family and friends to older people as a source of information on every-day life emerges strongly in the literature (Tinker 1993; Williamson 1995; Williamson 1998).

Although preferred information channels differ depending on the type of information that older people are seeking (Wicks 2004), personal word-of-mouth sources, such as general practitioners (Howe 2008) and family members and friends (Tinker 1993; Williamson 1995; Williamson 1998; Barrett 2005) are consistently cited as the preferred mode of information provision for older people. Libraries and other formal organisations were usually a last resort. A key factor in choosing which information channel to access was the amount of effort required. Goodman (1992) commented that *'it takes greater effort to visit a doctor than a neighbour'*, which may explain why formal channels of information are not pursued as often as informal channels.

Informal information sources are particularly important to older people. Talking to a person provides the opportunity for deciphering salient information, revealing quickly what is important and it allows for repetition and reinforcement. There is a tendency to talk to people who are already trusted due to their position or personal relationship (Curzon 2005). Word-of-mouth information sources are not only considered important for the narrow aims of the task in hand but also for maintaining social contact and ensuring social inclusion.

Williamson (1995) highlights that incidental information acquisition is seen as a key feature of how older people access information necessary to them. Williamson (1998) applied this term to the information people discover unexpectedly as they go about their usual daily routines. While most day-to-day communication exchange doesn't involve active use of the information imparted, older people do tend to rely on their day-to-day interactions to keep up to date with information that may be relevant to them at some point.

However, it is important to note here that as people age they may face limited access to social contacts for a variety of reasons, such as disability or moving into care which often reduces the scope of older people's information pathways and the volume of information available to them, especially through informal contacts in the community. Informal sources of information can also be ill-informed as noted in one survey where 40 percent of respondents indicated that information from close personal sources was not always reliable (Wicks 2004). Regardless of the information source it is considered essential that the information provided to older people is considered trustworthy.

Effective Information Provision

Tester (1992) and Carter (2000) state that public service information provision to older people should be guided by well established conclusions on information provision in the literature. They argue that:

- 1 Information should be targeted to specific groups of the population and various subgroups among the population
- 2 Information should be targeted to a specific geographical area
- 3 The content and form should be appropriate to the group for which the information is produced
- 4 Information must be widely accessible and made available at the right time, at critical points in people's lives
- 5 Information should be of immediate relevance, clear, attractive and brief
- 6 Information should be appropriate to people's abilities, experience, knowledge, language and culture
- 7 Information providers should take account of the particular needs of specific groups including:
 - People with limited mobility and dexterity
 - People with sensory impairment
 - People with limited literacy skills
 - People from ethnic minorities

Ruddle et al. (2002) highlight three main ways older people identified that public service information could be provided more effectively:

- the way information is provided;
- the importance of personal contact in the delivery of information;
- the characteristics of the information holders/providers themselves.

It was recommended by the National Council on Ageing and Older People that information for older people should be user-friendly and accessible to older people. It is especially important that information is provided in a user-friendly manner for older age groups to cater for the various cognitive, sensory and physical changes associated with ageing (Ruddle 2002).

Barriers to Information

It is recognised that older people encounter many barriers to accessing information. The primary barriers identified in the literature were lack of awareness of available resources and confusion as to the appropriate person to contact for their information needs (Tinker 1993; Barrett 2000; Quinn 2003). It was noted that the passive approach that some information providers adopt of 'come and get it' discriminates against those individuals who are not capable, or do not know where to 'come and get it' (Bowen 1986).

Information and access to services is inextricably linked for older people. It was found that having information on a service was not adequate for the individual unless they were able to access the service required.

As information is increasingly provided through communication technologies, a new array of access issues for older people emerge (Everingham 2009). This includes accessing increasingly complicated telephone systems and negotiating the world-wide-web. While the numbers of 'silver surfers' are increasing as the demographic profile of older people changes, the fact remains that only a small proportion of older

people use the Internet. It is noted in the literature that the majority of older people retired before computers became common in the workplace and many have had little access or motivation to learn how to use them (Mates 2000). As information and communication technologies (ICT) are used increasingly as a mode of information provision for public services, older people are at risk of being left behind and suffering further social exclusion. According to Rabbitt (1999) studies suggest that people have a strong propensity to stick with familiar strategies for information searching developed over a lifetime. Neurological and psychological research suggests that even when other skills are affected by ageing, such crystallized skills are likely to be performed to a higher level of expertise. Furthermore people take pride in their existing strategies (Rabbitt 1999). Sticking to a familiar strategy then is entirely rational for older people when accessing information.

Accessible Information for Older People

It is generally agreed that information should be accessible to older people, however addressing the wider variety of information needs and providing access through the information channels of preference is a complex process that requires sustained effort on behalf of public service providers. The WHO (2007), found that people want information to be coordinated through one easy-to-access service that is widely known throughout the community. Barrett (2005) contends that information must then be provided locally, particularly at locations frequented by older people or from people who are in close contact with older people such as their carers, family, friends and neighbours. To ensure information is accessible, it also needs to be communicated through the most preferred mode for older people: direct personal contact, whether face-to-face or speaking with an information provider directly on the telephone.

Everingham (2009) contends *'that it is not sufficient to provide information if users do not have the capability, resources or skills to use it'*. An important aspect of the older population is the proportion having some type of disability. Unlike younger adults there are physiological factors due to the normal ageing process that affect older adults information seeking abilities. The normal ageing process, including vision, cognition and physical impairments has an impact on the pathways of information seeking in older people. The complex age-related impairments that may become part of every-day-life for older people such as hearing and sight difficulties and dexterity need to be considered when designing effective information provision for older people. Previous studies highlight that older people have similar information needs to younger people, *'but information may be needed to cope with new situations for which past experience cannot prepare them'* (Tinker 1993). While older people have some distinct needs in relation to information provision (Emery 2002), it is well recognised within the Comhairle report *'Access to Information for All'* (Comhairle 2005) that providing high quality information in a variety of modes will benefit the population at large, including older people. Issues specific to older people should be addressed under a holistic approach to information provision for all. Akoumianakis (2002) argues that accessibility is a global requirement, which does not relate only to disabled or elderly people, but to the population at large. Therefore the provision of information that is accessible to the population in general will also encompass the needs of older people in the population.



4 Research Methodology

Research Strategy

The research strategy is the general approach to the research topic, a particular stance rather than a method (Robson 1996). According to Robson there are three main approaches to research: exploratory; descriptive and explanatory. The purpose of an exploratory design is to find out what is happening, to seek new insight and to ask questions (theory building). Descriptive designs set out to profile a person, event or a situation and require appropriate knowledge of the situation before the research begins (theory testing). Finally an explanatory design seeks to explore the casual relationships between variables or find the explanation of a problem (Robson 1997). The aim of this study is to consult with a purposeful sample of older people on their lived experiences of information pathways to public services. Essentially this study seeks to answer: what are the lived experiences of older people when seeking information on public services and what pathways do they employ when accessing information on public services? In this sense the research strategy is both descriptive and exploratory as it seeks to ascertain personal views on previous experiences and provide new insight into the information pathways of older people.

Specifically this study seeks to address the following research aims and objectives:

Aims:

- to provide factual and accurate data about individual older people's lived experience of trying to access information about key public services;
- to identify how older people negotiate these information pathways; highlighting best practice as well as obstacles and barriers;
- to consider, from the perspective of the older people concerned, the effect poor/unclear information has on their ability to access services and maintain independence and;
- to draw out the wider implications of these issues with a view to informing public thinking, best practice and the development and implementation of policy in the Irish setting.

Objectives:

The overall objectives of this study are to explore older people's individual experiences of trying to access relevant information to allow them to make informed decisions.

- Outline the respondents' individual circumstances; i.e. family, health status etc
- Describe the respondents' need for particular services. Bear in mind that when people need to access services they are often at their most vulnerable

- Map the respondents' experiences of trying to access relevant and sufficient information to make an informed decision; document the respondents' first point of call, where they were referred to, respondent's feeling of control throughout process etc.
- Assess the information respondents were provided with by service providers or support organisations. How accessible was this information; how clear, relevant, timely, accurate was it
- Elicit the key issues as perceived by the research participant
- Identify patterns in the issues emerging
- Draw out practical lessons for practice from individual experiences and outcomes

This study aims to provide an evidence base for information provision to older people facing transition times in Ireland. A literature review was carried out to ascertain the needs, preferences and experiences of older people when accessing information on services in later life. Primary research in the form of in-depth interviews was then conducted with seven older people who have recently experienced a transition time where they required access to public service information. Two of the seven research participants were accompanied by spouses during the interviews. Process mapping was then applied to the findings to generate the identified information pathways. For the purpose of this study, public service was defined as services that are provided by the Government to the public, including but not restricted to health, social care and welfare services.

Ethical Considerations

The researcher acknowledged that participants may be vulnerable and ensured that the aim of this study is ultimately to do good for the participants. To this end the ethical principles of research including anonymity, confidentiality, non-maleficence and beneficence were upheld. Participants retained the right to withdraw from the study at any time. The interview guide focused on the research aim and sought to avoid discussion of sensitive topics outside of the research purpose.

The purpose of the study was explained in full, in writing and verbally, to all participants in advance of interviews. Interviewees were required to sign a consent form in advance of the interviews taking place. All interview data was transcribed verbatim. All data was anonymised and each research participant was given a pseudonym in the report.

Research Design

In-depth interviews were the main method of data collection in this study. In-depth interviews are optimal for collecting data on individuals' personal histories, perspectives, and experiences, particularly when sensitive topics are being explored. The in-depth interview is sufficiently flexible to permit topics to be covered in the order most suited to the interviewee and also to allow responses to be fully probed and explored and to allow the researcher to be responsive to relevant issues raised spontaneously by the interviewee. The researcher can use a range of probes and other techniques to achieve a depth of answer in terms of penetration, exploration and

explanation (Ritchie 1994). The interviews lasted between forty to sixty minutes to ensure a rich breadth of data was collected from each study participant. The length of interview ensured participants were comfortable and focused on the interview. A short questionnaire was designed to capture the demographic profile of each participant (Appendix 1). The researcher also took field notes as an aid to describing the context of the interviews in the findings.

Two research tools were designed to address the aims and objectives of the study.

1. An in-depth interview schedule

An interview schedule was drawn up based on the aims and objectives of the study and informed by the current evidence base on information pathways for older people.

In order to establish participants' information pathways when accessing information on public services during transition times, participants were asked a series of questions throughout the interview such as:

- To describe their current transition stage
- Where they normally sourced information on public services
- Where they went for help and advice on accessing public services during their transition time
- To describe their experiences of accessing information from the services they contacted
- If they felt they had all the information relevant to them that they required
- How they preferred to get information they needed on public services
- Their experience of accessing information from public service providers in general
- Suggestions on how public service providers could deliver information more effectively to older people.

2. A demographics questionnaire

A short questionnaire was designed to capture the demographic profile of each interviewee. This was administered by the researcher and completed prior to the interview commencing.

An information pack was sent to the home addresses of participants and included:

- a participant information letter (Appendix 2) explaining the study, and formally inviting them to take part in an interview and
- a consent form (Appendix 3) to complete in advance of the interview.

All participants were contacted directly by the researcher in advance of the interview to set up the interview time and venue. The venue was decided between the interviewer and the participant at the choosing of the participant. The majority of interviews were carried out in the participant's home; one was conducted in a local hotel.

Sampling Framework

A purposeful sampling framework was used to select participants according to pre-selected criteria. The pre-selected criteria were established around the nine transition times that are specific to older life. Other criteria were also applied to participant selection including: geographic distribution of study participants; age; gender; marital status; functional ability and levels of family and social support. It was envisaged that between seven to ten participants would be interviewed to ensure data saturation. In total seven participants were interviewed.

Participant Recruitment

Participants were recruited through identified gatekeepers who were working with older people in the community.

Inclusion/exclusion criteria

The criteria for the study were as follows:

- The person must be willing and able to participate in the interview;
- The person must be willing to have the interview recorded;
- The person must be 60 years of age or over;
- The person must have had recent experience of a significant transition time as identified in previous research (Ruddle 2002).

While selection criteria specified that all participants should be over 60 years, it was necessary to extend the age profile for participants to capture the experience of a carer who was seeking information for her elderly mother who had suffered a stroke and is now heavily dependent and unable to communicate her own information needs or source information on her own care needs.

Data Analysis

The interviews were audio recorded and later transcribed verbatim for the purpose of analysis. Findings are presented in two parts. The first part describes the individual experiences and pathways of participants when accessing public services. These are presented as case studies. Data were then analysed using a Framework approach whereby a coding frame was inductively constructed and systematically applied to the data (Strauss 1990) to highlight the key issues for participants and describe patterns in the findings. Framework analysis is flexible during the analysis process in that it allows the user to either collect all the data and then analyse it or do data analysis during the collection process. In the analysis stage the gathered data is sifted, charted and sorted in accordance with key issues and themes. This involves a five-step process:

- familiarisation;
- identifying a thematic framework;
- indexing;
- charting and
- mapping and interpretation (Ritchie 1994).

Framework analysis is deemed appropriate for the following reasons:

- Primarily based on the observation and accounts of the participants;
- It is a dynamic process that allows the change or addition or amendment throughout;
- It is systematic in that it allows a methodical treatment of the data;
- It is comprehensive in nature.

The framework approach employed in the analysis of the interview data was developed in the context of conducting applied qualitative research. This method has been refined and developed over the years and the general principles of the approach have proven to be versatile across a wide range of studies (Huberman 2002). Applied research can be broadly distinguished from 'basic' or 'theoretical' research through its requirements to meet specific information needs and its potential for actionable outcomes (Huberman 2002). Qualitative research can offer the policy maker a theory of social action grounded on the experiences – the world view – of those likely to be affected by a policy decision (Walker 1995). Qualitative data analysis is essentially about detection, and the tasks of defining, categorizing, theorizing, explaining, exploring and mapping are fundamental to the analyst's role (Huberman 2002). A bottom-up approach was used to generate key themes in the analysis of the interview data, which was then organised into a thematic framework analysis (Appendix 4).

Assessing inter-rater reliability, whereby data are independently coded and the coding compared for agreement, is a recognized process in quantitative research. Some researchers have found that the use of more than one analyst can improve the consistency or reliability of analyses in qualitative studies (Bryman 1993). After the researcher had coded the first transcript, a second researcher performed a coding exercise of a sample of the data to ensure rigour of the data analysis.

5 Findings and Case Studies

Demographic Profile of Participants

Seven participants were identified and took part in the study. In two cases, participant's spouses also contributed to the interview, and while their contribution is included within the findings, demographic information was collected only on the main participants. The heterogeneity of older people was captured in the considerable variety between participants in regards to their demographic backgrounds and range of experiences. Older males who met the selection criteria were difficult to access for the purpose of the study therefore the majority of participants interviewed were females (n=5) and two participants were male. In general, participants had worked in skilled or technical professions and all were retired. Some had retired early either for disability reasons or to care for ageing relatives. One participant was forced to retire in 1972 as a result of the marriage ban. Some of the females continued to work in a voluntary capacity and some of the participants spoke of caring for grandchildren. One participant in particular was an active member of several organisations and contributed significantly to voluntary organisations in her locality. All participants were literate and some took great pride in their writing skills. Only one out of the seven participants had any third level education. Surprisingly three female participants had trained and worked as nurses. Only one participant had engaged in any training or education as a mature student. Two participants could use a computer, however only one felt proficient enough to search for information on public services. There was a diverse mix of household composition between participants. Two participants were widowed and one was separated. Two of these participants were living alone and one participant was living with her brother. One participant had a son still living at home with her and her husband. One of the participants had lived abroad for a significant proportion of their working life and had returned to Ireland in later life. All participants owned their own home. Two participants were living in very rural areas, while others were living either in or close to a village or an urban area. All of the female participants took responsibility for seeking information on public services in their household; one male relied on his wife to access information on his behalf. The participants ranged in age from 53 years to 80 years of age.

Participants' Information Pathways: The Case Studies

1 Helen

Helen is a 72-year-old woman who suffers badly from arthritis. She moved house some time back to a new neighborhood. She is separated and lives on her own in a semi-detached house in a housing estate just on the outskirts of the village. She has developed arthritis gradually in recent years and while she finds it painful and debilitating she tries to minimize its impact on her life. As she developed her illness she became a frequent user of the health services. She learned a lot about arthritis through her local GP and found her experiences of accessing the health services as generally positive. Although she moved house several years ago she still attends the same GP and is happy to travel the extra distance to be seen by him rather than switching to a new GP who would not be familiar with her history.

My doctor is 12 miles away, so I stuck with him, when I moved to here I stuck with him because he knows me for so long and I think its very important if a doctor knows you, why should I have changed over to a doctor who knew nothing about me.

There are also support groups that meet regularly in nearby towns, but they meet late in the evenings and she finds it hard to travel to them. Although she only moved twelve miles away, looking back she doesn't think it was a good idea to move so late in life.

Its not a good idea, its not a good idea when you move, I would have been 58 then, it is very difficult because all my friends were left behind and you move to an area like this, even though the people are very nice, they've all got their own friends so you feel like an outsider.

While Helen stays informed by listening to the local radio and reading the local papers and the national papers on a Sunday, she still finds it difficult to get information on events or services in her new local area. She relies on a nun that she met in her new village for information on local social services and she contacts her if she requires help or information on local services. Although Helen feels that she manages her illness quite well she is losing mobility and can no longer move around her house with ease. She has spent many nights sleeping in her sitting room as she has great difficulty getting upstairs to her bedroom. She has applied for a garage conversion under the Housing Adaptation Grants scheme. Although she believes she should be, she is unsure if she is entitled to it and is waiting to hear back from the Council. Helen

described her arthritis as very bad and painful and said that it sometimes gets her down. She would really love to have her garage converted so that she would not have to climb the stairs to get to bed at night.

Well at the minute I do suffer from arthritis very bad at times, you know and it can get you down and everything and at the moment I'm hoping to get that garage converted into a bedroom....I'm sleeping upstairs and some nights I've had to sleep here on the couch when my hip was really bad and I couldn't get up the stairs..... [The garage] has been inspected by the local Council and he doesn't really know whether I'll be given the grant or not. You know and I would love that done.

Helen had read about the Housing Adaptation Scheme before and thought she would be entitled to it because of her situation so she contacted the Council and asked to be put through to the relevant section. She had no problem accessing the right section and she was told directly what information she would need to provide to apply for the adaptation grant. She provided all the information that was requested.

Well I just wrote [to them] and they wrote back to me telling me I'd have to have a doctor's letter and I'd have to have receipts about my income and bank statements, all the usual stuff so I sent all that in to them....So they have everything, anything they wanted from me I gave it to them, I've nothing to hide.

She was also requested to provide a quote from two different builders on the estimated cost of the conversion. However she found this quite difficult. She only knew one builder in the locality and he had gone out of business with the recession so she had to ask around to see if someone could help her source a builder. Eventually, the nun she often goes to for help put her in contact with builders in the area who were used to providing quotes for the Council.

Helen had expected that the assessor would phone her to let her know when he would be visiting, but she was surprised when he just landed at the door.

He rang me three days ago, I was over at the doctors and he left a number for me to ring him back, I rang him back and he said he'd ring me again before he came but he didn't, he just came to the door...so whether he was trying to catch me out...or something, I don't know.

She was annoyed to hear that he had called to the house on one previous occasion also but she had not been home and she would have liked some time to clean the garage properly for him coming to assess it.

I would have thought he should have [phoned] really, now I may not have been here like, I mean he called the other day, I didn't know he was calling, he told me on the phone he had already been here and I was a bit annoyed over it really, I thought well the least he could have done was ring me because I'd be the sort, I would have liked the garage to have been a bit tidy and I'd

have got my daughter over to help me to move a few things out and have it clean looking but he didn't give me the chance.

When the assessor had finished looking around, he queried the price difference between the two quotes which upset Helen. She felt that she had done what was asked of her and didn't understand why he was querying her.

And then he said to me there's two estimates here, one for €8,000 and the other €5,200 but sure that's not my fault, they asked me for estimates, I got them for him.

At the end of the visit Helen asked the assessor if she would be entitled to the adaptation grant, while he didn't sound hopeful, he did not give her any indication and told her that she would be informed of the decision at a later date.

I'm just hoping the garage can be done but he didn't hold out much hope, I don't know why.

Helen had previously applied for the Housing Insulation Grant and although it had taken her several attempts to access information on the scheme she was surprised at how efficient the service was in the end. She had read about it herself in a national paper and called the number provided but did not hear anything for six months. Then she called again and she was sent a form immediately and the work was carried out soon after that.

So when I saw the number I said I'll ring it, not thinking I'd a hope in hell, so I rang them, they took all my details, I heard nothing for 6 months, I kept the number and I rang it again and they said they were only doing from Tullamore up along towards Sligo but they gave me another number to ring which I think was a Dublin number and I rang them, they took my details and I told them that I'd already applied 6 months before that and I got an application form within a week and I couldn't believe it that it came so quick...So that was a brilliant job when I got it done and I got it done ever so quick in the end.

Helen was then surprised at the delay with her application for the Housing Adaptation Scheme as she felt she was entitled to it. At the time of interview Helen had been waiting some months on the outcome and was still sleeping downstairs on the sofa when she couldn't manage the stairs.

Participants' Information Pathways: The Case Studies

2 Anita

Anita is a 53-year-old single woman living in a large urban area. Anita used to be self-employed but over a year ago now she had to give up her own business to become a full time carer for her mother who had suffered from two bad strokes. She now cares for her mother full time and finds it difficult to access health services on behalf of her mother. She has also had difficulty accessing a Carers Allowance and a medical card for herself.

Why was it necessary to start caring for your mother?

It was necessary because mam had two very bad strokes, so she's paralysed on the right side. So she needs hands on, she can't do anything for herself, it has to be done for her now at this stage. So it was a matter of having to give up the work and to be here because she can't be left on her own. So she needs someone here 24 hours a day.

Anita found the transition from working full time in her own business to becoming a full-time carer very challenging.

And how did you find that process of becoming a carer for your mother?

Well I was thrown into it suddenly, like one minute I'm working and then it's like next of all your whole life changes and we're not prepared for that. I found that was a big, big upheaval, it was like one minute you're out there mixing with people and the next minute then you're in this small little world with just your mother, yourself and it's like that's for 24 hours.

Her mother is unable to speak as she was paralysed from the stroke and Anita is now responsible for accessing information on her mother's care. Anita was very happy with the level of care that her mother received in the hospital and with the carers who were organised to relieve her at home, but she became increasingly anxious that her mother was not receiving the physiotherapy care that she was entitled to in the community. Initially, Anita was advised by the hospital staff that a physiotherapist would be visiting her mother at home. However, after waiting some time and following up by calling the hospital on several occasions she was still unable to access physiotherapy care for her mother. Anita had to fill the gap by massaging her mother every day.

We were sitting here from May last year till nearly October of last year without someone coming...And I had to go up every morning and massage my mother to make sure to keep the limbs going and the whole lot and its not easy.

Anita described the process of accessing information on health care services in the community as a 'chase' and found that she was continually being referred on to a different service or ignored completely.

I just found when you left the hospital it was like you were out of the system and they didn't want to know, they kept referring you back to [X service], you know and I found that hard because every time, oh yes there is a referral gone up but you were sitting here waiting and waiting and waiting.

Eventually Anita attended an information event in her local community centre run by the HSE and she spoke to someone who followed up her query. This person called her back the next morning and said that there had not been any referral letter sent from the hospital and she would organise it from there. Anita felt very let down that her mother was not receiving the physiotherapy care that she was entitled to and needed.

How did it make you feel?

Angry and annoyed because it was like this is supposed to be a back up service when I came home, to give me help, physio with my mother and it was like I was left high and dry doing it on my own. And it was like my mother does need physio because she's putting the weight on because she can't move.....I felt that door was shut on us.

Anita also had similar problems when trying to organise the follow-up appointment with the consultant in the hospital. She did not realise that she should make the appointment until the Public Health Nurse advised her and when she tried to make the appointment she found herself chasing the services again. Anita relies heavily on the Public Health Nurse to advise her on her entitlements.

They told us that they would be sending out an appointment, now I had to ring them up in January, this month, it was only through the district nurse coming over and she was saying Anita have you got the appointment yet and I said no I haven't. So she said get the appointment because if she goes a year in May she's out of the system and then they'll have to start all over again...So I had to chase the doctor's secretary and ask them for an appointment and they said there was no referral put back in. So he should have automatically sent us out an appointment but there wasn't any, so I had to go again, keep ringing them for an appointment, leaving messages for them to get back to me. So I just found it a pain, now I really did because it's like everything, I'm busy enough without having to chase hospitals up.

Anita's biggest concern now is making sure that there is no problem with the hoist she uses for her mother. The hoist was approved by the HSE, but it was delivered to Anita's home by a private company. There appears then to be a gap in terms of who takes responsibility for repairing the hoist in the event of it breaking down.

Its like the hoist we have inside, that was delivered but like when the man delivered it to us, that was grand, set it up but the district nurse says... that's the biggest problem people have because the people that deliver it won't take responsibility for it, the hospital won't take responsibility for it so who do you ring, who do you contact and that's my worst fear, if that broke down.

Anita finds the hardest part is trying to find out what she and her mother are entitled to.

The biggest issue is, its like first thing you don't know where to go, ok that's the biggest issue and it's like you're trying to just ask people am I entitled to this, I don't know what I'm entitled to, I didn't even know I was entitled to the medical card till the district nurse says to me Anita you're entitled to it, you're on Carer's Allowance.... I mean the first year of caring I lived off my savings, the whole savings went because I didn't know I was entitled to the Carers, it was only the district nurse came across and she says Anita you're entitled to the Carers.

Although she has visited information agencies in her locality she still feels that she is not getting the right information or that even if she gets the right information she has to make a second trip back to the Health Centre to then apply for the services. Anita finds this difficult as she cannot leave her mother on her own.

They [information agency] help you as much as they can but I still find they're not giving you the full entitlements, it's like you're asking a question and they're going well I think you're entitled to that but you'll have to probably go over to the centre and ask them so it means having to spend a day over there and I can't because I can't leave my mother.

While Anita acknowledges that many staff in the Health Centre are nice and do their best to help she has also had some negative experiences and sometimes feels blocked or that staff are fobbing her off by giving her forms to fill in.

...you get some of them that just don't want to know, you know and you feel it coming at you, you feel like, they just have no interest in their job or like my brother was saying, maybe they're fed up with everybody coming to them....I just find sometimes that you're not fully given the information, its all the time having to keep going and asking and if you don't ask the right questions, they're great at handing out forms, ah yeah fill that form in and fill that but if you come over and you go well that's not what I was really looking for, then you have to go back over and explain yourself again.

And would that prevent you looking for information?

No it wouldn't, only if I had the time now, I mean I would take the bull by the horns, put it that way, I won't let anything slide until I get the information I need at the certain time, I would be on the phone or ringing and sometimes you come up against blocks.

Why do you think those blocks are there?

I think the blocks are there because the way the system is gone now I think there's no care anymore, especially for older people and stuff like that, I think when you get to a certain age and that's just my opinion, they just don't want to know.

Anita also tries to attend Carers Group events to find out more information on entitlements, but again finds this difficult because they are held in the morning and she can only get someone else to care for her mother in the evenings. At the time of interview Anita was still waiting to hear if she would receive a medical card. She admits that she is becoming increasingly frustrated with trying to access services and refers to it as a constant battle.

[It's a] constant battle, constant battle because you're getting bits of information off one person and another bit off another person and its just not good enough, like I said they should have it all down, laid out, simple, what your entitlements are and there should be no delay in getting those to you, you know if you pick up the phone and say I need this, it should be dealt with and it should be dealt quickly, not 6 months down the line.

Participants' Information Pathways: The Case Studies

3 Mary and Frank

Mary is a 60-year-old woman, living with her husband **Frank** on a small farm in rural Ireland. Mary worked as a psychiatric nurse until she was forced to retire in 1972 due to the marriage bar. Since then Mary has worked at home, looking after the homestead and their small farm. Mary relied on her husband's income to run the family home and provide for their children. Mary was always used to budgeting but had come to rely on the income generated from the sheep subsidy as an extra source of money for the house. Although the amount of income generated from the sheep subsidy was quite modest, Mary became very concerned when the payment was withdrawn without notice.

The payments stopped and it was ritual in this house because that's the only income I had and its only €900 a year but it was mine and every Christmas I'd have the forms stuck up there and it would be in the day before the thing was up, its always in January, then they didn't send me the forms any more to fill and I didn't know what....was gone on. [...] But I was never told, nor never got a letter from the Department to say I wasn't getting it.

Mary didn't understand why the subsidy had been withdrawn as her circumstances hadn't changed and as far as she knew she was still entitled to it. She tried to resolve the issue by contacting the relevant offices but couldn't get a satisfactory reply. Eventually Mary sought the help of her local political representative who followed up the query on her behalf and discovered that her application had been turned down because she had provided the wrong maps. However Mary had been told that the maps she was providing were the right ones.

Then I just kept enquiring and enquiring and I kept getting all these negative things and then I finally discovered, [political representative] discovered what happened was that the right maps hadn't gone in. But when I'd brought them into [the Council office] they told me they were sufficient, they'd do and that's what I was told.

Although Mary discovered the reason her application had been rejected, she was upset that she had never been informed and it had taken so much effort contacting the services to get to the bottom of it. It then took a further three years for the subsidy to be reinstated.

Around the time the subsidy had been withdrawn, Mary's husband was nearing retirement age. They were more concerned with the loss of the income than as they discovered that Frank's pension was not going to be as substantial as they had expected, even though he had worked in a public service occupation all his life. However, soon after this, Frank got ill and had to retire early due to his illness. Frank was then entitled to sickness benefit and Mary was surprised and happy with the efficiency of the Social Welfare service. Although Mary feels this may be because she sent the forms in to her local Social Welfare office instead of to the central applications system as instructed.

They said now you're supposed to send your form to some place but [Mary] of course played ignorant and she just put the form in to [local office] and it went from there, I didn't send it to where I was supposed to send it to.

And do you think that worked in your favour?

I think it did because it didn't go up there and back here, it just started here. Sure there's too many people looking at it and there's nobody doing anything, they don't care whether it ever got back or not, it's as simple as that.

Mary and Frank worry about their finances as they grow older and worry about what they are entitled to. They have found their experiences of enquiring about entitlements very negative.

[It's] bad on the whole, you feel like a little bit of dirt and they don't care whether they tell you or whether they don't and you're there, I wonder am I looking for something I'm not entitled to, do you know you're feeling so bad. Like we had never got nothing for nothing during our life and all of a sudden we're at this age now, two yokes looking at one another (laugh), you don't know what you're entitled to.

They have also found that advice on their entitlements is conflicting and are not sure where to go to ask for entitlements. Mary described one incident in her local health centre when she enquired about Frank's entitlements to glasses:

Frank has diabetes and he was told in the hospital last February 12 months when he was diagnosed that he was entitled to everything free, his glasses and everything, I went in to [health centre] the other day and I asked about it, I had to go in for a birth certificate and I asked and this lady shouted, there was two of them in the office, there was the receptionist and..she shouted oh you're not entitled to anything here, you have to go to your doctor. She hadn't the decency to come over to the [desk] and talk to me and explain anything to me, no and they told him in the hospital. We phoned the hospital and there was a phone number and they said leave your name and number and they'll get back to you, and I just left Frank's name and number and said he was enquiring about his glasses, they never phoned us.

They are afraid to ask about entitlements in case some other benefits are withdrawn.

I'll give you one incidence now. Frank is retired, he was always paying PRSI, we have no medical card, are we covered with the insurance now? I don't know. I'm afraid to enquire because if I'm not because I'm waiting to go to the hospital next week and if I'm not, we have to pay.

Their worries are compounded by the fact that they both have serious long-term health conditions. They are both looking forward to the day they are entitled to a medical card. Although Mary acknowledges she will have a longer wait.

If I could live to see the medical card I would call the queen my aunt, I sort of live for that day, I say maybe Frank will get a medical card because I'm so many years younger than him (laughs).

Participants' Information Pathways: The Case Studies

4 Paddy

Paddy is an 80-year-old man living in a two-roomed cottage in a quiet, rural area in Ireland. Paddy's wife died some years back and he has been living on his own since. His cottage has a nice large garden out the back and he has several neighbours who call in to see him regularly. As his family live quite far away, he relies on neighbours to help find out his entitlements and access services for him. Although Paddy had very few health problems over the course of his life, he has seen a rapid decline in his health and functioning in recent years. Paddy is proud that he was always very active, walking four miles before breakfast every day with his dogs. However about two years ago, he started to notice a pain in his hips if he stopped for a rest when he was out walking. As the summer went on it got progressively more painful and prevented him from taking his morning walk.

The blossoms were getting scarcer and at the same time the hip...was beginning to get painful, with the result that if I stayed for a little longer, it would be inclined to seize up a little. The longer I stood in a particular place the more painful it became and when I walked a certain distance it would come back alright. I'd do my four miles and be back here for the eight o'clock morning news. You know I always went at a very brisk pace. All the flowers like pussy claws and all the wild flowers were here up until a while back. I would have collected them on my walks but I don't have any of them here now.

The doctor diagnosed him with arthritis and put him on medication and he was delighted to get back walking. But gradually the pain began to affect his other leg and he had to give up his morning walks. He went back to the doctor and following x-rays he was told that the doctor was putting him on the waiting list for two hip replacements. Paddy continued to take his medication but found that his arthritis was becoming increasingly painful. He needed to use two walking sticks to get around and he was finding it difficult to negotiate getting around his cottage and the garden. Eventually one of his neighbours suggested that he should get a wheelchair. He had not really considered this before and nobody in the health service had mentioned it to him so he didn't know he was entitled to it or how to go about it.

I hadn't ever really thought of a wheelchair, I fiddled around on the walking sticks for a good while; you see I'd never been sick so I didn't ever think of a wheelchair.

He mentioned it to the Public Health Nurse when she called but he never heard anything further. After some time had passed and he was becoming increasingly isolated in his cottage, his neighbour contacted a disability organisation and they provided him with a wheelchair. He was surprised when a wheelchair arrived from the health services at the same time. After waiting for months, he now had two wheelchairs.

Mr. X is the neighbour there. He'd have a great pull. He'd know this one and that one. He got me the chair. The IWS, someone that he knows got me the wheelchair. [...] This is the extraordinary thing about it. When it rains it pours. Just as this chair was delivered, the Public Health Nurse arrived with the next chair, almost within an hour.

Paddy now uses his wheelchair to get around but he still finds it difficult as his house is not adapted for wheelchair use. Although he has asked the Public Health Nurse, he does not have any home help or personal care assistance and he was unable to access meals-on-wheels when he applied for it before and he doesn't know who else to ask about it.

I would consider the meals-on-wheels, but when I looked for them, scarcity comes into it. I'm afraid that due to the influx of so many there isn't room for you, so I asked my neighbour then and she offered to make me my dinners. I don't really know who I would contact about getting meals-on-wheels. The only one I could contact about stuff like that is my neighbour up there.

Paddy finds it very difficult and painful to get dressed every morning. During the interview, Paddy demonstrated how he uses the fire tongs to pull up his trousers every morning. He also excused the pile of dishes on the table because he was hoping that if the Public Health Nurse came in she would realise he needed extra support.

So that's why I have all the dishes there now, so that if they come along they will see I can't look after it.

Paddy is disappointed that he had seen so little of the Public Health Nurse since he became ill.

The community nurse has been up here I think twice now since it all began. She has seen how bad my legs are as well. But there has been no extra medication or anything like that. Nothing seems to be able to be done except with the wheelchair and that.

As his house is not suitable for adaption, the health services have provided an accessible prefab house in his garden. However, months after it was supplied, he is still waiting for it to be appropriately set up with plumbing and heating so that he can move into it. Although Paddy keeps up to date with the news, reading the local newspapers and listening to the radio he still doesn't know where to turn to for help. He does feel that using a computer would be beneficial to access information on services he might be entitled to, but he is in too much pain at the moment to take it up.

I hear of the emails going and it would be good. I'd like to use a computer and to learn, but first and foremost I would want to be out of pain and have that sorted.

Paddy was still waiting for his hip replacements at the time of interview and was looking forward to being mobile again.

Participants' Information Pathways: The Case Studies

5 Kathleen

Kathleen is a 66-year-old woman who retired early from nursing to care for her parents as they got older. After Kathleen's father passed away, her mother moved in to Kathleen's home and she cared for her full time. Kathleen's mother has also passed away. She has three children and lives with her husband and one of her sons in an urban area in the South of Ireland. Kathleen is very active within the community in a voluntary capacity, helping out others who need assistance in accessing public services.

Although Kathleen had worked in the health services for the duration of her nursing career, she did not know where to get the information she needed as a carer and she found it difficult to negotiate the services.

I did need help when I was caring for my mother. The information, I didn't know where to go because you were shifted from one place to the other, you know what I mean, when you'd ring one place you were shifted around so you were getting very frustrated and annoyed because I didn't know where to access everything.

Although Kathleen was caring full-time for her mother, she was not entitled to a Carers Allowance. As Kathleen was caring for her in her own home the entitlement was then assessed on her husband's income at the time. She was also turned down for a grant to build a bathroom downstairs for her mother. Up to this point Kathleen had never looked for any services from the State and felt that it was unfair when she needed services to care for her mother she was turned down. She felt increasingly isolated as a carer and Kathleen found it very difficult to access aids and other services on her mother's behalf.

And health services was an issue, trying to get actually, you know for your mother, trying to get things actually that I wanted that would be of help, to help her, aids, medical aids was another issue, you didn't know where to access them and there was such a who haw about it.

She did not feel that her needs were being listened to by the health service and felt isolated as a carer.

...all the doctors, well the doctor is not bad, but the nurses, the health board, they don't care about you, you know what I mean, they don't listen to what

you're saying or they just, just forget about you and that's it, they come in maybe once a month, the nurses do and that was it. I felt actually as a carer when I looked after my mother, you were at a standstill, you're just in the house and no one else thinks of you, that's it.

Kathleen was especially disappointed by the Public Health Nursing service.

They should also be able to give us a lot of information, that was our first port of call, was the district nurse....and they're the ones that should give us all the information but it's not forthcoming. [...] I knew I needed aids to care for my mother, I also needed day care to give me a break. As she got worse actually I needed some night help but that wasn't forthcoming. I would have needed maybe a home help as well to help me, that wasn't forthcoming. They [Public Health Nurses] are the first people that you access, it's the nurse who assesses all these needs or puts you in touch with these people, who will access those for you.

Kathleen felt that she could not rely on the Public Health Nurses to access the help she needed for her mother so she took it on herself to find out about the services and try to access them herself.

I went out there and I fought to get it myself. Once I knew where to access everything, I fought for everything myself...I went to meetings, I lobbied TD's, I got myself a bad name because they all know me from out there saying you know I need this, you know. Yeah that's the only way to get things. [...] I'd just keep lobbying, keep sending letters out, keep ringing, emailing, you know that was the only way I kept on top of it, you had to.

Kathleen became skilled at accessing information on services for carers and now she is able to help others caring for relatives who find themselves in a similar situation.

I was looking for everything, not only for myself but for everybody else too.

So would you find that you're more skilled now at accessing information?

Well I'm fairly skilled. I can access [it], I know where to access things now, I've a big list of whoever I access.

Kathleen also feels that older people nowadays are better able to access information on their care needs.

I think actually maybe eighty percent of us now as we get older are a little bit bolder, we actually know how to access things now.

In more recent years, both Kathleen and her husband had experience of using hospital services and although she received good care, she is disappointed at the level of communication by nurses in the hospital.

Patient nurse relationship is very poor, not like my day where we had a good relationship with the patients and you know made them feel so secure and so relaxed, now they don't do that. They have no communication or they're too busy, its not that either, its actually they actually spend too much time at the desk writing, on the computer and not enough time out with the patient, that was my experience.

However Kathleen says that she is well able to speak up for herself but she feels sorry for other people who may not be able to speak up for themselves, who are in pain and waiting for services and don't know where to access them. She feels that older people are not treated equally in the health services and thinks that an advocacy group should be set up to access public services on their behalf.

[They are] putting older people on the long finger because they cost too much money. [...] It would be good to have an organisation which they could contact and say look I have a problem would you be able to, somebody that would be able to access things. [...] I think they should be more informed, to reassure them that they're not forgotten, you know because people are just sitting waiting and they think they're forgotten.

Participants' Information Pathways: The Case Studies

6 Norah

Norah is looking forward to her 80th birthday, which is coming up soon. She lives with her brother in a bungalow on the outskirts of a village in rural Ireland. Norah spent most of her adult life working in the textile industry in England, where she met and married her late husband. They moved back to Ireland and following her passion for textiles, Norah set up a successful dress making business working from home until she retired some years back. When Norah and her husband returned to Ireland they invited her parents to live with them and she cared for them in her own home until they both passed away. Norah's husband also passed away eleven years ago. In the years since Norah returned to Ireland she has had reason to access public services on many occasions, mainly in relation to support when providing end of life care for her relatives at home. Norah decided to care for her husband at home without the help of the Public Health Nurse when her husband was diagnosed with advanced-stage cancer. However, when it came to accessing medical supplies it was very difficult. Everything had to be sanctioned by the Public Health Nurse and she found that services were linked together in a complicated system and she didn't know where to look for help. She suspected that the Public Health Nurses were tasked with providing much of the information on what her husband was entitled to, but she was not able to find out the information that she needed because she was not linked into the system.

So I found, if you don't have this you can't get that, there is no in between.

In recent years both Norah and her brother had serious operations, which needed a significant amount of post-operative care. She had not been informed on either occasion that they would be entitled to assistance from the Public Health Nurse when they returned home and was disappointed to find this out some time later. Although Norah felt that she needed the help at the time, she was not aware she was entitled to it and did not feel like she could contact the health service to ask for it. She feels that this is the same for other public services.

At the time when you're saying you could have badly done with her, did you feel like you could contact the services and ask them for a visit?

Quite frankly I didn't think I was entitled to it.

Ok and why is that?

Because I didn't know it was available and that would that be the same for a lot of other public services.

Norah's most recent contact with public services was in relation to an insulation grant for her home. Norah especially noticed the cold last winter with the prolonged snowfall but she only became aware of the insulation grants when a local walking in the park told her brother about it one day. She is disappointed that older people are not informed about schemes like the insulation grant.

Well I suppose it's like the thing now with insulating the loft. I mean I read the paper from cover to cover every day and I know everything that's going on but nobody really tells you that these things are available and its only when quite by chance you might hear somebody say 'oh I've had so and so and so and so done', but there's no, you're not given these, all this information is not given to you. I think when you're this age and you're a pensioner and you're drawing a Contributory State Pension, I think all these things, it would be very, very easy for them to send you out a pamphlet now and again and say this is what you're entitled to.

However, when Norah enquired about availing of the insulation grant she was told that she would not be eligible for it if she was not eligible for the fuel allowance. Norah had been turned down eleven years ago when she first applied for the fuel allowance on the basis of her second pension income from England. She found this surprising at the time because she was receiving other benefits under the State Household Benefits Package and her extra pension income was quite modest. However she didn't follow it up at the time. She decided to reapply for the fuel allowance recently and discovered that she had been entitled to it all along, and that the total income from both her pensions was slightly under the income limit for the fuel allowance scheme.

So I had asked was I entitled to it and they said no, that was it. But then I find when I go into it then, I make enquiries, I was on the borderline money wise, I would be slightly underneath the limit so in actual fact I should have been drawing it. It was just marginal now but you see nobody ever tells you that.

Norah has now reapplied for the fuel allowance and the insulation grant. Although Norah disagrees with people contacting their local political representatives with such concerns, she had been advised to speak with a local politician who helped her with the application process. She filled in the forms and sent them off five weeks before the interview. Norah was waiting for a reply at the time of interview.

Norah also decided to try changing her phone provider to avail of a better deal. She contacted the Social Welfare Services and they told her she would be entitled to change her provider and retain her entitlement to having her phone bill paid. However she encountered difficulty getting her bills paid after changing provider and ended up paying extra because she didn't want to have her service cut off.

I changed my phone provider to [new phone company], my line rental and all was with [previous phone company], they were to transfer my entitlement. [They] tell me they applied for it. It went on and on and on from late November and I kept getting the bills...so I keep paying the bills because I don't want my electricity cut off.

Although Norah feels that older people are treated well in Ireland in general and she is happy with the wide variety of benefits and services that she is entitled to she feels that there is a lack of information provided to older people on their entitlements.

Participants' Information Pathways: The Case Studies

7 Marty and Gina

Marty is a 75-year-old man living with his wife **Gina** in a two story townhouse close to the centre of a small urban area. After working for most of his adult life in a local company, Marty was let go when the company closed down and he was unemployed for a few years. He then got a job as a caretaker in a local school and Gina took a job in a leading retail store in the town. Both Marty and Gina are now retired and although their health is otherwise very good, they both suffer from arthritis. After presenting to his local GP with his condition almost ten years ago, Marty was put on a waiting list to have a knee replacement. As time went on, Marty's condition got progressively more painful and there was no word of when he would have the operation. He was accessing the public health service at the time as neither Marty nor Gina had private health insurance. Marty is a quiet, private person and he relies on Gina for accessing information on his behalf, however neither of them knew where to go for advice. Eventually they went back to his consultant and after being advised that they could pay for the operation, they decided to take out a loan.

He would have been waiting for over a year he was told. So then I said well, I said what about if we pay and he said would you like it done tomorrow when we said we could pay. [...] So we didn't have much money at the time because we just didn't and [Marty] was after being idle for a little while and I went out to work then when he lost his job. And I said well people borrow money for cars, I said we'll borrow the money and get your knee done.

After having his first knee replacement, Marty needed a second one and he went back on the waiting list. Some time after that, Gina also needed a knee replacement and was put on the waiting list. As Gina was then entitled to avail of the National Treatment Purchase Fund, she applied and both Marty and Gina's appointment came up at the same time. Gina realised it would not be a good idea for both of them to have the operation at the same time, but she was advised to go ahead with it.

And I worked in [retail store] you see and then mine just came at me and I couldn't walk and the doctor just said you need a replacement and he sent me to [the consultant] and I was on the list and I was on it that long as well, I availed of that treatment thing.

The National Treatment Purchase Fund?

Yes and that's how we happened to get it done together because I got word to go in for mine and I had said it to the same [consultant] and I said I think I'll cancel it and he said to me no don't, he said because God knows how long, you'll still be waiting, you'll be waiting a long time.

When they came out of hospital, they found it difficult to get around their house and needed a lot of support from their neighbours and friends. They were surprised that there was no follow-up care from the health service when they got out of hospital.

But it was a very bad idea but we had plenty of friends, because we didn't have one health worker calling or nobody called to see us.

Their bedroom was upstairs and they found it difficult getting up and down to the bathroom as their only bathroom was downstairs. However, they were not aware that they could apply for a grant to adapt their home and only discovered this by chance when Gina was advised to get steps out the back of their house.

Yeah but then we got the knees done and we had a very high step out the back and somebody said to me oh God you need steps out there, I said yeah how would I go about getting any of them and there was another place, I can't even remember the name of it and they said if you go in there, somebody might come down and have a look. So I went in and said both of us had our knees done, shortly after we got our knees done and we went in and about a week later this chap [...] came and he put four steps out the back and two handrails. So he said to me, it was him, it was actually that man that said to me how do you manage sleeping arrangements and going up to the toilet and that, I said well its very hard, so he said why don't you apply for a grant. Well I never knew there was such a thing as a grant.

They felt that if they had the medical card at the time, they probably would have been looked after better and been more aware of their entitlements. When Marty turned seventy, he was automatically entitled to a medical card and Gina contacted the services to enquire about her own eligibility. Although she is younger than Marty, she had to give up work on disability grounds and hoped that she would be entitled to some level of coverage. Eventually Gina discovered that she was entitled to coverage, but it was again just by chance that she spoke to the right person in the health services.

Were you made aware of the circumstances that would entitle you to a medical card?

Not then, no but then I got a phone number and I phoned and this girl said to me when I phoned, but your husband will be entitled to a medical card in his own right as soon as he's seventy, it was the year he was going to be seventy... [and] I said well that's no good to me I said because my husband is older than I am and I need medication as well because I take quite a few tablets for blood pressure and my arthritis and that. So I said that's no good

to me. So I said can I talk to somebody else and she put me on to somebody else. I was chatting to somebody else and I said well what are we to do, we're paying all this much money and she says have you got any other earnings, have you any other income and I said no all we have is Marty's pension and what I get on the insurance, you got no money from [workplace], you got nothing anywhere. Well she said there is a special one you're entitled to if you only have, if you only live on social welfare. And she sent me out the form.

Ok so would you have known that unless you'd asked to speak to the other person directly?

No, no, I wouldn't have known at all. Only I pushed her, because I mean we were going to the doctor quite a lot and paying €50 a visit plus paying for our medication and I mean Marty's job wasn't pensionable either so he's only a State Pension and I only have a state pension now as well.

Gina was disappointed that she had not been informed of her entitlement to a medical card without having to push for it and she felt that the first girl she spoke to had just dismissed her on the grounds that her husband would be getting a medical card anyway.

When you were accessing the services, how did you feel they were treating you?

Well I felt the first girl that was treating it was just dismissing me, as me, but not the, I mean she was saying like well your husband will have one in his own right but that was doing nothing for me in my right... You know I mean she was just saying that he'd get one but I'd have to wait until, but she didn't ask me had I any other income or she didn't tell me there is a form that's just for anybody on social welfare.

Gina has become very active in her local senior citizens club now and finds that she is much more informed about services and entitlements in her area because of it. She finds the local resource centre for people on social welfare benefits a really helpful service and would go to them if she ever needed information in the future. Marty is still reluctant to go directly to the services to ask for information and is happy that Gina can find out information on his behalf. But he would like to see more information provided through the post, and he stresses the importance of making information leaflets on services accessible for older people.

We got a booklet one time giving you all the information you could be looking [for] but it was like double Dutch, the big words and like it was for professors or someone to read... It just goes over the top of your head sometimes.

What do you think they can do to improve that?

Just put it in plain English.

Key Findings

1. Multiple Transition Times

This study was designed to assess and describe the information pathways of older people during transition times, however, during the course of the research it became evident that deciphering pathways for a specific transition time cannot be done in isolation, as individuals often encounter one transition time in conjunction with another. For example, becoming functionally disabled can coincide with needing long-term care, or becoming a full-time carer can coincide with taking early retirement. The information pathways employed to negotiate access to services for one transition may be different to those employed for others. Information pathways during transition times in later life are then complex; depending on a variety of factors including the transitions the individual is facing, past experiences, social connectedness and individual preferences. Information pathways are not fixed and can often change depending on the context of the individual situation, the information query that presents and the responsiveness of public services to the ways that older people employ to access information.

The transition times investigated in this study include:

- becoming functionally disabled;
- becoming a carer;
- returning to Ireland from abroad and
- reaching retirement age

Other transition times that emerged during the course of the research include:

- bereavement;
- developing an illness and
- experiencing a security breach.

2. Public Service Information Needs

The information needs of participants identified in this study generally support the wider evidence base on the information needs of older people. Health was a primary concern, followed by home adaptation, support services in the community, and information on welfare entitlements and pensions. Individuals employ different pathways for accessing information on these different needs. Information needs of participants in this study can be attributed to two domains. The first, which I refer to as continuous information, is a broader base of general information that is continuously accrued throughout life and in later years, which is tapped into regularly and is useful for routine activities. The second domain is context specific. This is information which is not generally useful for everyday living, but which is critical for negotiating service and entitlement access at transition times during later life. Exploring the relationship between these information domains is beyond the scope of this study, however it would seem likely that participants with good access to continuous information resources would also have good access to context specific information resources. It is the second domain of information that is most highly

valued by the participants and is directly linked to independent living. Participants feared that their access to context specific information would be limited when they needed to access it. They saw it as important to be 'informed' on the services available to them, should a need arise for such services. Several participants feared that their independence would be compromised in later life and stressed the importance of being able to access relevant services at appropriate times to avoid losing their independence.

Maintaining independence into old age was a paramount concern for participants. This was especially true for those participants who were widowed, living alone or had suffered serious health problems leading to disability.

My main fear is that I will live too long.

What is that fear based on?

It's based on the fact that I would hate to be dependent.

Good quality information provision on health and community services was considered essential to ensuring independent living.

Several participants reported the need for home adaptation in the study as a result of increased frailty or conditions associated with ageing such as arthritis. They found that information on home adaptation was not readily available, confusing and some participants reported conflicting information from service providers on how to access the services.

Two of the participants had previous experience of caring for dependent relatives in their own home and one participant had recently retired from her own business to care full time for her mother. All three participants spoke of difficulties in accessing information on appropriate services in the hospital and the community when caring for their family members. A key concern for one of the participants was accessing information on repairing a hoist provided through by the HSE and installed by an independent company in her home.

It's like the hoist we have inside, that's the biggest problem ...because the people that deliver it won't take responsibility for it, the hospital won't take responsibility for it so who do you ring, who do you contact and that's my worst fear, if that broke down, who am I going to contact to service this?

This situation highlights the complex nature of public service provision and the gap in service awareness when private companies are providing equipment and services on behalf of the public services. This was also true for Norah when changing her phone provider. Having been told that she would be entitled to change her provider and retain her benefits, however she encountered difficulty getting her bills paid after changing provider and found herself out-of-pocket for her phone bills.

I changed my phone provider to [new phone company], my line rental and all was with [previous phone company], they were to transfer my entitlement. [They] tell me they applied for it. It went on and on and on from late November and I kept getting the bills...so I keep paying the bills because I don't want my electricity cut off.

Participants found that being 'linked into the services' was very important. Otherwise it was difficult to know where to go for information on services during crucial times. This was especially true for Norah when she was caring for her husband. She had cared for her husband at home with the help of her local G.P. and did not avail of the public health nursing service at the time. The day before her husband died she contacted her local pharmacy to purchase incontinence pads, however she was told that they did not stock them and she would have to request them through the HSE. However, as she had not been assessed by the services, she was not able to access supplies.

I rang [the health board], you can't have them unless the district nurse sanctions it, but I didn't have a district nurse. So only that my friend knew somebody else who knew somebody, they gave me a packet of them. [] So I found [a] division between if you don't have this you can't get that, that there is no in between.

The needs of older people are largely dependent on their individual contexts and often the older people themselves don't know what those needs are until they are faced with a particular situation. Therefore it was considered important that there would be clear signposting for individuals towards services at their time of need.

Building on the findings of Ruddle (2002) this study highlights the concerns of older people when faced with new situations arising out of transition times such as developing an illness or becoming a carer. Many of the participants did not know where to turn for information or advice on their service entitlements once they encountered a transition time. Clear pathways to information on context-specific public services, is then an essential first step in ensuring access to appropriate services. In addition, there is an evident gap in information provision where services are provided by private companies on behalf of public services. This can further complicate an already difficult task in seeking information on public services during transition times in later life. This study clearly demonstrates that participants were unable to identify their needs in the context of existing statutory services, thereby diminishing the older persons ability to source relevant services in response to their needs.

Irish governmental policy has for many years supported the rights of older people to remain living independently (Robins 1998), however, the provision of timely and appropriate information required to access essential public services remains a significant challenge and a barrier to independent living. While the reorientation of health and social services in line with the international policy on active ageing is an admirable goal, this study highlights that the gap between public service information provision and the information needs of older people remains a serious impediment to achieving this goal.

3. Information Modes

The information pathways used to access information on public services varied among participants, reflecting the heterogeneity of the older population in Ireland. In general, older people were avid listeners to radio. Many spoke of watching television but they associated television viewing more with entertainment rather than as a resource for becoming informed. They also reported buying newspapers on a daily basis and

reading the Sunday papers weekly. Some did point out that purchasing newspapers could be quite expensive and that other older people may face a choice between paying for newspapers and other essential services such as heating.

Papers are very expensive now, so people actually have cut back a lot, the pensions are quite small so consequently they have to look after it, they have to think which would be more suitable for them, would it be heating or would it be the papers per week, you've to think of that too.

One participant praised the free papers available in her locality.

We have a couple of free papers coming in, I find them great for information too as well [...] I actually love them. They're delivered to your door, can you believe it, great service and I find them absolutely brilliant for accessing services.

Participants relied heavily on local papers and their local radio stations to keep informed on community news and events. They considered local media as important resources for accessing information on public services.

The older participants in this study appear to use fewer resources when seeking information than the younger participants, this finding is in keeping with Asla (2006) who reported that older people's information channels narrow as they grow older. It was invariably the youngest old who used a variety of sources for accessing key information on services. In general as people got older, they placed more emphasis on receiving key information from relevant professionals and emphasised the preference for face-to-face communication. They also appeared to be more reliant on family members and, to a lesser extent, on friends, than they were on other information sources, this finding supports the previous work of (Williamson 1995). Friends seem to be less of a resource for the dependent older people interviewed: as people become more isolated, they tend to rely more on their family or neighbours to relay necessary information.

4. Information: the Gateway to Services

A clear finding that emerged from this study is the inextricable link between information provision and access to services. Participants found it difficult to distinguish between information provision and service provision. They regarded information acquisition as the 'gateway' to accessing the services they were seeking. In this context, information was viewed as a currency for accessing services that may be required throughout later life and specifically during transition times. The majority of participants had experienced difficulty in accessing services and associated this with a lack of appropriate information provision.

Pathways to information also varied depending on the service required. While some participants were happy to contact the services directly for certain queries, others were reluctant to enquire about some services directly and preferred others to do this on their behalf. Several participants reported a reluctance to enquire directly about services such as social welfare payments in case they had their current entitlements withdrawn.

I'd be afraid, maybe I'd lose on it, what would I do then?

There was a general lack of knowledge and confusion about public services and the rights and entitlements of individuals to those services.

Well we didn't know where to go or who to ask...there should be literature about it or something about it saying you are entitled to this, I mean you could go to the Corporation and to the County Council and they might give you some [information on housing grants] but who do you go to down there and what do you ask, do you go to the housing place or do you go to the place for repairs or what?

This resulted in a continual struggle for participants to establish the best pathways to securing reliable information to help them through their transition times.

During the course of the study, many situations emerged where participants had needed to adapt their information pathway to access a service they were entitled to. When Helen first saw the advertisement for insulation grants in her local newspaper she contacted the phone number supplied in the advertisement. She spoke to an administrator and they took all her details and said they would get back to her. After waiting for a response for six months, Helen contacted the number provided in the advertisement a second time and was told that she needed to contact a different office to process the application. Once Helen contacted the appropriate office her application was processed immediately and she was very happy with the service. However, Helen's access to the service was delayed significantly by the lack of clear signposting of access points for applicants. This lack of clear signposting often meant that participants did not receive the correct information on services and thereby the services they required. They were very appreciative when information was provided in a timely manner.

That's how I found out about the grant for insulation for the house I saw it in the daily newspaper. They took my details [...] and I got an application form within the week. I couldn't believe it came so quickly. So that was a brilliant job when I got it done and it was done ever so quick in the end.

Many participants commented on the lack of clear information as a barrier to services.

Access to services varied and participants found that they were in a position to acquire information relatively easily on certain services, however they found it more difficult to access information on other services. Information provision became a key issue when participants needed to access entitlements such as Carer's Allowance or Fuel Allowance. Participants reported many incidences where they had tried to gain the relevant information on entitlements and had either not had a response or had been provided with inaccurate information. In one case, Anita who recently became a carer for her elderly mother was told she was not entitled to a Carer's Allowance as she was self employed.

[I] didn't know I was entitled to the Carers, they told me because I was self employed I wasn't....the first year of caring I lived off my savings, the whole savings went because I didn't know I was entitled to the Carers, it was only the district nurse came across and she says Anita you're entitled to the Carers.

Norah also received the wrong information when she initially applied for the fuel allowance.

So I had asked was I entitled to it and they said no, that was it. But then I find when I go into it then, I make enquiries, I was on the borderline money wise, I would be slightly underneath the limit so in actual fact I should have been drawing it.... just it was marginal now but you see nobody ever tells you that.

A key concern for participants was that they did not feel informed about the services that they were entitled to. They were concerned that there is no central source of information on older people's entitlements in general and felt that there was a '*muddying of the waters*' when it came to deciphering individual entitlements. Many participants reiterated that '*nobody told them*' they were entitled to certain services and therefore they had not even tried to access the service. They were often surprised when they found out that they were entitled to services. Marty was delighted when told that he was entitled to a grant to adapt his house after a visit from an occupational therapist. However, he was surprised that he had not been made aware of this entitlement until some weeks after his knee replacement operation.

So he said to me, how do you manage sleeping arrangements and going up to the toilet and that, I said well it's very hard, so he said why don't you apply for a grant. Well I never knew there was such a thing as a grant!

In general, he felt that older people are happy with what they have and they wouldn't ask for anything unless they really need it. However he did feel that services such as house adaptation would really benefit other older people in his situation and that they should be made aware of their entitlements rather than making do with what they have. Norah felt that there are a lot of entitlements on offer but that the information is not made available to those who may need the services.

You see what we're given is very good but you're not told then the other things.

Many participants had discovered that they were entitled to services by chance or what Williamson (1998) refers to as incidental information provision.

Then somebody, my brother walks in [the] park every morning and somebody down there was telling him about it too. So he gave me the phone number and I rang up about it.

Several participants felt blocked when they tried to access information on service entitlements. In some cases this blockage was more subtle than in others. Many incidences were discussed where participants had tried to access information on services, but their calls were not returned or their letters were not responded to.

We phoned the hospital and there was a phone number and they said leave your name and number and they'll get back to you, and I just left Frank's name and number and said he was enquiring about his glasses, they never phoned us.

5. The Information Struggle

Although efforts have been made in recent years to improve the information-seeking experiences of older people, this study found that accessing information on essential public services largely remains the responsibility of the individual older person or their carers. This supports previous findings from a study of the information needs of older people and disabled people in the United Kingdom (Barrett 2005). The 'come and get it' approach to information provision as described by Bowen (1986) emerges in this study as a discriminating factor for those who do not know where to 'come and get it' or are simply unable to for personal reasons such as disability.

Participants stressed their lack of confidence in accessing public services on two levels. Firstly, they felt that they needed to possess the skills for negotiating access to information: where to look and who to speak with. Secondly, participants were continually trying to establish which pathways or access points were the most fruitful when seeking information on public services. Participants described many instances where their information-seeking journey was cut short due to unreliable service providers or not knowing where to look. Blockages in information pathways often occurred when information on more than one public service was required. Participants found that phone calls were rarely returned and the onus was on the individual to follow up with services in the absence of a response. Several participants described their attempts to access information on services as a 'struggle', 'chase' or 'fight'.

Once I knew where to access everything, I fought for everything myself.

I won't let anything slide until I get the information I need at the certain time, I would be on the phone or ringing and sometimes you come up against blocks.

I'd just keep lobbying, keep sending letters out, keep ringing, emailing, you know that was the only way I kept on top of it, you had to.

Participants felt that it was up to themselves to continuously chase the services to look for the right information or access to the right people who may be able to inform the individual on their entitlements. Some of the older participants rose to this challenge.

Once I knew where to access everything, I fought for everything myself. Yeah, I got very bold [...] I had to [...] I'd just keep lobbying, keep sending letters out, keep ringing, emailing, you know that was the only way I kept on top of it, you had to [its] the only way you could get things, they will listen to you, they will do something eventually.

However, others found the difficulties in accessing information increasingly frustrating, specifically when they could see disparities in the services.

Very annoyed, very annoyed because you see all these people at the top who can just click their finger and everything is done for them, like we're paying our way as best we can and still we can get nothing.

The ability to negotiate this challenge in acquiring information on entitlements appears to be dependent on several factors including physical capacity, personal characteristics,

social connectedness and previous experience of accessing services. Participants who had previous experience of difficulties in accessing services appear to adopt coping mechanisms for accessing information relevant to their life situation or transition phase. This coping mechanism is often to involve another, more informed person in the community in their quest for information on specific public services or entitlements.

6. 'Key Imparters'

In the course of the interviews several 'key imparters' of information were identified. These included local political representatives, a nun, community workers, a neighbour and a Public Health Nurse. Often the 'key imparters' were not in a position to impart knowledge themselves, but acted as conduits between the individual and the services to locate the best source of knowledge on the particular entitlement or service in question. Many of the participants felt reliant on these 'key imparters' to access information on their behalf.

How do you feel about relying on other people to get information for you?

Well really it's the only way you can get it.

While the older person's choice of key imparter was often dependent on the context or the specific service, such as the Public Health Nurse acting as a conduit for the carer in accessing hospital services, this was not always the case. These 'key imparters' were found not only to facilitate access to information, but participants also put their faith in them to secure entitlements to public services. Services that the older person may be aware of, however they are unsure how to negotiate access to them on their own behalf.

Again the notion of information as currency emerges in that older people did not feel they had the same capacity as these 'key imparters' to access the information they required to secure services they are entitled to. This was often referred to as 'inside information'. Participants felt that those who were already linked in to the services, working in the services or had direct access to the services such as politicians, had the 'inside information' and these were the best people to contact in relation to securing information and entitlements. Not only could the local political representative find out information, but they could also do something about the older persons need for support. Mary has relied on her local political representative for information in the past and has been successful every time in securing entitlements. She feels at a disadvantage now that he has left politics.

He was brilliant, no matter what you wanted. [...] He had inside information, he must have been able to go to the right people at the right time but he was brilliant, it broke me heart the day he left politics.

However, participants were selective in what they would ask their local political representative to assist with. While they found them very helpful for securing entitlements such as their pension and welfare benefits, they did not see them as having a role in negotiating access to the health services.

Would you go to him [political representative] about the health services if you felt you needed to?

I suppose if I was on the last track I would go to him, you know but I think health service is more when there's something wrong with you, you feel more, say private, you don't really want to discuss it.

Although Norah has accessed her local political representative in the past, she acknowledges that their work should be focused on other more substantive issues, rather than securing entitlements for individuals in their constituency.

I suppose most people think oh well he must know somebody who knows somebody and I think that's wrong too, I think a TD is there to run the country or help to run the country, not to do fiddly tiddly little things like, that shouldn't be his function.

Participants felt they had to rely on these 'key imparters' to make sure they would be fully informed about their entitlements. They recognised that these people have access to the appropriate information pathways and acknowledge that they are able to 'get things done'. This reflects a greater issue of concern for older people in the study: there is a clear distinction between information 'haves' and 'have not's'. It is well understood that having access to the right information, or at least the right people to access the information, ensures that the older person will not be disadvantaged. Those who felt they did not have access to either of these resources identified themselves as living in disadvantaged situations. Paddy had made several attempts to access services he required in his home including home help and personal care however he was not able to identify the appropriate information source and was becoming increasingly isolated.

Do you feel like there is anyone you could go to, to get the information you need?

No, you're on your own and sure I keep myself like that then.

Access to the 'key imparters' is an important aspect of information seeking for older people in the study and they stressed the importance of these individuals in their information pathways. They were particularly important for participants who were isolated in their homes and had little contact with their community. Anita and Paddy identified themselves as being quite isolated for different reasons, and both have highlighted the important role of the key imparter in their lives. Paddy lives on his own and is wheelchair dependent, waiting for a double hip replacement. His neighbour is a local farmer, with a long family involvement in politics. Paddy was impressed that his neighbour was able to source a wheelchair for him in the absence of the health service providing one and attributes this to his neighbour's connections.

Mr. X is the neighbour there. He'd have great pull. He'd know this one and that one. He got me the chair [...] someone that he knows got me the wheelchair.

Anita is caring for her mother full-time and is unable to leave her unattended in her home during the day as all her relatives work office hours. She feels increasingly isolated as information providers do not offer services outside of office hours. She has experienced a lot of difficulty in accessing services for her mother since her last stroke and found that the Public Health Nurse was very helpful in pointing her in the right direction and advising her on the appropriate questions to ask.

It was only through the district nurse coming over and she was saying Anita have you got the appointment yet and I said no I haven't. So she said get the appointment because if she goes a year in May she's out of the system and then they'll have to start all over again.

Participants who had been through transitions themselves sometimes found themselves as conduits or 'key imparters' of information for other older people.

So you found yourself becoming a filter for information?

Yeah [...] and not only for myself, for everybody else. I learned as I went along.

Ok so you built up some experience at it?

Yeah.

So would you find that you're more skilled now at accessing information?

Well I'm fairly skilled [...] I can access it, I know where to access things now, I've a big list of whoever I access.

While participants had gained skills in accessing information on certain services, it is interesting to note that they still did not feel fully confident in accessing information on other public services. Becoming skilled in accessing information on one public service did not necessarily predict success in accessing information on another. Information on public services was seen as elusive, there was no direct pathway for accessing information and even when a participant had negotiated a service, they would still not predict success in accessing the service again. However, to those who required information on services, those who were already in receipt of the service were seen as '*in the know*'. It appears that those who have had previous successful experience of accessing one public service are inclined to help others to negotiate the same services.

7. Formal and Informal Information Pathways

The types of information pathways that older people employ can be divided between formal and informal channels. Participant's situation and social connectedness often predicted which pathway they would employ. Overall the most popular channels were interpersonal, including information seeking from professionals such as physicians and pharmacists, family members, friends and neighbours. Word-of-mouth information was considered a valuable resource for older people in transition times. Participants valued interacting with other older people in the community who may have been through similar experiences in the past. More isolated, dependent

participants reported a reliance on family members and close neighbours to negotiate information on public services. Reliability of information sources featured as a key concern in the literature on older people's information needs. While this did not emerge as a separate theme in this study, participants did refer to their struggle to identify reliable sources of information and it was apparent that they adapted their pathways to ensure that the sources they used would return good quality information. Others reported unreliable information as a deterrent when attempting to access services. Some participants however reported speaking to as many sources as possible both formal and informal to receive information in the hope that they would eventually get the right information.

Participants who had previous formal contact of services appeared to become 'linked in' to the services. Those participants who reported experiences of being 'linked in to services' also reported regularly attending meetings and social events in their locality and demonstrated a strong connection to their community and support network. Once participants crossed the threshold of information seeking to access formal services they reported positive dealings with service providers and many were very satisfied with the service they received. Some participants had employed several pathways to access information on one service, before they crossed the threshold. One exception to this finding was the carer accessing information on health and social care entitlements for her mother. It appears that becoming 'linked in' to healthcare is a more complex issue than for other services discussed in the study. The problem with health care may be that the services involved are likely to be multiple and cross-disciplinary for any one condition. For example, Anita's mother who had several strokes required hospital appointments as well as health care in the community. The gaps in formal information provision appear to be most acute when service users require information that may span disciplines or service providers.

Several participants were aware of the Citizens Information offices and one participant relied on this as a primary source of information on public services. However, while other participants were aware of the services, they were not physically able to access the services, either due to disability or their role as full time carers. Most of the participants were in some contact with voluntary organisations in the community and found that contact with such organisations was beneficial when it came to accessing information on services. While participants were aware of ageing organisations, few of them reported contacting an ageing organisation for information on their public service entitlements. This study corroborated Goodman's (1992) theory that it takes greater effort for older people to access formal channels of information and this perhaps explains why those interviewed often pursue informal information channels in advance of formal channels.

8. Information and Communication Technology (ICT)

While some of those interviewed were keen to learn about computers they were reluctant to learn how to use them for accessing information. Some of the participants had taken courses, others had been shown how to use a computer by family members, however they still did not feel sufficiently competent to retrieve information efficiently. They felt more adept at accessing information through other sources, skills which they had developed over their lifetimes, such as using the telephone or looking up the

local newspaper. This supports previous findings (Rabbitt 1999) reporting the reluctance of older people to adapt to new strategies for information seeking.

Some felt ashamed that they were not able to use a computer and felt marginalised from society as a result of developments in technology such as mobile phones and computers.

I never used a computer and I feel ashamed of that. My daughter has a computer in the house you know and all the children use it to write letters and that and I would like to be able to sit down and write my letters on it.

The issue of older people using computers is especially important as public services increasingly adopt technology for communicating key information to public service users. However, none of the participants expressed a preference to have information on public services communicated through online sources.

One participant reported her annoyance at automated telephone services and expressed a preference to speak directly with a service provider to ensure she gets the correct information.

I go through all the thing, press 1 for this and 2 for that and 3 for something else and if you want to speak to somebody press 5 and I press 5.

Why do you think that is preferable?

Because I'll get all my answers in one go.

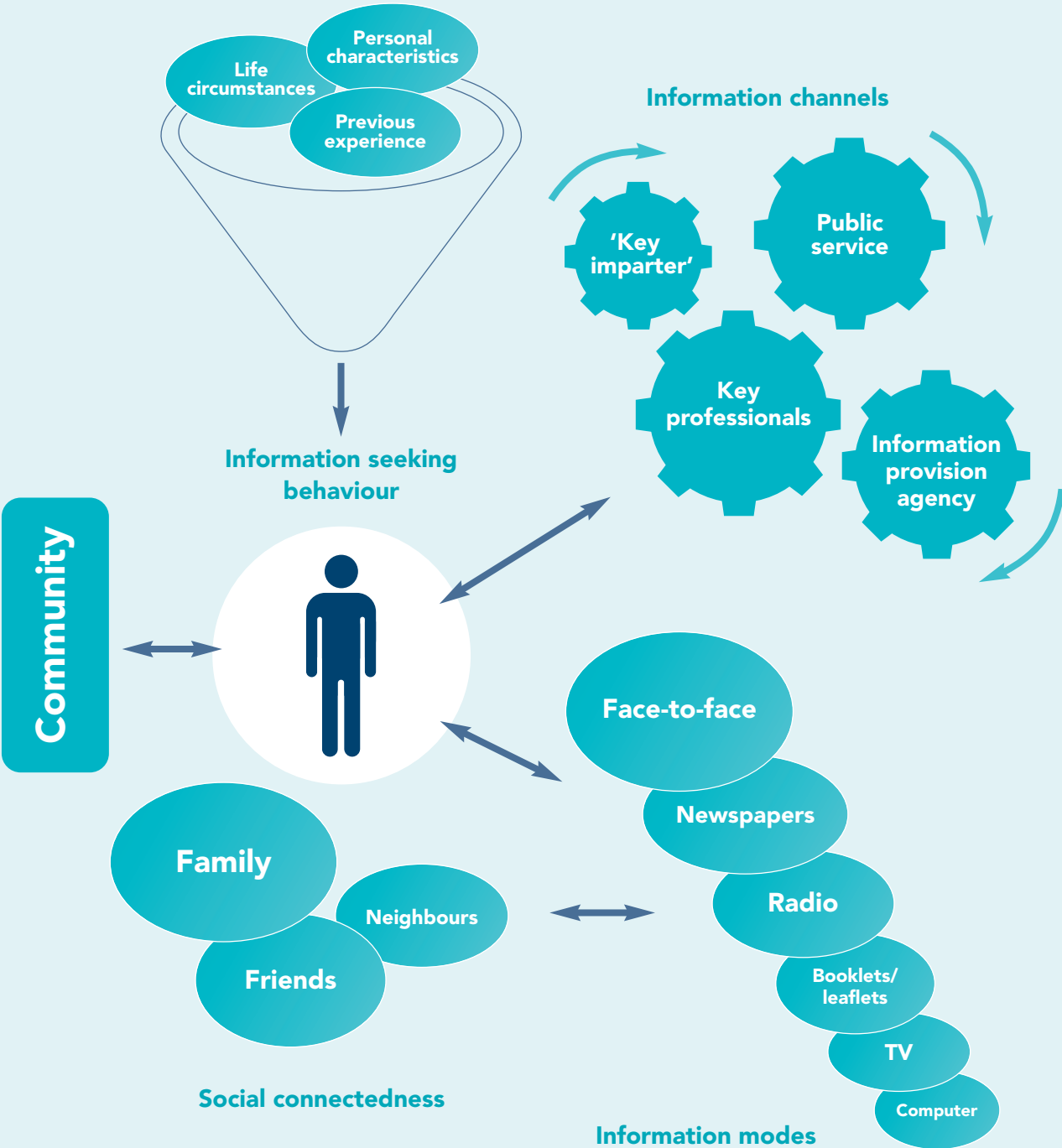
Although participants did not feel they were in a rush and had time to hold in order to speak to a telephone assistant, they still did not like being placed on hold.

Instead of, you know instead of going through all this rigmarole, you know and then when I hear your call is valuable to us, please hold, somebody will be with you in a moment and on and on and on and somebody is going to come but luckily I've plenty of time, so I sit there and wait and sometimes I'll turn it on loud, the phone and I have that there and I'm doing something else and when the somebody is ready we'll talk.

While getting an immediate response to an information query may be a concern for many people when accessing information on public services, it did not come across as a key concern of older people. Participants were more concerned that their information sources were reliable and that accurate information would be provided in a timely fashion so that they would be equipped to deal with their needs when required. They also expressed a clear preference for speaking with service providers directly rather than relying on the information provided through answering services. Some participants reported dissatisfaction with attitudes of service providers and a lack of competency. However in general, older people found their experiences once they did manage to speak with a service provider to be mainly positive. There was a sense from the interviews that older people themselves felt marginalised from mainstream information provision and some participants attributed this to a sentiment of ageism among service providers.

The diagram presented below outlines key elements of information pathways to public services that are identified through the interviews with older people. Participants used a variety of strategies, information modes and channels to access information that was pertinent to their experiences during their transition times. The multitude of information needs and the heterogeneity of older people and their experiences dictate a complex pattern of information pathways. However some clear conclusions can be drawn from the pathways outlined in this report.

Figure 1. Information Pathways to Public Services at Key Transition Times in Later Life





6 Conclusions

The ageing population has emerged as a key policy concern in recent years. Of specific relevance is how public services will organise themselves to deal with this changing demographic profile. The challenge for policy makers and service providers alike is to ensure that potential service users know how to access suitable services during times of need to ensure that people can remain living independently and enjoy a good quality of life as they age. Transition times have been identified as significant times of need in later life. The information pathways of older people are complex. This study found that older people may be faced with more than one transition time in later life and this further complicates an already difficult task in providing appropriate and effective information on access to services during these transition times. People in this age group are faced with many obstacles when it comes to acquiring the information they need to fully participate in society. They are often faced with significant changes in their lives, which present challenges when seeking information on public services. For example, when people retire, their previous mechanisms for gathering information diminish, they may lose touch with colleagues and their informal network of information providers may narrow. Others may face limitations forced on them with declining health and reduced mobility. Older people like all ages in society face challenges in adapting to new technology, which affects both positively and negatively their ability to gather and disseminate information. According to Wicks (2004), public service information delivery mechanisms should acknowledge the challenges that face older people in seeking and accessing information that is required for them to enjoy a good quality of life and participate in society.

The information needs and the responses to those needs identified in the interviews varied between participants, depending on their life stage and transition. Two broad domains of information were identified: continuous and context specific. Older people viewed access to context specific information as most important and actively engaged in behaviours to accumulate continuous information in order to become more informed on context specific information. It was access to context specific information, which proved more problematic in this study. While all participants had recent experience of accessing public services, some participant's journey to access the services was still incomplete. Information on public services was seen as elusive, there was no direct pathway for accessing information, leading participants to adopt a variety of information pathways to access vital information on required services during their time of need. Participants often referred to their attempts to access public service information as a '*struggle*' or a '*fight*'.

Older people do not distinguish between accessing information on services and accessing services. They regarded information acquisition as the '*gateway*' to accessing the services they were seeking. In this context, information was viewed as a currency for accessing services that may be required throughout later life and

specifically during transition times. The majority of participants had experienced difficulty in accessing services and associated this with a lack of appropriate information provision. The pathways that older people embark on in their quest for elusive information on entitlements are ultimately aimed at receiving public services. However, many older people are unwilling to even embark on this quest for fear of losing existing entitlements. There is insufficient information available to older people on the range of services available to them, their entitlement to those services and the expected outcomes of accessing information on services. Participants were unclear on service entitlements in particular and while they often encountered situations where they required public services, they had not been aware of their right to such services at their time of need. This lack of transparency created a sense of anxiety among participants. They relied on word-of-mouth to decipher whether they should attempt to access information on entitlements for fear that their current entitlements would be curtailed or withdrawn, this was particularly true for welfare services. Often participants discovered their entitlement to a service by chance reflecting the poor level of information provision on behalf of public service providers. Some participants queried the motive behind the lack of information provision. They felt that while services were available, there was a concerted effort on behalf of service providers to conceal their availability.

While there is now a clear evidence base on older people's information needs and information pathways preferences, this has been relatively overlooked in mainstream practices for informing older people on key public services. This may be contributing to the overriding fear of older people that they will miss important public service information and suffer the consequence of being marginalised from mainstream society, to eventually lose independence. ICT is rapidly becoming the communication tool of choice for many public services, and while evolving information and communication technologies can be welcomed as useful tools, they can also be criticised as instruments of social exclusion for older people. Therefore, public services have a responsibility to ensure that an appropriate variety of information modes and pathways are available for the population at large and that these are also targeted towards and encompass the specific needs of older people.

Participants in the study demonstrated a heavy reliance on their social support network for accessing information on public services. The extent of participants' social support network varied enormously. Older participants were mostly reliant on family and in the absence of family they became reliant on neighbours and friends. They considered their relationship with 'key imparters' as vital to accessing public services. All participants had identified 'key imparters' either in their community or in their family. They placed a lot of trust in the individual and relied on them for accurate information on public services. They recognised that these people have access to the appropriate information pathways and acknowledge that they are able to '*get things done*'. The pivotal role of the local political representative emerged as a significant theme in the study. They were considered as being 'linked in' to services and having direct access to the information, which eluded the participants themselves.

A key challenge for information providers lies in reaching those who are socially isolated: because they live alone; have diminished social networks or are unable to leave their home either due to their caring role or reduced physical capacity. The

findings of this study highlight the specific need to engage older men in service provision. The one socially isolated participant in the study was male and living alone. While he had access to a high volume of continuous information: he was an avid reader of newspapers and listened to the radio every day; his context specific information resources were poor. Although he was in desperate need of personal care and healthcare, he was effectively alienated from public services. He did not know who he could ask for help with accessing public services. Many studies are underway to assess the most appropriate way of targeting those at risk of social exclusion. One-to-one outreach appears to be the favoured approach either through volunteers or social workers who visit the individual's home or by telephone. The role of advocates for older people has been highlighted as a successful way of ensuring those at most need of services and at most risk of social isolation and increased dependence access required services in later life.

The gaps in formal information provision appear to be most acute when service users require information that span either disciplines or sections within the same public service or between service providers. The study also identified gaps in information and knowledge around services privately provided through a public service, such as a private company providing a hoist in the home on behalf of the HSE. While older people preferred accessing information on services through direct face-to-face contact, they are generally not facilitated to receive information on public services in this way. There is an identified over reliance of public services on automated telephone systems, written material and web-based information. Participants are not opposed to accessing information in a variety of these modes, with the exception of web-based information, however their experience in accessing services shows a higher success rate when they have spoken directly to a service provider. Opinions on the competency of service providers vary, however it is generally recognised that once an older person has established face-to-face contact with an appropriate representative within the service, they are more likely to receive the service. It should be noted that while services are provided in the community to assist people accessing information on public services, this does not cater for the needs of carers who are unable to get relief during working hours and also people who are frail or disabled. Therefore a variety of information modes should be used to facilitate the needs of these individuals who are at most risk of social isolation.

Building on the significant international and national evidence base on the information needs and preferences of older people, this study contributes a new evidence base on the information pathways of older people undergoing transition times in Ireland. The pathways employed by participants to access information on essential services at their time of need demonstrate the significant challenges faced by older people during such transition times. This study found that negotiating access to services and entitlements as an older person during a transition time is a complex and often unsuccessful task. This is reflected in the diversity of pathways that older people use in their pursuit of accurate information. Findings in this study also highlight the individual struggles of participants when attempting to access public service information. Participants reported how a lack of access to timely and accurate information has caused them undue stress, increased their frustration with public services and compromised their quality of life. It has also evidently contributed to the social isolation of some of the participants. Passive information provision through a

narrow range of mediums, discriminates against those who are not in a position to access information for themselves, thereby leading to an increasingly dependent older population. This will emerge as a key challenge as the resultant demand for social care and health care services increase with the ageing population. This study highlights the need to substantially improve information provision to older people in Ireland, to provide clear guidelines on entitlements to public services and to consequently increase accessibility to those public services which older people are entitled to. A pro-active approach to information provision targeting specific transition times in later life would lead to a more 'informed' older population with improved access to public services, supporting them to maintain independence and a good quality of life as they age.

Limitations and areas for further research

While this study endeavoured to cover the most significant range of transition times encountered in the older population, it was not possible to fully explore all transition times as identified in Ruddle et al. (2002). Those transition times that require further exploration include information on access to pension, bereavement and moving into public long-stay services. The information pathways of older men were under represented in this study as it was difficult to access male participants. During the course of the study, it emerged that males were more willing to discuss their information pathways in the presence of their spouse. This is an important consideration when designing future studies. The majority of participants had some contact with local service providers. There may then be a difference in the experiences of those who have had no linkage with local services. The specific needs of older people with sensory impairment are important and require further investigation, which was beyond the scope of this research.



7 Recommendations

1. Pro-active systematic approach to public service information provision

Public services should adapt a pro-active systematic approach to providing information to older people: this should be housed within an overarching policy of 'information for all'. This systematic approach should ensure that all service providers are fully informed on the appropriate pathways to direct older people to the services they are seeking adopting a 'no wrong door' approach to providing information on services. Services should target information towards older people to ensure that they are receiving the information required to enjoy a good quality of life. Ensuring that reliable information on public services is getting through to older people who need it at critical times will enable older people to become informed citizens. This is likely to have preventive benefits and increase the ability of older people to maintain independent living.

2. Holistic approach to information provision

Addressing the wider variety of information needs and providing access through older people's information channels of preference is a complex process that will require sustained effort on behalf of public service providers. It is essential that the two domains of information needs of older people: 'continuous' information and 'context specific' information based on transition times are facilitated within this process. This is likely to lead to a more empowered older person who will be in a position to negotiate services to access relevant information at critical times in later life.

3. Appropriate formats of information for older people

To ensure an informed older population, public services should provide information through appropriate formats for older people, including written materials and direct access to informed service providers. While providing web-based information may be an effective mode of information provision for many demographic groups, this may lead to increased social exclusion of older people. Web based sources should compliment existing information pathways of older people rather than replace them. The provision of information to older people should acknowledge that older people are not a homogeneous group, however adopting an information-for-all approach would ensure that older people's needs are catered for.

4. Streamlined information provision – multiple pathways, multiple access points, one coordinated approach

Information pathways of older people are complex and variable, dependent on a variety of factors including the transitions the individual is facing, past experiences, social connectedness and individual preferences. Public service information provision needs to be responsive to these complex information pathways and adaptable to ensure that older people's information needs are facilitated at multiple points during the older people's pathways to information. Older people should be guided through the services to ensure that no matter what point they attempt to access information on services they will be provided with the appropriate information in an efficient manner.

5. Appropriate targeting of information

Information on public services should be targeted to those most in need. This ensures that isolated older people have equal access to information and that services adopt a pro-active approach to informing difficult to reach older people. It is acknowledged that even with a quality information provision service, older people may still encounter difficulties in accessing information on public services. Therefore further support should be provided to assist such older people in accessing the information and services they require. Attention should be paid to the role of advisors and advocates in assisting older people to negotiate public services. There is increasing evidence that developing social networks is an effective way to widen access and improve information about services targeted at older people. It is important that 'key imparters' and other actors in the pathways to information for older people are well informed to ensure that older people will receive accurate information through informal channels.

6. Empowering older people

Equipping older people with the skills necessary to negotiate information on public services and ensuring that all older people become informed with regards to public services would remove the struggle that many older people encounter when accessing public services. Ensuring that older people are in a position to assess their own entitlement to services would remove the anxiety that many older people have in relation to their entitlements being curtailed or withdrawn. Equality of access to information on public services would ultimately lead to greater service uptake. Adopting an active ageing approach in line with the United Nation's principles of independence, participation, dignity, care and self-fulfilment, will ultimately empower older people and promote independent living and a reduced dependency on public services in later life.

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9 Appendices

Appendix 1 · Demographic Questionnaire Older & Bolder · Research Project

1. Participant name

First name _____ Family name _____

2. Gender

Male _____ Female _____

3. In what month and year were you born?

Month _____ Year _____ or

Date of birth ____ / ____ / ____

4. What is your marital status?

1. Married _____
2. Living with a partner as if married _____
3. Single (never married) _____
4. Separated _____
5. Divorced _____
6. Widowed _____

4. What is the highest level of education that you have completed to date?

1. Some primary (not complete) _____
2. Primary or equivalent _____
3. Intermediate/junior/group certificate or equivalent _____
4. Leaving certificate or equivalent _____
5. Diploma/certificate _____
6. Primary degree _____
7. Postgraduate/higher degree _____
8. None _____

5. Did you complete any education as a mature student?

No _____ Yes _____

..... If yes, describe

6. Were you born in the Republic of Ireland?

Yes _____ No _____

7. Are you currently living in a(n):

Rural area _____ Urban area _____

8. Are there other individuals living in your household?

1. Spouse/partner _____
2. Child _____
3. Other relative _____
4. Other individual _____
5. Individual living in other family members home _____
6. Other _____

9. Can you describe your current work or retirement status?

1. Retired _____
2. Employed _____
(including unpaid work in family business, temporarily away from work, or participating in apprenticeship or employment programme – such as Community Employment)
3. Self-employed _____
4. Unemployed _____
5. Permanently sick or disabled _____
6. Looking after home or family _____
7. In education or training _____
8. Other (specify) _____

10. If currently retired.....What was your work status before retirement?

1. Employed _____
give job title: _____
(including unpaid work in family business, temporarily away from work, or participating in apprenticeship or employment programme – such as Community Employment)
2. Self-employed _____
3. Unemployed _____
4. Permanently sick or disabled _____
5. Looking after home or family _____
6. In education or training _____
7. Other (specify) _____

11. Can you please describe your current living situation?

1. Living in owner occupied house _____
2. Living in a rented property _____
3. Living in assisted living accommodation _____
4. Other _____

12. Who in your household takes responsibility for accessing information on public services?

Self _____
Other (describe) _____

Thank you!

Appendix 2 · Participant Information Letter

Older & Bolder · Research Project

Invitation to participant in a project on 'Mapping Information Pathways – a research study examining older peoples' information pathways to public services'.

Dear participant,

I am a researcher working on behalf of Older & Bolder, a national organisation representing older people. Older & Bolder is an alliance of non-governmental organisations that champions the rights of all older people, and seeks to combat ageism. During the 2010 Older & Bolder national campaign many older people throughout the country spoke of issues they experienced when accessing public services. The most significant issue was getting the right information on public services at a time when they needed it.

There has been some research work already completed on the information needs of older people. This work highlights the importance of 'transition times' in people's lives when they need to access specific information relating to their individual situation. These times include:

- | | | | |
|---|-------------------------------------|---|--|
| 1 | When reaching retirement age | 7 | When returning to work/education |
| 2 | When becoming functionally disabled | 8 | When a security breach or other traumatic event is experienced |
| 3 | When developing an illness | 9 | When returning to Ireland from abroad. |
| 4 | When needing long-term care | | |
| 5 | During or after a bereavement | | |
| 6 | When becoming a carer | | |

Older & Bolder are now conducting this research study to explore the experiences and preferences of people when accessing information on the public services they require when going through one of the transition times referred to above.

As a study participant, you are being requested to consent to a 45-minute interview on your experiences of accessing information on public services. The interview will be tape-recorded but your identity will remain anonymous. If you take part in an interview, all that you say will be merged with what other interview participants have said. The conversation in the interview will be used as findings to inform the overall report for Older & Bolder. We guarantee that your interview will be anonymous and your identity will be confidential. You are free to choose whether or not to participate in the study, however I would encourage you to contribute to this very important study for older people.

If you have any questions about participating in the study please contact me directly on X.

Yours sincerely,

Researcher

Appendix 3 · Informed Consent Form

Older & Bolder · Research Project

To participate in an interview for 'Mapping Information Pathways – A research study examining older people's information pathways to public services.

Background:

Older & Bolder is an alliance of non-governmental organisations that champions the rights of all older people, and seeks to combat ageism. During the 2010 Older & Bolder national campaign many older people throughout the country spoke of issues they experienced when accessing public services. The most significant issue was getting the right information on public services at a time when they needed it. Older & Bolder are requesting your consent to participate in a study to explore older people's individual experiences of trying to access relevant information to allow them to make informed decisions.

If you are willing to take part, please sign and return this consent form to the researcher. The interview will last less than 45 minutes and you must only take part if you feel that you are fit and well enough to do so. The attached information sheet outlines the study in more detail. If you require further information or if you have any questions about this study please contact [researcher] on [telephone number].

Declaration:

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I have received a copy of this agreement.

I understand I may withdraw from the study at any time.

Participant's name: _____

Contact details (please choose desired method of contact):

Phone: _____

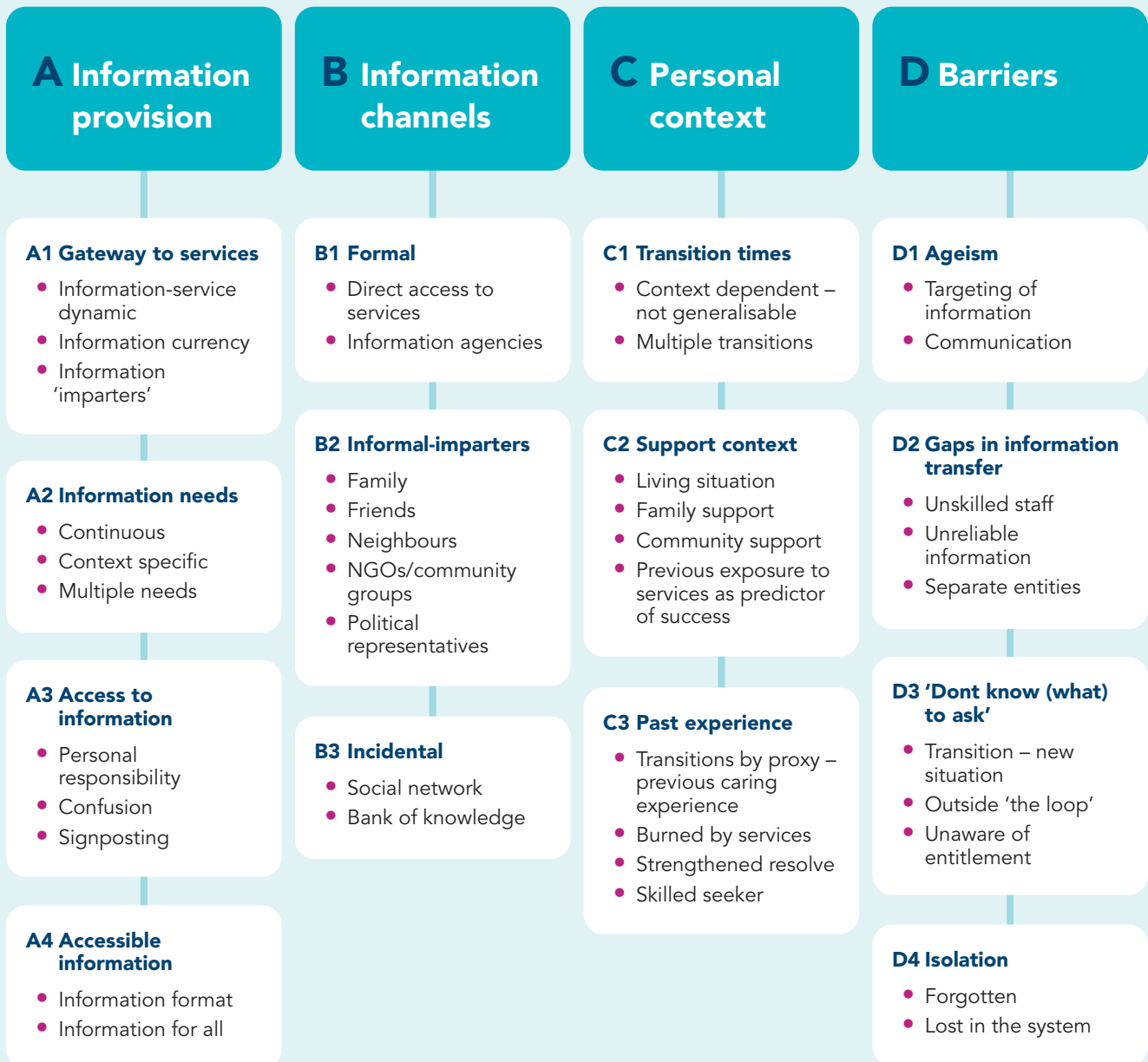
Email: _____

Participant's signature: _____ Date: ____ / ____ / ____

Statement of investigator's responsibility: *I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.*

Investigator's signature: _____ Date: ____ / ____ / ____

Appendix 4 · Framework Analysis Diagram





Support equality for older people

Jervis House
Jervis Street
Dublin 1

Tel: 01 878 3623
Email: info@olderandbolder.ie
www.olderandbolder.ie

