



Evaluation of a Healthcare Passport to improve Quality of Care and Communication for People with Dementia (EQuIP)

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Funded by: Health and Social Care R&D Division of the Public Health Agency and The Atlantic Philanthropies

(January 2015 – October 2017)



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Executive summary

Background

Increasing numbers of people will experience dementia, as many as one in three people who reach the age of 80 years. These later years of life are also likely to be impacted by other health problems. How to better support people living with dementia and multiple comorbidities is a major challenge to the individual and their families. It is also an increasing problem for health and social services, particularly so when demand is high and resources are shrinking. It is long recognised that specialisation and fragmentation in health and social care is inefficient and may give rise to suboptimal patient outcomes. There is a need for interventions that assist people living with dementia to navigate treatment and support in ways that are 'joined-up' and enhance their autonomy and dignity. Healthcare passports are available for different patient groups but their acceptability and usefulness in dementia care has not been assessed.

The Northern Ireland Public Health Agency in collaboration with the Royal College of General Practitioners and the voluntary sector in dementia care, developed a 'Healthcare Passport' held by patients and family carers which was designed to provide essential knowledge and information between people living with dementia, their families, and the full range of services with which they are in contact. A key function of the healthcare passport is to support those who are living with dementia and their carers in the work of self-management. The passport aims to stimulate among health and social care professionals a sense of the personhood of the individual with dementia. In its current design, it is constructed to allow a compendium of information about the person with dementia such as their close family members and friends, activities, interests, and beliefs. Quality of life has been recognised as a significant indicator of the impact of interventions for people living with dementia, and as a primary objective of dementia treatment. Improving quality of life for people living with dementia, particularly those with complex physical health problems, may depend upon the communication of their needs, strengths and life situation. Unfortunately, people living with dementia still find communication with, and between, health and social care professionals lacking.

Aims

- (1) To contribute to the evidence base on the use of services, communication needs and decision-making processes of people living with dementia as these unfold over time.
- (2) To examine the true practical potential of a healthcare passport for people with dementia and their family carers and to consider how it may be improved.

- (3) To provide a more highly grained, multiple perspective, understanding, of the potential implementation issues for a full evaluation trial.

Method

As a component of a feasibility assessment of a dementia healthcare passport, we undertook a realist review of the evidence. This approach seeks to provide a more explanatory analysis of the evidence on what works, for whom, in what circumstances and why. The assumptions behind interventions designed to enhance communication and information sharing for people living with dementia was explored by means of stakeholder interviews and a realist review of the literature. The review was carried out in 3 stages. The first stage involved a stakeholder (academic and 'experts-by-experience') engagement to gain their perspectives on the potential utility of a healthcare passport and to elucidate possible underlying theoretical assumptions of the healthcare passport i.e. what are the intended or implicit outcomes of this approach, and by what means will these be achieved. The second stage of the review explored the research evidence to examine if a patient-held 'healthcare passport' might be acceptable and useful for people living with dementia, for whom and in what circumstances. This stage explored patients', carers' and professionals' experiences of using tools for communication and information-sharing. The third stage of the review used findings from the realist review findings to inform design of the feasibility study and the implementation strategy for the health passport.

For the evaluation, we used a qualitative longitudinal study to examine the experiences of a purposive sample of people living with dementia and their family carers and their use of the healthcare passport at different time points. We explored barriers and facilitators of the use of the passport with other service user groups and with healthcare professionals. We also examined General Practitioners' views on the passport. Additionally, we undertook a realist review of communication tools in healthcare that may be relevant to dementia care. This approach is a relatively new but rigorously inclusive method of examining the mechanisms, often hidden, that effect positive (or negative) outcomes in a programme.

Findings

The review found that shared information and standardised systems between different providers and clinicians, even within the same organisation, are rare or provided sub-optimally. Beyond advanced care directives or planning in palliative care, only a small number of tools such as the healthcare passport currently have been developed for people living with dementia. In other clinical areas where patient held records have been used, the evidence of their effectiveness is somewhat

limited. In line with other findings we noted a general failure within dementia studies to comprehend the complexities of living with dementia, and thus, the need for multifactorial interventions to assist communication and effective care. The qualitative longitudinal study found that while the passport, at a very general level, is acceptable to people living with dementia, and considered as potentially worthwhile, there are various barriers that deter more effective and widespread usage.

- General facilitators of passport use include a strong patient-carer dyad, moderate to advanced dementia, good quality of care, manageable comorbidities, and family support. The barriers to effective passport use included patients living on their own, early stage dementia, carers feeling 'overwhelmed' by the diagnosis or the daily concerns of caring, and anxieties about data protection and confidentiality.
- The passport requires more clarity about 'ownership' – we found that it is predominantly held and used by the family caregivers.
- The response of people with dementia and their carers is often determined by how recently they have received a diagnosis of dementia and/or the severity of the symptom. At early stages, the passport is deemed unnecessary, at later stages where the carer assumes greater control, it is sometimes regarded as an additional burden.
- Preparation for, and engagement of, health and social care professionals is essential to effective implementation of the passport. The negative or 'lukewarm' response by clinicians dampened or quashed further use by families. Patients and family carers need assurance that the passport is widely known and used by health and social care staff, with greater clarification of how it may be of benefit to them.
- There are concerns that medical information must be reliable, accurate, and follow a standardised format to ensure consistency and completeness. An additional electronic version may have advantages over the current 'hard-copy' version, including easier access for some. It may also enable accurate dating, data protection, and legibility.
- In order to safeguard personhood and improve communication all health and social care professionals require training and assigned time within patient consultations to engage with the passport.

Conclusion

The realist review highlighted the importance of taking a person-centred approach to understanding individual needs and contexts when implementing the healthcare passport. The aims (and thus content) of healthcare passports should be clarified and agreed with the full range of stakeholders.

The pivotal position of key family caregivers must be acknowledged and their contribution to the passport made explicit. Considerable preparation (e.g. training and publicity) within and across services and health professionals is necessary to facilitate good uptake of the passport.

The evaluation found the purpose and potential advantages of the Healthcare Passport are reasonably appreciated by people living with dementia. Our study has uncovered the significant contexts and mechanisms which must be considered before a more effective and widespread implementation of the passport is undertaken. While it does not constitute a stand-alone solution to current problems in dementia care, with some alterations, and with health and social care professionals' knowledge and understanding of the passport and its purpose, it has the potential to improve quality of life for the patients and carers. The introduction of the passport in itself cannot and will not bring about positive change. Retaining personhood, improving communication and promoting self-management require the commitment and dedication of all health and social care professionals, in collaboration with family carers and patients. Policy and practice implications are discussed and recommendations made for changes at systemic level necessary to achieve these aims. They include, but go considerably beyond, changes to the current version of the Healthcare Passport.

Acknowledgements

We are tremendously grateful to all of the participants in this study who let us into their homes and their lives and offered their experiences, openly and generously. We thank the staff at the memory clinic, especially Alison McCallion and all the members of the Alzheimer's Society community groups who provided very helpful comments and suggestions. We also wish to thank the Royal College of General Practice who have supported the study throughout.

Abbreviations

| | |
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| AD | Alzheimer's Disease |
| AS | Alzheimer's Society |
| EOAD | Early onset Alzheimer's Disease |
| EPO | Engagement and Participation Officer |
| GP | General Practitioner |
| HCP | Health care professional |
| HP | Healthcare Passport |
| HSCP | Health and Social Care Professional |
| JCP | Joint Crisis Plan |
| LD | Lewybody Dementia |
| OT | Occupational Therapist |
| PADs | Patient advance directives |
| PCC | Person centred care |
| PD | Parkinson's Disease |
| PHA | Public Health Agency |
| PHA | Public Health Agency |
| PHCHR | Parent-Held Child Health Record |
| PHR | Public health records |
| PLWD | People living with dementia |
| QLR | Qualitative Longitudinal Research |
| QoC | Quality of care |
| QoL | Quality of life |
| RCGP | Royal College of General Practitioners |
| SMS | Self-Management Support |
| WHST | Western Health and Social Care Trust |

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SECTION 1: BACKGROUND TO EQUIP STUDY

Increasing numbers of people across the world will experience dementia. How to better support people living with dementia is a major health and social care challenge. In the UK alone it is estimated that dementia care and treatments incur an annual cost of £17billion [1], more than cancer, stroke and heart disease combined [2]. Over the next 40 years, as our society ages, dementia will become more common in Northern Ireland. Approximately 19,000 people currently live with dementia, a number projected to rise to almost 60,000 by 2051, the fastest expected rate of increase in the UK [3]. As our society ages, health and social care expenditure on services for PLWD could be expected to double within 20 years. In 2013/14, the cost of acute care (in-patient and day case only) for PLWD in Northern Ireland was £913,091 [4]. The Northern Ireland government's *'Improving Dementia Services in Northern Ireland: A Regional Strategy'* [3] underlines the importance of proactive, seamless and accessible services, that adopt person-centred care (PCC) principles, where families and carers are 'well informed and supported' [3].

We require new and imaginative ways of living with and managing dementia care so that people living with dementia ('PLWD') can lead full and meaningful lives and receive high quality, coordinated, and person-centred care. Ideally, PLWD and their families should play an essential role in determining the kinds of services that are needed and also, when and how these are provided. Currently, this may not be the case for many people [5].

When dementia is accompanied by multiple and complex health problems, care and treatment can often be experienced as disjointed, with people being moved between services in a somewhat compartmentalised and fragmented process and with limited consultation with patient and their carers [6]. This may become more distressing during episodes of illness and injuries, or where there is accelerated cognitive and functional challenges, adverse events and hospitalisation [7, 8]. Almost by definition, contact with multiple medical services reduces the likelihood of receiving holistic care and diminishes personhood, defined by Kitwood [9] as "a standing or status that is bestowed upon one human being by others, in the context of relationship and social being". It has been argued that what it is to be a person is central to our understanding of person-centred care. Kitwood suggests that even the best services may be unintentionally complicit in the disablement and marginalisation that is often associated with dementia [10]. In this context, modern medical care is increasingly regarded as mechanistic and lacking compassion [11]. The Alzheimer's Society states that a person-centred approach should "see the person with dementia as an individual, rather than focusing on their illness or on abilities they may have lost. Instead of treating the person as a collection of symptoms and behaviours to be controlled, person-centred care considers the whole person, taking

into account each individual's unique qualities, abilities, interests, preferences and needs". Families may play a key role in ensuring that these aspects are acknowledged and upheld.

1.1 Families, service contact and decision-making

Maintaining the autonomy and independence of PLWD is of central importance. However, in most instances of help-seeking for healthcare needs, people tend to obtain support from other family members [12]. Unfortunately, navigation through the different layers and agencies of health and social care is often difficult and stressful, especially so in the midst of complex and changing health needs. Thus, supporting families in caring for relatives with dementia must be a pivotal element of any national strategy [13-15]. While family and friends are generally willing to provide an extraordinary range of informal caring which would otherwise be carried by public and charitable services, [15, 16] their support can be taken for granted by professionals. However, while many family caregivers derive satisfaction from doing so, they are likely to experience disruption to their own working and family lives in order to attend meetings with doctors and care staff. Evidence from our consultation with carers and supported by research evidence reveals a weary resignation of having to explain and negotiate care with an ever-changing cast of professionals. Families of PLWD are known to face greater emotional and physical strain than do those caring for people with other illnesses ([17-19]. Where there is strain, this is likely to be compounded by challenges to knowledge and help-seeking in dementia care, difficulties of communicating need and decision-making. A recent European report highlighted the need for person-centred care, communication and shared decision-making, continuity of care and family care and involvement [20].

In the UK, recent evidence from primary care revealed that family members (not professionals) were the main care coordinators, and that transitions between services -for example from specialist care to general practice were challenging [21]. It is acknowledged that families of PLWD require support to help them in their role as proxy decision-makers. However, families of patients with complex needs are often daunted and distressed by a health and social care system perceived as poorly integrated. A recent national report by the Royal College of Psychiatrists indicated a lack of advice, information and support on legal matters such as power of attorney, welfare benefits, advance directives and managing finances [22]. Poor provision of information by services to family carers is recognized as a major determinant of low satisfaction [23, 24]. However, when and how to provide information is unclear [25]. Our own study indicated the difficulties that family carers face related to various aspects of organizing care and areas of decision-making for relatives with dementia [26]. The challenges included, contradicting the demands of the family member, gaining permission to receive confidential information, negotiating referral to specialist services, and obtaining professionals'

agreement. Family carers sometimes describe frustration with services and the person for whom they are caring, increasing isolation and diminishing self-esteem [26] some of which can be attributed to lack of information and service contact. Thus, family carers may feel that they lack the knowledge and competence to deal with their family member's needs or how to seek appropriate help [27, 28]). There have been attempts to address service barriers through care planning strategies but their use is generally confined to hospital and hospice settings [29]. Thus, they are likely to neglect the full range of possible contacts between PLWD, families and healthcare agencies at different stages of illness. Moreover, interventions designed to improve communication between PLWD, family carers and clinicians may be overly focused on clinical decisions and pathways, to the neglect of person-centred approaches, which encompass the personhood of the individual (e.g. personal history, habits, social, spiritual and emotional) [30][32].

With a growing population of PLWD we need better-integrated health and social care, which purposefully facilitates the involvement of families. In addition, there is a need to develop interventions that improve care planning and support for PLWD and family carers. Evidence supports the use of well-designed psycho-educational or multi-component interventions for caregivers of PLWD [31]. The factors that appear to positively contribute to effective interventions are those which: provide opportunities within the intervention for the person with dementia as well as the caregiver to be involved; encourage active participation by caregivers; offer individualised programs and provide information on an ongoing basis, with specific information about services and coaching regarding their new role [32].

1.2 The importance of communication

The quality of life for people living with dementia (PLWD) may be improved by communication of the individual's needs, their strengths and their life situation to the various health and social care services. However, research has increasingly identified that communication with, and between health, and social care professionals is increasingly experienced as poor[33]. Adopting a realist synthesis approach, Bunn et al [33] combined the findings from (a) a scoping review of the literature, (b) secondary analysis of population cohort databases, and (c) interviews with PLWD, their family carers and health care professionals working with different conditions (e.g. stroke, diabetes, visual impairment). Their review found a lack of continuity in health-care systems for PLWD and comorbidity, with little integration or communication between different teams and specialities. PLWD were found to have had poorer access to services than those without dementia. The analysis of a population cohort database found that 17% of PLWD had diabetes, 18% had had a stroke and 17% had some form of VI; and an increase in the use of unpaid care for PLWD and comorbidity over the last decade. The research literature and consultations found that communication was often

poor, with an absence of a standardised approach to sharing information about a person's dementia and how it might affect the management of other conditions. Although HCPs acknowledged the vital role that family carers play in managing health-care conditions of PLWD and facilitating continuity and access to care, this recognition did not translate into their routine involvement in appointments or decision-making about their family member. Whilst the study found some examples of good practice, these tended to be about the behaviour of individual practitioners rather than system-based approaches; current systems may unintentionally block access to care for PLWD. Notably, Bunn et al found that people living with dementia, family carers and HCPs all gave examples of poor information transfer between systems and specialities. During the interviews family carers described facilitating information continuity by collating records and actively transferring information between HCPs and different services. Both carers and PLWD expressed levels of frustration from having to repeat the same information to different HCPs.

Several of the HCPs interviewed by Bunn and colleagues recognised that the organisation of services around single diseases was a problem for PLWD with complex health needs. The authors noted that current infrastructure is unable to assist the exchange of information; limited integration of mental and physical health services and different information technology systems, were barriers to medical records sharing, even within the same health care organisation. Health-care professionals from all specialities suggested that PLWD could have a hand-held record to take to appointments, similar to the ones carried by people with learning difficulties. But it was clear that HCP had limited awareness of patient-held records specially developed for PLWD or their carers.

Negotiations between services and clinicians have been described as inconsistent or repetitive, time consuming and error prone. Staff shortages and 'lone working' combined with increasing 'silo working' across different clinical and social services, mean that 'holistic' or person-centred approaches can be more difficult to achieve [34]. Moreover, the depersonalisation of the individual is regarded by many commentators as contributing to the erosion of compassionate care in our health services. Integrating the health care experiences of patients and caregivers into health service planning should ensure that their needs are met and that person-centred care is provided [35, 36]. Information about preferences for services and service delivery should be conveyed by service users. Individual needs may be facilitated through matching available services to patient treatment preferences, improving patient outcomes and satisfaction without increasing costs.

While, maintaining the autonomy and independence of people with dementia for as long as possible is crucially important, families continue to play a vital supportive role, particularly in contacting

services [12]. Unfortunately, obtaining appropriate and timely help can be difficult and stressful, especially in the midst of complex and changing health needs. However, while families must be integral in national dementia strategies [13-16] they are often taken for granted by professionals. Evidence from our consultation with carers and supported by other research studies reveals a weary resignation of having to explain and negotiate care with an ever-changing cast of professionals, compounded by challenges to knowledge and help-seeking in dementia care, difficulties of communicating need and decision-making [26, 37]. A recent European report, highlighted the need for person-centred care, communication and shared decision-making, continuity of care and family care and involvement [20]. Poor provision of information by services to family carers is recognised as a major determinant of low satisfaction [23, 24]. However, when and how to provide information to family caregivers is unclear [25]. Our study indicated the difficulties that family carers face related to various aspects of organizing care and areas of decision-making for relatives with dementia [26]. Family carers may feel that they lack the knowledge and competence to deal with their family member's needs or how to seek appropriate help [27, 28].

Attempts to address service barriers to communication by improved care planning strategies are generally confined to hospital and hospice settings [29], and thus are likely to neglect the full range of possible contacts between people with dementia, families and healthcare agencies at different stages of illness. Where interventions are designed to improve communication between people with dementia, family carers and clinicians have been developed, many tend to be overly focused on clinical decisions and pathways with less focus on person-centred approaches encompassing the personhood of the individual (e.g. personal history, habits, social, spiritual and emotional)[30]. However, Manthorpe and Samsi [36] expressed concern about the "elastic" quality of person-centred care by which the core elements of person-centered care appear to cover almost every aspect of care that are highly prized and thus, difficult to reject. Thus, over time person-centred care embraces self-management and shared decision-making, improving information provision, family involvement, peer support and attention to environment.

More effective care of people with dementia requires better-integrated health and social care, which purposefully facilitates the involvement of families. In addition, there is a need to develop interventions that improve care planning and support for people with dementia and family carers. Evidence supports the use of well-designed psycho-educational or multi-component interventions for caregivers of people with dementia [31]. The factors that appear to contribute positively to effective interventions are those which:

- provide opportunities within the intervention for the person with dementia to be involved;

- encourage active participation by caregivers; and
- offer individualised programs and provide information on an ongoing basis, with specific information about services and coaching regarding their new role [32].

1.3 A potential intervention - the NI Healthcare Passport for dementia

The Northern Ireland Public Health Agency (PHA), in collaboration with the Royal College of General Practitioners (RCGP) and the voluntary sector in dementia care, has developed a 'Healthcare Passport' ('HP'); held by patients and family carers. The HP is designed to provide essential knowledge and information between PLWD, their families, and the full range of services with which they are in contact. A key function of the HP is to support those who are living with dementia and their carers in the work of self-management ([38, 39]. In the context of an illness such as dementia, it includes the core involvement of family and carers [40] and potentially of wider communities in managing the adaptive challenge of maximising an individual's daily wellbeing while living with evolving illness. Richard and Shea [41] define it as "the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions". The HP has been designed to facilitate this process by acting as a conduit of the evolving key information, which is needed by an individual with dementia and their support network at differing stages of their illness journey. Crucially, the HP aims to stimulate among health-, and care professionals a sense of the personhood of the individual with dementia. In its current design, it is constructed to allow a compendium of information about the person with dementia such as their close family members and friends, activities, interests, and beliefs. It will also provide brief but key information about dementia.

Other sections are available to encourage the entry of information from health and social care professionals; these include information on co-morbid diagnoses, medication, and other treatments. It is designed to allow continuous updating by family and health-, and care professionals, and is therefore, intended as a 'live' synchronized record of changing need, service contact and information provision. While the content of the healthcare passport has been thoroughly discussed by professionals, PLWD and caregiver stakeholders, its implementation and use require evaluation. The study allowed us to examine how the HP works in the 'real world' of PLWD and as they engage with a range of health and social support services. Ultimately, the healthcare passport requires an evaluation by a randomized controlled trial but as a complex intervention this will require detailed and systematically recorded information relevant to its implementation [42].

Quality of life ('QOL') has been recognised as a significant indicator of the impact of interventions for

PLWD [43] and as a primary objective of dementia treatment. Improving the QOL for PLWD, particularly those with complex physical health problems, may depend upon the communication of their needs, strengths, and life situation. Unfortunately, people living with dementia still find communication with, and between, health and social care professionals lacking. Commonly, shared decision-making and planned care is either minimal or absent, a situation that is wasteful and likely to lead to poor outcomes for the individual with dementia and their families. Additionally, services may neglect the personhood of the individual, eschewing the personal, spiritual and social characteristics of significance from treatment and care. However, there is much that can be done to address these problems. There is an urgent need for the development of simple communication tools that convey clearly the strengths, assets and total healthcare needs of the individual with dementia while at the same time providing a strong sense of personhood to which the health and social care professionals will respond.

The HP will help to carry significant aspects of the individual's life and provide meaningful information between people living with dementia and the health and care services with which they are in contact. The key purposes of such a document are: (1) To help people living with dementia clearly communicate their social, health, and spiritual needs to a range of health and social support services in a way that enhances quality and continuity of care; (2) to allow people living with dementia the opportunity (if wished) to consider in some detail the challenges which their illness may bring, and to articulate preferences about how these challenges might be managed. The HP aims to embed these views and choices into the patient's documentation, so that it can be accessed and reviewed by them and by their healthcare team, as the course of their illness unfolds. While the concept and the content of the HP have been praised by various stakeholders, such tools need to be grounded in the everyday realities of the experience of dementia so that we can develop a deeper understanding of how integrated care can be negotiated across health and social care boundaries.

1.4 Aims and objectives

Our aims in this study were two-fold. First, the findings hope to make an important contribution to the evidence base on the use of services, communication needs and decision-making processes of PLWD and their family caregivers as these unfold over time. Secondly, the study findings should help us understand better the true practical potential of a HP and how it may be improved. The study also provided a highly grained understanding of the implementation issues for a full evaluation trial from multiple perspectives. It provided robust evidence of proof-of-concept for the HP. Adopting a realist review approach, we sought to examine the theoretical underpinnings of the healthcare passport in dementia care and to consider research findings from other clinical areas on patient-held records.

The longitudinal qualitative evaluation explored the acceptability and usability of the healthcare passport (see Box 1 for detailed evaluation questions)

Box 1 Evaluation Questions

Is a HP acceptable and useable for people with dementia, their family caregivers and health professionals?

1. Is a sense of 'personhood' in the midst of dementia conveyed by the use of HP?
2. Will the use of a HP help overcome problems of communication between people with dementia and health and care services?
3. Will a HP empower and support the autonomy and decision-making of people with dementia and family carers?
4. What is the level and quality of engagement with such a HP by health and social care professionals?
5. How do the needs of people with dementia and their family carers, with regard to service contacts and communication, evolve over time?

The overall objectives of this study were:

- (1) to undertake a realist review of communication and integrated health and social care for PLWD and family caregivers (reported in Section 2)
- (2) to examine the efficacy of a healthcare passport for people living with dementia and their family carers (reported in Section 3)
- (3) The evaluation sought to provide information about:
 - a. how this tool is used over time;
 - b. the engagement of relevant service providers;
 - c. the barriers to information and communication between and among family carers and H&SC professionals and how these can be remedied; and
 - d. how to refine and/or deliver the HP and similar interventions.

1.5 Patient and Public Involvement (PPI)

The healthcare passport was developed with the support of many community and voluntary sector agencies involved in promoting the health, wellbeing, rights and welfare of people with a range of long-term and life-limiting conditions, many of whom were directly involved in the development of the 'passport'. We have engaged with people who live with dementia and their carers from the conception of the current evaluation through to the recommendations for improvement in design

and roll-out. Thus, at the beginning of the project, we consulted with people with dementia and the people who are important to them about the challenges within the health and social care systems and of dementia, more widely. The very rich, sometimes painful, sometimes humbling, views and experiences of people living with dementia as participants have been recorded throughout the project. The Alzheimer's Society also helped us establish workshops with people with dementia and their family caregivers and these groups contributed substantially to an understanding of the passport and potential improvements.

1.6 Structure of Report

The findings from the study are presented in two sections. Section 2 presents the methodology, findings, and emergent recommendations from the realist review. Section 3 presents the findings from the longitudinal qualitative evaluation of the healthcare passport.

SECTION 2: THE REALIST REVIEW

2.1 Methodology

In recent years the realist reviews have been increasingly used to inform the design and evaluation of complex interventions [44]. Realist reviews seek to unpack the relationships between context (C), mechanism (M) and outcomes (O) of interventions i.e. how particular contexts have triggered (or interfered with) mechanisms to generate the observed outcomes. Thus, the realist review is an analysis of the evidence seeking to understand what works for whom, in what circumstances, and how. The core tasks required in such reviews are: thinking, reflecting; and interpreting [44]

Consonant with expert guidance on complex interventions [45] realist methodologies tend to favour multiple methods that combine qualitative and quantitative evidence on the appraisal of an intervention's processes and impacts. Pawson et al, [44] argue that "complex service interventions are theories" in as much they begin with a hypothesis that a programme will produce this or that outcome if delivered in a particular and specified way. Hypotheses of this kind are based on assumptions about what conditions or behaviours influence practice or policy. Thus, realist reviews highlight the theories upon which these and similar programmes are based. Importantly, complex (active) programmes work only through the knowledge, beliefs, preferences and rationale (interpretation) of various stakeholders, for whom, different things may be at stake. Moreover, from conception to execution, the journey to implementation requires the agreement and successful alignment of many relationships – the politics and power to achieve the required means and ends of a programme. The chief limitations of realist reviews include; (a) the need to prioritise which aspects of interventions to be examined; (b) constraints on the nature and quality of information e.g. access to unmeasurable behaviours such as 'hidden' power dynamics); (c) Recommendation constraints e.g. contextual advice about barriers and facilitators to implementation. As the health passport had a number of potential outcomes and its acceptability will depend on the engagement with, and the relationships between PWLD, family members, and a range of health and social care professionals, a realist review was considered the most appropriate methodology to inform the further development and evaluation of the dementia passport.

2.2.1 Review Purpose

The overall aim of the current realist review was to explore how the 'healthcare passport' might work in the 'real world' of PLWD as they engage with a range of health and social support services, by improving our understanding of the theoretical issues related to communication and the contextual issues that facilitate successful communication. In addressing this question, the primary source of evidence was derived from the evaluations of similar healthcare interventions on the use

of services, communication needs and decision-making processes of people with dementia and their family carers. The evidence from this body of literature will in turn assist in the refinement of the 'healthcare passport' and provide a more in-depth understanding of the implementation issues for a full evaluation trial from multiple perspectives.

The overarching question in this review was: What characteristics of healthcare-based communication tools work, for whom do they work, in what circumstances, and why?

2.1.2 Review approach

The realist review adopted the RAMESES standards for realist syntheses frameworks [46] encompassing four interlinked phases including:

1. Programme theory development;
2. Evidence retrieval, data extraction and synthesis;
3. Programme theory testing and refinement through the evidence synthesis; and
4. Development of actionable recommendations.

2.1.3 Programme theory development

Initially, the review process sought to identify the theories underpinning the healthcare passport through an iterative process of consultation with stakeholder groups (service users, family care-givers and health and social care service providers, voluntary and statutory) and discussions within our interdisciplinary team comprised three academic researchers (social science, social policy and psychology) and six health professionals from general practice, nursing, gerontology, palliative care and mental health. The consultations explored the implicit and explicit theoretical issues that underpinned the development of the passport. In addition, we held focus groups with service users and carers in order to explore the acceptability, content, and use of the passport. The in-depth discussions were carried out alongside a review of the literature. Following the consultation with stakeholders and the review of previous research on similar concepts, three theory areas were identified for greater exploration. These all related to communication approaches that were expected to enhance: 1) personhood; 2) integrated care; 3) therapeutic alliance and 4) self-management.

2.1.4 Search process

The realist review method is grounded in an eclectic evidence-based practice, continuously reviewed and synthesised to generate explanatory depth. As part of the searching process, a purposive literature search was undertaken in order to describe and scrutinize the programme theories

identified from the first stage of the review (programme theory development). For the search, a range of terms were compiled in relation to communication strategies and the use of a 'healthcare passport'. The intention of the purposive search was to ensure the inclusion of the most relevant material which had been indexed in all major health, social and dementia welfare databases, as well as the grey literature. Keywords used have been compiled based on group discussion and previous systematic reviews. Specific 'keywords' varied depending on the database searched. With the support of a Health Sciences Librarian, one of the members carried out searches of six online databases.

Box 2: Databases and search terms

| Databases searched | Search terms |
|------------------------|--|
| Web of Science | healthcare; passport; handheld patient record; healthcare |
| Medline | passport; patient-held records; family-held records |
| CINAHL | advance directive; advance care planning; self-management; |
| Embase | dementia; dementia care; Alzheimer's Disease; AD |
| PsycInfo | Communication; |
| Sociological Abstracts | Personhood; patient-activation; autonomy; |
| Grey literature | therapeutic alliance; care triad; decision making and integrated |
| Conference proceedings | care |

For the purpose of this review, the search strategies were kept as broad as possible (see Box 2). Some terms were combined and joined with the Boolean operator 'OR', to capture any instance of any term's use. These varying combinations of keywords intended to maximize sensitivity of the searches. Terms referring to communication strategies with the use of a passport were developed and incorporated into search strategies. Paying attention to relevance, searches were executed in May 2015 to cover the years from 2005 to 2015. We limited our searches to the previous 10 years, as this was considered an appropriate timeframe in the search for this type of intervention study. We also, manually searched the publication references for relevant individual papers that were part of a systematic review. In keeping with the iterative, theory-building approach of realist reviews, we introduced papers considered as informative to recommendations. A second team member reviewed the indexing terms and the databases searched, and team members reviewed the final references to ensure that the overall search strategy was executed appropriately. Details of the databases and search strategy are available in Figure 2.

2.1.5 Inclusion and exclusion criteria

Included in the review are reports of dementia specific workforce, practice and/or organisational development programmes and interventions (combinations of these may vary). Also, included is evidence supporting or rejecting the use of healthcare passports in other chronic and life-limiting conditions. Perhaps unique to realist reviews, we did not exclude evidence unless it was unrelated to the theories which were identified. The review was carried out with the intention of generating transferable evidence-based practice within the NHS system. The crucial realist criterion for inclusion in the review asks, is the evidence provided ‘good and relevant enough’ to be included [44]. Inevitably, there were some disagreements over the relevance of some articles. Thus, screening of articles was undertaken within the research team and involved discussion with the wider team members.

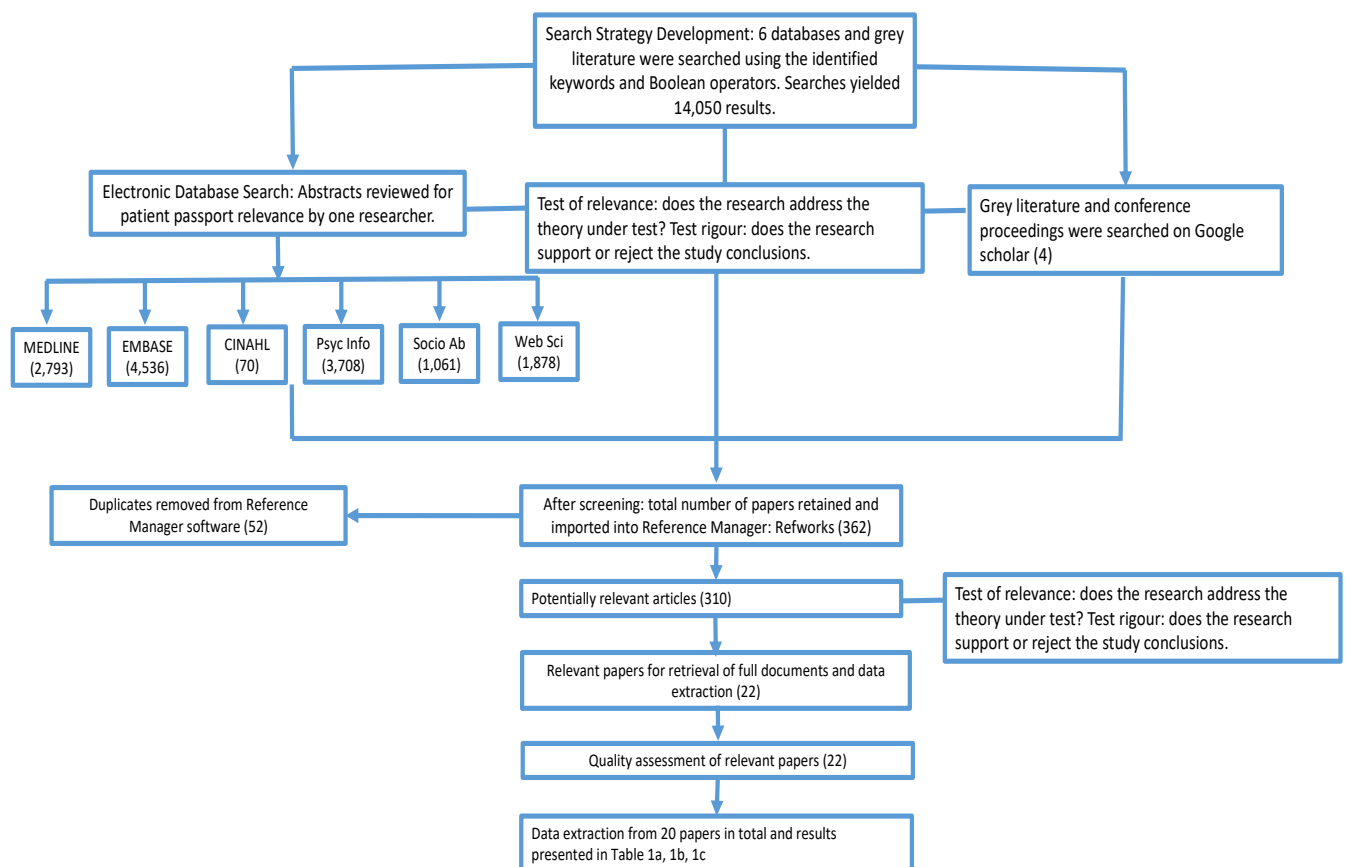


Figure 1: Search strategy and data extraction processes.

2.2 Review Findings

First, for the purpose of this realist review we have conceptualised the theoretical construction underlying patient passports. Second, the synthesis of evidence was intended to inform and clarify our understanding about conceptual, instrumental and the direct impact of communication tools.

2.2.1 Phase 1: Theoretical construction of the ‘healthcare passport’

A social model of disability describes separating impairment (what is wrong with a person) and addressing barriers which may lead to better inclusion in society [47]. For the development of services that promote meaningful inclusion, Barnes and Mercer [48] suggest that the social model goes beyond the level of individual psychology and interpersonal relations, bringing into its sphere of interest “a wide range of social and material factors and conditions, such as family circumstances, income and financial support, education, employment, housing, transport and the built environment, and more besides”. They also point out that the circumstances and contexts of people with disabilities are not static, and thus, disability has an ‘emergent’ and temporal character. It is essential that policy (e.g. health, environment, transport, education) and care systems are alert to changing needs. The social model of disability has been central to shaping self-management, in its inclusion of choice and control in services and support. Additionally, increasing involvement (of older people in general, of which many people with dementia are a sub-group) is grounded in the theory of critical gerontology. This perspective attempts to shift particular perspectives of older people as a burden on society, towards seeing value in their contributions to society [49].

Three overarching theoretical frameworks related to patient-held records or health documents were noted as a way of improving communication and outcomes. These theory-derived concepts can be tailored to the use of the ‘healthcare passport’. First, service user autonomy may be improved; (2) the therapeutic alliance can be strengthened; and (3) integrated care can be achieved, facilitating inter-agency working. Incorporating these concepts as underlying frameworks should affect the three levels of action [44] as prerequisites for successful implementation of a complex intervention. These levels are: (a) at the service user level; (b) at an intrapersonal level and relations between the patient, their informal carers, and clinicians (i.e. *the care triad*): and (c) patient activation may be promoted at an interpersonal level and at the level where care is organised. Through cross-referencing these three frameworks (see Figure 3) we highlight the levels of action which may support the ‘healthcare passport’ and the anticipated outcomes.



Figure 2: the expected benefits of the ‘healthcare passport’ intervention within its three levels of action and the three underlying theoretical frameworks



Figure 3: underlying assumptions about the 'healthcare passport'.

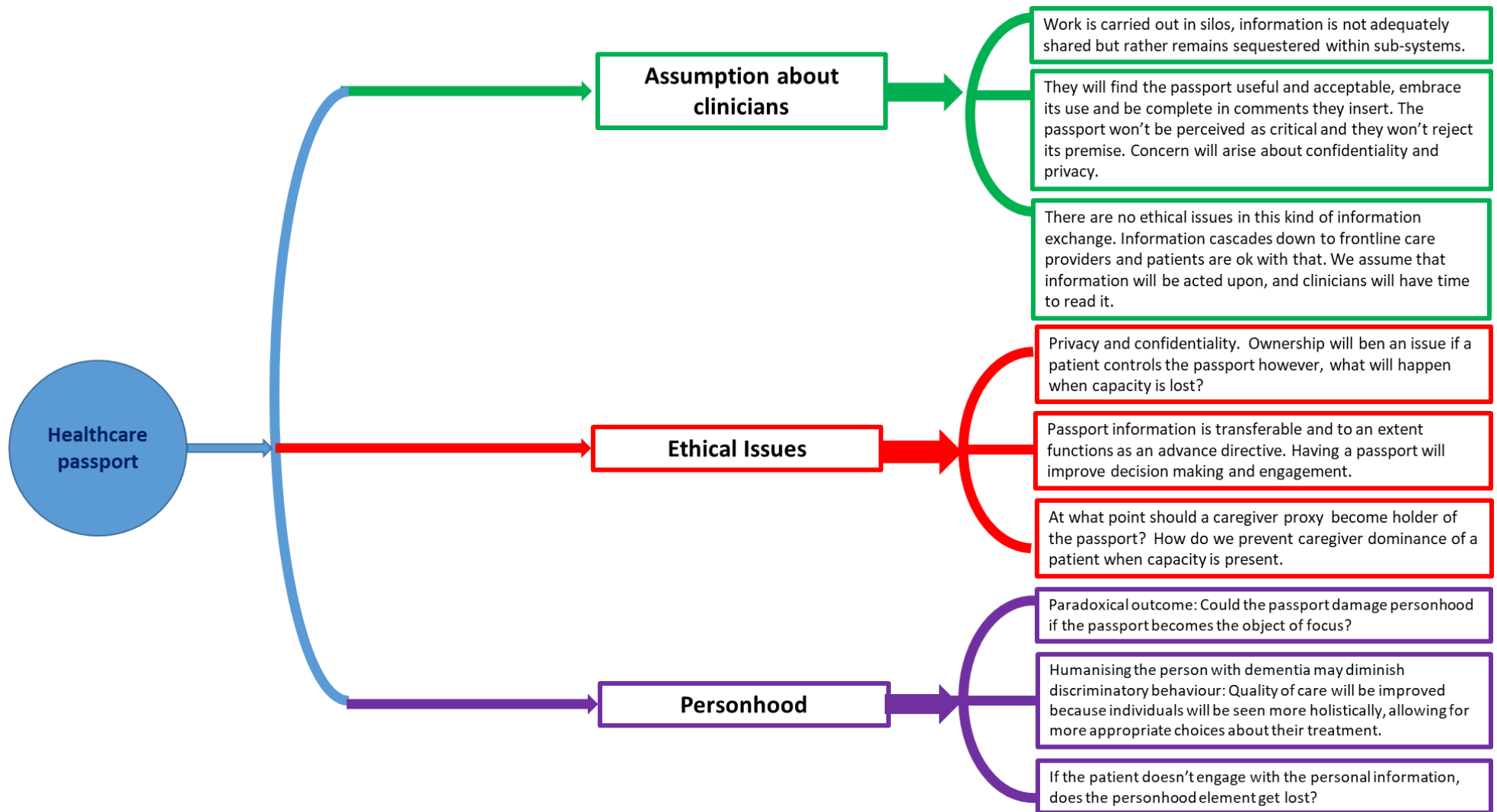


Figure 4: considerations given to the implementation of a 'healthcare passport'.

2.2.2 1st framework: Enhancing user autonomy and self-management skills

The initial framework underlying the 'healthcare passport' is the enhancement of the user's autonomy [50, 51]. This benefits the person with dementia at an intra-personal level by allowing them to express their preferences for treatment, assisting their involvement in treatment [51-53], thus improving their self-management skills. Within psychiatry, the use of patient directives improved various clinical outcomes such as user insight, self-esteem, accountability and satisfaction with treatment [54]. The potential for enhancing service user autonomy through the use of a passport, supposes that at an interpersonal level, feelings of empowerment will be developed and equal power dynamics will evolve [55, 56] [57]. Moreover, the passport can be a useful tool for managing treatment, to reduce distress by understanding symptoms and warning signs of deterioration, and importantly for the users to feel supported at both social and organisational levels [58, 59].

User autonomy feeds into the theory of patient activation, the concept of which is grounded in a behavioural model [60] and includes several core components around patient involvement, key to promoting active engagement and participation. Patient activation is defined as 'an individual's knowledge, skill, and confidence for managing their health and health care'[60]. Patients with higher levels of activation, are more likely to have a better understanding of the care process and feel more capable of engaging with health professionals. This will become increasingly important where people experience co-morbidity [61].

Between 25 to 40 per cent of the population have low levels of patient activation[60]. In this group, patients have a limited locus of control and thus are more likely to feel overwhelmed with the task of managing their health; have little confidence in their ability to have a positive impact on their health; misunderstand their role in the care process; have limited problem-solving skills; have had substantial experience of failing to manage their health; have become passive in managing their health; and would rather not think about their health. These factors are major barriers to treatment. For example, responding medical advice for a complex condition, when multiple changes to lifestyle are required (changing diet, increasing physical activity or managing new medications). Moreover, if a health care underestimates the patient's self-management skills, the patient's healthcare and outcomes are more likely to be poor [60].

Theories of self-management suggest the benefits of enhancing user autonomy. Self-efficacy considers the strength of a person's belief that they will be successful in any given activity or process, and these beliefs effect behaviour. Thus, a person with low self-efficacy will avoid tasks they perceive to be difficult. Self-efficacy is based on Social Cognitive Theory, with a focus on observational learning and how social experiences help form personality. Self-efficacy theory places an emphasis on the importance of an individual having confidence in their ability to accomplish specific goals[62] [63]. Additionally, Bandura [63] suggests that perceived self-efficacy is a behaviour-specific psychological attribute which can be learnt or

enhanced. However, self-efficacy may be predicated on individualised coping strategies in dealing with the challenges of varying task-orientated demands and situational environments [64]. For example, intervention studies relating to the perception of heightened self-efficacy amongst carers of people with dementia noted improvements to mood and health [65], in addition to positive effects on their abilities to cope and overall sense of well-being [66]. While individuals may have perceived high self-efficacy in one area, this may not correspond with high self-efficacy in other areas. For example, a person with dementia may have high self-efficacy managing at home, but lack self-efficacy when travelling on public transport, or visiting public places. Health providers can help promote a strong sense of self-efficacy through psychosocial or educational interventions. Unfortunately, some healthcare interactions can also unknowingly undermine self-efficacy.

Social learning theory advocates the opportunity for people to seek positive stimuli to assist in the development of coping mechanisms to deal with negative experiences and also in the 'modelling' of behaviours which can result in their subsequent adoption. This is clearly stated in the National Dementia Strategy [67] in relation to the development of structured peer support and learning networks in offering direct local support to not only encourage, but also to enable people with dementia and their carers to actively participate fully in the "development and prioritisation of local services". Self-efficacy is multifactorial in nature, and several components should be considered to promote self-efficacy. These can be accomplished through the following:

Mastery experiences: being successful can enhance confidence to keep trying. One of the most important factors in determining a person's self-efficacy is mastery. If there is perceived success it will raise self-efficacy, whereas perceived failure will lower self-efficacy. On an individual basis, past experiences that have been successful are significant contributors to a person's confidence. Mastery provides an individual with the opportunity to succeed and is a strong indicator of future performance. Trying something new, for example managing your own medication, or going out in the community after a fall, can be influenced by building positive perceptions of past experiences. For people living with dementia, some of the content of the 'healthcare passport' health may be devoted to a care or action plan with the aim of maintaining activities and skills by outlining steps that can be confidently managed and encouraging a reinforcement of success. Such activities are likely to be tailored to the individual's activities of daily living and also to their hobbies and interests.

Vicarious experience: Observing others with similar disabilities or conditions and perceiving success can contribute to increasing a person's self-efficacy. Vicarious modelling can also increase a person's confidence to try new things. In dementia care, this may be determined through the active encouragement of formal

and informal carers by creating social environments in which people with dementia and their families are 'invited' to adopt a more positive and empowering attitude towards the dementia. However, for some people such comparisons may provoke further demoralisation by people with dementia and/or frustration among some family caregivers.

Social persuasion: Positive encouragement may help increase a person's self-efficacy and this may be particularly effective when done by someone else with the same condition or in the same situation. Positive reinforcement can inspire confidence and act as a strong motivator. This may be important in the uptake and use of the healthcare passport, particularly so when the passport appears to be endorsed by health and social care professionals. It may be that some individuals may be more persuaded by deference or professional authority. Age, education and social class may be key factors within social persuasion.

Reinterpreting emotional and physical reactions to experiences: Understanding one's reaction to stress is important to dealing with it more effectively. Physiological factors are an important consideration as when a person is in a stressful situation, e.g. they may experience physical symptoms such as anxious autonomic nervous sensations such as nausea or sweating. It is how a person perceives their physical symptoms that will affect their self-efficacy. This may be relevant to both service users and carers. For carers, it is important to understand what agitation is and what trigger factors are associated with these behaviours so that it can be managed more appropriately. Health providers are in a powerful position to help promote self-efficacy, by incorporating the aforementioned strategies into the implementation of the 'healthcare passport'. It should also be acknowledged by policy makers and service commissioners that in many instances, maintaining skills, activities and interests among PLWD are likely to have resource implications and will have more impact upon people from deprived backgrounds. Maintaining skills and thus, self-management, as far as possible, warrants a new form of social prescribing.

2.2.3 2nd framework: strengthening the therapeutic alliance

It was anticipated that the use of the passport would strengthen the therapeutic alliance[68] through regular exchange of information between service users and clinical staff [56] in turn increase mutual understanding and treatment compliance [69]. In addition, stakeholders' information needs might be facilitated and shared decision-making may also be promoted [50, 53, 70]. Consequently, quality of life and quality of care may be improved [71]. At the organisational level, early identification of deterioration or healthcare problems and appropriate swift intervention may be easier to achieve through the use of a passport, providing that the patient and/or informal carer has been provided with appropriate information. This may enable more people with dementia to stay at home, rather than to be admitted to hospital for emergency treatment and care. However, implicit in the design of the passport is that a meaningful partnership in the care of someone with

dementia can be achieved through an enthusiastic appreciation of person-centred care on the part of formal and informal carers rather than the more established medical model. Characteristics ascribed to the biomedical model of healthcare include a focus on the treatment of individual disease or symptoms, asymmetrical knowledge and care hierarchy, and objectification of the patient who is decontextualized from social circumstances and environment [72]. The biomedicalisation of dementia has been criticised as leading to the person with dementia being viewed as a disease entity and a source of burden[72]. Often neglected within medicalisation is that some individuals, regardless of the degree of neuro pathology, are able to cope and manage the dementia much more effectively than others. This may be partly due to the immediate and long-term response of others to the diagnosis to dementia; in particular, if the clinical and social response brings about premature and unnecessary disempowerment of the person with dementia [73].

Sabat and Harre [74] apply a social constructionist approach, similar to labelling theory, that once someone with dementia has been depicted as helpless and confused, this is the version of the person that becomes irretrievably accepted by others. Kitwood's [75] pioneering theoretical work considered the interaction between psychosocial and neurological factors in dementia in which he stressed the importance of psychosocial factors in the erosion of personhood. He noted that subtle processes occur, which disable and marginalise people with dementia and that self-esteem was crucial to learning, efficacy and good social relationships. When self-esteem is compromised by a "malignant social psychology", the individual is set on a spiral of discouragement and failure. Thus, the positive effects of maintaining personhood should be emphasised – the maintenance of activities and environment that mitigate against cognitive and physical deterioration [72].

Various commentators [11, 76] identified the basic principles of personhood: the right to dignity, autonomy, worth, and a set of unique moral principles, view, histories, and desires. They also identify the importance of personalised environment, and experience flexible routines and continuity of care partners. There are several additional specific clinical strategies described in the literature on person centred care, and these include incorporating biographical knowledge into care [77] reminiscence [78] validation therapy [79] and prioritising the quality of relationships ahead of completing tasks [80].

Optimally, health professionals should communicate effectively with patients, patient's families, peers and colleagues consistently throughout the individual's care. Importantly, the patient is communicated with as an individual and it is the duty of the practitioner to understand and empathise with patients[81]. Existential elements are directly affected by the quality of communication. Thus, when a person experiences distress or is in a critical situation, it is imperative that existential concerns are recognised and managed. To achieve this, a tool fit for this achieving this purpose must facilitate effective and positive communication.

However, person-centred care must allow for the direct involvement in decision making by persons with dementia, families, and service providers. Moreover, this requires that attention should be paid to the importance of these relationships at the different stages of the disease progression in dementia. Thus, while the individual's condition may deteriorate and their needs may become more complex, it should be acknowledged that their environment and social circumstances and support is also likely to undergo change. A patient's needs may be attended to within a delicate ecosystem of various carers, each one reliant on each other and the stability of certain factors and conditions, social and interpersonal; when any one of these factors is disturbed or compromised there are likely to be ramifications for the provision care. It is also worth noting that family relations are not always harmonious and 'care' may be provided by family members resentfully, poorly or not all. Even when families are compassionate and supportive, there is some evidence to indicate that caregivers (adult children) were reasonably accurate in predicting their parents' overall preferences for care but overestimated parental desire for predictability, routine, and control while underestimating their desire for enrichment and personal growth" [82].

Collaboration between the service user, carer and health care professionals was a key intention of the 'healthcare passport' but may require considerable time for reflection, not only on what is important to document about the individual and his/her needs but also time for reading and absorbing by new staff and when the illness progresses. Moreover, while the 'healthcare passport' was designed with the patient's needs central to communication between all parties, it is possible that as an unintended consequence, the passport becomes the conduit for all communication about the patient's needs, in which the patient's input becomes increasingly redundant.

2.2.4 3rd framework: Integrated care

The third framework is based on the need for integrated care, the 'joined-up' partnership of health care providers. Within the area of advance care planning, the evidence suggests that this is generally carried out, only during critical intervention rather than attended to throughout the care process. Specialisation is a key characteristic of modern healthcare systems in which each specific disorder is treated and managed by separate specialist professionals. This may work reasonably well where an individual has one health problem at any one given period but more problematic when he/she has a number of co-morbidities. An aging individual with dementia may also have diabetes, depression and Coronary Heart Disease. They may also be prone to falls and fractures. While modern health care systems have invested in electronic sharing of information between health care professionals, they remain limited in their reach. They also exclude the patient and carer from this information exchange. Moreover, while each of these conditions and health care contacts require exchange of information and advice to the patient and his or her family caregiver there are no single platforms for this to happen.

The 'healthcare passport' is intended as a tool to assist the co-ordination of care between various health and social care professionals. Thereby, the various care needs of the user will be well documented and gaps in the delivery of care can be avoided [83, 84]. The dissemination of patient information may promote knowledge exchange and active learning between health care providers[85]. The success of the 'healthcare passport' is predicated on the willingness of practitioners to share information and knowledge, via the passport, to people living with dementia, and indirectly with other professionals. This also requires a continuous flow or regular updating of information when conditions and circumstance change. It may be that clinicians regard this a burden or that they have insufficient time to make entries to a health care passport. There is also an assumption of 'openness' in the entries made by professionals (and by carers) but this may not be the case as it may sometimes involve ethical consideration and degrees of self-censorship as to what might be helpful or injurious.

2.3 Evidence retrieval, data extraction and evidence synthesis.

In Phase 2, we included a process of evidence retrieval, data extraction and synthesis which involved searching for relevant evidence to test and refine the initial programme theory. In this phase, additional data extraction was carried out from the evidence and sources we identified as relevant. Firstly, to inform this stage of the research, information and research relevant to the use of the healthcare passport was identified by our main advocacy organisation (The Alzheimer's Society), service users and carers, and health professionals working dementia care were incorporated into the review. Although our search strategy was focussed predominantly on the evidence base related to improving communication in dementia, we also explored the literature on communication interventions in various disease or disability specific areas (e.g. cancer, palliative care) which had objectives and features similar to those of the health care passports. We did not seek to address end-of-life care and advanced directives comprehensively because the unquestionable consensus of the stakeholder groups was that the passport should not be focussed on palliative care issues. Nevertheless, the research and expert consultation team felt that we should include review evidence on advance directives or planning that might illuminate any shared issues related to the passport use. Additionally, we considered qualitative research and discussion papers which might have relevance to theory building and implementation. Thus, we also considered papers that addressed the facilitators and barriers associated with such communication tools. The search strategy located systematic and realist reviews, as well as primary studies.

A total of N=310 potentially relevant papers were located. After initially screening by the research team, n=20 papers were quality assessed, data extracted and synthesised in a narrative format. From the 20 papers, n=13 were reviews (systematic or realist reviews), n=1 was an opinion paper, and n=6 reported on evaluations of communication tools for different patient groups. Three of the primary studies described

evaluations of tools for people with dementia. Tables 1a and 1b provide a summary of the included reviews, and Table 1c provides details of the primary studies.

Fourteen of the papers described approaches or interventions aimed at improving communication. Two reviews [86, 87] and three primary studies [88-90] described the evidence on the effectiveness of patient held records with a range of different populations including PLWD, mothers of young children, people with chronic conditions. Two of the reviews [91, 92] examined the research evidence on the advance directives for people with mental illness, and one primary study used an RCT to evaluate the effectiveness of Joint Crisis Planning (JCP). Advanced care planning was examined in a narrative review by Hayhoe et al [93]. Approaches to improve self-management were the subject of a concept analysis and a review [94, 95]. Two reviews [33, 96] explored the literature on approaches to improve more integrated care. Box 3 presents a description of some of the approaches described in the reviews and primary studies.

Box 3 Description of some of the approaches described in the located literature

| Term | Description |
|--------------------------------------|---|
| Advanced Treatment Directives (ATD) | Advance treatment directive is a document that specifies a person’s future preferences for treatment, should he or she lose the mental ability to make treatment decisions (lose capacity). They have traditionally been used to stipulate treatment in end-of-life situations. However, people with mental health problems can also have periods where they are unable to make treatment decisions, and an advance statement could help with choosing suitable medication, saying who should look after children and specifying choices in other areas of their life and treatment |
| Joint Crisis Plan (JCP) | The JCP is a negotiated statement by a patient of treatment preferences for any future psychiatric emergency when he or she might be unable to express clear views. |
| Patient Held Records (PHR) | Patient-held records are tools to designed to inform and involve patients in their care and to facilitate communication between the different groups of people caring for the patient, thus facilitating continuity of care. Some are known as ‘logbooks’, ‘patient travelling records’, ‘personal records’, ‘client records’, ‘shared care records’, ‘care diaries’. They take many forms ranging from a dynamic tool used by the patient and all health-care professionals providing care to the patient, to a print-out from the patient's medical record or general information sheets. |
| Psychiatric Advance Directives (PAD) | Psychiatric Advance Directives (PADs) are documents that allow users with severe and chronic mental illnesses to notify their treatment preferences for future crisis relapses and to appoint a surrogate decision-maker for a period of incompetence. |

| | |
|--------------------------------------|---|
| Self- Management Support (SMS) | SMS refers to comprehensive sustaining approaches toward improving chronic illness outcomes consisting of patient-centred attributes (involving patients as partners; providing diverse, innovative educational modalities specific to patients' needs; individualizing patient care), provider attributes (possessing adequate knowledge, skills, attitudes in providing care), and organizational attributes (putting an organized system of care in place, having multidisciplinary team approach, using tangible and social support). |
|--------------------------------------|---|

2.4 Evidence synthesis

We reviewed a range of publications related to the use of patient-held records within various clinical or disorder specific areas allowing us to consider any potential ‘cross-over’ and transferrable knowledge or implications. Given that a key assumption of the need for a healthcare passport in dementia related to co-morbidity, the review also covered literature relevant to problems of fragmented care provision for people living with dementia and in doing so, emphasize the need for interventions that address this major challenge in health care. Maintaining personhood for PLWD was central to the stakeholders’ requirements and aspirations for the healthcare passport and this was anticipated as being realised through a more personalised approach to the individual and his or her needs.

Shared information and standardised systems between different providers and clinicians, even within the same organisation, are rare or sub-optimally provided. Beyond advanced care directives or planning in palliative care, there appear to be few communication tools such as the healthcare passport currently being evaluated in Northern Ireland for people living with dementia. In other clinical areas where patient held records have been used, the evidence for effectiveness is somewhat limited. Often, it is not a question of the acceptability of PHR but rather, differences between patients and health professionals about their function. In palliative care, the provision and uptake of advance care planning remains limited, stuck as it seems, between widespread theoretical acknowledgement and a pervasive reluctance to use it on religious-ethical (Cultural) grounds. Again, in line with other findings we noted a general failure within dementia studies to apprehend the complexities of living with dementia, and thus, the need for multifactorial interventions to assist communication and effective care [97].

Table 1a: Summary of reviews focused on approaches to improve communication

| AUTHOR & YEAR | FOCUS OF REVIEW | NUMBER OF STUDIES INCLUDED OR TYPE OF STUDY | SUMMARY OF KEY FINDINGS |
|---------------------------------|---|--|--|
| Campbell et al (2009) | <p>Cochrane review: examined advance statement leads to less hospitalisation</p> <p>Population People with mental illness</p> <p>Intervention: Advanced directives</p> | <p>Search strategy described</p> <p>Inclusion criteria: RCTs</p> <p>The review located 2 trials of n=321 patients</p> | <p>Findings: There are too few data available to make definitive recommendations. More intensive forms of advance directive appear to show promise, but currently practice must be guided by evidence other than that derived from randomised trials. More trials are indicated to determine whether higher intensity interventions, such as joint crisis planning, have an effect on outcomes of clinical relevance.</p> |
| Gysels, et al (2006) UK | <p>Review: patient-held record (PHR) in cancer care</p> <p>Population People with cancer</p> <p>Intervention Patient held records (PHR)</p> | <p>Systematic Review</p> <p>Seven RCTs and six non-experimental studies were identified.</p> | <p>Findings:</p> <ul style="list-style-type: none"> • randomized trials found an absence of effect • non-experimental evaluations shed light on the conditions for its successful use. Most patients welcomed the introduction of a PHR. Main problems related to its suitability for different patient groups and the lack of agreement between patients and health professionals regarding its function. • Further research is required to determine the conditions under which the PHR can realise its potential as a tool to promote continuity of care and patient participation. |
| Hayhoe, et al, (2011) UK | <p>Narrative Review of Advance Care Planning (ACP) based on a narrative review of the literature</p> <p>Population Not specified</p> <p>Intervention Advance Care Planning (ACP)</p> | <p>Narrative review (no inclusion/exclusion criteria)</p> <p>PubMed was searched using the terms ‘advance care planning’, ‘living wills’, ‘advance decisions’.</p> | <p>Findings: ACP is supported by both patients and doctors and has documented benefits in extending autonomy and facilitating decision-making. Though currently under-used, partly through widespread lack of knowledge, it could be a valuable asset in end of life care if routinely discussed with patients.</p> <p>ACP is likely to be particularly relevant for older people, who are at greater risk of conditions affecting their capacity to make decisions. However, specific problems associated with ACP in older persons care do exist, ranging from drawing up a plan that incorporates all potential future clinical scenarios, to the complex assessment of capacity to participate and concerns about coercion. In addition, there may be a greater sense of urgency, in ensuring that discussions take place while patients still retain capacity to decide on their future care. Continued low uptake of ACP suggests that further education of both public and health-care professionals need to take place regarding the benefits of ACP.</p> |
| Kawi (2012) Review USA | <p>Concept analysis of self-management support (SMS) to provide clarity for systematic implementation in practice.</p> <p>Population Chronic conditions</p> <p>Intervention/approach Self-management support (SMS)</p> | <p>Concept analysis – narrative review</p> <p>No inclusion/exclusion criteria</p> <p>Rodgers’ evolutionary concept analysis method was used. Data sources included systematic multidisciplinary searches of multiple search engines.</p> | <p>Background: SMS refers to comprehensive sustaining approaches toward improving chronic illness outcomes consisting of patient-centred attributes (involving patients as partners; providing diverse, innovative educational modalities specific to patients’ needs; individualizing patient care), provider attributes (possessing adequate knowledge, skills, attitudes in providing care), and organizational attributes (putting an organized system of care in place, having multidisciplinary team approach, using tangible and social support). SMS is a concept in its early phase of development. It is increasingly evident in literature on chronic illness care. However, the definition has been simplified or vague leading to variable SMS programs and inconsistent outcomes. Elucidation of SMS is necessary in chronic illness care to facilitate clear understanding and implementation.</p> <p>Implications: A well-clarified SMS concept is important in theory development. The attributes offer necessary components in SMS programs for systematic implementation, evaluation, and research. There is great potential that SMS can help improve outcomes of chronic illness care.</p> |

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| <p>Ko et al, (2010)</p> <p>Australia</p> | <p>Review: patient-held medical record (PHR), compared to usual care, improves clinical care, patient outcomes or satisfaction.</p> <p>Population Chronic conditions</p> <p>Intervention/approach Patient Held Records (PHR)</p> | <p>14 studies, explored the use of PHR in diabetes, oncology, mental health, rheumatoid arthritis, stroke and palliative care.</p> | <p>The studies used a variety of designs of PHR and compared this with usual care. PHR were implemented with varying degrees of patient and staff support and education, mainly for six months or less. Outcomes included attitudes on the usefulness of PHR, the quality of information exchange, process indicators, and clinical and physiological indicators. The evidence on the effectiveness of PHRs is generally of low or very low quality, with the majority of studies having a high risk of bias. These studies do not demonstrate a significant benefit of introducing PHR. Conclusions: There is no clear benefit of implementing a PHR, and due to medium to high risk of bias these findings should be interpreted with caution. More high-quality studies are needed to evaluate properly the effectiveness of PHRs in chronic disease populations.</p> |
| <p>McCorkle et al. (2011)</p> <p>USA</p> | <p>Review: self-management interventions.</p> <p>Population Patients with cancer</p> <p>Intervention/approach Self-management</p> | <p>RCTs (n=32) of self-management interventions.</p> | <p>Findings: Self-management is poorly defined and a common set of self-management actions for cancer care notwithstanding, oncology practices can now build strong relationships with their patients and formulate mutually agreed upon care plans that enable and empower patients to care for themselves in the way they prefer.</p> |
| <p>Murphy et al. (2016)</p> <p>Ireland</p> | <p>Cochrane Review: improving palliative care delivered to people with advanced dementia</p> <p>Population Patients with advanced dementia</p> <p>Intervention Interventions aimed at improving palliative care</p> | <p>Cochrane Review</p> <p>Extensive searches and inclusion criteria described</p> <p>2 studies located both from the USA</p> | <p>This review focused on interventions aimed to impact one or more of the following domains:</p> <ul style="list-style-type: none"> • The PLWD focusing on managing pain or on psychological, social, or spiritual dimensions of the patient • The family/carer, with an emphasis on carer well-being, carer burden and grief or bereavement support • The quality of care, which may include interventions such as advance care planning, staff education programmes or the organisation and delivery of care. <p>This study found that giving relatives this information made it a little easier for relatives to make decisions about what methods would be used to feed the person with dementia.</p> <p>Very little high-quality work has been completed exploring palliative care interventions in advanced dementia</p> |
| <p>Nicaise, et al (2013)</p> | <p>Realist systematic review of Psychiatric Advance Directives (PADs); (e.g. Treatment preferences during crisis)</p> <p>Population People with severe and chronic mental illness</p> <p>Interventions Psychiatric advanced directives</p> | <p>Forty-seven studies were retrieved, ranging from 1996 to 2009.</p> | <p>Findings: take-up rate is low and contradictory results for organisational outcomes. Intermediary results are available, however, which rely on different theoretical views about how PADs are supposed to work. A realist systematic review considered the PAD as a multistage intervention including the definition of the document, its completion and its access and honouring. Although designed in the first place with a view to sustaining the user's autonomy, results indicate that the intervention is more efficient within a therapeutic alliance framework. Access and honouring of the PAD are uncertain. The mixture of expectations makes the purpose of PADs unclear, for example, crisis relapse prevention or management, advance planning of long-term or emergency care, or reduction in the resort to coercion. The shape of the whole intervention at each stage relies on such clarification. More research is needed, particularly on the later stages of the intervention, as the evidence for how PADs should be implemented is still incomplete.</p> |
| <p>Reilly et al., (2015)</p> <p>Cochrane Review</p> <p>UK</p> | <p>Cochrane Review: case management approaches to home support for people with dementia.</p> <p>Population PLWD</p> <p>Intervention/approach Case management</p> | <p>13 RCTs involving 9615 participants with dementia in the review.</p> | <p>Findings: Some studies examined the benefit of case management in reducing admissions to residential or nursing homes (institutionalisation). They found benefits at six months and 18 months but not at 12 and 24 months. Case management increases the use of community services but there was some indication that overall healthcare costs may be reduced in the first year. Some studies reported that case management was no more effective than usual care in improving patient depression, functional abilities or cognition.</p> <p>There was not enough evidence to clearly assess whether case management could increase the length of time until people with dementia were admitted to care homes.</p> |

Table 1b: Summary of reviews focused on needs of PLWD

| AUTHOR & YEAR | FOCUS OF REVIEW | NUMBER OF STUDIES INCLUDED OR TYPE OF STUDY | SUMMARY OF KEY FINDINGS |
|---|---|--|--|
| Dooley, et al (2015) Review UK | Review: observational studies of communication between patients, companions and healthcare professionals Interventions None | Eight databases searched. 23 studies were identified observing: diagnostic, follow up, day centre, primary care and research consent interactions. Companions were present in 14 studies | Findings: Three themes emerged: emotional impact of diagnosis, level of patient involvement and participant strategies to save face and cope with cognitive impairment. varying patient involvement, showing marginalization in primary care but not in assessments or diagnostic feedback. Patients used humour and metaphor to compensate for difficulties retrieving information and responding appropriately, suggesting preserved awareness of the pragmatics of interaction. Companion roles fluctuated between patient advocate and professional informant. Professionals encountered challenges adapting to heterogeneous patient groups with varying capabilities and needs. Patient-companion-professional communication in dementia care raises various ethical questions: Healthcare professionals need guidance in delivering a diagnosis and strategies to optimize patient and companion participation. |
| Street (2013) Essay/Opinion paper USA | Theoretical paper: clinician–patient communication contributes to a patient's health and offers recommendations for future research. | No search strategy described. | Findings: communication measurement is complicated because relationships among communication behaviour, meaning, and evaluation are complex. Conclusion: Researchers must do more to model pathways linking clinician–patient communication to the outcomes of interest, particularly pathways in which the communication effects are indirect or mediated through other variables. To better explicate how communication contributes to health outcomes, researchers must critically reflect on the assumptions they make about communication process and choose measures consistent with those assumptions. |
| Van Der Roest et al (2007) Qualitative review The Netherlands | Narrative review on the subjective needs of people with dementia Population PLWD living in the community Intervention: none | Narrative review 34 studies | Findings: Few studies specifically aimed to measure the needs of people with dementia. Reported most frequently by people with dementia was the need to be accepted and respected as they are, the need to find adequate strategies to cope with disabilities, and the need to come to terms with their situation. Overall, people with dementia do not frequently mention how they want their needs to be met. |
| Steeman et al. (2006) Belgium | Narrative Review: qualitative studies on the management of daily life with dementia. Intervention: None | 28 qualitative studies (reported in 33 articles) | Findings: Memory loss threatens perceptions of security, autonomy and being a meaningful member of society. Individuals use self-protecting and self-adjusting strategies to deal with perceived changes and threats. Thereby causing frustration, uncertainty and fear. Results support the integration of proactive care into the diagnostic process, to improve quality of life. Care should actively involve both the individual with dementia and their family. |

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| Barlow et al, 2002 | Review: self-management approaches for people with chronic conditions | 145 papers on chronic conditions | No studies of self-management found for dementia (most chronic conditions covered were asthma, diabetes, arthritis). Self-management approaches mostly group-based, individualised, or a combination of both. Group approaches were often supplemented with written materials and audiotapes. The format of self-management approaches varied and included booklets, lectures, role play and goal setting. Most approaches combined at least two formats of delivery (e.g. lectures and manual). Evidence from RCTs suggests that self-management approaches may be effective in increasing participants' knowledge, symptom management, use of self-management behaviours, self-efficacy, and aspects of health status (e.g. depression). However, not all approaches target all of these outcomes. Multi-component programmes do not show improvements on all outcomes. |
|--------------------|--|----------------------------------|---|

Table 1c: Primary studies of evaluations of interventions to improve communication

| AUTHOR & YEAR | FOCUS OF STUDY | DESIGN | SUMMARY OF KEY FINDINGS |
|--|---|---|---|
| Barber, et al (2015) Evaluation UK | <p>Aims: An evaluation of 'My Medication Passport' - its value to older patients</p> <p>Population: Older patients</p> <p>Intervention: A booklet, recording details on patient's medicines.</p> | <p>A total of N=200 patients were given the passport</p> <p>Follow-up study of n=133 who participated in structure telephone interview interviewed 40% aged 70+ years</p> | <p>More than half of the respondents had found their medication passport useful or helpful in some way; 42% through sharing details from it with others (most frequently family, carer or doctor) or using it as a platform for conversations with healthcare professionals.; One-third of those questioned carried the passport with them at all times. Conclusions: My Medication Passport has been positively evaluated; the study provided a better understanding of (a) how it is used by patients, (b) what they are recording and (c) how it can be an aid to dialogue about medicines with family, carers and healthcare professionals. Further development and spread is underway including an App for smartphones that will be subject to wider evaluation to include feedback from clinicians.</p> |
| Ito, et al (2015) Japan Evaluation | <p>Aims: utility of patient-held records for patients with dementia in the community.</p> <p>Population PLWD living in community</p> <p>Intervention patient-held records</p> | <p>workshops with health professional across Japan on family held/ patient-held records. Searches of the literature were also conducted.</p> | <p>The searches identified were eight sets of family-held/patient-held records in Japanese communities of various sizes, all of which were aimed at integrating information from various services, including information provided by medical and psychiatric professionals to the family and patient. The review did not examine effectiveness of these tools. Innovative tools have been available in the areas of the hopes and preferences of the patient, medication and monitoring, sharing information, and the use of information technology. Family held/ -held records may have potential as a tool to enhance the integrated care of people with dementia.</p> |
| Stacy, et al (2008) USA | <p>To examine (a) mothers' satisfaction with use of a personal parent-held child health record (PHCHR), (b) frequency of use (c) behaviour changes, and (d) perceived barriers</p> <p>Intervention Patient held records</p> | <p>A total of N=100 mothers were given the PHCHR for one year. n=82 mothers completed the 22-item validated evaluation instrument.</p> | <p>Patients reported high levels of satisfaction with all applicable use of the PHCHR. Respondents believed the PHCHR was a useful tool that served as a cue to increase their action in health seeking behaviours.</p> |

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|--------------------------------------|--|--|---|
| Robinson et al. (2010) | <p>An intervention to improve patient centred communication in outpatient reviews of patients with dementia. A thematic analysis of recordings, with interviews and literature review.</p> <p>Population PLWD</p> <p>Intervention: No specific intervention – exploratory study</p> | Semi-structured interviews with patients, carers and clinicians on their views about barriers and facilitators to patient centred care | <p>Difficulties included:</p> <ul style="list-style-type: none"> • Developing a therapeutic alliance, especially with patient companion conflict • Facilitating shared responsibility whilst promoting patient autonomy • Presenting information in manageable amounts so that patients with dementia can make informed decisions • Exploring person with dementia’s experience and promoting quality of life. • People with dementia very rarely identified issues in response to direct questions • Consultations tended to focus on negative aspects of a patient’s life. • The way in which doctors structured their consultations could be as important as the communication skills they use. |
| <p>Young, et al (2011)</p> <p>UK</p> | <p>Development of a communications advice package for PLWD.</p> <p>Population PLWD</p> <p>Intervention Communication Advice Package (for professionals)</p> | <p>Iterative consultation process with multidisciplinary professional and lay stakeholders, including PLWD in the UK.</p> <p>Stakeholders were asked to reflect in detail on their own experiences of communication in relation to dementia.</p> | <p>Participants reported dissatisfaction with current communicative practices, particularly during contact with medical professionals. Both lay and professional participants reported general dissatisfaction with currently available communication advice. An agreed version of a dementia toolkit for effective communication (DEMTEC) was produced. This consists of three “levels”.</p> <ol style="list-style-type: none"> 1. The foundation Level details beliefs about the psychosocial effects of dementia on communication, as well as empowering approaches to communication involving PLWD. 2. Level 2 consists of practical considerations and advice in eight key areas. 3. Level 3 uses case studies to show how the principles and advice in preceding levels are applicable to individuals in different care contexts and at different stages of dementia. <p>This project has produced a free-to-users instrument that is empirically supported and adaptable.</p> |

2.4.1 Diagnosis and support

Healthcare services should continue to address any concerns of people who have been diagnosed with dementia and provide information about symptoms that might be experienced. Literature in this area has identified several common needs that a person with dementia might experience soon after their diagnosis: the need for an explanation; the need to relieve the pressure of maintaining a normal appearance; and the need to feel supported [98]. To mitigate the effects of dementia-related stigma, and the denial of a dementia diagnosis, family members are encouraged not to 'cover up' or avoid discussing problems regarding dementia [98]. Psychological and psycho-educational interventions are needed to support for patients with dementia to aid adjustment to the diagnosis and deal with issues such as potential perceptions of loss, incompetence, intimacy, control and independence. Unfortunately, the evidence on effective psychological self-management support components is of limited quality [99]. However, minimally, it may be helpful for service providers to develop written care plans or provide a document to convey important information at the time of diagnosis and contact with services [99]. Patients reported being most likely to share such a document with members of their family and many commented on how useful it was to both patients and carers.

2.4.2 Case-management

In the UK, people living with dementia have, on average, 4.6 long-term medical conditions in addition to their dementia. Despite this, health-care services are generally organised around single conditions rather than caring for the person as a whole. UK wide health care policy has recommended the development of a more comprehensive system for case management [100]. Newly-evolving, the GP commissioning consortia is focusing on commissioning more cost-effective models of care for people with dementia [101](Joint Commissioning Panel for Mental Health, 2012). Co-ordinating effective care has featured heavily in recent guidance and commissioners have been advised to work towards the implementation of a more robust model to achieve improved co-ordination of dementia care [102]. A recent report has indicated that case management would substantially reduce health and social care costs, however, the costs of unpaid care are still likely to increase [103]. Case management interventions may overcome the problem of service fragmentation and may reduce carer burden. However, definitive evidence for case management is uncertain given the heterogeneity of the disease topics, interventions, outcome measures and reporting[96]. However, addressing issues of substitution and auxiliary information was not always available in the studies [87]. A recommendation for future studies is to demonstrate the extent to which case management interventions are delivered as planned. It is advised to have well-developed training and protocol manuals ensure the fidelity and replicability of the intervention [85].

While a health care passport (HCP) is not a substitute for integrated health care systems, it may be more effective were case management to be adopted. Importantly, in such circumstances, a HCP may be more

explicitly regarded as the patient-family document.

2.4.3 Patient held records

A review of patient-held records [85] found 14 eligible studies and these included diabetes, oncology, mental health, rheumatoid arthritis, stroke and palliative care. Most of the studies show signs of bias and there is little evidence that PHRs in these areas are effective. More specifically, patients and staff reported no clear benefit of using the intervention compared with usual care while staff in two studies expressed reticence in using the PHR due to an already heavy work load [104, 105]. The contents were often unclear or combined the PHR with auxiliary components (e.g. education, intervention coordinators and/or posters in clinics) whereas, some studies provided a PHR with minimal written instructions on its use. Thus, it is difficult to identify a 'standard' PHR even with specific disease areas. Moreover, the timing of implementation, generally limited to between 3 and 6 months, is unlikely to have been adequate in many cases.

To assist the implementation of a PHR, the following changes may be considered: the form and content of the PHR; attitudes of staff to utilise the PHR; and attitudes of patients to be proactive in their own care. To improve the success of a PHR intervention, future studies could consider the best usage of auxiliary tools to improve the effectiveness of a PHR. Additional organisational support, such as coordinators, in some studies may have mitigated this barrier to implementation. However, such support may be unavailable in most clinical environments. Staff 'buy-in' and organisational support might be influential to the outcomes of PHR interventions, but these are insufficiently described. Importantly, most of the reviewed studies showed that patient uptake of the PHR was low.

Previously, the successful use of the PHR has been compromised by the low level of engagement from health professionals. The PHR was often not used by professionals as intended: i.e. for the sharing of care with patients. Professionals tended to use it as a means of communication with other professionals rather than with patients. Another study found that the PHR served separate functions for health professionals who treated it as a document to confer technical information, and for patients for whom the record represented a vehicle through which to express their values and views about treatment and future care. In all studies, the PHR was intended to function both as a clinical and as an informal document. The importance of the latter in the management of a patient's care was sometimes overlooked. Even with its patient-driven purpose, health professionals have a crucial role to play in the acceptance and successful use of the PHR.

We found no publications related to an evaluation of patient-held (or family-held) records for dementia. However, Ito et al (2015) undertook a review of family-held/patient-held records in services that were developed in collaboration with psychiatric services patient. This review was done in Japan where dementia services are part of psychiatry. However, the researchers did not evaluate the PHRs but merely sought to

report their existence, aims and content. As elsewhere, most hoped to reduce fragmentation and improve continuity and coordination of care. The authors noted that the use of family-held/patient-held records was to assist a multidisciplinary clinical pathway, and these records promote other components such as self-management support, clinical follow-up and case management. They are also intended to capture the hopes/preferences of the patient, medication and monitoring, sharing information, and the use of information technology.

In an evaluation of a medication passport (MP) (Barber et al., 2014)[88] most service users reported positive results; they felt their MP was useful, that it facilitated dialogue about medicines and that a patient held, this patient-filled portable document was evaluated by its users as 'a good idea'. Most service users reported that the passport facilitated communication between them and their contacts with professionals (Barber et al., 2014). Carers regarded it as a useful reference point when conversing with the patient or healthcare professionals [88]. However, only a small percentage of patients (less than 20%) discussed their passport with their GP. Others, however, indicated that they intended to discuss its use with GPs at future consultations. Ownership and usability of the passport was unclear. Some service users tended to perceive the passport for their personal recording but were aware that it could be used to aid discussions with doctors. Others considered it to be most important as a diary or memoir for the user.

2.4.4 Advance Directives

As noted previously, guided by concerns for patient needs and preferences for care, the healthcare passport was originally conceptualised with advance directives in mind. That is, could a patient held document assist in influencing processes of care and achieving the kind of care that he or she would like to be given. While advance directives (AD) and Advance Care Planning (ACP) have a more focussed or limited remit than the dementia passport for PLWD, we considered that there would be sufficient overlap of context, mechanisms and outcome (CMO) to warrant the inclusion of AD and ACP. For example, advance directives in psychiatry concern stigmatised, complex conditions with a high level of carer involvement. A realist systematic review which investigated the use of Psychiatric Advance Directives (PAD) noted various challenges as a complex and multistage intervention [106, 107]. Thus, although the document was initially designed to promote a user's autonomy, findings strongly indicated that PADs are more effective in improving the therapeutic alliance. In support of this it has been reported that when facilitation features are designed to assist users in completing a PAD or JCP, are feasible and respond to user's interest and needs, it will increase the rates of uptake and improve the working alliance [104]. Decision making becomes even more difficult when individuals lose the capacity to express their wishes, and often in such situations professionals have to rely on information from others in order to make decisions based on their best interests. Advance care planning should help with making these decisions clearer, based on the documented preferences of what the patient

would have wanted while capacity was still present. However, such documents are still very rarely used, and even if they are, health-care professionals are often wary of them for the multitude of ethical and legal problems that can arise.

Authors of an RCT which focused on joint crisis plans (JCP) concluded that the best measured outcomes were obtained where the definition of the document and its content are negotiated among all of those in the care triad [108]. Although the primary use of a PAD intends to enhance the users' autonomy, professional buy in and endorsement is crucial to its effectiveness. Several studies have indicated that PAD endorsement is higher when professionals play a key role in the development of the document, making them less likely to override the directives [105]. The designation of a surrogate decision-maker may assist in the uptake of PAD. However, in some instances, having this designation may, counterintuitively, produce relationship conflict and thus, inadvertently weaken the therapeutic alliance. In this study, many of those using a PAD designated their own physician as surrogate decision-maker and overall, results indicated that the therapeutic alliance was strengthened [105].

An operational barrier to the use of PADs is that they are freighted with a range of different expectations placed upon by various stakeholders, most obviously and problematically the contrasting demands from clinicians and patients, obscuring the purpose and possibly explaining the low take-up rate [109]. The shape of the intervention at each stage relies on the clarification of these expectations. Thus, PAD's conceived in terms of therapeutic alliance are more feasible than the 'classic PAD'. There are concerns about proscriptive PADs that service users may refuse treatments and about possible conflicts arising from surrogate decision-making. However, these concerns may be addressed when a PAD is completed in consultation with health professionals within a therapeutic alliance framework. In terms of the completion of the PAD, a consensus may be reached among groups of stakeholders as to the information to include [104]

In a review of 145 self-management interventions for people with chronic conditions [110], no studies in dementia were noted, suggesting that the progressive nature of the disease, may influence a perspective that self-management in this area has not been considered relevant. However, while there appears to be growing interest in the potential for self-management interventions in dementia, work in this area is still rare and mostly limited to qualitative, concept development and pilot studies for people with early stage dementia [111, 112]. The synthesis of the evidence on interventions supporting self-management for people with dementia indicates that healthcare services need to provide information about symptoms or concerns about associated symptoms. This information should also be provided to family and other informal carers[99]. The 'stigma' surrounding dementia and its progressive nature [98], can make discussion about it covert and problematic. The literature identifies several common needs at the time close to a diagnosis of

dementia: the need for an explanation, the need to relieve the pressure of maintaining a normal appearance, and the need to feel supported' [96].

Parent-Held Child Health Record (PHCHR) offered to pregnant women and mothers of young children have been in widespread use for some time. Although used in an obviously very different domain, we wished to examine the factors that allowed them to be acceptable and popular over many years [113-117]. Behaviour changes associated with the use of the PHCHR included improvements in: keeping appointments; maintaining vaccination schedules; obtaining prenatal care; knowing when to call their doctor; and staying informed about their own and their child's/children's health. Low uptake was not a concern in this population but the reason cited most often for not using the PHCHR was low engagement from staff members. This suggests that the PHCHR is held by parents with a clear, central aim of building and safeguarding their child's health at its most vulnerable stage. It is thus, highly focussed and structured towards appointments and key milestones, rather than dealing with multiple concerns and pathology.

2.5 Summary of actionable recommendations

1. Healthcare passports may be directed for the ultimate benefit of the patient but it should be acknowledged that they will also benefit family members and healthcare professionals. Moreover, such passports can only meet their intended utility in a system of relationships. These relationships (stakeholders) should be identified prior to the inception of the passport.
2. Multiple and varying expectations makes the purpose of passport-type interventions unclear and may explain the low take-up rate. Future development of healthcare passports may require a more focussed consideration of their aims, and thus, content.
1. Acceptance of and commitment to the passport from primary care, community and hospital staff is essential. GPs may be particularly pivotal in the success of passports but most reticent to be involved. This will require high level policy engagement, managerial commitment and additional resources for discussion, consultation and training. HCPs need to be persuaded that the benefits of the passport outweigh the perceived additional staff burden. More generally, the evidence suggests that staff at all levels, including more senior staff, need appropriate training on dementia.
2. A patient's diagnosis of dementia is often not shared with other health professionals and thus may compromise effective care and treatment. A diagnosis of dementia should be flagged up on medical/electronic records. This should include systems for automatic updates of a dementia diagnosis to be transferred to health-care services that the PLWD is already attending. This 'acknowledgement' could also assist the introduction of a dementia passport to those who may benefit.
3. To improve the implementation of HCP (acceptability and usage) there is a need for auxiliary tools such as manuals (e.g. CD-Rom or internet-based) and other explanatory materials. These may require

evaluation. Well-developed manuals and protocols should be more widespread, since they can help to ensure the transparency, replicability and integrity of a complex intervention.

4. The ownership and shared use of patient passports need to be clarified. To do this, it should be acknowledged that the circumstances, capacities, needs and support, among other things, of individuals are different for each service user and that these factors may also change over time.
5. While the 'healthcare passport' was designed with the patient's needs central to communication between all parties, it is possible that as an unintended consequence, the passport becomes the conduit for all communication about the patient's needs, in which the patient's input becomes increasingly redundant. Future implementation and evaluation strategies must bear this possibility in mind.
6. Healthcare providers are in a powerful position to promote self-efficacy by incorporating self-management strategies into the contents and implementation of the passport. It should also be acknowledged by policy makers and service commissioners that in many instances, maintaining skills, activities and interests among PLWD are likely to have resource implications and will have more impact upon people from deprived backgrounds. Maintaining skills and thus, self-management, as far as possible, warrants an assets-based approach to care.
7. Families are crucial to the care of people with dementia, especially as the person gets older and the disease progresses. Their role as proxy decision-maker of the passport is likely to require additional discussion and agreement. Goal-setting and environmental adjustments including carer training in problem-solving strategies were also found to be important components of family carer interventions.
8. The use of models such as the triangle of care model may be helpful in ensuring that the input of family carers is properly recognised. This should include appropriate training in carer engagement for staff, and policy and practice protocols regarding confidentiality and information sharing.

SECTION 3: THE EVALUATION OF THE HEALTHCARE PASSPORT

3.1 Methods

Complex interventions are usually described as interventions that contain several interacting components (Craig et al. 2013). Complex interventions can have several dimensions of complexity such as a range of possible outcomes and/or variability in the target audience. The MRC New Guidance on Complex Interventions [118] highlight the need to understand the effectiveness of the intervention in every day practice and how the intervention works: what are the active ingredients and how are they exerting their effect. The development and evaluation of complex interventions may require an iterative approach underpinned by both qualitative and quantitative data process [119].

3.1.1 Evaluation design

Thus, in this, the largest part of the study, we used a qualitative longitudinal approach to examine the use of the healthcare passport by a sample of people living with dementia over time. Importantly, we explored the passport use in the context of their lives and family situation in the midst of changes to health and social care needs. Qualitative Longitudinal Research (QLR) methods are relatively new. QLR uses mainly in-depth interviews and is invaluable when there is a need to record and explore change over time, and the processes associated with such changes [120]. Although more time consuming than one-off or retrospective interviews in which a person is invited to reflect on past events, QLR can help explore current situations and anticipated issues and then also seek to understand how these unfold in ways that are planned or not planned [121]. In this way, we can investigate, back and forth, through the concerns and experiences of the participants as they respond to emerging events and needs.

3.1.2 Recruitment procedures

Service Users

The project was undertaken in collaboration with the Alzheimer's Society (AS). The recruitment of service users with mild to moderate dementia was facilitated through the Memory Clinic at the Western Health and Social Care Trust (WHSCT). Patients and families who were currently receiving support ¹ from the Memory Clinics were approached by staff and provided with information about the passport and the study and were

¹ In the original proposal, it was intended that an Engagement and Participation Officer (EPO), a newly created post within the Alzheimer's Society, would support and advise participants on the HP's use. Thus, following consent, the EPO was to arrange an appointment to meet individual participants and a family member. However, due to staff changes and turnover within AS, we were never able to make use of the EPO services fully. Instead, the researcher made contact with participants and their families following recruitment within Trust services where the passport and its use had been explained by a senior member of staff.

asked if they might be interested in participating. Following a positive response, a meeting was arranged with the researchers who provided further information and discussed participation. After written informed consent, interviews were arranged.

Service user engagement groups

Our third source of data came from focus groups with two service user engagement groups, one in Ballymena, and one in Strabane, and lastly, we took photographs of the HP contents at wave 3, with the participants' permission

3.1.3 Data collection

Service users

We used tailored, in-depth interviews at three time points over 18 months in order to capture salient changes or issues that occurred over that time period. In collaboration with the Alzheimer's Society and service users, we developed a structured topic guide covering the main research questions (Appendix 2b). In the first interview, we began with question related to (a) family and social circumstances; (b) help seeking and dementia diagnosis and response; (c) response to dementia and coping; (d) contact with health and social care; (e) personal resource and interests; and lastly (e) a discussion about the passport, immediate thoughts, concerns and expectations of use. In the second and third waves, we examined changes in health and current circumstances and their use of the passport (see Appendix 4). Additionally, we sought to examine the likely recruitment and adherence rates and how participant recruitment and retention can be improved in dementia research.

There were a number of key ethical issues related to this study. PLWD have varying degrees of capacity and this is likely to change over time due to dementia and a range of psychosocial, situational, medical, psychiatric and neurological factors. A threshold for competence relates to individual tasks including the competence to make a decision about participating in research. The importance of making such a distinction is to determine whether the potential participant should consent to participating in a particular study or whether somebody else should make that decision on his/her behalf. We sought to confirm capacity to participate in this study with responsible service managers and clinicians and continued to check with families and professionals on the mental health status of the person with dementia and capacity issues related to consent and continued involvement in the study. The study received ethical approval by the Ulster University Ethics Committee (REC reference 15/NI/0129) and was given favourable ethical opinion by the Office for Research Ethics Committees Northern Ireland (ORECNI) on 21 July, 2015.

Following ethical approval interviews with participants and their main caregiver/s (65 in total) were undertaken at three time-points: January – March, 2016 (28 interviews), July – August, 2016 (21 interviews),

and January - February 2017 (16 interviews). With one exception interviews were conducted at participants' homes, where they were in familiar surroundings and were least inconvenienced. Participants were provided with the brief and information sheets at each interview (separate versions for patient and caregiver) and asked to sign a consent form (Appendices 3e, 3f, and 3g). The interviews, usually lasting between 60 and 120 minutes, were audiotaped, transcribed, and entered into the qualitative software programme N-Vivo, version 11, for data coding and management.

During wave 2 interviews it became apparent that many participants had not engaged with the HP. In order to remedy the situation, the researcher explained the HP and its use again. In addition, it was decided to engage the Dementia Support Workers from the Alzheimer's Society in order to call the families and offer to help them with the use of the HP. However, this offer was not taken up by any of the families. We gave the families another phone call eight weeks prior to the last wave of interviews to ask them how they were getting on with the HP, to listen to potential concerns, and to indicate that we would be in touch in a month's time to arrange the final interview. At the last interview, 12 out of 16 participants had made entries into the HP, and five had taken the HP to a health appointment.

General Practitioners

Prior to the study, the Royal College of General Practice publicised the healthcare passport and the project within its newsheet. Following written informed consent by the participants, their GPs, respectively, were sent a letter explaining the study in full and indicating their potential role in it (Appendix 6a). When participants reported at wave 2 that GPs did not know about the HP, it was decided to send them a second, much shorter, letter (Appendix 6b) accompanied by a sample HP. This was followed by an email which included the link to the educational video about the HP on the RCGP site (Appendix 6d), and a reminder that we would be in touch regarding a brief survey about the HP. We telephoned the participating GP practices with the view to conducting the survey, over a period of four weeks in order to encourage GPs to participate. Only five GPs took part, however, some preferring to do so via telephone, others providing their responses in writing. It was pointed out that GPs have to "wade through an avalanche of information on a daily basis", as a result of which correspondence sent to them with regard to the HP likely went unnoticed.

3.1.4 Data management and analysis

All data were kept in strict adherence to good clinical practice (GCP) guidance, which includes storing data in a locked cabinet in a locked room and destroying recordings after transcription. Qualitative interview data were collected and stored using digital audio recording with permission from interviewees. Physical data (e.g., digital audio-recordings, hand written field notes) were kept until data were transcribed and checked to allow traceability and stored in a locked cabinet in a locked room. All data were anonymised. Electronic files were password-protected. Data were collected in accordance with the study protocol and procedures

through regular meetings between the PI and researcher. The PI reviewed the quality of interviews and field notes at regular points across the period of data collection to ensure they were of a high standard.

Data analysis was informed by the findings from the realist review which were incorporated into a Framework approach [122, 123]. We coded and indexed the data, using spreadsheets in order to generate matrices into which the data were 'charted'. This involved summarising the data by category from each transcript, building themes with the support of memos and data display (matrices and diagrams). Transcripts were coded and analysed independently by the researcher. Some specific areas that we covered: (a) a retrospective examination of the experience of PLWD, family carers, help-seeking and communication needs – prior to using the HP; (b) practical use of the HP, differentiated by different care characteristics and contexts (e.g. dementia stage, social class and social support networks, gender and care-relationship); and (c) change in use of the HP over time in response to need; (d) care planning and advance directives for end of life care; (e) joint decision making (family and patient); (f) comprehension and ease of use by stakeholders (professionals and family); (g) reasons for discontinuation. Additionally, we sought to examine the socio-demographic and contextual factors of people in the use and maintenance of this type of intervention and how it can be more effective. From our realist systematic review, we sought to develop specific questions on contextual and intervening conditions that may additionally help guide analysis. The differential quality and quantity of information that is shared by families and professional services – for example, what type of information is withheld, if any, by whom and for what reasons? What might be the unintended consequences of using the HP? Where appropriate, we adopted a narrative approach in order to illustrate the complex issues that arise. Thus, we attempted to combine a deeper understanding and portrayal of the experiences of the participants while also situating and interpreting these experiences within their wider personal (and medical) contexts and with reference to specific events of significance to the person with dementia and family members. Using this approach, we attempted to understand the commonalities while exploring and highlighting issues that arise from unique or different perspectives; family support or complexity of care, for example. Thus, particular note was taken of new themes arising and any unusual perspectives. Where possible, we intended to examine the HP use of people from a range of socio-demographic backgrounds, different contexts and needs.

3.2 Findings

3.2.1 Participant recruitment and attrition

The Memory Clinic identified and assisted in the recruitment of 28 patients with dementia and their families (15 males, 13 females) who were contacted prior to the first wave of interviews by the researcher. Following some attrition after wave 1 (N=11; 6 males, 5 females), four additional participants (1 male, 3 female) were

engaged, which meant that 21 participants in total took part in wave 2 (10 males, 11 females). After wave 2, five further participants opted to discontinue with the study (1 male, 4 females), leaving 16 families to take part in the 3rd wave of interviews (9 males, 7 females) (see flow chart – Figure 6) providing us with a range of individual situations and experiences. We made no assumptions about participants’ prior use of health and social care services. Having recruited 28 patient-carer dyads for the first wave of interviews with the help of the Memory Clinic at the Western Health and Social Care Trust, two declined when contacted by us, and interviews were conducted with 26 patients and carers. Five females and six males opted to withdraw following 1st interview, leaving 17 participating families. Following recruitment of six further families by the Memory Clinic to counteract attrition, two declined when contacted by us, but we were able to add four patients and carers to our participants, resulting in 21 interviews at wave 2. Following wave 2, one male and three female patients withdrew, which left us with a total of 16 patients for the final wave, nine of whom were male, and seven were female.

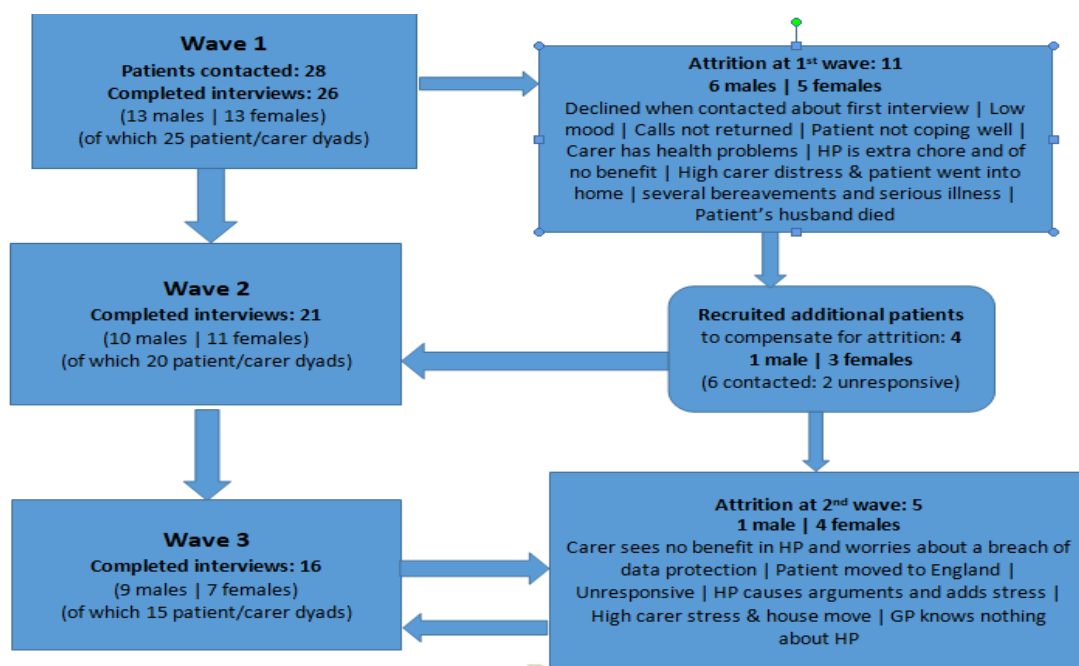


Figure 5: Flow chart of Participant Recruitment and Attrition waves 1-3

Reasons for attrition ranged from declining when contacted about the study, to not returning calls, low mood, patients not coping well, carers not coping well, carer having health problems, the HP being regarded as an extra chore and of no benefit, high carer distress and patient going into care-home, bereavements and

serious illness, dying of spouse, worries about breach of data protection, patient moving to England, HP causing arguments and stress, high carer stress and house move, GP not knowing about HP.

Table 2: Recruitment and attrition

| | Wave 1 | Wave 2 | Wave 3 |
|----------------------------|---|---|---|
| Number | 26 | 21 | 16 |
| Patient gender | 13 females 13 males | 11 females 10 males (new: 3 female 1 male) | 7 females 9 males |
| Carer gender | 18 female 8 males | 17 females 4 males | 12 females 4 males |
| Age | 57-89 | 57-87 | 58-88 |
| Stage | Mild-moderate | Mild-moderate | Marked deterioration: 3 males |
| Living arrangements | With carer: 17 Living alone: 9 Other: 2 | With carer: 14 Living alone: 5 Other: 2 | With carer: 11 Living alone: 4 Other: 1 |
| Attrition | 5 females 6 males | 4 females 1 males | N/A |

The findings are presented thematically in line with the thematic framework (see Figure 6) and organised into five main topic areas. Under each topic area are a number of main themes which were in part researcher driven, i.e., they resulted from our research aims reflected in our topic guides, while others emerged directly from the data (data driven). They will be introduced here, each illustrated by carefully selected participant quotes.

An understanding of the use of the healthcare passport is meaningful only in the context of the lives and experiences of the people with dementia and their family members. Thus, in our interviews we aimed to build a picture of how their world has been altered by dementia, how they manage their dementia in the midst of other health and social challenges and how the uptake and usage of the healthcare passport might be influenced by these factors. Our findings are structured into a thematic framework comprising of five main areas of interest as depicted in Figure 6. The arrows in the framework graph denote the interaction between the areas. What stands out is the central role and responsibility of the carer.

- Patient Background and Medical Information
- Personhood and Identity
- Carer as Lynchpin
- Healthcare Passport
- Health and Social Care Professionals ('HSCPs'; experience of, and communication with)

Each area of interest comprises of a number of themes which will be introduced and illustrated in the following in order to provide as clear a picture as possible of the lived experience of being a person with dementia, a dementia patient, or a carer of someone with dementia. This will provide a better understanding as to what influenced attitudes to, and use of, the passport.

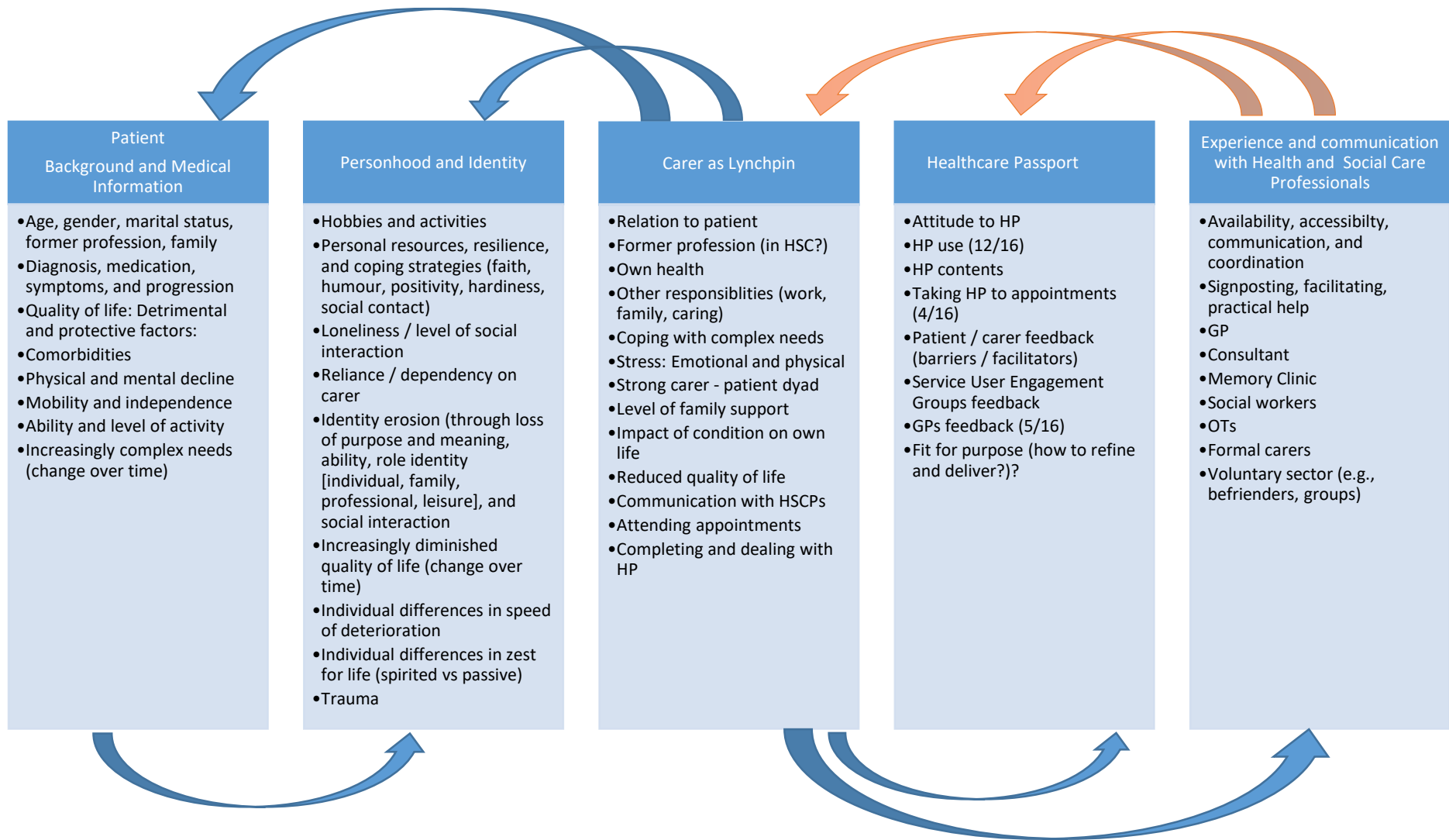


FIGURE 6: THEMATIC FRAMEWORK

3.3 Patient background and medical information

The majority of patients (22) were married, with 11 being widowed. For age and gender of patients see Table 2. Their former professions, hobbies, ways of coping, outlook, and main theme in interview are detailed on the Participant Profile Table in Appendix 1. Table 3 below illustrates the types of memory problems across the three interview waves.

Table 3: Memory problems: types and numbers at waves 1-3

| Wave 1 | | Wave 2 | | Wave 3 | |
|---------------------------------------|----|---------------------------------------|----|---------------------------------------|---|
| •Alzheimer's Disease | 20 | •Alzheimer's Disease | 13 | •Alzheimer's Disease | 9 |
| •Early onset Alzheimer's Disease | 3 | •Early onset Alzheimer's Disease | 2 | •Early onset Alzheimer's Disease | 2 |
| •Parkinson's with Alzheimer's Disease | 1 | •Parkinson's with Alzheimer's Disease | 1 | •Parkinson's with Alzheimer's Disease | 1 |
| •Parkinson's with Lewybody Dementia | 2 | •Parkinson's with Lewybody Dementia | 2 | •Parkinson's with Lewybody Dementia | 2 |
| •Dementia unspecified | 1 | •Dementia unspecified | 1 | •Dementia unspecified | 1 |
| •Vascular Dementia | 0 | •Vascular Dementia | 1 | •Vascular Dementia | 1 |
| •Not clear | 2 | •Not clear | 1 | | |

All 28 participants were retired, or not working. Eighteen of their family caregivers were also retired from work, six still working (one carer worked part-time only to facilitate care), and four not working (one of whom gave up work to facilitate care). We were able to obtain a socially heterogonous sample; among those were a joiner (company owner), a manager at the NI water board, two teachers, a member of the clothing industry training board, the owner of a contract cleaning business, a butcher, a social worker, and a housing executive manager. The remaining 21 patients had worked as caretakers, cleaners, childminder, home-makers, lorry-, and taxi-driver, bricklayer, factory workers, labourer, and home-help.

Only five patients lived alone in their own home, one lived in residential care (by choice), and 20 lived with either their spouses, or a daughter or son. Thirteen patients reported having good family support. Of those who lived alone, and/or in residential care, all received support from one or more of their children, or a sibling.

Patients lived with different types of dementia, including Alzheimer's Disease (22), Early Onset Alzheimer's Disease ('EOAD') (3), Parkinson's Disease with AD (1), Parkinson's Disease with Lewybody Dementia ('LD') (2), Dementia unspecified (4), and Vascular Dementia (1). Table 2 shows types and frequencies of patients' memory problems at waves one, two, and three. In addition to memory loss, 12 people experienced considerable confusion and disorientation, with three appearing disengaged and withdrawn. Six experienced

agitation while six others had displayed aggressive behaviour at some point. Fourteen had experienced one or more falls. While most people remained relatively stable over the duration of the study, three male patients had significantly deteriorated at wave 3 (P12, P17, and P20), needing help with everyday tasks and 24/7 care. Dementia diagnoses were arrived at in different ways. Sometimes diagnosis followed a diagnosis of Parkinson's Disease following a fall, for others memory loss was a result of a series of mini strokes. A deterioration of memory, or a change in behaviour prompted a visit to the doctor, resulting in a dementia diagnosis.

“... we took her to the doctor's not that long ago, late on last year for her Parkinson's health check, and when the doctor asked mammy about her mind, mammy openly admitted that she didn't, she couldn't remember, and she scored, I think it was 23 out of 30 in her tests, so they referred her on then for memory assessment and they come back and they said, yes, that she has dementia.” (C15)

“But they said that I had a mini stroke down the side of my face and here is damaged.” (P25) “TIAs.” (C25) “They said that was why I was forgetful. This is how it started and then they decided we should see more about it, so I agreed and we went down there to see...”

3.3.1 Reactions to Diagnosis

Wishing for death or preferring death to diagnosis

Several participants either said directly that they wished they were dead after they received their diagnosis, or that they would have preferred a more immediately fatal/terminal illness than dementia. Participants often commented on hoping they would die before certain things happened, the most common of which being forgetting their children or requiring help with intimate personal care.

Anger

Many male participants expressed anger at their diagnosis, with some admitting that at the time of diagnosis they were angry at the doctor. One participant went as far as to say he fantasised about punching the doctor delivering the diagnosis in the face. Some participants expressed anger at feeling they had been 'cheated' by the diagnosis out of their later years. This was particularly the case in younger participants (60-75).

Shock and Denial

Shock and denial were the most common responses to diagnoses, and this was reported to be the case even where participants were anticipating the diagnosis or had been experiencing/witnessing the symptoms for a long time. Many participants spoke about not being able to eat or speak to each other/family members for several hours, and sometimes days. Most reported immediate changes in their behaviour, such as carers doing more for participants, or patients exhibiting signs of depression. There were many participants who were 3-6 months post diagnosis who reported still being in shock or denial, and who described avoidant behaviours of things which reminded them of their condition.

"To be quite honest, the day he [the consultant] told me he could have put a bullet right through there. I really was that annoyed. No, I wasn't expecting it. I wasn't expecting it, I really, really, I was that upset, and nobody knows how I feel about this [dementia]." (P25)

"We drove back up the road again, you would have thought the two of us were fighting, we weren't speaking to one another. We were just in shock. What happens now, what do we do now?" (C3) "That is the truth; that is the complete truth what she's telling you."

(P3)

The immediate emotional impact of the diagnosis on both patient and carer is noticeable in their comments as their thoughts turn to the future and the prospect of ever decreasing mental faculties. Our findings suggest that some clinicians may underestimate the effect this has on patients and families and services may consider the provision of a safe space at the health centre or hospital, which would allow patients and families to gather their thoughts, and get over the initial shock. While acknowledging the time limits put on health professionals, patients nevertheless described receiving their diagnosis in a perfunctory manner, without empathy or immediate aftercare, which left them feeling distressed and vulnerable.

"We nearly collapsed. We had the hankies ready because he knew we weren't even..."
(P1) "He says how do you feel? I says "I'm shocked, because I thought it was the depression". (C1) "We sat and cried, I thought then Jesus, Mary and Joseph, how is any of us going to drive up the road?" (P1) "It was a shock, now, to be honest." (C1) "It was a real shock. But then I thought, no I'm not going to let it overcome me, I'm going to try ...I thought then sure if I had cancer it would be worse, and you just have all the things that

you keep thinking to yourself, God, I'll never see my grandchildren grow up and things like that. It was awful. It's still awful, only I try to keep myself busy.” (P1)

“How we were told it was shocking - shocking.” (P3) “They don't have the time...” (C3)

“No, they don't have the time...” (P3) “...but at the same time, it's when you get out and you think about it you say ‘oh my God’, it was just a punch in the belly.” (C3)

3.3.2 Quality of life ('QoL')

The factors noted as either protective of, or detrimental to, the patients' – and carers' – QOL, were: (a) comorbidities (type and number); (b) physical and mental decline (stage and speed); (c) mobility and independence (degree); (d) ability and level of activity; (e) increasingly complex needs (change over time), and (f) family support.

3.3.3 Comorbidities

In our sample, we noted the following comorbidities: Depression, diabetes, arthritis, COPD, heart problems, hypertension, breast-, and prostate cancer, benign prostate condition, hearing, and vision impairments, Dupuytren's contractures, learning difficulties, back, and knee problems, and expressive dysphasia. Table 4 indicates the types and frequencies of comorbidities our participants reported living with. Depression (37%), arthritis (30%), diabetes (27%), and cardiac conditions (27%) were the most frequently occurring comorbidities in our final sample. Eighteen participants (60%) suffered from multiple comorbidities, with between two and eight separate conditions in addition to their dementia. Comorbidities were expressed as having a very detrimental impact on the QOL of both patient and carer, by restricting the range of activities of daily life. It is worth emphasising that these are the comorbidities as reported by the participants and may not entirely correspond to their medical records. Some participants may have forgotten to mention particular conditions or have chosen not to disclose them.

One participant (C16), discussed how her husband's Parkinson's disease caused him more trouble than the AD. It severely restricted his mobility and was frustrating and embarrassing.

Table 4: Comorbidities

| Comorbidity | Number of patients |
|--|--------------------|
| Arthritis | 9 |
| Cancer | 1 (3 previous) |
| COPD | 4 |
| Depression | 11 |
| Diabetes | 8 |
| Cardiac conditions | 8 |
| Other (incl. hearing-, and visual impairments) | 15 |

3.3.4 Mobility and independence

Some of the response to the debilitating impact of dementia appears to be influenced by the personal resources and psychological resilience of the individuals. One participant (P7), appeared to have given up on life after the death of his daughter. He suffered from depression (recently diagnosed post-bereavement), diabetes, and ulcerative colitis, and lived alone. His son, who had his own young family, cared for him. Having had a very active life, he now spends much of his time in an armchair. While he was aware of this decline, he had no motivation to improve his health. By contrast, another man (P17) in similar circumstances was keen to hold on to his independence despite being more physically restricted than P7. However, such differences in attitude and behaviour may also, in part, be attributed to family and social support.

“Where was I yesterday and I had to walk, and I hadn't a breath. I know I'm not getting enough exercise, granted. There's nothing to ail me and I don't know how many times to walk from here around the block and back in again and build it up. I was younger all right, I used to do a wild lot of cross country running and stuff like that and I could run for miles, now I couldn't walk.” (P7)

Although, mobility aids facilitated movement and encouraged independence, they were unpopular with most patients. A typical case (P20) a former manager, had been a very active member in the community, leading a varied social life. He was diagnosed with Parkinson's and dementia, in addition to various comorbidities (Depression, arthritis, headaches, sore back, psoriasis, impaired speech and vision). His health deteriorated rapidly after being diagnosed with cancer. Having deteriorated significantly over the duration of the study, his QOL was greatly impaired. However, he found the idea of a walking aid not compatible with his self-concept and his refusal to use a walking aid also affected his wife who remained housebound unless

someone relieved her. One man (P16) had a walking aid (rollator) and a walking stick for use indoors, due to several falls, but refused to use them, admitting that his pride deterred him. His wife was upset by his refusal to go out with the walking aid. Three other participants (P17, P20, P14 - two male, one female) had been provided with walking aids but also avoided using them. Arguably, they associated the walking aid with old age, illness and infirmity, and did not wish to identify with this status. One woman uses her walking aids on a daily basis as she would be unable to walk without them.

One participant (P3) discussed how he could no longer work in the garden the way due to hypertension and a recent back injury. He got bored in the house and longed for something productive to do. His wife and carer (C3) reminded him that he is *not allowed* to dig. For others, falls produced loss of confidence, exacerbating the loss of mobility, independence, and social contact. This, of course, led to deterioration in QOL for both patient and carer who are both restricted in their movements, activities, and opportunity to exercise as a result of the patient's arthritis.

"But, I mean, some days T. is very good and other days he finds it very difficult, and that's the days I think he should be on something, even something very mild, you know. Some type of thing, because he is, he's on nothing for it. And actually, his mobility is worse, isn't it, T., really, than your memory sometimes? I would say you've more bother with your mobility than his memory, really." (C16)

"Has he been given one of those walking aids?" "Well, don't go there!" (C20) "He doesn't want it. [laughter]. (C20a) "A walking aid?" (P20). "That would be much, much, much too sensible. It's very true but we're hoping that we have a stick...we have two sticks, actually, but he tries them sometimes." (C20) "He would actually benefit from one of the trolleys with a seat, because whenever his back gets sore he could sit and rest. We haven't introduced this yet." (C20a) "He would have a fit. But it means I could push it and he could sit and rest, because he can't walk very far without a rest." (C20a)

In several cases, mostly men, the recognition of physical deteriorations, along with the loss of role and reduced social contact presaged a deterioration in confidence, low mood and further withdrawal. Another similarly felt bereft when informed he could no longer drive, feeling that his freedom of movement, and his independence were taken away from him. Demonstrating that personality and outlook can make a big difference to wellbeing and QOL, P8 (aged 87 years) who was in the same predicament, opted to re-take his driving test, passed and had his licence renewed, and is now driving again.

“The worst thing that happened was when they said to me about not driving; it was just like cutting off your right arm...just to say that I wasn't allowed to drive anymore.” (P7)

Other people described the importance of maintaining routine activities and household tasks to maintain daily structures, purpose and a level of continuity. Thus, in order to cope with the progressive nature of dementia, some carer-patient dyads found that structured days helped to maintain a sense of normality and control. By maintaining a strict daily routine, they maximised remaining abilities and maintained a decent QOL. It is likely that such structures and routines also provide stability within the patient-carer relationship.

“That's what I find helps us to keep on track, routine. We have a wee routine every morning. We get up at 8 o'clock, have the breakfast, not everybody wants to get washed every day, Dagmar, but we work around it, get the shower going.” (C32)

3.3.4 Family support

While the amount of support from the wider family varied, practical and social interventions were equally important to support ability and independence, ensure continuity of lifestyle, preservation of QOL, and maintenance of social contacts. Some families may only have had one relative who is willing and able to help, but this could make all the difference when other family members were less forthcoming.

“The memory clinic did give us some information, books on dementia and things about the Alzheimer's Society and... My niece used to be the advocate for the Alzheimer's Society so she has given me some information. She has been a tower of strength, she really has. She told me about dementia Lewy bodies before M. was even diagnosed.”
(C23)

The daily activities of various participants depended on the time, concerns and capacity of family members.

“Aye, down in the Aberfoyle, aye. We were always used to walking, we liked walking, we were healthy enough, we enjoyed good health so we were lucky that we could do that. But because M. has arthritis in his knee too and it does cause him a bit of trouble,

walking, and a lot of the footpaths are very uneven and the roads that they're perpetually digging up, and therefore to stumble or hit anything...you've got to watch your feet all the time, where you're putting your feet, and he did sort of fall a couple of times.” (C17)

One carer (C33) had given up work to care for his mother who had been displaying increasingly hard to manage behaviour, and no longer recognised him. She could no longer be left on her own (because she, a) did not like it and became fearful, and, b) because she was “sun-downing”, i.e., kept trying to ‘go home’), so the son was very restricted in his movements. Attempts to let his mother (P33) attend day centres failed as she appeared very fearful. Colourful language and racist views were behaviours that she had not previously exhibited and which her son found puzzling, and embarrassing. Both patient and carer had a much diminished QOL.

“Aye, She's a nightmare at times. They take her out to their houses [her children], she has to get back here, she won't stay in their houses, she wants here. I finished work altogether, she's no good on her own.” (C33)

“Does she know you now?” “Not really, no.” (C33) “That's hard.” “Sitting in there last night, ‘Where did the other Charles go?’ I said ‘I'm the only one’, ‘No, there's 2 or 3 Charles, you're not my Charles’... what do you do like, you know what I mean? You feel sometimes like... (20:50 unclear) but that is the way life is.” (C33)

“She told us not to bring that woman to any day centres, she said the fear on her face, she must be thinking that we are going to put her into a home. She said the fear is unbelievable on her face. She got out the door and I had her by the hand, they were all standing behind us, and she said ‘Thank f..k!’ She's got a wild curser, her language is terrible at times, and she has got very racist, for some reason or other.” (C33)

3.4 Personhood and identity

3.4.1 Personal resources, resilience, and coping strategies

One of the putative benefits of the use of the healthcare passport was the maintenance of the individual’s ‘personhood’, by ensuring that health and social care professionals could identify and relate to the person

behind the condition. Thus, dementia is a life-limiting condition which, over time, greatly diminishes and eventually erases a sense of self. As such, personhood and identity are directly compromised by dementia and by the social and medical response to the condition. We found that some personal, as well as socio-environmental, attributes appear to delay the process, and increase the patient's – and carer's – QOL in the interim. Among these are a positive attitude and outlook, good coping abilities-, and strategies (such as humour, faith, social contact, and personal interests), regular social interaction to combat loneliness, an active approach to life, and meaning & purpose in life. In terms of personal resources, we found (above section) that a number of participants derived great strength from their faith, while some others used humour; some seemed naturally hardy and resilient; some had a positive outlook, and some sought social interaction. It was not uncommon that a person did all of these things (P1, P8, P13, P19, P21, P27).

These attributes not only impact directly and significantly on QOL, but also on the attitude to the HP. Acknowledging these individual differences and recognising the difference they make to a patient's experience of dementia are key to the provision of person-centred care. These personal and socio-environmental differences are presented below.

3.4.2 Hobbies & activities

We noted considerable differences in the activities, interests, outlook, and coping strategies among our cohort. While some participants had one, or several, regular hobbies, others ceased to be active due to deteriorating health. Others had stopped for other non-health reasons. For example, one woman (P14) used to be a keen piano player and while she had no physical condition to stop her playing, she and her husband had not replaced her old piano. Both patient and carer appeared very subdued and apathetic during interview. Despite being aware of the patient's love for piano playing, they did not seem to care sufficiently to facilitate this hobby, or perhaps lacked the finances to do so. P14 suffered from depression.

“... if I got her a piano she would enjoy playing the piano.” (C14) “I love playing music.” (P14) “Aye, she loved music.” (C14) “We used to have one, it was very old and I had to get rid of it.” (P14)

3.4.3 Religion

Other people tried to maintain their links with the church. Thus, P30 was heavily involved in her local church and relished her role and associated tasks. Similarly, one woman (P13) was very reliant on her faith, as it gave her strength and solace, as well as purpose. She prayed for her family and friends for hours every day.

Living with her daughter and carer, she no longer had a “function” and was absolved of all responsibility. Her daughter described her as restless. Praying helped her fill a void and provided her with some measure of perceived control. Others derived most enjoyment and meaning from being involved in family life and helping out whenever possible.

“We had a lady minister...and she asked me would I assist her and I asked what I had to do and got my own prayers. I bought a lot of books to get the prayers and I would lead the service. I do everything except preach the sermon, and I help with communion.” (P30)
“So, she enjoys baking, that would be one of the other things.” (C30) “And I organise all the funeral teas in the parish.” (P30)

“I just believe, well this is the way that I look at it, I say ‘Right, Jesus, you gave me nearly 77 years, And I said ‘if it's your holy will, will you let me live for a while before so I can enjoy this here wee home in here, and I love it, and if it's not to be then your holy will be done.’ But I get up every morning and I say thank you for this day and be grateful.”
(P13)

3.4.4 Humour

Humour was a recurring theme in terms of forming a natural part of peoples’ personality, and subsequently serving as a way of coping with adversity. C25 talked about how herself and her four siblings had always resorted to humour in order to deal with difficulty. The humour of the participants was evident in many of the interviews. Where the capacity for humour appeared to be diminishing, it was regarded as a loss of a part of the person’s personality, of what made them who they are, their self-identity. Others also expressed how laughing even in difficult times was regarded as a very helpful and necessary thing, and how resorting to humour and laughter induces positive feelings which help to counter-balance negative ones. P27 expresses very well the critical role humour plays in his life.

“We usually laugh our way through things, that’s how we’ve all coped with stuff in our lives. We’ve found the... maybe even the blacker jokes, the darker side of a joke, if you know what I mean, about ourselves like, but we have always... humour, that's how we get through things. Mammy doesn't always get the humour. We’re more my daddy’s dry wit,

but sometimes mammy doesn't get it. [laughter] Sometimes she's disgusted with us but that's what we use to get through life." (C25)

"He always had a good sense of humour. He still has, to some extent, but it's going, you can see it waning. It's an awful disease. So, that's where we are." (C12)

"You need the humour, don't you?" "It's better than food to me, and I like my food as well." (P27)

3.4.5 Positivity

For those participants who were in the early stages of dementia, maintaining a positive outlook was a conscious strategy to remain active and happy as long as possible. One person (P13) lived contentedly, surrounded by a large, supportive family, good neighbours and friends, great faith and acceptance. Her dementia had hardly progressed over the course of the study.

"What I have found is I just like to sit on my own with the dog or my wanes calling or coming and going, the likes of J. coming for a holiday, and just looking out. I can't be bothered with this socialising, company any more. I would have gone places when I was younger. But I'm so happy with the situation, the way I'm feeling now. To me, I'm just so happy, because I'm never alone because Jesus and his mother is with me all the time anyhow, so I'm never alone. I have beautiful wanes and good wanes and they're there all the time for me. And I've two great neighbours if I had a need of them at any time, they just say "M., just bang the door", you know what I mean? I can truthfully say now, at this stage, and it must be near three years now, I know it's going to get worse and I'm going to get to a stage where I'll not know my children or my grandchildren, but sure when it gets to that stage it's not going to do me no harm because I'll not remember, for I don't know, so I'll not be sad, you understand what I'm saying? I'm prepared for all that there anyway. The way I look at it, it's just an advancement towards death now, this illness. So is every illness." (P13)

3.4.6 Social contact and social exclusion

While most people wanted some form of social contact, not everyone wanted to attend community groups and clubs. In some cases, this was because patients and carers felt there was no need as the patient had enough social interaction with family and friends. In general, most participants enjoyed having a social structure to their week, which involved contact with different people as well as different activities. The combination of social contact and meaningful activity made for a good QOL.

“We are all a close family. T. was always very close to my two sisters. My sister M., we have this routine where we go, winter and summer, every Thursday, it's got a routine, and now if we can't go we get this...if she can't go one week or I can't go it's disappointing but we try and go every week. You never get bored going there. We just go for the sociality; we don't go because we're going to the beach for a day. Even if it's cold, it doesn't matter, you just put on an extra coat or whatever. And T. enjoys F. Although F. is 75, he's very good, isn't he, T.?” (C16)

Despite maintaining active lives, many people, particularly males, described their loneliness (e.g., P3, P7, P8, P16, P17). We noted a pervasive reluctance among male participants to engage in regular social contact with people other than their immediate family. For some this is associated with the stigma of dementia. For example, one person (P3) who had been very distressed by his dementia diagnosis, did not want to talk to others about it, or engage with others with the condition. Unlike others, he had not come to terms with the diagnosis, as was his wife, who, at wave 3 was being treated for depression. They both found it almost impossible to accept the situation and were constantly ruminating on the events leading up to the diagnosis which they believed somehow contributed to it.

Patients in their 70s and 80s did not necessarily consider themselves to be old, and some did not want to join a group which they believed to be for “old people”. One person, did not want to attend the local day centre for that very reason. *“It's all old people together.” (P16)* Yet another reason some patients may not have wanted to socially interact after a dementia diagnosis could be stigma, or rather the fear of being regarded as different from who one was before, and different from others. This particular issue is well illustrated by a dialogue between P3/C3. Importantly, individual differences between people are pointed out, too.

“J. doesn't want anybody to know that he has dementia.” (C3) “Oh, why not?”. “Well, it doesn't do me any good if I did do it or I didn't do it, you understand; it's a vice versa thing. People could make you worse than you actually are and you could be frigging listening to somebody else, somebody tells somebody else, you know how talk goes from one to another. So I just say "the less said". I'm not any different to you or your husband and to my wife. We're just actual people.” (P3) “That is why J. doesn't go to meetings. (C3)

“The point is you just want to try and have everything normal. This is the way it is; we want to keep it as long as possible because there's nothing really that anybody can do for you anyway so why should they have to know? J. doesn't want anybody coming over here to stay or talk to him, because at the moment...” (C3) “It would send me over the rails, that.” (P3)

One participant, a widower, had lost his daughter only a few months ago, was not interested at all in joining a community group. He had had lost interest in most things and spent most of his time on his own. As described below, the problem of inertia and passivity of the family member with dementia sometimes provoke significant exasperation, sometimes hostility, among the family caregivers. A reluctance to seek social company and support external to the family, adds to the feelings of burden within the family. In contrast, females with dementia were more likely to actively seek social interaction.

“I wouldn't be annoyed going to those places.” (P7) “He's not a great mixer at times.” (C7) “I will sit here, I won't turn on the TV or nothing, just sit looking out...” (P7) “He won't go anywhere for us. Our social worker, he's very good; he was trying to get him in... But my Daddy thinks he has to go a home, he'll not go.” (C7)

3.4.7 Identity erosion

In terms of retaining a sense of self, the study showed that this presented a challenge for all participants. People's personhood is demarcated by various identity roles, and these may become increasingly compromised in older people (loss of job identity due to retirement, diminishing of parental identity as children become adults) generally, and in PLWD in particular. There is a pervasive lack of purpose, and subsequently, meaning, as abilities and independence diminish, and confidence is lost as a result. In a rapidly

transforming relationship, some people appear to be moved by their family members into a passive patient role, losing agency (and possibly personhood) along the way. This is very often for the best of intentions but demonstrates the tension between 'caring' and 'control'. The case of P3/C3 is a particular salient example of such a scenario as the interview excerpt below demonstrates.

"You see when K. goes out, I wouldn't even go out to the driveway, out to the gates, because I have learnt a terrible long lesson with being disobedient. That's the word I would use. I was being disobedient. When I was told not to do something, I done it. I wasn't doing it for myself I was doing it for the family, I was doing it for my wife." (P3)

"But he could have killed himself. I don't know if that has anything to do with that, but that was never like J. But there's just things that J. has to accept now." (C3)

"Can't. When you are sitting here all day and you're on your 'check' it's very lonely. That is the only problem I have." (P3)

3.4.8 Loss of purpose and meaning

It was important to many patients to engage in meaningful activity, be that work, sport, baby-sitting, volunteering, or hobbies (e.g., P1, P3, P8, P13, P15, P17, P18, P19, P21, P27, P28, P30, P31, P32). They needed a purpose in life, a reason to get up in the morning. Men, in particular, talked about their former occupation, and now faced a vacuum without the structure it provided (P3, P8, P17, P23). One person (C15) discussed her belief that, since her mother moved out of her home into assisted housing, she developed both Parkinson's Disease and dementia. She attributed these conditions to poor social interaction and loss of personal agency.

"But since mammy's moved out, mammy has developed these two conditions, because... well the way I see it, she's not... she doesn't have to think, she only has to think about herself. But I think because she doesn't have to focus her mind, I think that's having an effect, because she doesn't have somebody to look after, she doesn't have the people coming and going and because... so she sits in here and she does whatever she wants, and she's perfectly happy, aren't you?" (C15)

3.4.9 Loss of ability

When receding mental capacity is compounded by physical decline, the impact on our sense of self and efficacy is yet more detrimental. Loss of ability affected the carers directly, provoking them, perhaps prematurely, to take up responsibilities as proxies. However, some carers encouraged independence rather than absolving the patient from all responsibility.

“He never can put on his own shoes and socks, you’ve to put them on for him anyway, but other than that he’s putting stuff in the wrong place, which he never did before, and he’s pulling on a t-shirt underneath and then putting a vest over it, things like that, you know, just wee things, but you can see the difference in it.” (C5)

“So it’s great that she’s fairly independent, she can light the fire, to a certain extent, I would clean out the fire and take in the coal for her, and I normally let her work at the fire, just keep an eye on the fire and on her, because I think it’s far better that she’s able to do certain duties. (C19).

3.4.10 Driving and independence

Driving was cited as a source of independence by a number of participants and losing the right to drive was seen as a significant loss by most participants who had been drivers. This was particularly the case in male participants, two of whom indicated that they would happily defy doctor’s orders to stop driving if they thought their carer would let them. These two participants spoke at length about the importance of being able to drive, and the need to have the freedom to access other places, citing their savvy with directions and listing reasons why they should be permitted behind the wheel.

3.4.11 Individual differences in speed of deterioration

The course and speed of deterioration was different in each participating patient. Over the course of the study, of those patients who participated in wave one to wave three, wave one to wave two, or wave two to wave 3, three males displayed the greatest deterioration (P12, P17, P20). The most able at wave 3 were P1 and P13 (both female), and P8 [87], and P27 [86] (both male). It is perhaps worth mentioning that P1 and P13 were both cared for by daughters who had worked as formal carer and mental health nurse respectively. The most depressed patients were P3, and P7, while eight (P1, P13, P15, P18, P21, P24, P27, P30) were the

most content. P3 and P7 were struggling deeply with loss (of a spouse, and of the ability to work respectively), and were both cared for by carers who were highly stressed (C7) and depressed (C3) on account of the patient's condition and facing the challenges that comes with it.

3.4.12 Loss and depression

A theme which was consistent across our sample of participants was that of recent, or long-standing grief, mostly involving early bereavement of one or more loved ones. Fifteen participants with dementia discussed premature bereavements of close family members (children, spouses, siblings), both recently as well as some years ago. Eight of them have suffered from depression since then. One patient (P7), who lost his wife some years ago, and lost his daughter very recently, expressed the impact this had on him. He had lost interest in life, did not look after himself, and spent his days sitting in a chair and looking out of the window. He had been diagnosed with AD shortly after his daughter died, and was also being treated for depression, and diabetes. His son (C7), stated that his father seemed unable to process his daughter's death, and only some months on stopped asking where his daughter was. Confusion was replaced by depression and resignation.

It is worth noting that meaningful usage of the healthcare passport by people living with dementia requires a more active engagement than some of the participants were able to give. Thus, the attitude and behaviour of people such as one man (P7) who refused to see a doctor, was non-compliant with regard to his diabetes, and severely lethargic, does not lend itself to proactive self-management.

"You see, what's wrong as well too [] daddy had lost his daughter and I lost my sister in January, you see, so that's why we haven't got this...we're sort of grieving. Dropped dead in front of him. 48, she was. My mother died of the same thing. She was 53." (C7) "I found her in bed beside me in the morning, dead." (P7)

"Up until a month or two back, not even a month or two back, he was asking me where G. went, the girl that died, my sister, he was asking me where G. was and why she wasn't coming down. He was wild confused there for a long time, but touch wood, I've got him back." (C7)

Some patients had suffered from depression for a long time as a result of bereavement and had received treatment for it. One carer relates the impact the death of their son-in-law had on the family. The pain of the granddaughter at the loss of her father affected him greatly, and he described it as the hardest thing that

ever happened to him. Both carer and patient were passive, subdued, and joyless during the interviews. Both had diabetes, and the patient had depression and Parkinson's in addition to AD. Another person (P15) who appeared withdrawn and un-engaged during interview, talked about her losses. It was apparent that the enormity of losing many loved ones in one year had taken its toll on her and affected her health and wellbeing long-term. Her daughter tried to explain how life had changed for her mother since her father's death and the deaths following that, and that she was not able to cope.

"I lost my only sister too the same year as K. died. My brother in law, my brother in law died with cancer and then C. died a couple of weeks after that, and then K. died the same year. All in '13. It's just...." (P15)

3.5 The Carers

3.5.1 Carer as lynchpin

Most carers were female, (daughters (N=13), and wives (N=11). Husbands made up the next biggest group (N=5); others were sons (N=3), brothers (N=1), and sisters (N=1). Six carers were working; the remainder were retired /not working. Among the skilled professions were teacher, nurse, bank clerk, psychiatric nurse, co-owner of a contract cleaning business, chief environmental officer (council), and joiner, with less skilled jobs including factory worker, carer, tiler, plasterer, domestic help, cleaner, and home-maker.

In some cases (N=5), caring was shared between two or more family members. Eight carers (daughters and sons) also had their own families to care for; one carer (wife) also cared for a mother with AD and an elderly, infirm aunt. Thirteen carers had serious health problems such as follicular lymphoma, diabetes, high blood pressure, arthritis, depression, sciatica, and epilepsy. A large number of participating carers (N=19) were (di-)stressed by the situation and found it difficult to cope. One carer expressed very clearly how she felt her husband's diagnosis has affected not only him, but them both as a couple, impacting on their lives together.

"It's not about one person. J. might have dementia but it's not about really J. It's about both of us. We both need help, not just J. As you said earlier on, yes, he has it, but I'm his wife and his partner and it affects me just as much as it affects J." (C3)

"And then phoning for doctors and trying to get tablets updated and you have to ring at a certain time, it's all this whole thing, a complete change to your day and your life. It's

just unbelievable. And just being on call all the time because you can't move until somebody's here." (C17)

3.5.2 Difference in perceptions or reporting of symptoms

There was often a sense between patient and carer that the patient was not as aware of symptoms as their primary care provider. In most cases, the patient accepted the assessment of the carer, and very rarely did a patient challenge his/her carer. Carers, however, frequently challenged patients on their perception or description of symptoms. The researcher in many cases got the sense that the carer felt like their role, or the amount of work/stress/difficulty they were facing was being diminished and that it was important to them for the researcher to see how things 'really' were. Carers presented often as frustrated by a patient's casual attitude towards their diagnosis. This was more common in dyads with lower memory scores or more time post-diagnosis.

All our study participants relied on their carers to a greater or lesser extent, that is, none were living entirely independently. Help needed ranged from assistance with medication, to providing assurance and company, to making meals, helping with personal care and daily tasks, finances, transport, looking after during sickness, and attending health appointments. Those in the later stages of dementia, particularly when accompanied by one or more comorbidities, naturally required the most help. Three male patients needed help with most aspects of daily living at the end of the study. They were between 75 and 77 years of age, of different socio-economic backgrounds. They had two things in common: 1) Difficulty in communicating (due to expressive dysphasia; Parkinson's Disease; and advanced dementia respectively); and 2) Difficulty in movement due to arthritis.

To a very large extent, the responsibility appeared to be on the carer to ensure medication adherence, attend health appointments, maintain healthy food intake, hygiene and safety, provide social company and stimulation, as well as moral support. This was a full-time occupation which became increasingly onerous as the condition progressed. It is important to note that patients can also be carers as in the case of P25 (79) who cared for her husband who suffered from cancer (deceased post wave 2). This was a very demanding task which, no doubt, took its toll on the patient.

"It's a fair while since she was out on her own. She used to storm out there when she was on those other tablets "I'm away down the town. I'm away out of here." She doesn't seem to go out at all now without me." "Is she on tablets or is she on patches?" "She's on a squirt thing. I sneak it into her." (C33)

We noted only two cases of a strong patient-carer dyad in terms of both the carer's supportive capacity, health, and coping ability, as well as in terms of a robust relational bond. Discussions with most carers indicated a high level of unmet need. Our findings highlight that informal carers are the lynchpin between the patient, family and friends, and health and social care professionals. The level of care required was intense in terms of time and effort necessary in caring for the family member with dementia and facilitating professional health care and social support. This was challenging for most informal carers, who, in the current study, often struggled with their own health problems. Carers in employment and/or with young families to support, also found their caring responsibilities very taxing.

"I clear the place up in the mornings and when I come in in the evening it's as bad as ever again. Like, I'm leaving the children to school, sorting my daddy, getting him up, getting his breakfast, getting everything...going and doing a day's work, coming back, lifting him at night, getting him his dinner, leaving him home, making sure everything is okay and then I'm trying to do my own things." (C7)

One man (C7) was under permanent stress both day and night, on account of his father's behaviour associated both with his dementia and his depression, and it had been taking its toll on him. Moreover, challenging behaviour put the carer under significant pressure. For example, one man (C33), until his mother's medication was eventually adjusted, experienced significant problems as a result of his mother's agitation.

"Our doctors will not give her nothing." (C33) "When you say really bad, was she aggressive?" "Oh aye, she would have beaten that door down to get down to her house, opened the windows to get out, shouting out at people to help her. She just wanted down to Foster's Terrace, which is gone 40 years ago, down to her Ma and Da. So, what can you do? You can't let her walk the streets."

"I was only in, I couldn't sleep, then I fell asleep at 5 o'clock and again at 5.10 am the phone rang again: Telecare, and at that time of the morning then it's like a computerised voice, it's not someone proper talking to you. "Hello, your father has set the alarm off, could you please check again?". So I rang again, so he answered the phone. So you see that whole weekend then, I couldn't settle." (C7)

3.5.3 Work life

Caring alongside full-time work put a great deal of pressure on the carers. In some cases, other family members retired in order to support the main carer. Some people were the sole carers and were unable, financially, to retire. This left them in a very stressful situation, both emotionally and physically, feeling guilty for not being able to provide more, or better, care to the patient. They had to carry out daily caring responsibilities before and after a full-time job, as well as caring for their family.

“So I'm working full-time and I'm coming home to do another full-time job, because my father has since retired, since my mum has been diagnosed. He was retiring age anyway, but he was a fit and healthy man but he just felt that there was too much pressure on me, because of my working days.” (C1)

“See if I was to say I was to stop working and I would go with him, he'd go. But that's where the girl, (name) was telling me, especially now with me the only one to look after him, I've no other family, you see, she said that you're going to go through all these different stages yourself, you're going to go through guilt and a bit of anger, and I am feeling guilty because I have to work and I can't do things, but I've two young children and a mortgage and it sounds selfish but I just can't.” (C7)

3.5.4 Carer health

We noted that although family caregivers were pivotal in facilitating care and support to the person with dementia, many struggled with their own poor health with 14 carers reporting various and multiple health problems. One participant (C31), experienced anxiety and depression, and presented as highly stressed at interview. She was her mother's primary carer (mother lived with her) and had a large family; an imminent house-move added to the stress. Another person (C23), diagnosed with epilepsy, and sciatica, was hampered in her efforts to retain a healthy lifestyle for both her and her husband, P23, by the intense sciatica pain.

“I had a stress test done on Thursday for my heart, because I was taking pains in my chest, but I think it's just pure stress, because I did 10 minutes on the treadmill, which was excellent, I think. They told me everything was okay so I'm assuming it is okay.” (C31)

"I have been killed with sciatica so I had to go to the doctor for myself and see if I could get something for sciatica. So, I was out yesterday morning, I was out this morning, only doing half of what I normally do so hoping to get back...we try to do 2 mile every morning but the weight is going up the way instead of going down the way. I have a wedding in 4 weeks' time and I just can't get..." (C23)

Other people raised their constant concern about providing care if the primary carer was unable to do so. For example, C5 worried about the possibility of an admission to hospital, and who would care for P5, if this happened.

"I put it off, I said if I've to go into hospital, in to stay, because I took sick myself last August and only the girls were off on holidays I never could have managed, for they came and did everything. I never was sick in my life but I took a chest and kidney infection myself and was in bed for four days. I never was in bed sick, never, even when they were youngsters, never took a day in bed, and I would be up every morning before 8, and like that, it just knocked me for six and it took me ages to come around, and I said only it was the holiday time, and I said P., what would I do if anything happened to me?" (C5)

Again, the challenge of trying to cope with different aspects of life were discussed by several carers; for example, C7 described how he struggled to manage work, find time with his own family, and keep caring for his father. Trying to remember to arrange health appointments, and frequent ordering and collecting of medication were responsibilities which added pressure to his day, along with other caring duties.

"Grand, I must ring now, and then I go out to the van and such and such ...and before you know it it's too late in the evening. It's the same too with the chemist I've to ring and order the insulin, they're not allowed to automatically send it out, because my daddy has dementia, in case he injects himself... So I've to go and order it over the phone and then go and lift it. That has to be ordered every week." (C7)

Several people were regarded by their families as the 'caring person', the person whose unspoken role is to care for everybody. For instance, C31 balanced caring for her mother (P31) with meeting the needs of her large family.

“I don’t work, myself. I haven’t worked for a while. I used to work up until I had the wee boy and then I stopped working altogether. But I would class myself as a very busy sort of person. I’m the oldest of the five of us and maybe that, too, is another reason why I’ve the responsibility. I’ve always had that role, I think, and with my own children and my own grandchildren, it can be very hectic.” (C31)

3.5.5 Caring for someone with complex needs

A major aim of the healthcare passport was to help mitigate some of the difficulties posed by the presence of multiple co-morbidities, specifically the problems these pose in relation to communicating the various treatments to family and other healthcare professionals. One woman and her daughter shared the care of a man with complex health needs, day and night. He (P20), had dementia with Lewy bodies, Parkinson’s Disease (including impaired speech), arthritis, depression, psoriasis, back pain, headaches, impaired vision, and previously cancer of the bladder. They found it very difficult to cope with his needs, but were unable to get appropriate help.

“There was very little point in ringing the nurse, either.” (C20a) “They would say ‘You’re on your own, every Parkinson’s individual is different’ and it is true.” (C20) “That is the worst thing, the Parkinson’s nurse told Mummy she was on her own with this, and I really am angry that she said that.” (C20a) “She said ‘You’re on your own, I will do all I can but you’re the one that’s there and you see the things that’s happening.’” (C20)

Similarly, another participant explained that caring for his mother, which he shared with his father, had become infinitely more complex since she had been diagnosed with AD. She had previously had heart problems and had recently had a triple bypass. His father had diabetes, and a recent diagnosis of follicular lymphoma. The family were completely overwhelmed by P11’s diagnosis and all the other health problems they had to cope with and withdrew post interview wave 1.

“You know, more so that it was bad enough after her operation, but since she’s been diagnosed with the memory loss there’s more people has come into it. We’re going to [the hospital] for different things, we’re going to the Waterside in Derry, the hospital, for different things because of the problem, plus also the visitors that we’re having. At the

moment there's been an awful lot of information coming at us. And, you know, we haven't actually come to terms with all of this, we haven't even read all the information."

(C11)

3.5.6 Carer stress (emotional, physical)

We found that most carers (21) experienced considerable psychological stress. This was as evident from what they said in interviews, as it was from their behaviour, which included fidgeting, wringing hands, crying, pressured speech, and defeated demeanour.

"At the moment J. doesn't want (informal) carers, but sometimes, not all the time, sometimes you just feel that you need that wee break on your own. I found at the start that everything was going to be left on me, and my head was away haywire and I was forgetting more than J., and I said it's not fair putting this all on me. I just decided if I forget a name so well, so good, if I forget if something is said, when they come back I will just ask them what they said the last day. I'm not going to worry anymore." (C3)

"I don't know about you, but if your husband's not well and a bad back, you have to get up during the night, help him out of bed, take him to the toilet, and you're no spring chicken yourself, up and down that hall, would you not? Would you not give out to your husband? You see, it's falling back on me. He doesn't see that. He would go out there today, 'Oh, I'll do this wee bit.' I wouldn't mind J. going out if J. knew when to stop." (C3)

Their problems are compounded when carers feel that the person with dementia could do more to help or, conversely, their activities added to the carer's concerns. For example, C3 felt that her husband was not compliant. Thus, while she thought that he should not be doing any work at all, he found this impossible as he had always been active and persisted in remaining active. This made her very anxious as she would be left to deal with any adverse consequences and doubted her capacity further. Similarly, C7 had great difficulty getting his father to attend his health appointments, and often resorted to deception in order to ensure treatment for his father.

"And those are the things why I'm angry. I can't blame myself for being angry with him because he's throwing everything on my shoulders and it's not fair on me. I didn't start

world war three. I'm going to have more problems and I can't handle it at the moment because I'm down myself.” (C3)

“I don't tell my daddy now when we're going to these places because he would refuse to go. I've to get him washed and changed, it's a whole huff, because if I tell him we're going certain places 'I'm not going', he refuses point blank. So once I tell him and we just land there, there's nothing he can do then.” (C7)

3.5.7 Carer – patient dyad

We noted previously that in many cases, especially in those with advanced dementia, the healthcare passport will require the co-ordination and management of the family carer and the maintenance of carer support, in any case, is crucial to meeting the needs of people with dementia. It should be acknowledged that not all relationships between caregiver and care receiver are likely to be ‘healthy’ – that is, demonstrate sufficient warmth, affection and compassion; these may be long-standing relationship problems or relationships that have deteriorated through the course of the dementia. We found that the carer – patient dyads were, for the most part, very strong on a relational level and mutual fondness and affection were transparent in many (15) interviews. Patient and carer fear the loss of their ‘old’ relationship and strive to keep things as they were. They are aware of how much they need each other (e.g., C5), and do not want other people to intrude into their lives. With implications for the healthcare passport and for care generally perhaps, several couples suggest that they try and manage things themselves (e.g., C2, C28/P28, P30). The capacity of some people to maintain this was more apparent than others. For example, despite communication difficulties (verbal and visual), one woman was very relaxed at interview, clearly fully trusting her son-in-law (C24) to act in her best interest. This dyad was not only relationally strong but also strong in a practical sense, because the patient was cared for by her son-in-law and her daughter (not present at interview). C24 was of good health, mentally strong, eloquent, and confident. He was also extremely protective of the patient.

“I keep kidding him on. He says 'you're so good,' I says 'no, I'm not a bit.' I says 'I've you killed long ago...' He'll say 'what would I do without you?' And I was thinking 'what would I do without you, Duckie?' And he was saying 'what would I do without you?'” (C5)

"We handle things ourselves. As far as we can, we'll do it. Wherever she goes, I go now." (C2)

"You look very content." "Yeah, because I know I have a solid citizen here." (P24) "I know she's contented." (C24) "Well, you see, we like one another; we get on well together. No secrets." (P24)

"No, we're not at that stage yet, that we need anybody." (C28) "We work with one another. He's a very good partner; I couldn't complain about him." (P28)

Some dyads were mutually supportive, as in the case of P31 and C31 where the patient (mother) was in the early stages of dementia and still able and willing to help with looking after the great-grandchildren. This gave her a sense of purpose and provided her with a very meaningful occupation and a sense of belonging, along with enjoyment from her grandmother role. Her daughter greatly appreciated having her mother's help and saw their arrangement as mutually beneficial.

"Do you have any particular ways of coping? Is it the fact that you have the support within the family?" Definitely. I think it would get to me more if I was out on my own, more so now, because of the depression now. I don't think I would want to be here, to be honest with you. A. [her daughter and carer] is magic, so she is." (P31)

"Mummy being the way she is and everything else, she is a great help to me. She's as much good for me as I am for her. She helps me and she likes the children being about her. I know it can be very stressful for her sometimes because they're very noisy when they're all together." (C31)

"They keep me going, you know. I always think you have more time for your grandchildren. I think it's because you're too busy when you have your own family and bringing up your own family. But I seem to spend more time now with the grandchildren." (P31)

3.5.8 Reduced quality of life

Improving the quality of life for people living with dementia was a central aim of the healthcare passport. That is, by improving communication between health and social care professionals and families, might result in more effective, appropriate treatment and support. While the person with dementia's quality of life (QOL) is the primary focus, we suggest that the QOL of the patient is inextricably linked with the QOL of the care giver. In many cases, we found that the QOL was impaired for both patient and carers in our sample population, not least by confinement to the house. Many carers felt trapped by the dementia and the behaviour of the family member.

"He doesn't want to walk anywhere. See when the Clipper was here, the big boat, I parked at Sainsbury's car park and all he had to do was go through the gap in the wall and we were on the... 'go on take me home.' He didn't want to walk." (C7)

"True. Pride - is that what you said? You say to yourself, 'F..k, I'm not going to use a stick. Me?'" (P7)

One woman (C12) was struggling when her husband's health worsened over the Christmas period, wanting to leave the house and "go home" all the time, and not recognising her or other family members. He would not sleep at night but continued to wander around, which left the carer unable to sleep and depleted of energy.

"I mean, the thing was we weren't getting to bed until 4 or 5 o'clock in the morning sometimes, you know. I was just so exhausted. He was exhausted and I was exhausted by the next day." (C12)

"I feel I'm the one that's left to do all that, type of thing. If I want to go away for a night or go away for a couple of days, I have to get everything organised and you have to make sure everything is left and that everybody knows this and everybody knows that. By the time you get away you're ready to go. It's not that you want to get away from the person, you just want to get away from the situation for a couple of days. You think about nothing else. (C16)

3.5.9 Communication with HSCPs

The crucial importance of the family caregivers to the use of the healthcare passport should not be underestimated. While self-management may be an important dimension, this may require a different conceptualisation for those with dementia (compared to conditions without cognitive impairment). Communication with Health and Social Care Professionals (HSCP) was almost exclusively done by the carers. Very few patients (e.g., P8, P18, P27) took the lead in contacting HSCPs, making appointments, ordering medication, attending appointments and asking questions. Furthermore, this sometimes requires skills and tenacity. For example, a former mental health nurse (C13) understood how the healthcare system operates and believed that this knowledge gave her a distinct advantage. She was also very confident and had no problems communicating with any of the professionals involved in her mother's care. The advantage of having a carer with medical or social care experience was noted in several interviews.

“Because, as T. will tell you, I do talk a lot. I ask a lot of questions when we're in the doctor's, you know. Or, you know, such and such, and such. Because, if you don't ask you won't be told, you know. So, I do that, but I would keep... as well as that, all his appointments come in, in letters, so I stick them all into one place. We have a wee office place down there, so I just put them all along and then we know what day we have to go and things like that.” (C16)

“It is, probably, because I know what I'm talking about and I know my game. I would listen to what they have to say and I would be able to ask questions and that, like I said even about the housing situation I was able to ring the OT department and got a domiciliary visit organised. He said "oh 8 month waiting list, but as soon as she got diagnosed with Alzheimer's they were out within 3 or 4 weeks. So people that wouldn't have had that networking skills, or people that wouldn't have had the confidence or the insight probably would find it so much more difficult, where I don't feel the need to go to people unless I really need them. I know what's out there if I need it but I don't need it yet.” (C13)

C32 had on occasion taken her daughter, who is a nurse, along to important health appointments for her husband in order to ensure that no important information is missed, and that all the right questions are being asked and answered. She was very articulate, thorough, and confident herself.

“Any piece of information...when we went to see Dr O., the girl in Antrim [daughter] came with us. A. is a nurse so she was there as well, and any appointments that R. has, I always go. When you're going anywhere I think another pair of ears is very good, especially if you're talking in medical terms. If you have to say anything you can say: “Look, I'm not quite sure that I've understood what you're saying, could you maybe run that by me again?” or “what did you mean by such-and-such?”. (C32)

3.5.10 Attending appointments

All carers attended the patient's appointments, not only memory-related ones, but all other ones, too. In cases, where the patient had one or more comorbidities, appointments with, and visits from, various HSCPs became numerous. The making, keeping, and follow-up of all appointments were ensured by the carer, as was most of the responsibility regarding taking on board any health-, and care information that was provided. This could be quite a tall order, more so still when the carer had to deal with their own health problems at the same time. For example, the husband and carer of P11 had considerable health problems (a lymphoma and diabetes). The diagnosis of his wife's AD came as a shock on top of his own health problems and her triple heart bypass. Husband and son were both overwhelmed by the amount of health visits. They made a point of saying that they were very happy with the care they received. When both carer and patient had various conditions requiring appointments this led to a lot of time spent at making and coordinating appointments as well as attending them. In addition, participants reported that the information provided immediately after having received the dementia diagnosis, was overwhelming. However, they regarded the healthcare passport as an additional chore, and withdrew from the study after the first wave interview.

“At the moment there's been an awful lot of information coming at us.” (C11)

“And, you know, we haven't actually come to terms with all of this, we haven't even read all the information.” (C11) “We're getting that much.” (C11a)

“And I'm running to the hospital myself. So, you know, and that's all happened in the last 12 months, two years.” (C11)

“Dad's just diagnosed with Follicular lymphoma, which is a form of blood cancer. So, it's okay at the moment, it's just everything gets thrown in at the one time.” (C11a)

3.6 Using the Health Care Passport

In the first wave of interviews, we also covered the patients' and family caregivers' initial views on the passport and how they might use it. In the following sections, we provide an overview of these.

3.6.1 Attitudes to the Passport

Attitudes towards the passport at this stage were variable, and dependent on several factors. Most participants felt unable to report on their views of passport usefulness without some more time to look the documents over. We noted differences in the depth of comment between the two families who had seen the passport prior to meeting the interviewer and those who had only received a summary from the memory clinic staff. There was only one family with an openly negative response to the passport, though many expressed scepticism on both its usefulness and their ability or willingness to use it.

There were several participants who openly admitted that they were unlikely to write anything at all in the passport over the course of the research. Of importance for future development and implementation, participants worried that there was a 'right' way to use the passport, and most respondents were keen to get more directions from the researcher on the 'correct' usage. Overall, the most common response was 'we will give it a go' – a tacit agreement to try it out, with no indication one way or the other of strong feelings about the process.

The Passport is Redundant/Unnecessary

Many participants considered the passport being unnecessary at this stage of their healthcare. Mostly, this was because they did not feel they needed to keep track of too many appointments at this time. This was particularly true of care dyads with a diagnosis less than 6 months prior to interview, and for those with few/no co-morbidities. However, some people stated that they may find it useful later on, as the illness progressed, and of particular use if something were to happen to the carer.

Few participants believed the passport was unnecessary because they were able to keep track of this information themselves or believed the healthcare professionals would already be sharing/recording the information without prompting. In each of these cases, the opinion of those individuals did not change with further explanation of the passport, and so it is unlikely that the response was due to poor understanding of the purpose of the passport. It is important to note that carers' attitudes to information-sharing with healthcare professionals may be complex and the concept of promoting 'personhood' in healthcare is not

necessarily appreciated by all carers. Thus, several families were unwilling to share personal details with the doctor beyond medical history and did not understand the relevance of that part of the passport. These families preferred compartmentalised approaches to care (If her hip is sore, the doctor doesn't need to know anything about her that doesn't have to do with her hip.) or were suspicious of sharing personal information with paid carers in particular.

The Passport is too Onerous

The perception of the passport being too onerous was commonly expressed by carers. Male carers who were not spouses were the most likely to express concerns that the passport might create more work for them. Carers stated they were unlikely to remember, wouldn't have time, or would feel overwhelmed by another task for them to do. There were no complaints about the passport being too much work from patients, however there was very little ownership taken for the passport by patients themselves.

The Patient will be Unable to Use the Passport/No Ownership of Passport from Patients

Most carers indicated that the patient would not be able to use the passport, or somehow dissuaded the patient from using it. In one case, this was because the patient did not want to use the passport, and in a few cases, this was due to problems with writing as a symptom of the condition. There was quite a range, however, in the carer's perception of the patient's ability to use the passport amongst people with the same/similar memory scores. Carers expressed a number of reasons why the patient would not use the passport, including an inability to write, forgetting to use it, not understanding how to use it, or not wanting to use it because it is a reminder of their condition. Male carers were slightly more likely to say that patients would not fill in the passport.

Healthcare Professionals Will Not Use or Read the Passport

Some participants, particularly carers, believed that doctors were unlikely to use the passport, or even to read it. This was particularly true when people spoke of GPs or consultants (with the exception of the memory clinic staff). People who mentioned this were also more likely to discuss doctors being disinterested or pressed for time when discussing their relationships to healthcare professionals. They were also more likely to relay negative stories about experiences with HSCPs. People who had direct experience working in the healthcare sector, however, were more likely to say that they thought the doctors and nurses would find the passport very useful and that they were likely to use it. Many of the participants who did not believe the doctors would use the passport said they could still see the value in the passport for their own care dyad, even without engagement from professionals.

What the passport is useful for

Participants who expressed enthusiasm for the passport were likely to list specific things for which they would find the passport useful. The most common of these was keeping organised and as a memory prompt. Carers were likely to mention that the passport would help them keep track of the range of professionals where patients were more likely to mention keeping track of medication (though this was mentioned fairly infrequently). Carers who were one of several carers in the family could see the value of using the passport to communicate across the caring network. It was interesting to note that no participants mentioned that the passport would be useful in communicating information about the patient to the HSCP without some prompting or discussion from the researcher. Again, this suggests that the concerns about threats to the personhood of the family member posed by health professionals' responses and attitudes, does not register significantly with caregivers or was overshadowed by healthcare needs.

3.6.2 Healthcare Professionals' experiences

While there were a number of common themes in experiences with healthcare professionals, there were also quite a varied range of responses and attitudes towards health and social care staff. The majority of participants had a neutral, mainly positive view of health and social care professionals, and people were more likely to express frustration with the system than individual service providers. The exception to this were individuals who had a specific negative experience with a health and social care provider. There was also differentiation between attitudes towards primary and secondary professionals. The majority of participants had been with the same GP or surgery for an extended period, and several of the participants reported having personal relationships with their GP. People were more likely to speak generally about GPs, whereas they spoke about specifics when discussing secondary care providers. Participants also seemed to use names more often when referring to consultants (as opposed to saying 'the consultant') than when talking about GPs. One possible explanation for this is that several of the participants, while likely to report having a preferred GP, saw several different doctors in their practice.

Passive recipients of Care

There were very few individuals who approached care as a consumer, so to speak, and most participants reported fairly passive relationships with healthcare providers, even if they said that they felt comfortable being assertive. Adult child carers were more likely to be assertive and challenge healthcare professionals than spouse or sibling carers, and female spouse carers were more likely to put disclaimers around any complaints or negative speech about professionals (providing potential explanations or qualifying the impact of the negative behaviour).

Time as an Indicator of Care

The majority of participants mentioned issues around time or limited time when discussing healthcare professionals. This was particularly true when discussing primary care providers. There was a sense from many respondents that spending more time with a patient was an indicator of increased interest or caring. This was not necessarily reported as leading to improved quality of care or improved outcomes, but seemingly had an impact on how the participant felt about their experience and in their trust and confidence in the care provider (increased time = increased trust and confidence). Many participants reported feeling dismissed or ignored by the doctor. These feelings were often associated with the doctor cutting the appointment short, writing notes, not making eye contact or asking any questions.

Familiarity and Increased/Improved Access

There were a number of participants and carers who mentioned having a personal relationship with a care provider, or knowing someone in the practice/department/ward. All of these individuals reported some kind of improved treatment or access which they perceived to be related to the personal relationships. These included the GP spotting symptoms of dementia quickly, GP's willingness to listen to the patient and carer and what they needed, getting seen by a consultant quickly, and taking more time during an appointment. Participants also mentioned the advantage of having a family member who understood or was savvy about the health and social care system (due to their work experience or knowing someone in the system), and reported having a family member like this led to improved or more timely services. One might hypothesise that individuals with family members who have knowledge or experience with the health and social care sector were more likely to participate in this research, given the high percentage of participants who reported this.

Accessibility and Continuity of General Practice

Most of the participants mentioned that they often saw different GPs at the surgery, and most said it was difficult to get an appointment (naming the long wait to see their preferred GP as the biggest obstacle). However, there was very little indication from people that this was a problem, and most reported a positive relationship with their GP. There were other indications in the findings that there were benefits to continuity of care, however. The biggest of these was people who had good relationship with their GP in several cases reported that their GP identified their symptoms and recommended them to a memory clinic. Most participants had been with the same surgery for a long time, but still reported seeing different practitioners on a regular basis. Two respondents spoke about a scheme at their surgery (both referred to by different names) by which when they phoned the surgery, their name would be on a list of critical patients and they

would have fast access to the practitioner. Both reported this scheme reassured them and enhanced their relationship with the GP.

Condescending or Dismissive Treatment

An experience of condescending or dismissive behaviour, as experienced by the patient or carer, was quite common among participants. This dismissal was often more through action than verbal communication and included a range of 'signals' that the HSCP was not interested or paying attention to what they were saying. This included things like reading or looking at the screen while they were talking, being verbally unresponsive to what they were saying, or not seeming like the things they were talking about were serious. This was more likely to be reported about secondary care providers than GPs, though was reported in both. Carers were more likely to report this, as were younger participants. Older participants were more likely to defend or dismiss the behaviour by explaining away the behaviour, blaming the system rather than the individual, or questioning their own perception of the treatment. In most cases, participants reported this feeling of being dismissed made them more hesitant to speak to a doctor about their concerns.

Problems with the system rather than individual, abstract rather than practical discussion

When talking about health and social care professionals, there was a tendency to speak in the abstract, about HSCPs in general, or in the case of negative responses, about problems with the system or institution rather than an individual. The researcher got the sense that these were not questions (the idea of whether or not they felt comfortable talking to the doctor, how they were treated by HSCPs) were not things they had considered or reflected upon, but rather something that simply was. The exception to this was when participants had a specific, significant incident. In these cases, the emphases were entirely on the individual practitioner – though there was some indication that these shaded their experiences with HSCPs more generally after the experience (not enough to really call it conclusive), and in some cases made them extremely distrustful.

3.6.3 Communication with Healthcare Professionals

Feeling more comfortable with female GPs

There were a handful of female patients who indicated that they would only feel comfortable with a female HSCP, or that they would feel more comfortable with a female HSCP. There was no discussion about why this was the case, though they appeared to feel quite strongly about their preference. These participants tended to be older (80-90).

Giving space for patient to talk and feeling 'heard'

Several participants, particularly younger carers, reported that doctors don't give time and space for people with dementia to speak, and that this created a negative experience. Participants reported several behaviours which made them feel the doctor was listening to them compassionately: leaning closer (and in some cases even making physical contact), making eye contact, not participating in any other activities (note taking, checking computer)

Written communication and anxiety

The issue of feeling anxious when reading or seeing written communication from the hospital or doctor was raised several times by different participants, with carers hiding letters from the hospital in some cases. Patients reported that seeing a letter from the hospital or doctor, where the language was sparse or vague, would leave them wondering and worrying about it all day. In one case a carer reported that the clinic had been phoning to tell them about appointments rather than sending out a letter, and that this was an improvement for her husband who had found the letters (even seeing the envelope) anxiety inducing.

Difficulties in Communication between Carer and HSCPs

There were a small number of carers who felt frustrated by what they perceived as a refusal by HSCPs to speak to them about the condition of the person for whom they were caring. The participants who were the most vocal about this were adult child carers (or in one case a significantly younger sibling carer) of parents who were living on their own. In all of these cases carers reported persisting with the GP to get a diagnosis, feeling that their concerns were dismissed or ignored by the HSCP, and that the patient was lying or deceiving the doctor – no one could see how bad things really were except for them. In all of these cases, the carer spoke openly (and angrily) about this in front of the patient, and the patient did not interrupt or correct the carer.

3.6.4 Relevant Social Norms/Expectations

Stoicism

The idea of 'just getting on with it' was extremely prevalent across participants, and the phrase 'just get on with it' or 'take each day as it comes' was spoken in almost every interview. This was particularly strong in spouse carer dyads and older couples. There is, however, some indication that as the illness progresses, participants are less likely to use such language and participants become more open about their frustration/exhaustion with the experience.

Reverence to Professionals

Many of the participants either directly stated that they were likely to always defer to what a professional told them or reported incidents or opinions which indicated that was the case. Participants reported not questioning what they were told by professionals, a requirement to not be burdensome, and a sense that the doctor's time was something to be protected as more important than others'.

Pride in not attending the doctor

Many of the participants reported having never been to the doctor and never been sick, and there was a tendency for this to be spoken like a badge of honour, even in some cases referring in a negative way to those who go to the doctor 'too much'. In some cases, individuals who reported pride in not having been to the doctor used this as a reason to defend their assertiveness or willingness to make demands of HSCPs, because they had 'earned' that right through years of working and not being a drain on resources.

Negative attitudes towards ageing

There was an indication in several interviews that participants had a negative attitude towards ageing in general, and a conflation of dementia symptoms with natural symptoms of ageing.

3.6.5 Reactions to Diagnosis

Wishing for death or preferring death to diagnosis

Several participants either said directly that they wished they were dead after they received their diagnosis, or that they would have preferred a more immediately fatal/terminal illness than dementia. Participants often commented on hoping they would die before certain things happened, the most common of which being forgetting their children or requiring help with intimate personal care.

Anger

Many male participants expressed anger at their diagnosis, with some admitting that at the time of diagnosis they were angry at the doctor. One participant went as far as to say he fantasised about punching the doctor delivering the diagnosis in the face. Some participants expressed anger at feeling they had been 'cheated' by the diagnosis out of their later years. This was particularly the case in younger participants (60-75).

Shock and Denial

Shock and denial were the most common responses to diagnoses, and this was reported to be the case even where participants were anticipating the diagnosis or had been experiencing/witnessing the symptoms for a long time. Many participants spoke about not being able to eat or speak to each other/family members for

several hours, and sometimes days. Most reported immediate changes in their behaviour, such as carers doing more for participants, or patients exhibiting signs of depression. There were many participants who were 3-6 months post diagnosis who reported still being in shock or denial, and who described avoidant behaviours of things which reminded them of their condition.

Immediate Changes to Self-perception and perception by carers

Many participants described feeling an immediate loss of confidence and mistrust of their own abilities. This was visible in participants' behaviour in interviews, as the vast majority of patients were very quiet and passive in interviews, speaking usually only when directly addressed. Many patients checked with carer or researcher to see if what they had said made sense or was correct. It was also common for participants to become more animated and confident when speaking about something totally unrelated to healthcare and their diagnosis, for example a hobby or a family pet, which indicated to the researcher that the self-perception associated with the diagnosis was directly impacting their ability to communicate effectively on issues of their health and care.

3.6.6 Symptoms of Dementia and Life Since Diagnosis

Participants reported a range of symptoms of dementia, though many of the participants were still in the very early stages post diagnosis, and so there were not many symptoms to report. The symptoms reported are listed in the nodes.

Difference in perceptions or reporting of symptoms

There was often a sense between patient and carer that the patient was not as aware of symptoms as their primary care provider. In most cases, the patient accepted the assessment of the carer, and very rarely did a patient challenge his/her carer. Carers, however, frequently challenged patients on their perception or description of symptoms. The researcher in many cases got the sense that the carer felt like their role, or the amount of work/stress/difficulty they were facing was being diminished and that it was important to them for the researcher to see how things 'really' were. Carers presented often as frustrated by a patient's casual attitude towards their diagnosis. This was more common in dyads with lower memory scores or more time post-diagnosis.

3.6.7 Completing and dealing with HP

Ideally, use of the healthcare passport was intended primarily for the person with dementia. However, we anticipated that in many cases this would be unlikely, particularly so in the context of severe dementia. It was the carers mostly, apart from P8, who took ownership of the HP, and made entries, with some taking it

to appointments. It is difficult to say with certainty why this was so. A fair assumption would be that the patients had been, for the most part, absolved of practically all responsibility, and had adapted to their new, much more passive, receiving role. A new identity of illness and infirmity may have taken hold, following the loss of various previous, long-held identity roles. This new identity may have precluded a sense of agency and ability. Over and above that, there were some physical conditions which made it hard, or impossible, for some patients, to write.

“As regards M., my husband, he won't be able to fill that in because he can't write now because he has problems with using his fingers and hands [Dupuytren's contractures]. He's had operations on his hands a few years ago and now they've left him that it's very difficult to write, to hold anything. Therefore, he wouldn't personally be doing this, it would be me. So does that change anything?” (C17)

Other patients were reluctant to use the passport because they were anxious about misspelling words, and pointed firmly in the direction of their carer to take on the task of filling in the HP. People lacked the confidence for other reasons. This included people with Parkinson's.

“I can't write anyway, he'd have to do all the writing because my writing is not good. Sometimes if I'm writing I can't remember how to... what do you call it?” (P18)

3.6.8 Experience and communication with health and social care professionals (HSCPs)

Many participants felt confident in speaking to their HSCPs, and reported good relationships with their GP in particular, arguably due to familiarity, trust, and having built up a rapport over time.

“I have no bother going to see the doctor love, I enjoy going to see the doctor, I think they're great (laughs). “Do you feel very confident talking to the doctor about what's going on?” “Aye. Dr. D., I get on very well with her, she is a very good doctor.” “Is that your GP?” “Aye. It was her that put me on the memory tablet, you know. It was her that first recognised it on me, she made a sentence and I had to repeat it and I couldn't repeat it. She put me on the tablet, thank God.” (P14)

"Well, I wouldn't be nervous or nothing going, but if questions need to be asked, I would ask, you know." (P22)

Generally, participants reported being assertive at a health appointment, but there were situations where they lacked confidence to intervene, or ask questions, as in the case of one participant (C10) who accompanied her father to his GP, and with whom she was not familiar.

"I find it uncomfortable with Dad's doctor, because on the one occasion I went in with him after his diagnosis, his own doctor was sort of being quite blasé about the diagnoses, which obviously me, as his sole person down here, and my husband. My brother lives in Lisburn so it's just my husband and I... getting to the point where we knew this diagnoses had to be made, as with my brother, because we talked with him, and then I went in with dad, because we were getting concerned with his driving and everything, so we made an appointment to go in, which I thought at that stage was the thing you did, to go into Dr H., but he just ignored me for the whole time, and I was in looking his take on everything but I found him rude now that day, I have to say, as if he just... he was directing everything at Dad and sort of "she's talked you into this," you know that sort of way."

(C10)

C30 became very assertive when she thought that her mother had been disadvantaged in terms of medication, and her health was being compromised. Having had a bad reaction to her dementia medication, her consultant had prescribed the patches, however, the GP did not follow that prescription but put her back on tablets.

"I phoned the GP and said, "Look, I know...I've a BNF [The British National Formulary for medications], I'll look it up and tell you that they're more money, so I know. So all the drugs are in it and it tells you the price. So there was a difference, and I said, "do you want me to tell you what the price difference is here, because I'll tell you, because that's what this is all about, money". I know it is a business." (C30)

The frequency of visits to GPs, consultants, and other health professionals varied considerably between and within families, depending on a) the stage of dementia; b) the type and number of co-morbidities; and c) the

carer's health. For example, C5 spent a lot of time at appointments. She had high blood pressure, a chest infection, and a kidney infection, while P5 suffered from memory loss (AD), disorientation, diabetes, was blind in one eye, and had a heart stent. A major issue that the healthcare passport was intended to alleviate was the constant repetition of needs and circumstances that the families were obliged to give to different health professionals was.

"... but it is frustrating that you're having to go to different professionals that you've to keep regurgitating everything again. Some of them do use the computer systems that have all the information on but, again, I know that they don't have time to read it." (P27)

Family members who had worked in the healthcare sector felt more confident and competent to communicate with all HSCPs involved in the patient's care, a good example was a former mental health nurse (C13), who felt she knows "what I am talking about and I know my game. I would listen to what they have to say and I would be able to ask questions and that." She felt this was a distinct advantage in terms of providing a good level of care for her mother. This was a strong patient-carer dyad, with manageable stress levels on part of the carer, and a content patient with good support and a good QOL.

"So, people that wouldn't have had that networking skill, or people that wouldn't have had the confidence or the insight probably would find it so much more difficult, where I don't feel the need to go to people unless I really need them. I know what's out there if I need it but I don't need it yet." (C13)

The family had various members working in the health service and found that this was of help in terms of information, signposting, and getting things organised in a timely fashion. Knowing what you are entitled to, and knowing how to go about getting it, who to contact, etc., was helpful. Mother and daughter had previously lived in a one-bedroom apartment which was becoming increasingly difficult, so with the help of GP, OT, social worker, and memory clinic they were able to secure two-bedroomed accommodation enabling her to maintain care at home rather than having to go into residential care. With increasing numbers of comorbidities, as well as dementia, patients commonly have many appointments which can be difficult to keep track of. People tended to employ some kind of memory system, e.g., whiteboard or similar to ensure they would not miss an appointment. Others may have a social worker as well, and consultants for different comorbidities. This can take a considerable amount of organising, particularly when dates and times change, or staff changes, for example, the onus for which is on the carer, adding a considerable amount of pressure.

“Remembering appointments, we always stick the letters up on the fridge so that keeps reminding us about the appointments. We would have to do that or we'd forget. (P14)

“There's that many appointments that times you do get mixed up in the dates.” (C14)

“You have a lot with diabetics, eye clinic, and different clinics with diabetes.” (P14)

“He has got the carers morning and evening for tablets, and lunchtime now to give him a sandwich. He has Seven Oaks [Alzheimer's Society café] on a Tuesday, he has Praxis [Care] for an hour on a Thursday, and then A. is a dementia specialist nurse, obviously, but after the last visit with her she was concerned about all these falls and got quite uptight about it. So he has to go now and see...it's not actually Mr T. this time, although that's who we saw after his initial diagnoses appointment, it was Mr T. we saw down in Waterside, but it's another foreign gentleman, or he has a foreign surname anyway, he could be English, I don't know, and we're due to see him, I think, in the next couple of weeks, and we have OT too to come out.” (C10)

“They were to come last Tuesday, but on Dad's notes it says any visits for him has to be a Wednesday or Thursday because that's the days that I don't work. But it didn't get carried through and it was a Tuesday, when I just couldn't be there, and already, as you can appreciate, I spend a lot of time, even at work, making phone calls and receiving phone calls.” (C10)

Accessibility, availability, communication, and coordination

Patients were asked about their experiences with the HSCPs they came in contact with in connection with the patient's dementia and comorbidities, in terms of accessibility, availability, communication, and coordination. For the most part, patients reported no problems, satisfactory service, and good relationships with their health-, and social care.

“There's a whole structure. I think it's amazing. I can't get over it. A real appreciation for the medical profession and the nursing staff! I am pleasantly surprised, in fact I am amazed, at the number of things that have happened since I have been diagnosed. A general follow-up, I just can't believe it. I don't know where the finance is coming to

employ all but I think it's unbelievable. You hear that many adverse things about the National Health scheme but..." (P8)

Others experienced poor communication and coordination between departments. This degree of fragmented care, requiring numerous but separate attendance at different clinics on different days, was costly in terms of time and travelling expenses for the families.

"I mentioned this at the beginning to the nurse, I said 'Doctors need to get a grip, hospitals need to...' - you're going one day for an appointment and then maybe you're going back in the evening or back the next day for another appointment, you know what I mean." (C33)

"She gets her ears done too, she's a hearing aid, and it's the same department. The man says before that he'd try to get us two appointments in the one day, get the two done, then they wrote back and said they couldn't do it, so that means you're going one day and then back again and all that. See taking her out, she has no patience, she can't sit about, and you know what I mean?" (C33)

C33 reported some problems trying to get his mother's medication reassessed. While he found that the Memory Clinic wanted to keep their original appointment rather than bringing it forward, their social worker proved effective in getting an earlier date for assessment which resulted in a change of medication to good effect. It is not clear whether this delay was a case of miscommunication, coordination, or availability of staff, but until the change of medication was eventually arranged, C33 had to deal with P33s difficult behaviour on a daily basis.

"No, the memory clinic crowd. They wouldn't push it forward. They just kept it at the same date it was. The social worker was pushing, she needed it assessed. A girl came out, right enough, I don't remember all their names, came out and took her off the tablets straightaway and put her on new medicine and she is a bit more settled." (C33)

He also reported on some difficulty they'd encountered when his mother seemingly had had a stroke, as they were sent from the out-patients department to casualty, and from there back to his mother's GP. At the end of this exercise it seemed that P33 had not received a diagnosis, or an intervention.

“Outpatients is what it's called here in [hospital]. I remember that they thought she took a stroke and the brother took her over to Outpatients, and he said to take her over to Casualty, Casualty told him to take her back to her doctor. They thought she had a wee stroke but they never did anything, they couldn't work it out themselves in [hospital].”

(C33)

In order to afford a more specific examination and clearer distinction between the various health-, and social care providers, the following sections serve to present and illustrate respective findings.

GP

Many patients reported positive experiences and good relationships with their doctor. The matters that were identified as problematic in terms of experience and communication with GPs were partly of a systemic (1.-2.) nature, and partly a matter of personal, individual differences (3.-5.), or personal preferences (6.):

1. Difficult to get an appointment with the same doctor every time
2. Brevity of appointments
3. The importance of being comfortable with the GP
4. GPs taking time to listen is key
5. Attitude of GP (condescending, emphatic, warm, dismissive, etc.) has consequences
6. Patients trying to ‘stay away from GP’ (either afraid to get yet another diagnosis; or not wanting to ‘bother the doctor’)

Experience with GPs has generally been reported as good, although not exclusively so. For example, P20/C20 preferred younger GPs to more mature ones on account of their attitude and approachability. The couple discuss a certain reverence which was afforded to doctors in the past, and which in some cases may still linger. In addition, they talked about doctors complaining about patients taking up too much time in consultation.

“We are blessed with a very good doctor. She is really, really sharp, but she is very good to R.” (C32)

“But then the young doctors are definitely very good, and the older ones, the majority of them are all right. Some of them are very dismissive, you know.” (C20) “I’m the doctor”. (P20) “My mother would have had you genuflecting....” (C20). “Trampled underneath the horse. The doctor often complains about the time taken to... as if it was a major issue.” (P20)

Conscious that consultation time may be only 10 minutes was noted as detrimental. Another systemic problem discussed by participants was the problem of not being able to get an appointment when required with a particular GP, whom the patients have come to appreciate and trust. Participants reported a preference for seeing the same GP over time, which often proved difficult. Once people were comfortable with a particular doctor, they wanted to be able to say “this is my GP”, and be safe in the knowledge that the GP will know their case, and that they will be looked after well, and treated well, and that the consultation will be a positive experience for them. Having to see different doctors was unpopular and participants talked about the difficulty of getting an appointment with their own GP.

“We stick to the one GP. We had one before this one for about ten years or more, and now we’re with another one now and we’re doing the same with him, we’ve more or less kept him as our GP.” (C11) “And is it easy enough to get seen there?” “No, it’s not easy to get to see him.” (C11)

“You never see the same doctor twice. They are always booked up, and others don’t know your case.” (C16)

“I’ll get one the next day if I want to go to any doctor but if I want to see Dr D. I’d have to wait for two or three days.” (P28)

C24 talked about the excellent relationship the family had with their GP, whom they regarded as their primary point person; and they were very happy with how the system worked for them. The family were well known in the community and were acquainted with a number of GPs and other health professionals. However, several participants described negative experiences, most of which were associated with a GP not taking their concerns seriously or disbelieving them in some way (C25, P27).

"I have a good relationship now. I think I had a bad relationship at that time that Dr H. blamed the tablet. [] (C25)

You can read whatever you like in a book but the body is mine and that's where I have it over you." (P27)

We also noted the problems for families when receiving contradictory advice from different health professionals. When this occurred, people tended to follow their GP's advice. For example, one carer (C30) was particularly perturbed when she found that her mother went back to taking her dementia tablets after having seen her GP, despite the fact that she had been prescribed patches by her consultant. In this case, the carer indicated that she believed this was done for financial reasons and was very upset and frustrated about the decision the GP had taken without consulting either them or the consultant. This would have reduced her confidence in the GP considerably.

"Yes. I phoned and said, "Mummy, what do you mean you're taking tablets?" and she said, "I'm taking tablets, I'll try it if that's what the doctor wants, and I'm not going to-" and I said, "No, Mummy, that's not the point. The consultant has prescribed medication for you, which your GP has decided, because it's cheaper, to give you tablets instead of patches." (C30)

"I said, "this is a vulnerable patient and you're making her even more vulnerable, and she's expecting you to be acting on her behalf, and I'm not impressed". Normally, I wouldn't lose the head-. And I said, "there is a protocol that the hospital is following and now the GP has taken it upon himself to not follow protocol". Mum would be embarrassed if she had known I went over what I went over, but I just got a bit annoyed at that stage." (C30)

Feeling comfortable with the GP is paramount to patient engagement, which is necessary for early intervention, regular monitoring, and compliance. However, the professional relationship can be compromised by non-professional familiarity. For example, a female participant with dementia (P30) was initially to embarrassed to see her own GP after her diagnosis, whom she knew through her previous job. When she went to another GP, he informed her own who invited her to come and see her. Fortunately, the participant found her kind and understanding and was very happy with the consultation.

“Well, Dr R. couldn’t have been more helpful and I felt very confident with her and very relaxed when I went out from her. And I’ve no qualms about going back to her again. She said, “you know, my father has it” and I thought, ‘your father’s older than me’. And I talked over it all with her and went out feeling more confident, and happy that she was very helpful.” (P30)

“She was more than nice to me and we got on really well. She wanted then to address it with me and tell me not to be embarrassed about it. [] and I’m glad that I did tell her, because I’ve no hesitation now in going back to her again.” (P30)

We also noted that several participants with dementia were reluctant to visit their GP, for various reasons (P7, P15, P17, P20, P23, P28, P31), including not wanting to bother the doctor, or trying to avoid receiving a further diagnosis. The fear of being informed of deterioration or other health problems is a serious help-seeking deterrent for people living with dementia.

“If she’s complaining of something I’ll say, “you need to go and get it checked, there’s no point in telling me, I don’t have the answers”. Sometimes it takes her a wee while before she realises she should go and get it checked, and then she does eventually.” (C31)

“No, well I don’t often go into them, to be honest with you, as I say, but if I do go I... because I try to stay away from them as much as I can! [laughs] In case they tell me anything else.” (P15)

Consultant

Participant experiences with hospital consultants and other specialists were mixed. Inter-agency and inter-professional communication were highlighted as particular areas for concern; often provoking confusion and distress for the patient and their family, avoidable health appointments, and frustration on the part of the professionals.

“It was a bit of a mix-up because Daddy had Parkinson’s disease and the Parkinson’s disease nurse didn’t recognise the dementia. She suspected it was dementia but she didn’t think it was... She just said it wasn’t the way Parkinson’s disease behaved. She said go to

your GP and when we went to the GP he sent us to the Movement Disorder clinic, and Daddy had already been diagnosed with Parkinson's disease. so, when we went to the Movement Disorder clinic that consultant wasn't very pleased to see us. He was quite rude." (C20a)

In this case, the family was particularly concerned about the lack of respectful communication with their father. They had been following referrals between consultants, GP, and Parkinson's nurse in order to deal with their father's complex health needs. It appeared that there was a lack of clarity as to diagnoses and needs. This points to the need for a clear protocol in complex cases in terms of communication, and sequencing of responsibility, as well as for training of professionals in terms of person-centred care.

"Well, he didn't help himself. I think he was irritated, first of all because we shouldn't have been there and he talked nothing but Parkinson's, which we knew about Parkinson's, and he did not...he practically ignored C., and then he grabbed him by the two arms at the end of it and looked straight at him and said...and I think he suddenly realised that C. was quite capable of...you know." (C20)

"He was patronising, he was dismissive, he didn't look at Daddy, he didn't even look in his direction and he didn't give him any eye contact until the very end. He spoke to Mummy about the Parkinson's and then at the very end he turned to Daddy and started explaining everything that he had just said again. And Daddy was sitting listening the whole time, he could hear him." (C20a)

"And the next time we went, unfortunately we had to go to him again and he did the exact same thing. The one thing that happened then was that when he looked at C., and he was shouting, and C. just looked at him very quietly. I hadn't my hearing aid in and didn't hear, and he said 'I'm not deaf.'" (C20)

Memory Clinic

Commonly, participants were very satisfied with the service provided by the Memory Clinic, in terms of information provision and signposting to sources of support. However, some people still seem to fall through the net, consequently struggle alone, lacking knowledge about financial and social care entitlements. In the

quote below, one carer (C12) described her anxiety and isolation following her husband's AD diagnosis, unsure as to where to turn for help.

"I thought that once my Daddy was diagnosed, I thought everything would follow by, this would come and that would come, and I didn't know that I had to apply for a social worker, and I had to do this and that, so I went to the GP and asked the GP what I will do, she got M. [social worker], he's very, very good now, he's getting us different things sorted out for him." (C7)

"At that point I didn't know who I should have been contacting, you were in limbo, you didn't know how to go about anything, and nobody had said 'look, if this happens, this is what you do.' I started then to go to the Alzheimer's Society meetings. [] So, I don't feel as much that I'm out on a limb at the moment as I did at the start. At the start it was very scary, being totally responsible and knowing they were saying you're doing ok, so we'll not do anything about it at the moment." (C12)

In contrast, others' expectations had been exceeded, raising questions as to why patients' pathways are so different within the same trust area.

"I am pleasantly surprised, in fact I am amazed, at the number of things that have happened since I have been diagnosed. A general follow-up, I just can't believe it. I don't know where the finance is coming to employ all but I think it's unbelievable. You hear that many adverse things about the National Health Scheme but ..." (P8)

Patients were appreciative of the knowledge about dementia staff at the Memory Clinic had, as well as the prompt attention to their needs. Timely appointments and staff taking time to get to know the patient and their history in an unrushed atmosphere made patients feel that "someone cares". In other words, they felt the care they received was personal, and this meant a lot to them.

"She [Memory Clinic nurse] was able to talk about the Lewybody dementia without us having to explain anything. She was nearly telling us what was happening, she knew so much about it, and no one has done that apart from Dr T." (C20a) "And not only that but one day he was very different and I was able to ring straight through to the memory

clinic, they gave me a number and she said 'I'll ring you back in five minutes, I'll talk to Dr T.' And she did. So, that gives you great confidence in knowing that you just don't have to hope for the best and hope that you're doing the right thing." (C20)

"They take lots of time. The second time we went in it was a different nurse, it was just to see how he was getting on, it was within weeks, maybe a bit longer but it was a shorter time than you would expect, but it was a different nurse and she was a bit late. She said 'I'm a bit late because I was reading your notes' and she again took time and went through everything. 'How do you feel about this diagnosis?' things like that. You're just amazed when you go in there – and you feel like someone cares."

Social workers

Some patients regarded social workers as their first point of call for putting in place other help like Occupational Therapists (OTs) and carers (e.g., C20), whereas others (e.g., C24) considered their GP as 'gatekeeper'. Social workers and the assistance they provided were held in high regard and were much appreciated by patients and carers. Thus, they were seen as efficient, effective, and personable professionals who looked after the patients' welfare and endeavoured to meet their needs by looking at the whole picture and taking a holistic approach.

"And somewhere along there is a social worker and that was a call when you were here today from a social worker who'll call on such and such a day so I'm surprised and, in a sense, delighted. There's a whole structure. I think it's amazing. I can't get over it." (P8)

"She's J.'s social worker. But she said if my mammy ever feels the need that she needs one or that we feel that she needs a social worker that she would be more than prepared to take on my mammy as well. She's lovely. There's a great continuity there, so it's grand, she's nice. Very attentive, very, very good. I have to say if there's anything that he needs or whatever, she's on the ball straightaway. It was her that was trying to sort out the stair lift too, it would be grand for the two of them." (C25)

"We have a social worker, who's very good, and she's going to get somebody to call from the Parkinson's society as well, because he's got Parkinson's, that's what's giving him the

dizzy spells. So she's trying to organise that but there's quite long waiting lists for someone to come out. It's all in motion; they're all working together, so it's very good."

(C16)

Some patients believed that their social worker went above and beyond their duty to help them; though not everybody had a social worker, however, (e.g., P17), and some only had one initially but no longer did at the time of the study (e.g., P18). However, we noted that praise for social workers was not universal; one carer reported not having been contacted by her social worker for weeks, and not having her calls returned either. This was a very patient and reasonable person who was somewhat baffled and disappointed at not receiving the help they needed, or any communication as to when this may change.

"The social worker did, but we haven't had any word from her in weeks and weeks, so we're trying to follow that up. She hasn't been very much in contact at all. She contacted me at the beginning of the month and said there wasn't anything at the minute and she'd be in touch, but I haven't heard from her since. Yeah, I know there are lots of people looking for help and I know social workers are overburdened sometimes but I don't know, she didn't seem to keep in contact." (C17)

"But sometimes when you leave messages then no-one gets back or there's no ... we know the stresses and strains that social workers are under and we're not the only ones to be considered. So, we're being kind of fairly good about it, but you could still have a bit of communication even if there's no contact, as such." (C17)

Formal carers

In addition to the clinical services, people living with dementia are likely to require the support of formal carers. However, evidence suggests that such carers tend to be on low wages and employment in this sector has a high turnover of staff. Again, it was suggested that the healthcare passport might alleviate the communication problems created by high staff turnover by familiarising new carers with the health and social care needs of the person with dementia. This was highlighted as an issue for our participants who looked for consistency and continuity in formal carer provision; where this was lacking, patients were not happy, and did not feel comfortable with their carers "because they are swapping and changing faces" (C7), often leading to a lack of trust. Where there was the certainty of continuity, and trust had been established,

patients and carers were very satisfied. “We have two very nice girls [carers] and they’re now permanent with us.” (C16). One informal carer suggested that her husband would benefit from male health professionals, as everyone coming to the house involved in his healthcare had been female. She believed that male company would add another dimension to her husband’s care and would have a positive effect. Assigning carers to patients by taking a person-centred approach needs to be considered in terms of increasing patient wellbeing.

“The carers come in to wash and dress him in the morning and twice a week to shower him. But he can’t manage his clothes or anything like that at all.” (C17) “Oh, yes, and they’re very good, I’ve no complaints at all.” (P17)

“The one thing that would annoy me about the whole situation is we have no men in that situation to come to J. who do that work. It’s all young women, all very nice, but there is no man, J.’s talking to a woman all the time. I know if we get a carer, yes, we can request for a man, because you’d be better with a man because J. could talk about football and cars, or they could go out around the garden.” (C3)

One carer (C17) discussed the Reablement service which she found helpful and supportive. However, she was anxious about changes to this scheme, fearing the continuity would be broken, and the quality of support may suffer. In order to avoid unnecessary worry patients could be informed early on how their care will evolve and proceed. One very different view on formal care services was presented by a participant (C24) who was concerned about formal carers having access to information about the patient’s medication through e.g., the Healthcare Passport. A tendency for high turnover among health and social care professionals was seen as unhelpful. Families were unwilling to share personal, confidential information with someone who may not be there the next day. Personnel changes precluded the building of sufficient trust in this family.

“Well, I don’t want carers to know the medication, because they don’t need to know that. I don’t want the carers to know when her appointments are. If carers come in, I want carers to do what carers have to do and no more. I don’t want them building a history of what’s going on. That’s for us to control, it’s not for incidental carers, and we have found in the past, OTs change, mental health nurses change, carers can change, social workers

can change, and all they really do need to know is the continuity of the service they're providing. The GP is the primary contact." (C24)

"It's the same with the carers coming in, and I can't tell them not to because I am looking for that, but because they are swapping and changing faces, he's finding that..." (C8)

"When I saw you this morning, I didn't know ... I said 'Where did she come out of?'" (P8)

One patient with mild learning difficulties, who lived on her own, was aggrieved at the timing of the carers who came in morning and evening to administer her medication. She felt her life was severely restricted by this. In the morning, she had to get up earlier than she would otherwise have done "Getting up early in the morning just for your tablets, and away they go." (P21); and in the evenings, she had to abandon what she was doing and leave from wherever she was (e.g., at her sister's house for dinner) to hurry home in order to meet the carers "My whole life is tied down with it." (P21) Her sister confirmed that this arrangement was not helpful and was very distressing for her as she felt incarcerated in her home.

"That's right. It's only adding to her stress, because when she's up with me then she gets phone calls from the carers, that they're standing outside, you know what I mean? It spoils her social visits." (C21)

"M. says it's for good, [...] I said "No, M., I can't cope with it." I like my freedom. I don't want to be stuck in the house all the time. The worst about it, you're out for a wee bit of visiting, you're diving to get back to the house." (P21)

"Your life is tied in. I be craving to get out, see when I'm in the house I get wild down." (P21) "The house is her biggest problem." (C21) "Aye, I really...I cry." (P21) "That's her major problem, she'll tell you that, that she wants to be out and about. That's restricting her whole plan." (C21)

For others, the use of formal carers was rejected because of the stigma attached to dementia and other conditions. Thus, one woman (C20) explained that her husband would not tolerate carers coming into the house and looking after him because of his urostomy bag. So, his wife coped alone in terms of looking after her husband whose needs were very complex and who had deteriorated significantly at wave 3. It was clear at that point that her own health had begun to suffer, and she was exhausted and exasperated. They did

avail of a sitting service at night which allowed her to get some sleep, and this was of enormous value to the family.

“There's no point in bringing the carers because C. is very conscious of wearing the bag. I can do the bag no problem. But we get direct payments and we have people coming in and we don't have a... the main one is a girl, she does it all night, which it's very hard to get anybody to do an all-night.” (C2)

Voluntary sector (e.g., befrienders, groups)

Third sector services were widely used by patients and carers, for the most part. Alzheimer's Society's memory cafés, day centres, art & craft classes, befrienders, luncheon clubs all featured in patient's weekly programme. The mixture of social contact and meaningful activity was appealing to patients. It was noticeable, however, that there was largely an absence of physical activity except in two cases (P27, and P32/C32). Given the empirical evidence of the salutogenic effect of exercise on brain function (see also Cotman, Berchtold, & Christie, 2007), this is of considerable concern. Equally, participation in musical activity, which has been shown to be beneficial (Seinfeld, Figueroa, Ortiz-Gil, & Sanchez-Vives, 2013) was only evident in two patients (P8, P27). Participants also used the CrISP programme (Carer Information and Support Programme, now re-named TrIC programme = Training for Informal Carers), which offers information and support for informal carers one evening a week, over five weeks. This service was much appreciated by patients, providing them with information about dementia, how to care for someone with dementia, and signposting to available support and services.

“I went to the Alzheimer's Society in Seven Oaks, you got all these information packs and I went over there and she gave me a lot of stuff, so when we read up on that then a lot of things slotted into place. And after Christmas I got myself informed, and it's all a bit overwhelming, too, ...” (C32)

“That girl that came in, she was very good, she sorted it all out, she was easy enough to talk to and all that. We had actually gone to a course, me and my sister, a five-week course to learn all about what dementia is about.” (C33)

“And then the Alzheimer’s Society contacted me, and they were quite good as far as help, and they sent out loads of leaflets to me about practical things you could get, like a phone, which we haven’t got yet because he’s very used to his own phone. But they’ve another phone with the big numbers on it that you can put, you know, for example, Daddy, instead of having numbers on the phone they can put a picture of me.” (C10)

The importance of personality in befrienders staff was also highlighted by participants, along with the fact that hour-long visits may not be long enough for the patient to get the full benefit of the social intervention. Changes in befrienders and staff in similar position are not helpful, as it takes time to build rapport and trust, and is disheartening, and counter-productive for the patient to keep losing people they had come accustomed to only to have to start building a bond with another person. This would be disruptive for any patient but is likely to be particularly unhelpful for a dementia patient.

3.7 Healthcare Passport

In the previous sections, we provided a considerable level of contextual information about the lived experience of people living with dementia, their experience of services and how the varying degrees to which they managed the dementia-related challenges, medical and social. In doing so, we were able to confirm the fragmentation of services for people with dementia and complex co-morbidities; the associated health-, and social care communication problems barriers that highlight the urgent need for interventions such as the healthcare passport. In some of the previous sections we also briefly referred to some of the challenges to rolling out the healthcare passport. In the following section, we more directly address the use of the passport and offer a more nuanced account of its use – the barriers and facilitators to its acceptability and use. Thus, we examined the passport’s suitability for this particular population, participants’ attitude to the passport and how it was used over the duration of the evaluation. We also investigated participants’ views of the different passport sections and contents, with feedback from participants, user engagement groups, and GPs.

3.7.1 Attitude to and use of the HP

Having had the HP and its purpose explained to them, many participants said they could see the potential benefit in terms of sharing information, ensuring that everyone has the correct information thus avoiding mistakes, as well as unnecessary appointments, and patients having to repeatedly explaining their situation.

“There is a prime example of how that would be helpful. Daddy also has psoriasis, seborrhoeic psoriasis, and they sent him to a consultant called Dr P., and I wasn’t able to go, so she gave him about six different things and Mummy couldn’t remember what they were all for so she got a bit annoyed. And it was fair enough, there were too many, but if that had been written down that would have been great. I think it’s a perfect example of that.” (C20a)

Participants who had health and social care service experience (e.g., C1, C13) were quick to recognise the potential value of the passport in terms of improving communication between different HSCPs involved in someone’s care, and thereby improving their care, avoiding mistakes, saving time and avoiding frustration.

“I think it’s a useful thing, because it’s the same thing if people are pregnant now, they take their book wherever they go , and I find, especially with my friend now that has been diagnosed with cancer, it’s brilliant, because when the carers come in, they log in, and do what they’re doing and then they go to the book and the book gets taken, the medical records, because you need to be on the same page because so many mistakes have been made and things have been overlooked where people have not passed on information and maybe really things have happened that shouldn’t have happened. I know that with psychiatry, you know, from hospital to hospital even, because even with my friend getting... she was running for eight weeks to the hospital and it was in her notes that she had cancer and nobody had told her. So it was really, really bad. It leaves a lot of devastation for families so you’re better all being on the one page and just everything being transparent.” (C13)

“No I think it will, I work in the caring environment myself and I just heard about this last week. They were telling us at work that this HP was coming out, and I think it will be very helpful, because we have patients admitted to the ward, sure I know their name but I don’t know nothing about them. So, this would be available for us as carers I’m sure, to flick through and say “please don’t mention...likes or dislikes or whatever”, so I think it will be very helpful.” (C1)

Generally, patients and carers decided to “give it a go”, despite not being entirely sure how much time and effort it would involve on their part exactly. It was not completely clear to them whether and how the

passport would benefit them, but they wanted to be helpful, but also wanted to see how it might “work out”. “Definitely, if it’s a benefit to us and to yourselves that would be all right.” (C11) Others saw the benefit at the outset and had the best intentions of using it, but due to their particular circumstances did, in fact, not make entries into the passport sections. For example, one patient-carer dyad (P3/C3) were too much in shock, too overwhelmed by the impact of the dementia diagnosis, depressed, and barely able to cope with day-to-day life. They did try, however, taking the passport to various health appointments but reported that no-one was prepared to engage with it. They returned the HP without entries. “Don't talk about the passport - do not talk about the frigging passport!” (C3)

C10 suffered high carer distress, her father had further deteriorated prior to wave 2, and C10 opted to withdraw from the study as her father had to move into residential care.

“Definitely, for most certain. I appreciate all this help, I really do. Anything that has to be done, I’ll do it. I’m willing to do it. I’m not saying that it will be done perfect, you understand, you got to fit that in, but I will do my very best.” (P3)

“I don’t think so. It would really be... I think we should try it anyway, and especially with a view to us travelling, it mightn't be a bad thing to have that with me as well. He will not understand what you have told him today. His intake of information doesn’t work, and the outflow can be the same sometimes.” (C10)

Some people were reluctant to engage with the HP. “We'll have to sort of digest a wee bit of it first before we can decide.” (C11). P11/C11 were overwhelmed and decided to withdraw from the study post 1st interview. C17 expressed a degree of scepticism about its usefulness, that is – what is in it for them? Others had already been using other means of keeping note of the patient’s medical journey (e.g., diary) and thought that this would be enough, rather than starting something similar. There was the belief that there would be no point in the HP because doctors will not have the time to engage with its contents.

“It’s not so much reservations but will it actually really make any difference to Mickey or myself, really? Will it actually make any difference? [] Well, I’ve only glanced at it but really I don’t know.” (C17)

“Sometimes they don’t appear to have time to talk to you, and somebody with dementia, as I say, you have to give Daddy time to answer, and they don’t have time to talk to us so I can’t imagine them reading it.” (C20a)

“The doctor wouldn't have any objections whenever I come with that and ask him to fill it in?” (P7)

Crucially, the HP also served as a reminder of their illness and was not popular for that reason with some. “How much did [memory clinic] tell you about the HP?” “Nothing really. We haven’t taken a lot in yet. We don’t want to know, really, we just want to live our life the way we want to” (C2). Some people were simply too busy and were not inclined to prioritise the completion of the HP which they regarded as a chore, or as “intimidating” (e.g., C19a). It is interesting to note the extent that people felt that the passport represented a transfer of management responsibilities to the patient and their families. As one person perceived it – “doing the homework”.

“We weren’t good at doing the homework, I have to say. Some of it's done and some of it hasn't been updated. I have it sitting there beside you there; there's bits of if done Dagmar. It was busy, we were...you know there's periods when you don't get time to...”
(C32)

Some were anxious to take the HP to their GP, pointing out that there would be no time in the obligatory 10-minute consultation slot to cover health concerns, and ask the GP to read, and make entries in, the passport. This appears to be a reasonable and important point which needs to be considered if the HP is to fulfil its function. First, a review of the length of individual patient contact time may be required in order to make the passport a feasible intervention. Alternatively (or additionally), a more practical format of the passport may be considered.

“Taking it to your GP, that’s where I would find the difficulty, asking the doctor to take the time to fill that out for me there. [] You’re telling me that I have to take this here to every appointment, is that what your telling me, to take this book? [] Two different ailments and you were only allowed 10 minutes, like, and if your time is up and then you produce this book...” (C18)

Others were concerned that the passport may be an imposition on healthcare professionals and that they had no right to demand this. Thus, one man (C18) was apprehensive about bringing “the book” to GPs, consultants, or the hospital. He believed that he would be asking the impossible, and imposing on HSCPs, and he was not prepared to do that. The passport was referred to as “the book” by other participants, too (e.g., P3/C3). This may be interpreted either as a shorthand term for the passport or, more worryingly, expressing a negative view on its size.

“You'd be taking your life in your hands when you hand them the book and say 'can you fill that in?' They would just tell you that they don't have time and that would be the way like, and I wouldn't go back and ask a second time.” (C18)

There was also some uncertainty about what entries to make or how to fill it in and some who believed that “It's more for the future, for other people, isn't it?” (C33, referring to P33 who was 89). That is, the passport was regarded as something similar to advanced directives for people in the later stages of dementia. Commonly, participants did not consider themselves to be either sufficiently old or sufficiently progressed with dementia as to be eligible for the HP.

“I wonder about this, the sense of it. I'll go over it very, very quickly, don't worry now I'll not keep you hours and hours. There are lots of things. For example, what I would have filled in, or what has been filled in, "All about me"...that's the 7th May, oh whether it is relevant. For instance, "All about me", I'm such and such a height, my weight is such and such...?” (P8)

Importantly, ownership and authorship of the passport posed difficulties for participants, with a residual uncertainty about who ‘owned’ it and who was eligible to make entries in it. One participant (P21), who had slight learning difficulties, and lived alone, wanted to know whether the carers could write into the book (as she was not able to). It was eventually her social worker who made the initial entries.

Some pointed out that, as they have no need to see a doctor any time soon, the passport would, for the time being, be redundant and they'd have nothing to write into it (e.g., P30, who was new at wave 2 but withdrew prior to wave 3). Those who were in the early stages of dementia would not have as much contact with HSCPs, and not as many appointments with different strands of the health-, and social care system. There was a belief that there is no need for the HP early on, but that it may be useful in the later stages (e.g., C12, C15, C17).

“It’ll be some time before I’m going back to see my GP, and I’ll have to wait until F. comes back, so there’s really nothing I’ll be doing immediately, and it’ll be some time before I would get to use it.” (P30)

Because most participants were recruited for the study by the Memory Clinic they believed the passport related solely to their dementia, rather than being a passport that covered all their healthcare needs. Thus, many who were in the early stages of dementia did not see the need for the passport and did not recognise its value. In terms of its usefulness it was candidly stated that “It can’t do any harm.” (C25). This highlighted the importance of timing the intervention so that people feel they derive immediate benefit from it.

“That would be my... particularly if anything happens to me in the next couple of years and the Alzheimer’s progressed, that it might be important. But again, I think we would have someone anyway to help along.” (P9)

3.7.2 HP Use and Contents

At the 2nd wave of interviews it became apparent that use of the HP had been very limited. Consequently, we explained the HP again to the participants, and in addition, engaged Dementia Support Workers from the Alzheimer’s Society to call the families and offer help with the HP. The response to this offer was poor and none of the participants opted to take it up, insisting that they were happy to, and able to deal with the HP themselves. Following an investigative phone-call from the researcher eight weeks prior to the scheduled final interview, at wave 3, 12 out of the final 16 participants had made entries into the HP, and five had taken it to health appointments.

3.7.3 Use of HP between 1st and 2nd interview

At 2nd interview two things transpired; first, participants were still unclear on how to use the passport or if they were using it ‘properly’; secondly, they commonly reported lacking time to do so. Something that we had not anticipated was that some participants worried about not being able to write or spell.

Importantly, most carers took complete responsibility for the passport to the exclusion of the patients. It is possible that the label “carer” by default places the burden of responsibility on the person, who assumes that particular role identity and all it entails, which cascades through every task or effort in relation to the

patient. The passport was described by one carer as “my book”, indicating ownership (C16). C20a’s comment (funny as it is) highlights that it would be better if, where possible, the patient themselves is involved in putting together their personal narrative to ensure authenticity.

“I haven't really filled it out yet, I haven't had time, and I feel guilty about that. But I know that it's there and I often say 'I must do that'.” (C16)

“If I go and get my book and you explain to me again what things I have to fill in? That was puzzling me a wee bit, that was one of the reasons why I didn't fill it in.” (C16)

“Daddy is horrified that I wrote in that that he likes sausages!” (C20a)

“Why do you think you might not have wanted to use it?” “To be honest about it, I'd be more lazy than anything else.” (C14) “I can't spell properly, that's why I don't write.” (P14)

There was a belief that the patient is not yet at a stage where they would need the HP, indicating that the HP was associated with illness progression and patient deterioration. Few patients or carers saw themselves at a point where dementia had progressed sufficiently to warrant use of the HP. Most participants had been recruited to the study within a relatively short period of time following their diagnosis. This had two consequences: 1) People were still coming to terms with the diagnosis and what this means to them and their families; 2) People did often not have a need to attend doctors and hospitals over the duration of the study.

“I have part of it filled in and, as we said to Bethany the last time, Mammy doesn't have any real problems that she's going running with. To me, she's not at the stage yet where she can take advantage of this. Nobody takes her anywhere, except me. Nobody takes her to the doctor's, except me. There may come a time where I'm not able to take her here or there, or there's something wrong that I can't, and yes, it will come in handy then, but at the minute, and over the past whatever time she's had it, mammy has had no need for it.” (C15)

“No, I just filled in the basic information and that's it. That was all, really. I haven't really used it, because I didn't feel...because she hasn't been to any appointments so at this

stage...I would say maybe in the future it will be more relevant but, at the minute, no."

(C1)

Those who saw the value of the HP and were coping reasonably well (e.g., C17, C20a, P27, P32) made entries, including a narrative.

"Yes, M. liked gardening so I have put in some photographs of the garden when it used to be... I have sort of kind of tried to look after the plants now but..." (C17)

"There's bits and pieces there about likes and dislikes. I actually do have, and I didn't fill it in, I have already done that, I have got a list of R.'s ...she did print me, she did me a print out." (C32) "The GP? Of medication?" "Yes, and of his medical history." (C32)

3.7.4 Use of HP since 2nd interview

At 3rd interview, entries had been made within 12 passports, the nature and extent of which varied greatly from person to person. The most detailed entries came from C17, C32, and C12, who incidentally were the carers of the patients who had deteriorated the most, along with C20a. C17 provided a lot of information about P17's life, likes and dislikes, hobbies, food preferences, daily routine, and disease progression. This was mirrored by C32, with a little less detail from C12. In contrast, P8 who completed his own HP, provided no narrative but simply a few medical details and some contacts. Other carers (C1, C15, C16) similarly provided basic information, i.e., details referring to the patient's condition and medication, and some contacts. One family (C3/P3) who had been overwhelmed, stressed, and depressed since P3 had received his diagnosis, did not make entries into the HP.

"So you haven't actually written anything in the passport yourselves?" "No. It's empty now just with one letter from (GP name), she put a wee note in it." (C3)

One person (P21), who has a learning disability and was not able to complete the HP, had engaged her social worker to do so, but had not used it otherwise.

“So then what about the infamous passport, have you used it?” “God love her, she wouldn't have a clue.” (C21) “Do you still have it?” “I wouldn't have a clue. I was saying there was a book in there but it's not even getting touched.” (P21)

Another carer who did not use the passport was C13, a former psychiatric nurse who told us that her mother had not really had any health appointments recently. Additionally, she felt that the passport was “cumbersome” and should be smaller.

“No, we haven't used it because we haven't really got anybody else that we're going to for help, or taking her to the GP, because we really haven't been to (Doctor's name) since you got diagnosed. She gets a chest infection, she's always ?? with that, but really there's been no reason really to involve other professionals, because she's been keeping so well. And secondly, and this is only to help towards your research, I have found it cumbersome, there's far too many expectations of the HP. People think, 'I won't bother with it because it is so intense and there's so much to...' If it was made smaller and more generalised people would probably fill it in more, I think. Mammy the passport thing, you didn't start filling it in, didn't you not?” (C13).

At wave two some participants were still unsure as to how to use the passport. One person (C17's daughter), however, had made extensive and detailed entries. She described that C17 was exhausted and exasperated from the day-to-day challenge of caring for her husband who had significantly deteriorated. As with C3, it was clear that once demands on carers' time and substance became too great, and/or if carers did not cope well mentally, they did not find the time or energy to deal with the HP, which was essentially another responsibility.

“Yeah. We think, my daughter and I, that maybe the doctors and things could have been a wee bit more... when I asked they just sort of jotted down a few things on a sheet and put it in. I don't know; they don't really give you much information.” “Let's have a quick look. So you have tried to take it to the various appointments?” “No, we didn't take it, no. We just asked. Should we have taken it to the various appointments? I didn't realise that.” Well, Tricia has written in the notes anyway when she updated it. That came from the GP.” (C17)

“And just the normal day, getting up, just normal things, towels and clothes for the carers and tablets and eyes... and the more you're here in the house, the more you're doing and sometimes I say I just can't be bothered. And when the family would be phoning to see how M. was the previous night and I'd be running to the phone so then they decided they would just text because they didn't want me coming to the phone all the time because it's too stressful and if you're trying to do something it's just too much.” (C17)

The timing of the passport use related to severity and complexity of health care needs was an important factor. As noted above, as health care becomes more complex, some carers feel too burdened to complete the passport. However, one participant's experience (C12) highlighted that the passport may be valued as the patient's condition progresses, more HSCPs become involved, and care becomes yet more demanding. It allows the carer to record everything that happens on a daily basis at a time when patient health and behaviour can change rapidly, and the capacity and ability of the carer are significantly challenged. This record can then help to provide a complete picture to the health professional at the next appointment.

“The HP, at the moment, I think the HP will only be coming into usefulness now, because we are getting more people involved. Before there was nobody much except the social worker and the nurse practitioner and the GP involved, so there wasn't much to fill in, and he very rarely went to the GP, which didn't help either. I can see that it would be useful if there's more going on, so you can keep track of it all. It would also, I think, be very useful for somebody who doesn't have anyone to look after them.” (C12)

“You haven't had the opportunity then to take it to the GP or anyone? “I did take it to the nurse practitioner when he went for his review. She thought it was a really good idea. She just put her name in and her contact numbers, which was very useful, because I used them all over Christmas. I'll be updating that now, because there will be a lot more to put into it.” (C12)

“I think it depends on the progress of the disease, how it helps. As I can see, I am using it and will be filling it in more now than I was before because things are deteriorating. But I think that's when it becomes most useful. I would say that's when it's most useful. Because, for us, it was so steady for so long, I didn't need it, in a way, but I can see where it will become useful now, which is why I'd like to hang on to it, if possible.” (C12)

3.8 Healthcare Passport content analysis

During the 3rd round of interviews we made copies of the passport entries with the permission of the participants. We found that, with one exception (P8), carers had filled in the passport, rather than the participants with dementia. Most participants opted to keep their HP after the evaluation, except one (P14).

As previously discussed in the “Carer as lynchpin” section, it may be that family caregivers soon after diagnosis begin incrementally to assume control of various responsibilities in the patient’s life. Sometimes family intervention is a response to cognitive changes and the diminishing capacity of the person, for others it appears to be a pre-emptive and prematurely unnecessary intervention, prompted by anxiety about risks. In return, the family member with dementia assumes a new identity role which undermined their sense of agency and initiated an erosion of abilities and skills. Additionally, some of the participants with dementia had various co-morbid conditions and/or learning difficulties, which made writing problematic.

Each of the passports was completed in a distinctly idiosyncratic style. While this demonstrates the different individuals’ personhood, it may also present challenges for health-, and social care professionals. In other words, our evidence suggests that the passports may not conform to a standard information collection. For example, in terms medication and side effects, as well as comorbidities and their impact, and self-care, the level of detail varies considerably between patients, and some do not mention these at all, even when these are a significant aspect of their needs and difficulties. So, HSCPs may be concerned that vital information is not recorded and may consider that the passport in its current form is unreliable.

To be expected, perhaps, the personal narratives, hobbies, and activities also varied considerably in content and magnitude between participants. Of concern, we found that information was also recorded unsystematically. Thus, carers included details about dementia progression and patient deterioration, along with details on religion, likes, and dislikes, and activities. As there is no set format or prescribed detail, every HP is indeed a personal story, and this may make them difficult to work with for HSCPs.

Of the 12 completed HPs, four contained only undated entries, two contained partially dated entries only, all but two (P8 self-completed; P21: social worker completed) were completed by the carer. Those who were overwhelmed (e.g., C13), or coping very well (e.g., C13) did not complete the HP.

Table 5: Nature of HP contents

| Passport contents provided | Number of participants providing information | Variances |
|---|--|---|
| Medication and side effects | 8 | Type of information and level of detail varies |
| Comorbidities and impact | 11 | Level of detail varies |
| Narrative | 10 | Progression; deterioration; religion; likes and dislikes; content and extent vary greatly |
| Self-care | 8 | Level of detail varies |
| Hobbies & activities | 8 | Content varies |
| Completed by; date/s of entry; reasons for not using it | 12 completed: 10 by carers, 1 by patient, 1 by social worker; Non-completion by those who are either overwhelmed or very able; 4 not dated, 2 partially dated; | |

3.9 Taking HP to appointments

Ultimately, only five patients took the HP to a health appointment (P8, P12, P20, P21, P27). They found that doctors were not familiar with the HP and did not have time to engage with it. This made participants feel uncomfortable and led them to abandon the HP in terms of HSCP engagement.

*“We’ve tried to use it.” (C20) “When we saw the reaction to it, we don’t take it anymore.”
(C20a) “They just look at you as if-“ (C20)*

Patients and carers were concerned about the time constraints of HSCPs and believed that usage of the HP in its current format is unrealistic and incompatible with usual consultation times. In contrast to GPs and hospital doctors, professionals who came to the house (e.g. social workers, and Occupational Therapists), were better able to make entries into the passport. It may be that such individuals had more generous patient contact time and or that the power dynamic between patient and professional is considerably altered by these transactions taking place within the patient’s home.

“But what happened was, we went to Casualty and the doctor in Casualty was just like “I don't have time. [] You see, they are very busy. You can understand that. [] We had to go to A&E, and it was in the middle of the night. It was a foreign doctor, and it wasn't that he didn't want to, he just didn't know, and he had spent enough time too, explaining. I think in reality it's not realistic, [] because it's too time consuming.” (C20)

“Nobody wanted to know.” (P3)

“You say you took it to your doctor?” “We took it to Dr D. and Dr D. was sort of ‘What?’ I never bothered about it after. I took it so many times.” (C3)

“Especially the people who came here to talk to us, they were more than happy, because they had the time.” (C20)

3.10 Feedback on HP

Feedback on the passport was obtained from three independent sources: 1) Patients & carers; 2) GPs; and 3) 2 service user engagement groups, and Table 6 provides a brief overview. Following the GPs' feedback we present a summary of the main themes which emerged from the analysis of feedback from all three groups. The themes are substantiated and illustrated by quotes and excerpts from interviews and focus groups in Appendix 7.

Table 6: Summary of feedback on healthcare passport

| | |
|---|---|
| <p>Feedback from service users</p> | <ul style="list-style-type: none"> ❖ There is no need for HP during early stages of dementia; it will be more useful as the condition progresses and more HSCPs get involved. ❖ Participants had few appointments (4/16 took it to appointments.) over the course of the study, and therefore little opportunity to take HP to HSCPs. ❖ Some patients are, or feel, unable to write. ❖ Some have said they did not find the time for the HP. ❖ Some did not feel motivated to work with HP. ❖ HSCPs need to be fully on board for patients to feel confident to bring the HP to appointments. |
|---|---|

| | |
|--|---|
| | <ul style="list-style-type: none"> ❖ HP is too big, so HSCPs won't have the time to engage with it during consultation. ❖ The HP could be useful for people living on their own, but social workers or similar would need to complete it and be responsible for it. ❖ Being able to write a daily log in a designated narrative section in the HP through illness progression of the patient can be therapeutic for the carer. ❖ SUs do not engage with it, so the responsibility of dealing with the HP falls to the informal carers (who may already be overwhelmed). ❖ A HP on an electronic platform (updateable through GP computer systems or password protected access to essential information via NIECR or equivalent) would be better [ensuring legibility and confidentiality; not requiring patients to remember to bring their HP]. May not suit everyone, so could run have an optional paper version. ❖ HP is too bulky to carry around. ❖ A media campaign is needed to make sure everybody is aware and on board. ❖ HP would be great for hospital visit / stay. ❖ Some were sceptical about the HP's usefulness. ❖ The HP should be simplified. ❖ Fears about data sharing were expressed. ❖ The HP is a good communication tool. ❖ It is good to have all info in one place (RC). ❖ The HP needs a better layout (RC). |
| <p>Feedback from GPs</p> | <ul style="list-style-type: none"> ❖ 5 out of 16 GPs responded to the survey. ❖ They felt the HP was principally a good idea. ❖ For GPs it is useful to have all contacts in one place. ❖ Patients did not bring the HP to appointments. ❖ Some did not remember receiving a sample copy of the HP. ❖ The HP is too bulky. ❖ The HP is too wordy. ❖ It would be better as an electronic, online version. ❖ The HP only works if patients remember to bring it in. |
| <p>Feedback from service user</p> | <ul style="list-style-type: none"> ❖ People with dementia would have difficulty completing the HP. ❖ A family member / carer has to complete it. |

| | |
|--------------------------|---|
| engagement groups | <ul style="list-style-type: none"> ❖ Completing the HP could be therapeutic for the carer. ❖ The HP needs to be updated regularly. ❖ All entries need to be dated. ❖ HSCPs must be on board. ❖ People will forget to bring it to appointments, especially in stressful circumstances. ❖ The HP should be personalised with name and photo on the front cover ❖ The HP should be smaller. ❖ The HP should have two clearly demarcated sections: ME / MY CARE. ❖ It is currently too complicated and has too much information. ❖ It would be helpful when going to hospital or care home. ❖ It needs to be less complex and more enjoyable. ❖ It needs to be publicised with posters and logo in GP surgeries and elsewhere. ❖ It is a good idea but HSCPs will not have the time to deal with it. <i>"I can see no GP sitting down filling that in ..."</i> <i>"Hospitals won't look at it."</i> ❖ It will be more useful as the condition progresses. |
|--------------------------|---|

3.10.1 Service user engagement groups feedback

Our third source of feedback were two user engagement groups, in Ballymena, and in Strabane. Table 6 below provides a summary of what was seen as positive and negative respectively about the HP by the groups, along with their suggestions for improvement. This is supported by quotes and excerpts in Appendix 7. These focus group discussions yielded some very useful feedback, some of which echoed patients' and carers' views, and some of which brought new insights. The HP was regarded as a useful resource. The view that the HP was too big was shared by patients, carers and GPs, as was the suggestion to simplify it.

The focus groups additionally proposed to have two main sections – “About me” and “About my care”, and to personalise the HP with a photograph and the name of the owner on the front cover. Second, they recommended that all HSCPs involved with the individual's treatment and care should be educated about the use of the passport – a suggestion also shared by the patients and carers. Third, it was commonly perceived by various stakeholders that there should a stronger recognition that information will be entered into the passport by the family carer givers. Fourth, the focus groups argued that the passport will only be effective if entries are updated continually and dated reliably and accurately. Lastly, as patients and carers

also suggested, the public should also be made aware of the passport and its purpose, and the logo should be displayed e.g., at GPs surgeries.

Observations and recommendations from carer groups:

1. The passport could be made available in both paper and electronic format (password protected). Some carers and healthcare professionals stated a preference for an on-line format for communicating between the various services and family caregivers. It should be noted that this proposal tends to obviate the direct involvement of the person with dementia and may therefore challenge one of the central aims of the passport development.
2. The passport document was perceived as too big and complex by some users, i.e. with too many separate components and thus, may be intimidating. It could be simplified and divided into "About me" and "About my care" sections
3. The patient's name and photograph ought to be on the cover as this may encourage a more person-centred approach and may mitigate against confusion where two or more people in the same household have a healthcare passport.
4. HSCPs may not have the time to read all of the passport entries or to make their own information entries.
5. The passport would be very helpful for people who live on their own and/or have few immediate family carers.
6. The passport would be very useful in institutional settings (hospital stay; care-home).
7. HSCPs need to be fully trained and cognisant of the passport, and able to engage with it.
8. Leaflets and posters with the HP logo, and a media campaign should make the public familiar with the HP.
9. Documenting daily occurrences, particularly as condition progresses, can be therapeutic for the carer.
10. It is good to have all the information in one place.
11. Some may not be willing to share personal information or may be worried about data protection.
12. The information in the HP needs to be accurate and up to date; every entry dated.
13. It is the carers who complete the HP.
14. The HP could help improve communication.

Table 7: Summary of feedback from service user engagement groups

| Positives | Negatives | Suggestions for improvement |
|--|---|---|
| Essentially a very good resource: A concise, whole person information pack which may prevent wrong diagnoses / medication. | HP is too big. A lot of information is required. | The HP should be personalised with a name and photograph on the front cover, so it is personal, and also so that confusion can be avoided when there is more than 1 HP in a home. |
| Very thorough, sections are good so as to not to have to read everything. | Less is more – needs to be simplified along the lines of “This is me” by Royal College of Nursing and Alzheimer’s Society, albeit a little more substantial (2 sections – personal [about me]/ medical [about my care]). | All HSCPs involved in the care of the person would need to be familiar with the HP and its purpose in order for it to work. |
| HP may help towards independence. | Onus is on carer to provide all the information and update it. This is an extra challenge on top of existing demands and stress. | The HP is only going to be as good as the information that is put into it, and only as good as its last date. Thorough input and regular updates are key, along with dating of entries. |
| Could be beneficial to doctors and other HSCPS to get the whole person story. | It will take time to complete all the sections initially. This may not always be practical, particularly where PLWD live on their own and may not manage this by themselves, or where carers are overwhelmed. Also, where family is unsupportive. | HP logo should be everywhere (e.g., posters in surgeries). |

3.10.2 GPs’ feedback

The general consensus among the GPs was that “... the fundamental idea is very good, actually.” (CB) Some GPs had patients with maternity notes which they thought “... work well if the patients bring them” (CB) but said that often they did not. This resonates with the belief of some patients and carers that it is likely they would forget the notes when going for an appointment. Some doubt about the potential efficacy of the HP was expressed by one carer (C17) as to whether the HP will make a difference to her and her husband. This is a fair point, of course, particularly in light of the fact that the HP is regarded as requiring a lot of time and effort and regular input and updates from carers, GPs, and other HSCPs. While the benefits were clear to some, this was not the case for others and highlights that the benefits need to be made crystal clear to ensure buy-in and commitment from all involved.

“Another form! Will it improve lives of patients and carers? The others rarely do!” (Dr Mc)

In this study, few patients took the passport to their GP, and those who did, reported that the GP appeared to be unfamiliar with it or unenthusiastic about its use, which deterred them from taking it again. Many other patients / carers did not take the HP to appointments at all. This could potentially be remedied by having GPs directly distribute the passports to their patients.

“The idea sounds great in theory but my experience of patient held booklets is that they are rarely ever used except in the context of the first years of life when usually mothers bring them to child health appointments for vaccinations but never bring them to other appointments. Maternity booklets are similarly only brought to those appointments which expectant mothers think are directly related to antenatal care but not to other appointments.” (Dr O)

The practicality of and reasoning behind offering the passport in paper format was questioned in the context of ubiquitous digital technology within the healthcare system. That GPs mostly use technology-based communication now, and that the future of patient care may become increasingly paper-less, along with the obvious advantages an electronic platform would bring, and the suggestion that the latter is the best way forward.

“Clearly all the basic demographic and carer information and social work contacts info is great to have but “paper” is so last century that the concept that a booklet like this is envisaged as an advance of patient care is beyond me.” (Dr O)

“GPs do not write on paper any more except to sign prescriptions.” (Dr O)

“An electronic HP which is updateable through GP computer systems or that allows a service user & provider to have password protected access to essential information via NIECR or equivalent social care networks is the way to go with this type of idea.” (Dr O)

3.11 Summary

Our evaluation sought to examine the use of the passport by people living with dementia and their family caregivers in the context of their current and changing health and social care needs, and the challenges

created by service fragmentation and limited information-exchange between and within services. Specifically, we investigated the feasibility of the healthcare passport in the everyday use of people living with dementia and what issues are relevant to a wider 'rollout' of the passport for this population. The main areas of investigation are summarised and discussed below.

3.11.1 Patient background and medical information

Advised by the Memory Clinic to expect a high attrition rate in this particular population, we were fortunate to have had 16 participating families at wave 3 (48% of total contacted). Ages ranged from 58-88 (predominantly 70+), with gender fairly evenly distributed. Most patients lived with their female family carers. They reported varying degrees of family support. Most people (22) were married; the others (11) widowed. For the most part, patients' memory reportedly deteriorated a little during the interview period. Three patients' overall health had deteriorated significantly at last interview, needing regular and intense care. They shared a combination of mobility problems and communication difficulties.

A dementia diagnosis is distressing, the impact of which can be felt for some time. More thought should be given to the mode of delivery of the diagnosis, and to providing immediate aftercare. Participants found the amount of written information provided for them at diagnosis overwhelming, so it may be helpful to delay or reduce such information.

That is, if it is introduced soon after diagnosis and the dementia only mildly impact the individual's functioning, he/she (and their family) may reasonably feel that the passport is irrelevant to their situation and needs. For other recently diagnosed people, the passport may too strongly signify their transition from wellness to being a 'patient', and may seek therefore, to distance themselves from the diagnosis and consequently, the passport. Other people with more advanced dementia and/or with quite complex needs may feel overwhelmed at the level of information they believe should be included.

Safeguarding wellbeing and maintaining a good quality of life are key to good dementia care (Logsdon, McCurry, & Teri, 2007) and treatment (Whitehouse & Rabins, 1992). We noted several factors which impacted directly on to the patient-carer dyad's QOL: (1) Comorbidities (particularly Parkinson's disease, and mobility and communication problems); (2) Mental and physical decline and increasingly complex needs (agitation behaviours including "sundowning", aggression, sleeplessness, wandering, and communication problems); (3) the quality of care: availability of, and access to, services; timely appointments; consistency and continuity in HSCPs; integration of and coordination between branches; active listening and respectful communication; sensitive delivery of dementia diagnosis and immediate aftercare; (4) Mobility and independence (resistance to mobility aids; lack of exercise; (5) Depression (sometimes as a result of dementia diagnosis, sometimes linked to losses); (6) Personal outlook /resilience (attitude to illness varied

considerably due to differences in personality and circumstances); (7) Family support (social contact for both patient and carer; and in terms of practical help for the carer)

In order to retain a sense of personhood, the patient's identity and self-concept need to be protected, and meaning and purpose supported. The extent to which a health care passport for people living with dementia can assist in retaining 'personhood' and with achieving person-centred care is unclear. On its own, the passport cannot do this. Thus, the concept of personhood is elusive and not all of the participants, particularly carers, may appreciate its significance. This was noticeable when families insisted on the preference for, if not sole inclusion of, medical data above personal information. Traditional and current discourses on dementia are highly stigmatising, highlighting disability and decline. Moreover, some families, may unwittingly collude with a disablement process by taking over these activities of daily living.

However, as one carer pointed out, a dementia diagnosis is not just about one person "*We both need help;*" it affects both patient and family carer immensely in terms of QOL. Most carers appeared to be struggling with the demands of caring. It is well acknowledged that carers are the lynchpin between patients, families, community, third sector, and HSCPs in terms of communication, appointments (making, remembering, and attending), and organisation. Our findings strongly indicate that their needs are currently not being met. Along with timely and reliable practical and medical help and support, they need regular emotional support, and respite in order to safeguard their own health and wellbeing.

3.11.2 The role of health and social care professionals

Participants reported generally positive experiences with HSCPs, where they felt confident to speak out during appointments and felt they had good relationships with service providers. However, they also reported limited communication and coordination between departments, and individual professionals; miscommunication between HSCPs; delays; and cases of unprofessional manner. These caused confusion and distress for patients and carers, and frustration on the part of HSCPs. Moreover, participants reported considerable variation in information and service provision, with some participants not being clear as to their entitlements. Moreover, participants reported problems when formal carers changed. Continuity and consistency are key to ensure the building of trust and familiarity which are paramount to make patients feel comfortable with people coming into their home on a daily basis. Some families felt intimidated by unfamiliar doctors, while others became particularly assertive when they felt the patient was being disadvantaged. Those who had worked in healthcare or had family in the healthcare system were more confident and found it easier to get the service they needed. The amount of health appointments varied between families but generally increased with disease progression and the type, number, and stage of comorbidities, as well as failing carer health. The more HSCPs become involved, the more difficult it becomes

for the carer to keep track of, organise and juggle appointments. Having to repeatedly relate the same information at different appointments was a source of frustration.

The main issues patients talked about in terms of health and social care were the difficulty in seeing the same GP every time, the short consultation time, the importance of the GP taking time to listen, being comfortable with the GP, and the attitude of the GP (emphatic, warm, versus condescending, dismissive). Some avoided seeing their GP because they feared another diagnosis, or because they felt they should not “bother” the GP. When people do not feel comfortable with their GP they may avoid appointments and so miss opportunities of early detection and early intervention, regular monitoring, and regimen compliance.

Health and social care professionals play a central role in the care of people with dementia, both in terms of providing the best health and social care possible, and in terms of making the passport a workable tool. Their knowledge of dementia is as important as their understanding of people, and acknowledgement of individual differences. Their readiness to engage in an ongoing and personal dialogue with a patient - carer dyad is key to the health and wellbeing of both. Being trained to use the passport and being afforded the necessary time to do so are prerequisites to offering individualised care. Taking the time to engage with the person behind the diagnosis builds trust and compliance with a personalised therapy regime. Updating the HP regularly to facilitate information sharing and effective communication between HSCPs is also part of the foundation for this intervention. HSCPs need to have an awareness of the dynamics in a patient-carer dyad, and the particular circumstances of the carer, and devise a care plan fully cognisant of the medical and socio-psychological condition of both.

3.12 Summary of findings on the passport use

The use of the healthcare passport was devised for a generic population with long-term or chronic conditions, rather than specifically for people living with dementia. The many people who were involved at the development stage of the passport design were enthusiastic about its potential in improving the lives of people with such conditions, and this is likely to be unchanged. In this evaluation of the passport in which we examined its use in the ‘real-life’ contexts of people living with dementia, we found a qualified appreciation of the concept and a much more nuanced, individualistic or personalised approach to its desirability and use. How people perceive it and what they actually do with it, are strongly determined by individual contexts, dementia stage and other health problems, social and family needs and capacities. In turn, these factors necessitate a much more demanding, thoughtful and nuanced programme delivery for future implementation of the passport as an intervention in dementia care.

The delivery of the passport to all the participants and ensuring that they were confident in its use – for example, what information to enter and when, and who to share it with – could be much improved. In our evaluation, there were two major organisational issues which we feel impeded uptake and use of the passport. First, in the recruitment stage and first wave of the evaluation, the Engagement and Participation Officer (EPO), employed by the Alzheimer’s Society, was to provide advice and support to participants on the passport’s use. However, these other duties often precluded work on the passport. The post was based outside of the research team, creating challenges related to the timely identification of potential participants, their recruitment and provision of advice. Eventually, the researcher team assumed responsibility for delivering the passport to participants and explaining its use.

Second, the preparation of health and social care professionals, particularly among GPs, requires considerable preparation. We believe that we underestimated the resources and time needed for this. While we delivered educational seminars on the use of the passport to targeted key staff within the dementia services and sent information and passports to participants’ GPs, we were unable to reach out to all those involved in the care and treatment of individuals. While the existence of the passport evaluation had been disseminated to GPs across Northern Ireland, many GPs either failed to engage with its use or considered it another burden. In the section below, we list (a) general issues related to the use of the passport and (b) some additional specific barriers and facilitators for consideration:

1. People living with dementia and their carers accepted the healthcare passport and agreed to participate in this evaluation without fully understanding its use and the potential benefits. Sometimes, this is due to a predominant desire to please services or show a willingness to “help” the clinicians.
2. The timing for introducing the passport may influence uptake and actual usage. This is difficult to gauge. At the very early stages post-diagnosis, patients may have good physical and mental health and may reject the passport as unnecessary while, nevertheless regard it as potentially helpful as the condition progresses. Others, who appeared to be still in shock or depressed for some time after the diagnosis, found the passport as a painful reminder and didn’t want to use it. It was regarded as a “dementia passport” and associated with lack of capacity and decline, which participants in the early stages did not wish to identify with.
3. For those at a more advanced stage, and/or with considerable co-morbidity and thus, service use, were overwhelmed by the information that they felt was necessary to be inserted.
4. The use of the passport was predominantly assumed by the family carers. In some cases, we observed this to be reasonable and justified. In other cases, family members appear to undertake, and therefore undermine, the normal activities of daily living of the person with dementia, albeit in a

caring manner. The extent to which the passport is held and ‘owned’ by the family caregiver requires further examination.

5. Many people stated simply that they forgot to use the passport which was often put away “for safekeeping”. Again, some of this may be due to the uncertainty about using the contents.
6. Revealing participants’ tastes and dispositions within the passport was intended to create a sense of personhood and while some people understood and appreciated the concept, other participants were anxious about the sharing of this information, feeling that some formal carers or clinicians did not need to know the personal details or specific aspects of a person’s life.
7. Taking the passport to hospital and general practice appointments was regarded as difficult – some people forgot to carry it while others were greeted with bemusement by clinicians who appeared to be unaware of its existence. Others felt that it may be perceived by clinicians as a burden and did “not want to bother” them.
8. Participants were also concerned about who should have access to, and make entries in, the passport. Even though, it was explained that control over the use of the passport lay with the family, people were still unsure as to how this could be decided. They did not want to be seen to exclude some individuals but were apprehensive about sharing it with anyone – especially when there were multiple and changing formal carers. This requires clarification.
9. Content analysis revealed that each passport was entirely different from others. While this is to be expected when it comes to personal narrative, it is not helpful in terms of medical information, symptoms, progression, comorbidities, side effects of medication, etc. The current non-standardised format of the sections relating to information relating to the patient’s health may undermine the passport’s viability and efficiency. Essential information may be missing or not have been updated, or indeed not dated. Many entries were not, or only partially dated. As such, the information contained in the passport may not be regarded as reliable by some professionals.

3.11.1 Facilitators and Barriers to HP use

| | |
|---------------------|---|
| Facilitators | <ul style="list-style-type: none"> ❖ A strong patient-carer dyad: When the carer is in good health, both mentally and physically, and has, the capacity for coping. A robust relational bond between the patient and family carer is also important. ❖ Dementia at the moderate to advanced stage: Once the dementia advances and begins to impact more significantly on daily functioning and quality of life, families are more able to see the benefits of the passport and are more inclined to work with it. |
|---------------------|---|

| | |
|-----------------|--|
| | <ul style="list-style-type: none"> ❖ Manageable comorbidities: Where comorbidities have a minor impact on daily functioning and quality of life, participants more readily engage with the passport. Once comorbidities impact more forcefully on daily living, stress and distress of both carer and patient increase, and the HP is regarded as an added burden. ❖ Good quality of life: Patients and carers who are able to enjoy their lives, are content, and believe they have a good life, more readily engage with the HP. ❖ Good quality of care: Those families who believe that the standard and quality of care they receive from their HSCPs was good, more readily engage with the HP. ❖ Perception of therapeutic potential to carer: Using the passport to document the patient’s deterioration and the carer’s struggle with it, both in practical and in emotional terms, can be therapeutic. |
| Barriers | <ul style="list-style-type: none"> ❖ A weak patient-carer dyad: Where the carer is in poor health, mentally and/or physically; is (di-) stressed, and/or overwhelmed, and does not cope well, supportive capacity is lacking. This may be accompanied by a weak relational bond. ❖ Patient living on his own: People living on their own are less likely to complete or use the passport. The patient may forget, may not have the capacity to use the passport, and/ or may not be able to write due to a comorbidity. ❖ Carer has worked in the health service: Where carers are former HSCPs, have knowledge and understanding of the health service, and have contacts in the health service, they may not feel the need to use the passport. ❖ Concerns about data protection: Because the passport is currently openly accessible in the patients’ home by all HSCPs, including rotating, and changing formal carers and social workers, concerns about breach of data protection have been expressed. |

3.13 Recommendations for Policy and Practice

3.13.1 The Healthcare Passport

Despite the challenges to its widespread use, the health care passport for people living with dementia was still considered favourably by many participants, including formal and informal caregivers. Its potential for enabling effective and timely communication between agencies and carers is endorsed by most. However, in its current format, it will not suit the needs of all people living with dementia. In our evaluation, patients themselves rarely engaged with the HP directly but rather, through their proxy, the family caregiver, who

often expressed concern about taking on additional tasks. The use of the passport is therefore determined by the extent of the person with dementia's care needs and the caregiver's role in meeting these. While the research team anticipated this, and consulted the patient and carer together, it may be that future work in this area more explicitly covers the pivotal role of the carer.

1. The use of the passport is determined by the extent of the person with dementia's care needs and the caregiver's role in meeting these. While the research team anticipated this, and consulted the patient and carer together, it may be that future work in this area more explicitly covers the pivotal role of the carer.
2. Families will require much more in-depth consultation on the use of the passport and over a longer period of time than the resources permitted in the current evaluation. Thus, the passport should not be issued to families soon after diagnosis or at the early stages of dementia. Indeed, it may be that the criterion for issuing a healthcare passport is the presence of complex or multiple needs alongside a dementia diagnosis. Thus, a description of "health passport" rather than a "dementia passport" seems sensible. People living with dementia need to know that it is widely used by all patients, so that they do not feel stigmatised by its use.
3. Again, implementation will require a concerted policy drive to have the passports more widely recognised and accepted by health-, and social care professionals and this will necessitate time and resources to explain its purpose and level and type of professional contribution. Nevertheless, family use of the passport is strongly predicated on the passport's acceptance by professionals. Moreover, families need to know that the passport is in common use.
4. Widespread implementation will require a publicity campaign, perhaps using leaflets and posters in GP surgeries and other clinical settings. GPs may take the lead in introducing and explaining the passport to patients and carers in the first instance to avoid negative associations. Importantly too, it must be made explicit that the passport belongs to, and is for the benefit of, the person with dementia and their family.
5. The degree and exact nature of GP resistance may require further understanding about how, if at all, it may be overcome. Alternatively, future design and implementation may have to consider which service should take responsibility for the dissemination and oversight of the passport. While it is important that GPs' are committed to the aims of the passport, sustainability will be underpinned by HSCP's and long-term engagement with families.
6. A patient's diagnosis of dementia is often not shared with other health professionals and thus may compromise effective care and treatment. A diagnosis of dementia should be flagged up on

medical/electronic records. This should include systems for automatic updates of a dementia diagnosis to be transferred to health-care services that the PLWD is already attending. This may be easily resolved through the planned implementation of Electronic Care Records.

7. The carer is the lynchpin – everything hinges on their commitment and capacity, including the use of the passport, and communication with all HSCPs. This commitment and capacity is determined to a large extent by the perceived quality of life, including their own health, but also by the extent to which they believe that the passport will actually help them. The importance of their role cannot be overestimated. The implementation of the passport must accommodate the needs and values of families and the involvement of carers could be made more explicit.
8. Contextual factors such as organisational culture, the learning environment and the care environment itself, are acknowledged as posing the most significant challenges to person centred care and the development of cultures that can sustain person centred care (McCormack et al., 2011). The implementation and effectiveness of the passport is more likely to succeed when these wider determinants are also appreciated.

3.13.2 Passport structure and contents

1. An electronic version (on an internet platform or as a smart phone app) may assist communication as it could facilitate instant access to information by HSCPs, while being password protected and therefore not in breach of data protection (access could be provided or restricted as required). Entries could be dated automatically, improving effectiveness and accuracy; there would be no problems due to illegibility of handwriting; and there would be no concern about people forgetting to bring their passport to appointments. In the initial stages, and for those patients and carers who are uncomfortable with electronic platforms, it ought to be possible to hold a slimmer, simplified paper version of the passport with a “personal” section which could be scanned into their electronic HP, and conversely, patients would have the option of obtaining regular print-outs of their updated medical information to add to their paper version.
2. To ensure accuracy and consistency, any entries pertaining to medical treatment and therapies or interventions should be made and updated by the relevant HSCPs in their respective section/s. The “medical” sections of the passport ought to be standardised in order to ensure that all relevant details are provided for all patients.
3. Personal narratives also varied considerably in terms of detail, so perhaps some guidance would be helpful to ensure that basic information will be provided. There should be room for detailing progression, deterioration, comorbidities, and side-effects from medication within the “about my

health” section. The “about me” section should allow for personal narrative, hobbies, activities, likes, dislikes, etc.

4. A space for name and photograph of the patient should be on the front cover of their HP. The section “About me” can provide HSCPs with an accurate account of who the patient is and was, what they like and dislike. Importantly, this section should also offer space for carer notes and reflections (“Carers’ log”).

3.14 Conclusion

While it does not constitute a stand-alone solution to current problems in dementia care, with some alterations as suggested by key stakeholders, it has the potential to help facilitate and improve quality of life for the patients and carers alike. The introduction of the passport in itself cannot bring about positive change. Our findings related to the challenges of families living with dementia suggest systemic changes necessary to retain personhood, improve communication, and facilitate self-management. They include, but go considerably beyond, changes to the current version of the healthcare passport. This evaluation has provided rich, in-depth information about the uptake and use of a healthcare passport for people living with dementia. For example, recruitment to studies such as this may be relatively easy but meaningful participation is more difficult to achieve. Thus, a future trial will need to set much stricter parameters for participation including true informed consent rather than a willingness to please clinicians, complexity of care, disease progression and passport ‘ownership’. As a result of the evaluation, we understand more fully, the complex multi-level factors that must be addressed prior to widespread roll-out of the healthcare passport and a large-scale trial of its effectiveness.

SECTION 4: APPENDICES

Appendix 1: Participant Profile Table

| Participant | | Medication and side effects | Hobbies & Social activity | Coping with | Attitude | Main theme in interview |
|-------------|---|---|--|--|--|---|
| P1 | | Moved from tablets to patches and increased dose. | Arts & crafts | Creative hobbies | Happy, active | P1 enjoys her life now (since she has been put on medication) and enjoys her structured week with activities on each day. |
| P2 | W | Not discussed. | Colouring books and keeping a diary | Great family support. Strong patient – carer dyad. | Couple are distressed by diagnosis and memory loss. | Distress and loss of ability, independence, and confidence. |
| P3 | | On tablets. | Gardening | Faith. Coping badly. Wants wife with him at all times. | Not coping well. Loves gardening but “is not allowed”. | P3 is bored and agitated. They are both very much in shock following his diagnosis. C3 is depressed. |
| P4 | W | | | | | |
| P5 | W | Aricept | No longer able to do calligraphy or trombone | Strong patient-carer dyad; humour; supportive family. | Humour, light-heartedness | Patient very dependent on carer; no longer able to go out by himself. Various other health issues. Carer’s own health beginning to deteriorate. |
| P6 | W | - | - | - | - | N/A – Did not engage. |
| P7 | | On patches | Listening to classical music. | Withdrawal. | Given up. | Death of daughter and wife. P7’s unwillingness to look after himself, and take part in life. |
| P8 | | Nightmares from tablets. Donepezil? | Playing piano, painting, reading. Woodwork until recently. | Intense interest in many things. Curiosity; thinker | Not too worried about the dementia itself, more financial worries. | Worries about his house being sold and lost to his children if he has to go into a home. |

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|------------|---|---|---|--|--|--|
| P9 | W | Dislikes taking her medication. No side effects but “notices no benefit”. John makes sure she takes it. | - | - | - | - |
| P10 | W | ? | Praxis outings; day centre | Supportive family | ? | Sad loss of wife and daughter. Difficulty accepting loss of mobility and independence. |
| P11 | W | ? | Visiting sons in Ireland and England. | Journals, magnetic boards, weekly planners | Family is overwhelmed. Carer and other family members also unwell. | Fearful of taking on passport. |
| P12 | | ? | None. | Very dependent on wife. | Hard to say. | C12’s difficulties in coping with P12’s decline. |
| P13 | | Nightmares with initial medication. Was changed. | Faith, praying | Strong faith. | Very positive, and fully trusting God. Does not worry. | P13 loves life. She has complete faith and is grateful for everything and everybody she has. She is happy to accept whatever comes. Loves her prayers. |
| P14 | | On tablets. | None. Watching TV. | Not sure. | Disengaged | No active communication. Just answered questions very perfunctory. |
| P15 | | On patches. | Bingo, crosswords, shopping | Following a routine of her choosing | Disengaged | Carer thinks her mother is “fine”. P15 talks more when daughter is not there. She seems fairly happy in herself and enjoys doing her own thing. |
| P16 | | On tablets. | Outings with wife and relatives. Used to paint. | Not sure. Humour. Wife ensures routine. | Denial | Patient won’t use his walking aid, which means he cannot go out which annoys both him and his wife. |
| P17 | | Rivastigmine patches. | Loves good food and music. Can no longer | Family. Humour. | Accepting | Family, patient’s condition and how it affects him. |

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|------------|----------|--|--|---|----------------------------------|--|
| | | | garden, walk, or do voluntary work. Enjoys his grandchildren. | | | |
| P18 | | Donepezil | Walking her dogs; time with family and friends | Deep faith. Walking and socialising. | Disengaged | Both depressed and lost. Talk about various health complaints and C18 worried about the future, as P18 will get worse. |
| P19 | | On tablets. | Getting out with befriender | Outings; brother next door. Strong faith. | Positive. | Brother and niece (has autistic son she cares for) are finding patient's care extremely taxing. |
| P20 | | Problems with medication causing hallucinations. Put on patches. | None. | Not coping well. | Unable to communicate. | Carer is exhausted from caring for P20 who has much deteriorated. |
| P21 | | On tablets. | Cleaning. Going out. | Faith | Positive | P21 and her sister talk about their lives, their family members, their husbands (RIP), and hobbies/activities. There is sadness but also laughter. |
| P22 | W | ? | Gardening, large family | "Just get on with it." | Matter of fact. | |
| P23 | W 2 | Patches. | No outside interests. | Some family support. Memory board. | Resigned. | Sadness. |
| P24 | W 2 | ? | Daily contact with family. | Strong patient-carer dyad, good family support; humour. | We are in control. | We don't need the passport. We are looking after P24. |
| P25 | W | Leg cramps from tablets, now on patches. | ? | Supportive family | ? | The family's tough and violent past; pervasive ill-health in the family. |
| P26 | N | W | | | | |
| P27 | N | | On tablets. | Insatiable zest for life, myriad of hobbies. | Keeping active in mind and body. | Positive, pro-active P27's life story, his activities and interests. |

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|------------|----------|---|--|--|---------------------------|---|--|
| | | | Gardening. Writing, Reading, Ceili house. Climbed Kilimanjaro at 76. | Humor. R: It's better than food to me, and I like my food as well. | | | |
| P28 | N | W | C82 ensures that P28 takes her tablets. | Getting out for walks at the beach | Strong patient-carer dyad | Supporting one another as best they can. | Traumatic loss of son and near-loss of 2 nd son. Carer's ill-health. |
| P29 | N | W | - | - | - | - | - |
| P30 | N | W | Bad reaction to medication. On patches now. | Community engagement, particularly Church | Faith | Supportive family. Positive outlook. | P30's engagement with the community / church; as well as with the grandchildren. |
| P31 | N | W | On tablets. | Getting out for social nights; knitting | Supportive family; faith | High carer stress and health problems. | Tragic losses of family members. Division of work and care; house-build and move. |
| P32 | | | Memantine, full dose | Likes to go for a run in the car, and seeing grandchildren. C32 is also very keen to get out daily. Classical music. Enjoys company of brothers and sons. Walking and watching sport. Formerly very sporty. Pigeons. | Routine, Family | Practical, sensible. No drama. Madeline describes herself as "proactive". | Daily routine. P32's past interests. Past injuries impacting on today's health. Various illness in the family. The importance of getting out for exercise and socialising. Difficulties when routine is interrupted. |
| P33 | | W | ? | ? | ? | ? | P33's challenging behaviour. C33's restricted life. |
| P34 | | W | ? | ? | ? | ? | |

Appendix 2a: Interim Report Overview Table

| Participant | | Comorbidities | HCPs involved | Carer | Passport use | Feedback |
|-------------|---|--|--|-------------------|------------------------------------|---|
| P1 | | Depression, anxiety | GP, Memory clinic | Husband | Yes | Well designed. Paper format. Useful later on. Would be of great help to hospital staff. |
| P2 | W | COPD | GP, memory clinic | Husband | | |
| P3 | | Arthritis; Cataracts; back injury | GP, Memory Clinic, Social worker | Wife | Took it to HCPS who did not engage | HCPs did not know about it and did not engage with it, so stopped taking it. Would be useful in case of hospital stays. |
| P4 | W | | | Daughter | No | |
| P5 | W | Heart stent; trouble sleeping; cataract (removed); incontinent; diabetes. COPD? | GP, memory clinic; Social worker | Wife | No | "It's a useful book. It's a very useful thing to have and have the medical history." |
| P6 | W | | | | No | |
| P7 | | Depression; Diabetes; ulcerative colitis | GP, Memory Clinic, Carers, Social worker | Son (lives alone) | No. "No good at writing" | Carer overwhelmed and writing not his strong point, so did not use. Possibly better in electronic format. |
| P8 | | Prev. heart attacks – 4 stents; hypertension; benign prostate condition; Dupuytren contracture (now fixed); COPD | GP, memory clinic, Social worker | Daughter | Yes | A necessity for someone without family. Paper format. |

| | | | | | | | |
|-----|---|--|--|---|----------|------------------------------------|--|
| P9 | W | | Cholesterol (tablet); artificial hip | GP, memory clinic, ? | Husband | No | |
| P10 | W | | Hearing loss | GP, memory clinic, social worker, carers, OT | Daughter | | Daughter not convinced about practicality of passport. |
| P11 | W | | Had triple bypass. Ten-hour operation is believed to have sped up her memory loss. Diabetes. | GP, memory clinic | Husband | | See passport as extra chore and fear it will be too much for them. |
| P12 | | | Arthritis; Deterioration at wave 3 – “sun-downing” | GP, Memory Clinic, Befriender, Social worker, OT, (carer to come) | Wife | Yes, also took it to memory clinic | Will come into its own now that more people are involved. Very helpful. Invaluable to people living on their own. Keeping log as P. declined was therapeutic for wife. Electronic platform may be better but might not suit everybody. |
| P13 | | | Depression; COPD; chest infections; hearing impairment; acute glaucoma | GP, Memory Clinic, Social worker, OT | Daughter | No | Passport is too cumbersome and intense. Needs to be smaller. Daughter is retired MH nurse. |
| P14 | | | Depression; Diabetes; Parkinson’s; Hypertension | GP, Memory clinic | Husband | No. | The size is off-putting. Should be smaller and simpler. SU “cannot write” and husband is “too lazy”. |
| P15 | | | Depression; Diabetes; Parkinson’s; Arthritis; Gall stones; hearing impairment | Lives in supported housing; carers; GP, memory clinic | Daughter | Yes | No need at present. May be useful later on. |
| P16 | | | Diabetes; Parkinson’s; low blood pressure | GP, memory clinic, carers, social worker, OT | Wife | Yes | Electronic passport would solve the issue of illegibility. |
| P17 | | | Arthritis; expressive dysphasia; Dupuytren’s contractures on both | GP, memory clinic; social | Wife | Yes | Should be simplified. Paper version. High carer stress. Passport |

| | | | | | | | |
|-----|----|--|--|--|-----------------------------|---------------------------------------|---|
| | | | hands; sensitive eyes; much deteriorated. | worker; carers, OT | | | was just "too much". Patient cannot write. |
| P18 | | | Depression. Previously breast cancer (BRACA gene). Ruptured implant following double mastectomy. Recently fixed. | GP, memory clinic | Husband | Yes | Electronic platform would help ensure that passport is accessible. Avoid forgetting of passport. Too big for carrying around, and for HCPs to go through. |
| P19 | | | Arthritis | GP, memory clinic, social worker, befriender, carers | Brother/Niece (lives alone) | Yes | Intimidating. Passport should be an app on your phone, as well as paper-based. |
| P20 | | | Depression; Parkinson's; Arthritis; headaches, v. painful back; psoriasis; speech impaired through PK; vision impaired; previously cancer of the bladder. Much deteriorated. | GP, memory clinic, social worker; carers | Wife / Daughter | Yes | Doctors were not happy about it. The idea is very good, but it is unrealistic; too time consuming; too much. It is not realistic to expect HCPs to take the time required to read the passport. "None of the doctors filled it in." "It didn't work." |
| P21 | | | Depression; COPD, Learning difficulties; vertigo? | GP, memory clinic, social worker, carers, befriender | Sister (lives alone) | Yes (social worker made some entries) | Cannot use passport on account of learning difficulties; Sister is recently bereaved and unable to take it on. Key worker completed passport. "It's a good thing to have." |
| P22 | W | | ? | GP, memory clinic | Wife | No | |
| P23 | W2 | | Sleep apnoea; shuffling gait | GP, memory clinic | Wife | No | |

| | | | | | | | | |
|-----|---|--------|--|--|--------------------------------------|-------------------------|-----|--|
| P24 | | W2 | | Hearing-, and visual impairments | Social worker; [meals on wheels] | Daughter and son-in-law | No | Son-in-law very wary of passport (data protection?) and not in favour. |
| P25 | | W | | Arthritis; diabetes, TIAs, stroke, angina | Carers (“not needed”); social worker | Daughter | No | |
| P26 | N | N W | | | | Son and 2 daughters | No | |
| P27 | N | | | Heart surgery, bypass on leg (twice); hypertension; PAD; hearing impairment; diabetes | GP, memory clinic | Wife (Daughter) | Yes | Likes it. Good communication tool. Prefers paper version. “I’m all for it.” Carer did not engage. |
| P28 | N | N W | | Bone tablets; blood pressure tablets; sleeping tablets; Depression | [paid cleaner] | Husband | No | |
| P29 | N | N W | | | | Daughter | No | |
| P30 | N | N W | | High blood pressure | GP, memory clinic, social worker; OT | Daughter | No | |
| P31 | N | N W | | Back injury, depression, hip problems, blood pressure | | Daughter | No | |
| P32 | | | | Depression? Severe damage to knee joint (much pain); prostate cancer (disturbed sleep); balance issues | GP, memory clinic, OT; social worker | Wife | Yes | Happy with electronic and paper version, but points out we should cut back on paper. May be useful if situation gets worse. Needs better layout. Good to have all the information in one place. Could be helpful when going to hospital. |

| | | | | | | | |
|-----|---|--|--|--|-----------------------|----|--|
| P33 | W | | Hearing problems; challenging behaviour | GP, memory clinic, social worker, carers | Son | No | |
| P34 | W | | Hearing problems, previous heart attack. | GP, memory clinic | Wife and daughter (?) | No | Opted to keep passport but did not want to take part in study. |

Appendix 2b Interviews I, II, and III Topic Guides



Western Health
and Social Care Trust



Alzheimer's
Society

Leading the
fight against
dementia

EQUIP: Interview I, Topic Guide

Participant PIN.....

Introduction

Thank you for giving up your time. My name is.....

The purpose of this study is to find out if using personal health notes is useful in helping people with dementia² communicate with the doctors and other health care professionals. We want to find out if and how it changes the way you talk to your doctors, the way you feel about the care you receive, and whether or not it makes life easier for you. We hope that this will help us and others develop better approaches to treatment and care in the future for people with dementia.

Before we begin, I want to tell you a bit about what we are going to do today and what you can expect from me. The interview will last about an hour, maybe more, maybe less. It will be recorded. This means I can spend my time listening and talking with you rather than writing things down, and I can make sure I get the full picture of what you are trying to say here. Everything you say here will be anonymous and confidential – I won't share it with anyone, and once I have written down your notes, and taken out your name and anything that might give a clue as to your identity, I will delete the recording so no one can hear it. I follow the professional standards for research issued by my employer, Ulster University, and by the Western Health and Social Care Trust which include strict rules and guidance about confidentiality.

This will be the first interview, and if you choose to continue to participate, we will talk two more times in the next year and a half or so. This interview will help me learn a bit more about you, your health and care, and what you want and expect from your treatment and care. We will also talk a bit about the personal health papers that you will be using and how you feel about using those. In the next interviews we will talk more about what it is like using that personal health information pack.

You have already given your consent to participate in this interview, but I want to remind you that you can change your mind about participating any time, including during this interview. If at any point you feel tired, or the interview is upsetting for you and/or you want to stop, please let me know. We can take a break, or we can stop altogether and come back another day.

Starter Questions

² The researcher will check with the clinician and family carer prior to the interview and introduction about the most appropriate terminology to use with the participant. This is to ensure that referring to dementia will not be a distressing experience or trigger for the participant. In these circumstances, more casual terms like 'memory problems' will be used in place of dementia.

If you're ready to begin, I would like to start by asking you to tell me a little bit about yourself [interviewer will probe for/make note of age, gender, ethnicity, socio-economic background, and educational attainment as far as possible]

What are some of the things that have been important in your life? [Probe for personal interests and values important to the participant. Spirituality, faith, physical fitness, relationships, are there hobbies central to their life?]

Could you tell me a little bit about when you first began to notice problems with your memory? [Probe for who first noticed and how, feelings about these problems, help-seeking, social support networks]

And how is life different now, how do you feel now about these issues? What have some of the biggest changes been? [Follow up with some of the topics raised in the previous question – how have these things changed? Have they been impeded by progression of dementia? Have they helped as dementia progressed?]

Questions about current care arrangements

Would you mind telling me a little bit about your health at the moment? Do you have any issues which you are being treated for regularly? Tell me a bit about the care/treatment you receive for these things. [Include dementia treatment, probe for how, if at all, dementia impacts on the care received for other health issues.]

What is your relationship like with the doctors and professionals involved in this care? [Probe for differences between professionals and tease out any potential reasons for these differences. Are there any strong feelings about treatment? Is this related to the relationships with the professionals or the treatment themselves? Both? Do their feelings fluctuate? Do they have any awareness of what might cause that?]

Do you feel confident telling your doctor/carer what you need or what you want? Do you feel comfortable saying to your doctor or carer when you do not want or like a certain treatment or approach?

If you do state what you want or need, do you feel like they listen to you, or make changes to accommodate you? If they don't, do they explain why? [Probe for what makes them comfortable or not, how they feel when they are listened to, when they are not listened to, what type of language, action makes them feel 'heard']

Do you ever feel confused after leaving an appointment, or that you did not fully understand what the doctor or professional had been saying? How did you deal with that? Can you think of a way it could have been made more clear?

Could you tell me a little about the support you get at home, or support you get from family and friends on a regular basis? [Probe for primary carers, paid carers, how wide or narrow circle of support is, do they feel comfortable with the type and level of support they have?]

How are decisions made about your treatment/care? Is the process different for small, every day decisions versus bigger, more complicated decisions? [Probe for who is involved in the decision making process and feelings about those decisions]. Do you feel like your wishes are respected in the process of making decisions? Do you want to be more/less involved in decisions? Why?

How do you feel about planning for the future, and any changes that may come as your dementia progresses? [Probe for who they talk to about these changes, do they plan for it – do they feel able to plan, do they want to? Is someone planning on their behalf and if so are they involved?]

[Offer a break at this point if it seems necessary, check in to ensure that participant is still comfortable and able to continue. Take stock of responses to questions, the relationship and interaction between family carer and participant and make plans to create opportunity for one or the other to input more if necessary]

Questions about the Healthcare Passport

I want to talk now about the personal health information booklet that you will be using during this study. A lot of people are calling the document a Healthcare Passport, or just Passport? Is it OK with you if we refer to it as a Passport here?

First, tell me a bit about what you think about the Passport, and how you understand its use. Do you feel confident that you understand what it is used for? [Have all of the right things been included? Is it a good size, practical to carry around? What do they like about it?]

Do you think the Passport will help you better understand the information that is given to you in appointments and what you need to do with that information? [Find out why or why not, ask for specific examples if they have them].

Do you think the Passport will help your carers/doctors learn and understand more about your situation and about you as a person? Why or why not?

Do you have any concerns about using the Passport? [Probe for issues with privacy and confidentiality, knowing how to use it, worries over it getting lost, worries about whether or not they are creating work for the doctor or putting anyone out]

How did you feel about putting information into it? Will you continue to put new information into the Passport? Will anyone help you with this? [Probe for who will prompt them if necessary, who will physically carry and store it, do they see the value in it?]

Do you think your doctors/carers are likely to use the Passport? Do you feel comfortable asking them and encouraging them to use it? What kind of information would you like them to put in the passport? [Probe for perceived impact if professionals don't use/misuse and whether that affects their own use, as well as issues relating to relationships with carers/professionals]

Concluding remarks and consent issues

Is there anything that I have left out which you would like to talk about, or would you like to talk a bit more about any of the things that we have covered today? Do you have any more questions for me about the study?

As I mentioned before, if you choose to continue to participate in this study we will meet two more times. I want to talk about what you would like to do if the problems with your memory get worse between then and now. Do you feel like you would want to continue with the study in spite of these changes? Are there any circumstances in which you would wish to stop participating in the study? Is there anyone you would trust to make decisions on your behalf if you did not remember agreeing to participate in the study or feel able to understand fully what is happening with the study?

I want to thank you for agreeing to meet me today, and for speaking with me about such a personal subject. If you would like to speak to me after today, please feel free to contact me using the details on the information sheet. If you have any concerns or feel upset or angry about anything that I did during any point in this study, please contact my supervisor, Gerry Leavey, whose contact details are also on your information sheet.

EQulP: Interviews II and III, Topic Guide

Participant PIN.....

Thank you for giving up your time again. My name is....., and I want to take a few minutes to remind you of the purpose of the study and what we are going to cover today.

We are doing this study to find out if using personal health notes is useful in helping people with dementia³ tell the doctors and other carers involved in their treatment about what they need and want from their care, and help doctors and carers better understand the people they are working with. We hope that this will help us and others develop better approaches to treatment and care in the future for people with dementia.

Before we begin, I want to tell you a bit about what we are going to do today and what you can expect from me. The interview will last about an hour, maybe more, maybe less. It will be recorded. This means I can spend my time listening and talking with you rather than writing things down, and I can make sure I get the full picture of what you are trying to say here. Everything you say here will be anonymous and confidential – I won't share it with anyone, and once I have written down your notes, and taken out your name and anything that might give a clue as to your identity, I will delete the recording so no one can hear it. I follow the professional standards for research issued by my employer, Ulster University, and by the Western Health and Social Care Trust which include strict rules and guidance about confidentiality.

This is our second [or third] interview. While the first interview helped me learn a bit more about you, your health and care, and what you want and expect from your treatment and care, as well as discussing the personal health papers that you have been using and how you feel about using those. These next interviews will cover more about what it is like using that personal health information pack, and any changes since the last time we met.

You have already given your consent to participate in this interview, but I want to remind you that you can change your mind about participating any time, including during this interview. If at any point you feel tired, or the interview is upsetting for you and/or you want to stop, please let me know. We can take a break, or we can stop altogether and come back another day.

Starter Questions

³ The researcher will check with the clinician and family carer prior to the interview and introduction about the most appropriate terminology to use with the participant. This is to ensure that referring to dementia will not be a distressing experience or trigger for the participant. In these circumstances, more casual terms like 'memory problems' will be used in place of dementia.

- If you're ready to begin, can we start by talking about how things have been for you generally since our last meeting? [Probe for changes with memory and dementia? Any changes to treatment or health and social care? Changes in social support networks?]

Questions about using the Healthcare Passport

- Tell me a bit about what it has been like using the Passport.
- Improvements in your treatment or care since using the Passport? How (if at all) has the Passport helped with these things?
- Do the people responsible for your health and social care service provision use the Passport? Are you happy with the way they use it? Do they use it without prompting? Do you have an impression or their feelings about using the Passport? Have you discussed it?
- Have you had any practical problems using it? [Trouble filling it in, trouble remembering to fill it in? Does anyone prompt you to fill it in? Is it too big, too small? Missing useful sections?] Can you think of any improvements that could be made to the passport to deal with these practical problems?

Questions about ICT and Technology

- How much do you use technology in your day to day life [prompt for examples of how use ICT, how they learned, how often, etc.]? How comfortable do you feel with technology?
- If the Passport was on an ICT platform (i.e.: as an online version or an app), would you be more or less likely to use it? What kind of training or support would you need to use it?

Questions about the Passport and its' impact on relationships and communication

- Has the passport changed the way you communicate with your doctor or service providers? [Probe for whether it is easier? Do they find they need to repeat themselves less? Does it prompt them to raise things they may have forgotten otherwise? Do they feel more confident in talking to the doctor?]
- Has the Passport changed the way that your doctor or service providers communicate with you? [Do they involve you more in decision making? Do they speak to you about things other than just your immediate symptoms? Does it help them make connections between their services and other care or services you receive? Are there negative ways it has changed communication? Does the doctor/carer write in the Passport instead of talking directly to them?]
- Do you feel that having written notes from your health care providers has made your life easier? Do you better understand information which has been given to you? Has it changed the way you share information with your family carers?
- Do you feel that having more detailed, personal information about you has changed your relationship with your healthcare providers? [Do they feel they are consulted more? Are health care providers more compassionate? Do they look at the bigger picture or factor in more personal choice? Do they provide clear, concise instructions which make taking meds or following treatment easier?]
- Has using the Passport changed the way you communicate with your family carer(s)? [Do they input into the passport? Have conversations about inputting into the passport prompted other important care discussions? Do you feel more able to talk to them about your treatment or care? Why?]
- Has using the Passport changed the way your family carer(s) communicate with you? [Does it help them better understand what you see as a priority? Does it help them support you better in the coordination of your care? Does it provide a way to communicate about things you might not have talked about otherwise?]
- Has the Passport helped you prepare for future changes as your illness progresses? Has it helped you communicate those plans to your family carer(s) and/or health and social care providers?

Follow Up Questions for Interview III⁴

Have there been any changes in the way you use the Passport? [What prompted the changes? Has it change outcomes? For better or for worse? Will they continue to use it in this way, or return to the way they were using it before?]

Have there been any changes in the way your health and social care providers use the Passport? [What prompted the changes? Has it changed the outcomes? For better or for worse? Do they feel confident to comment on these changes with their health and social care provider?]

Will you continue to use the Passport when this is over? Why/why not?

How could the Passport be improved in future?

Concluding remarks and consent issues

- Please take this opportunity to tell me anything about your health and social care and the passport that you would like to discuss, including things I have not brought up, or something you would like to add to from our earlier discussion.
- [For Interview II] As we discussed before, we will arrange to meet again in about six months, so we can have a final discussion about using the passport, and just generally how you are getting on. Please remember that if you would like to stop taking part in this study you can choose to end your participation at any time. [If they do wish to discontinue, discuss the reasons for this with them and ask if they would mind talking about how we could approach it differently in future if it is related to the study in any way].

[For Interview III] That is the last interview for this study. Thank you so much for taking part, and for being willing to share so much about your life and your health and social care with me. Once I have finished looking at all of the information I have gathered, we will be writing a report discussing what we have found during this study. We will make sure you have a copy of this report, and you should feel free to contact me to ask about any of the contents. We also hope to host some events where we will discuss the findings of the report. We will keep you informed about these events in case you would like to attend.

I want to thank you for agreeing to meet me, and for speaking with me about such a personal subject. If you would like to speak to me after today, please feel free to contact me using the details on the information sheet. If you have any concerns, or feel upset or angry about anything that I did during any point in this study, please contact my supervisor, Gerry Leavey, whose contact details are also on your information sheet.

⁴ Interviews II and III will largely consist of the same questions. This section will outline the additional questions for interview III



EQulP Study - Participant Information Sheet

The evaluation of a healthcare passport to improve quality of care and communication for people living with memory problems

Invitation to take part

You are invited to take part in this important research study which aims to provide a better understanding of needs of people living with memory problems and their carers while they are in contact with health and social care services. The study is being undertaken by the Bamford Centre for Mental Health and Wellbeing at Ulster University with support from Alzheimer's Society and the Western Health and Social Care Trust.

- We are hoping that this study will improve the way that people communicate with the doctors and service providers they come into contact with, to help health and social care professionals understand better what is important to you in your care and treatment.
- We hope that this research will help improve services for people living with memory problems right across Northern Ireland. Please read through this leaflet, you can discuss it with others if you wish, and decide whether you would like to be involved in this research study.

What is the purpose of the study?

We are trying to find out whether using a new booklet, called a Healthcare Passport, can help you communicate better with your doctors and carers, and help them communicate better with you. We also want to know if that helps your care get better and how.

What is the Healthcare Passport?

The Healthcare Passport is a small booklet which you own and keep with you. In it you can record important parts of your life, and provide information about yourself, your family, your beliefs and the things that mean something to you. Some things it could do:

- Reduce the number of times you are required to repeat information to different individuals and help care providers be more connected on issues to do with your treatment.
- Give doctors and carers a place to write instructions and information which would help you understand better their instructions and advice.

These are the things we are trying to find out:

- Is the Healthcare Passport is a useful tool for people living with memory problems in organising their treatment and care and making their wishes and needs clear?
- How difficult or easy is the passport to use? Does it do what it is supposed to do?
- What are the best things about using it? What parts are difficult or not useful?
- Does the Passport help your doctors and carers understand what you want and need?
- Does the Passport help you remember and understand the information you get from your doctors and carers?
- Does it help you communicate what you want and need in your treatment/care to your family and carers? Do they feel like they have the information they need to make decisions with you if that need comes up?
- Finally, we want to get an idea of how health and social care providers will use the passport, and how the way they use it affects your experience of health and social care. **To do this, we will be talking to the doctors and health professionals involved in your care, if you agree that is OK. We will talk to them about how they felt about using the passport, and not going into detail about your personal circumstances.**

Why have I been invited to take part in the study?

You have been invited to take part as a person with memory problems who uses a memory clinic in the Western Health and Social Care Trust. Talking to you about your experience of using a Healthcare Passport with health and social care services in all parts of the trust could help us provide healthcare passports to a bigger group of people, and also improve the Passport making it easier to use and more effective.

Taking part is entirely voluntary. If you do not wish to take part you do not have to do anything in response to this invitation. Choosing not to participate will not have any impact on your health and social care or change your relationship with your health and social care providers.

What is involved if I decide to take part?

The study is led by researchers at the University of Ulster, as well as professionals from different health and social care backgrounds. If you decide to take part a researcher will arrange to meet with you two to three times over an 18 month period. Before the first meeting:

- You will have read this information sheet and have signed and returned the consent form;
- You will have met the Engagement and Participation Officer from the Alzheimer's Society who will fully explain the study, answer any questions you might have about the study or the Passport;
- You will have identified a family member or someone close to you who you would like to act as your "personal consultee". This person will make decisions about whether or not you will continue to participate in the study if at any point you are no longer able to consent to participating;
- The Engagement and Participation Officer will send us (the researchers at the University of Ulster) the signed forms and your contact details;
- We will then get in touch to tell you more and to reconfirm that you want to go ahead;
- We will arrange a time and place to meet with you;

- You decide where to meet, perhaps your home, the university, or at the memory clinic
- We will meet for about an hour, it could be shorter or a little bit longer depending on how much you have to say.

You can change your mind about being part of the study at any time, even during the interview. But if you are happy to stay involved we will keep in touch, maybe by letter, text, email or phone, and arrange to meet you one or two more times. Don't worry if life changes and you don't feel like continuing, it's ok to pull out of the study at any time.

You can also take someone with you to the interviews if you wish. This could be a member of your family or a friend, or a professional carer.

Who will hear or read what I have talked about in the interviews?

All the interviews will be recorded, so we don't miss anything you say. The recordings will be destroyed as soon as a typed copy of the interview has been made. These typed copies will not have your name on them, just a number, so no one will know who you are from reading the interview. We will anonymise your interviews before we use any of your words in reports. This means that as well as taking out your name we will take out detail that could identify you in any way, things like where you live or the name of your doctors/carers. All the information you give us will be kept confidential, it will be stored securely in a locked cabinet and on a password protected computer, in a locked room. Only the researchers on the study will have access to this. The interviews will not become part of your health records. The researcher who interviews you will not be connected to your services in any way.

We must however inform you that if you disclose information that indicates that either you or someone else had committed an offence, the researcher would be required to report this to the PSNI. In the same way, if you reveal information that either you or someone else is at risk of significant harm, the researcher would be required to report this to the relevant authorities. If this situation arises we will discuss all possible options for ourselves and you before deciding whether or not to take any action.

What are the possible benefits of taking part?

By taking part, you will be able to be some of the first people to use a Healthcare Passport in Northern Ireland. This passport could help you feel more in control of the information around your care, as well as give the people providing health and social care services to you better understand what you want and need. We hope that the information you give us will help to improve services for others in the future.

Further information

If you would like more information or have any questions please contact Dagmar Corry, the Researcher on the project, at dagmarcorry112@googlemail.com or 07756 873 293. You can also contact Beverly Todd, the engagement and participation officer with Alzheimer's Society. Her email address is bev.todd@alzheimers.org.uk and her number is 075 255 83311.

Complaints

If you are not happy with any aspect of the study and would like to make a complaint please get in touch with Prof Gerry Leavey, Bamford Centre for Mental Health and Wellbeing, University of Ulster, Coleraine, g.leavey@ulster.ac.uk, tel 028 7124326.

Thank you for your time.

****NOTE: This information letter will be used as the guide for the Engagement and Participation Officer to explain the study to the service user before obtaining consent. It is not intended to be handed

out to service users without explanation and support. It is supplementary to the Short Information Sheet which will be given to SUs prior to agreeing to meet the researchers to discuss the project.



Western Health
and Social Care Trust



A Healthcare Passport to improve quality of care and communication for people living with memory problems - Participant Information Sheet

Invitation to take part

You are invited to take part in this important research study which aims to provide a better understanding of healthcare needs of people living with memory problems and their carers. The study is being done by the Ulster University, with support from the Western Health and Social Care Trust and Alzheimer's Society. Please read through this leaflet, you can discuss it with others if you wish, and decide whether you would like to be involved in this research study.

What is the study for?

We are trying to find out whether using a new booklet, called a Healthcare Passport, can help you communicate better with your doctors and carers, and help them communicate better with you. We also want to know if that helps your care get better and how. The Healthcare Passport is a small booklet which you own and keep with you. In it you can record important parts of your life, and provide information about yourself, your family, your beliefs and the things that mean something to you. It is also a place where health professionals can write down instructions and information which can help you manage your care.

Why have I been invited to take part in the study?

You have been invited to take part as a person with memory problems who uses a memory clinic in the Western Health and Social Care Trust. Taking part is entirely voluntary. If you do not wish to take part you do not have to do anything in response to this invitation. Choosing not to participate will not have any impact on your health and social care.

What Happens Next?

If you agree to take part, someone from our research team will meet you to explain the study in more detail and answer any questions. If you still want to go ahead, you will use the passport in your healthcare while the study is ongoing, probably a year. You will get help to learn about and fill out the passport, and then you will talk to a researcher from Ulster University three times over the year about how you find using the passport. These meetings will take about an hour. The researchers will also talk to some healthcare workers, like your GP, about how they feel about using it. This will not be directly about your care, but may involve some general discussion about what things go into the passport.

If you would like more information or have any questions please contact Dagmar Corry, the Researcher on the project, at dagmarcorry112@googlemail.com or 07756 873 293. You can also contact Beverly Todd, the engagement and participation officer with Alzheimer's Society. Her email address is bev.todd@alzheimers.org.uk and her number is 075 255 83311.

Complaints

If you are not happy with any aspect of the study and would like to make a complaint please get in touch with Prof Gerry Leavey, Bamford Centre for Mental Health and Wellbeing, University of Ulster, Coleraine, g.leavey@ulster.ac.uk, tel 028 7124326.

Thank you for your time.



EQuIP STUDY - Participant Information Sheet

The evaluation of a healthcare passport to improve quality of care and communication for people living with memory problems

Invitation to take part

You are invited to take part in this important research study which aims to provide a better understanding of needs of people living with memory problems and their carers while they are in contact with health and social care services. We are hoping that this study will improve the way that people communicate with the doctors and service providers they come into contact with, to help health and social care professionals understand better what is important to service users in their care and treatment.

We are interested in talking to you as someone who has had contact with these services through your role as a carer of a service user. We know that this can be a challenging and difficult time, both for individuals living with memory problems and their carers, for a number of reasons. We are hoping that this study will improve the experience of the wide range of health and social care services for people with memory problems across Northern Ireland. Please read through this leaflet, you can discuss it with others if you wish, and decide whether you would like to be involved in this research study.

What is the purpose of the study?

The main aim of the EQuIP study is to find out whether or not the Healthcare Passport is a useful tool for people living with memory problems in organising their treatment and care, as well as making clear what their wishes and needs are in the process. We want to know if how difficult or easy the passport is to use, and if it does what it is supposed to do. We want to know what the best things about using it are, the things that are difficult or not useful, and whether you think it helped the health and social care professionals have a better understanding of what patients want from their care. We are also interested in finding out whether or not the Passport was helpful for you as a family carer in communicating with a range of professionals, and with the person for whom you care. Does the Passport help give you the information you need to make decisions with the person you care for if that need arises? Finally, we want to get an idea of how health and social care providers will use the passport, and how the way they use it affects you and the person you care for.

With this information we can then begin to design services that better meet the needs of people living with memory problems and their families.

What is the Healthcare Passport?

The Healthcare Passport is a small booklet which the patient owns, in which they can record things about themselves, their family, their beliefs and the things that mean something to them which might

help health and social care providers better understand what they want and need from their treatment, services and care. It is also a place where healthcare providers can put informal instructions and advice about the treatment which they might previously had only passed on verbally in appointments. We hope that using this passport will improve the quality and continuity of their care, reduce the number of times they, and you, are required to repeat information to different individuals, and to allow, if you wish, a chance to think about some of the challenges that memory problems may bring in the future and to make clear how the patient would like those challenges to be handled.

Why have I been invited to take part in the study?

Your role as a carer and/or family member of a person living with memory problems is of particular interest to us. We would like to hear about your experiences as the person you are caring for uses the healthcare passport throughout their contact with health and social care services. We appreciate the key role that carers play and believe you can make an important contribution to the study and to the way in which health and social care services are delivered to people with memory problems in Northern Ireland. Your participation is entirely voluntary. If you do not wish to take part you do not have to do anything in response to this invitation.

What is involved if I decide to take part?

The study is led by researchers at the University of Ulster, together with professionals from different health and social care backgrounds. If you decide to take part a researcher will arrange to meet with you and the person you care for two to three times over a 12 -18 month period. Before the first meeting we ask you to read through the information sheet and sign the consent form. The staff member who has told you about this study will then pass your contact details to us and we will get in touch to arrange a meeting, at a time and place that is convenient to you. The interviews will last about an hour, it could be shorter or longer depending on how much you have to say.

You can change your mind about being part of the study at any time, even during the interview. But if you are happy to stay involved we will keep in touch, maybe by letter, text, email or phone, and arrange to meet you one or two more times. Don't worry if life changes and you don't feel like continuing, it's ok to pull out of the study at any time.

Who will hear or read what I have talked about in the interviews?

All the interviews will be recorded, so we don't miss anything said in the interview. However, the recordings will be destroyed as soon as a typed copy of the interview has been made. These typed copies will not have your name or the of the person for whom you care on them, just a number, so no one will be able to identify either of you from reading the interview. We will anonymise your interviews before we use any of your words in reports. This means that as well as taking out your names we will take out detail that could identify you in any way. All the information you give us will be kept confidential, it will be stored securely in a locked cabinet and on a password protected computer, in a locked room. Only the researchers on the study will have access to this.

We must however inform you that there are some things we are not permitted to keep confidential, like if you disclose information that indicates that either you or someone else had committed an offence. In the same way, if you reveal information that either you or someone else is at risk of significant harm, the researcher would be required to report this to the relevant authorities. If this situation arises we will discuss all possible options for ourselves and you before deciding whether or not to take any action.

What are the possible benefits of taking part?

By taking part, the person you care for will be able to be one of the first people to use a Healthcare Passport in Northern Ireland. This passport could help them feel more in control of the information around their care, as well as give the people providing health and social care services to them better understand what they want and need. It could also help you as a carer have access to information all in one place, and help give you a chance to discuss and plan for future health and social care needs with the person you care for. We hope that the information you give us will help to improve services for others in the future.

Further information

If you would like more information or have any questions please contact Dagmar Corry, the Researcher on the project, at dagmarcorry112@googlemail.com or 07756 873 293. You can also contact Beverly Todd, the engagement and participation officer with Alzheimer's Society. Her email address is bev.todd@alzheimers.org.uk and her number is 075 255 83311.

Complaints

If you are not happy with any aspect of the study and would like to make a complaint please get in touch with Prof Gerry Leavey, Bamford Centre for Mental Health and Wellbeing, University of Ulster, Coleraine, g.leavey@ulster.ac.uk, tel 028 7124326.

Thank you for your time.

Appendix 3d – Participant Consent Form Carer



EQulP STUDY - Participant Consent Form

I, _____ have read the information letter provided as part of this study.

- I have spoken with a person working on the study and have had a chance to ask any questions or talk about any questions or concerns I may have.
- I understand that choosing not to take place in this study will have no effect on the health and social care provided to the individual for whom I provide care and support.
- I understand that I can choose to stop participating in the study at any time.
- I understand that the person I care for can still access the healthcare passport without choosing to take part in the study.
- I know that if at any point I would like to stop participating, or I have a complaint or concern about how I have been treated during this study, I can contact the person listed below, or another person I trust who will contact Ulster University on my behalf.

Signature

Date

Complaints

If you are not happy with any aspect of the study and would like to make a complaint please get in touch with Prof Gerry Leavey, Bamford Centre for Mental Health and Wellbeing, University of Ulster, Coleraine, g.leavey@ulster.ac.uk, tel 028 7124326.

Thank you for your time.

EQuIP STUDY - Participant Information Sheet

The evaluation of a healthcare passport to improve quality of care and communication for people living with dementia

You are invited to take part in this important research study which aims to provide a better understanding of needs of people living with dementia and their carers while they are in contact with health and social care services. We are hoping that this study will improve the way that people communicate with the doctors and service providers they come into contact with, to help health and social care professionals understand better what is important to service users in their care and treatment. We hope that this research will help improve services for people living with dementia right across Northern Ireland.

We are interested in talking to you as someone who provides health and/or social services to people with dementia. Please read through this leaflet, you can discuss it with others if you wish, and decide whether you would like to be involved in this research study.

What is the purpose of the study?

The main aim of the EQuIP study is to find out whether or not the Healthcare Passport is a useful tool for people living with dementia in organising their treatment and care, as well as making clear what their wishes and needs are in the process. We want to know how difficult or easy the passport is to use, and what any unintended consequences of use of the passport might be. We are also interested in finding out whether or not the Passport was useful for those individuals involved in the direct care of people with dementia – both formal and informal care and service providers. Does it support health care providers in understanding what patients want and need in their treatment/care? Do health and social care providers feel like they have the information they need to make decisions for patients if that need arises? Finally, we want to get an idea of how health and social care providers will use the passport, and whether or not that impacts on the experience of health and social care for patients with dementia and their family carers.

With this information we can then begin to design services that better meet the needs of people living with dementia and their families.

What is the Healthcare Passport?

The Healthcare Passport is a small booklet which the patient owns, in which they can record things about themselves, their family, their beliefs and the things that mean something to them which might help health and social care providers better understand what they want and need from their treatment, services and care. We hope that using this passport will improve the quality and continuity of their care, reduce the number of times they, and you, are required to repeat information to different individuals, and to allow, if you wish, a chance to think about some of the challenges that dementia may bring in the future and to make clear how the patient would like those challenges to be handled.

Why have I been invited to take part in the study?

Your role as a health and/or social care provider to people living with dementia is of particular interest to us. We would like to hear about your experiences as your patients use the healthcare passport throughout their contact with your services. We appreciate the key role that health and social care professionals make in the quality of life of people with dementia, and believe you can make an important contribution to the study and to the way in which health and social care services are delivered to people with dementia in Northern Ireland.

What is involved if I decide to take part?

At least one of your patients/service users has agreed to participate in the study, and will be using the healthcare passport. We would like you to agree to participate in the following ways:

- Training on use of the Healthcare Passport
- Filling out a questionnaire at the end of the 18-months period to reflect on your experience of the Passport
- A brief follow-up phone conversation, if desired, expanding on your reflections in the questionnaire.

You can change your mind about being part of the study at any time, and while the healthcare passport will be a part of your patient/service user's day to day care, you are not required to take part in the study itself.

Who will see the information I record in the Healthcare Passport?

Any written interaction you have with the Passport will be reviewed by the researchers at the end of the 18 month period, and will be used as anonymous data in the analysis. The researchers will strive to ensure that any identifiable qualities are removed from the analysis and reporting.

What are the possible benefits of taking part?

The Healthcare Passport has the potential to improve the quality of life for people with dementia by improving their communication with health and social care providers, and by giving professionals like yourself the opportunity to better understand the strengths, assets and total healthcare needs of the person with dementia, as well as providing a strong foundation on which to focus person-centred care. Various stakeholders have praised the concept and content of the Passport, but such tools need to be grounded in the everyday experience of people with dementia and their care and support providers. Your participation in the study will help us understand the practical potential of a Healthcare Passport and how it can be improved.

Further information

If you would like more information or have any questions please contact Dagmar Corry, the Researcher on the project, at dagmarcorry112@googlemail.com or 07756 873 293. You can also contact Beverly Todd, the engagement and participation officer with Alzheimer's Society. Her email address is bev.todd@alzheimers.org.uk and her number is 075 255 83311.

Complaints

If you are not happy with any aspect of the study and would like to make a complaint please get in touch with Prof Gerry Leavey, Bamford Centre for Mental Health and Wellbeing, University of Ulster, Coleraine, g.leavey@ulster.ac.uk, tel 028 7124326.

Thank you for your time.

Appendix 3f: Participant consent form SU



EQulP STUDY - Participant Consent Form

I, _____ have read the information letter provided as part of this study.

- I have spoken with a person working on the study and have had a chance to ask any questions or talk about anything I am worried about.
- I understand that choosing not to take place in this study will have no effect on my health and social care, and that it is completely voluntary.
- I understand that I can choose to stop participating in the study at any time, and that I can still access the healthcare passport without choosing to take part in the study.
- I understand that my GP and other health and social care providers who work with me may be contacted to talk about their experience with me using the passport as part of this study.
- I know that if at any point I would like to stop participating, or I have a complaint or concern about how I have been treated during this study, I can contact the person listed below, or speak with someone I trust to have them contact the University of Ulster on my behalf.
- If there were ever a point when someone might need to make decisions on my behalf relating to this study, I would prefer for _____ to be that person. This person will be called my 'personal consultee' from this point.

Signature

Date

Complaints

If you are not happy with any aspect of the study and would like to make a complaint please get in touch with Prof Gerry Leavey, Bamford Centre for Mental Health and Wellbeing, University of Ulster, Coleraine, g.leavey@ulster.ac.uk, tel 028 7124326.

Thank you for your time.

Appendix 3g – Participant Consent Form HCP



EQuIP STUDY - Participant Consent Form

I, _____ have read the information letter provided as part of this study.

- I have spoken with a person working on the study and have had a chance to ask any questions or talk about any questions or concerns I may have.
- I understand that choosing not to take part in this study will have no effect on my employment with the Western Health and Social Care Trust.
- I understand that I can choose to stop participating in the study at any time, and that my patients can still access the healthcare passport without choosing to take part in the study.
- I know that if at any point I would like to stop participating, or I have a complaint or concern about how I have been treated during this study, I can contact the person listed below, or a relevant individual in the WHSCT.

Signature

Date

Complaints

If you are not happy with any aspect of the study and would like to make a complaint please get in touch with Prof Gerry Leavey, Bamford Centre for Mental Health and Wellbeing, Ulster University, Coleraine, g.leavey@ulster.ac.uk, tel 028 7124326.

Thank you for your time.

Appendix 4 – Passport use

| Participant | | Carer | Completed sections in passport | Took passport to HSCP | Opted to keep passport | Feedback and suggestions for improvement |
|-------------|---|--|--|-----------------------|------------------------|--|
| P1 | | C1 (daughter) and other family members | Yes | No | Yes | No need at the moment. Would be of great help to hospital staff. |
| P2 | W | C2 (husband) | No | No | No | - |
| P3 | | C3 (wife) | No | Yes | Yes | HCPs did not know about it and did not engage with it. Stopped taking it. Would be good for hospital stay. |
| P4 | W | C4 (daughter) | No | No | No | - |
| P5 | W | C5 (wife) | No | No | No | - |
| P6 | W | C6 (daughter) | No | No | No | - |
| P7 | | C7 (son) | No. Son too stressed and not confident in writing. | No | Yes | Carer overwhelmed and writing not his strong point. Did not use. |
| P8 | | Lives alone. Daughter (nurse) pops in. Has cleaner. | Yes. Only factual information, nothing personal. | No | Yes | Necessity for people without family. |
| P9 | W | C9 (husband) | No | No | No | - |
| P10 | W | C10 (daughter) | No | No | No | C10 not convinced about practicality of passport. |
| P11 | W | C11 (husband) | No | No | No | See passport as extra chore and fear it will be too much for them. |
| P12 | | C12 (wife) | Yes | Yes | Yes | Passport would come into its own as needs and service use increase. Invaluable for people living on their own. Keeping a log as P12 declined was therapeutic for C12. Electronic platform might be better but may not suit everyone. |
| P13 | | C13 (daughter; mental health nurse). Other daughter's carer and midwife. | No. Moved house and lost 1 st passport. Did not | No | Yes | Passport not used. Daughter is retired MH nurse. |

| | | | | | | |
|------------|---|---|---|-----|-----|--|
| | | | use 2 nd passport either. | | | |
| P14 | | C14 (husband) | No. "too lazy" / "can't spell properly" | No | No | Did not use passport. SU "cannot write" and husband is "too lazy". Passport should be simplified. |
| P15 | | C15 (daughter) | Yes | No | Yes | No need at present. "Forgot all about it." |
| P16 | | C16 (wife) | Yes, after wave 2; was not clear and did not have time | No | Yes | Electronic platform would be better – ensures legibility of entries. |
| P17 | | C17 (wife). Daughter is social worker. | Yes. Input plus photograph after wave 1. Then, with progression, nothing more, and photographs taken out. | No | Yes | High carer stress. Passport was just "too much". Patient himself cannot write. |
| P18 | | C18 (husband) | Yes | No | Yes | Passport too bulky for carrying around, and for HCPs to go through. APP would be better. |
| P19 | | C19, C19a (Brother and niece; grand-daughter) | Yes, after wave 2. Both brother and niece too stressed. | No | Yes | Passport is intimidating. Should be available as APP alongside paper version. |
| P20 | | C20 (wife) | Yes | Yes | Yes | It is not realistic to expect HCPs to take the time required to read the passport. "None of the doctors filled it in." "It didn't work." |
| P21 | | C21 (sister); but patient lives alone | Yes. "I can't write." Social worker made entries. | No | Yes | Lives alone and has learning difficulties. Key worker completed passport. "It's a good thing to have." |
| P22 | W | C22 (wife) | No | No | No | - |
| P23 | W | C23 (wife) | No | No | No | - |
| P24 | W | C24 (son in law) and his wife (her daughter) | No | No | No | C24 very wary of passport (data protection?) and not in favour. |
| P25 | W | C25 (daughter) | No | No | No | - |

| | | | | | | | |
|------------|----------|---|-------------------------------------|-----|-------------------|-----|---|
| P26 | N | W | C26 (Shared by son and daughters) | No | No | No | - |
| P27 | N | | C27 (wife) | Yes | Yes, after wave 2 | Yes | SU prefers paper version. It is a good communication tool. "I'm all for it." Carer did not engage with it. |
| P28 | N | W | C28 (husband) | No | No | No | - |
| P29 | N | W | C29 (daughter) | No | No | No | Was not contactable. |
| P30 | N | W | C30 (daughter) | N | N | N | - |
| P31 | N | W | C31 (daughter) | No | No | No | - |
| P32 | | | C32 (wife); one daughter is a nurse | Yes | Yes | Yes | Needs better layout. Good to have all the information in one place. Could be helpful when going to hospital. OK with paper and electronic format. |
| P33 | | W | C33 (son) | No | No | No | - |
| P34 | | W | C34 (?) | No | No | No | Just wanted the passport; did not want to take part in the study. |

Appendix 5 – Passport contents

| Participant | | Medication recorded | Other health problems recorded | Narrative | Hobbies & Activities recorded | Completed by | Self-care recorded |
|-------------|---|---------------------------|---|---|----------------------------------|--|--|
| P1 | | Patches (increased 08/15) | | Does not enjoy reading as has difficulty concentrating. | Arts & crafts; sewing & knitting | Daughter. One entry is dated 11/16. | Needs prompting to wash, dress, change clothes, and have hair done |
| P2 | W | | | | | | |
| P3 | | | | | | No entries in the passport. Neither of them are coping at all well. | |
| P4 | W | | | | | | |
| P5 | W | | | | | | |
| P6 | W | | | | | | |
| P7 | | | | | | No entries in passport. P7 has “switched off”; son & carer is overwhelmed. | |
| P8 | | | COPD; hypertension; heart attacks – 4 stents; prostate condition, Dupuytren contracture | P8 only provided contact details of his HSC team and conditions / medication. No information about himself. | | P8. Not dated. | |
| P9 | W | | | | | | |
| P10 | W | | | | | | |
| P11 | W | | | | | | |

| | | | | | | | |
|------------|--|--|---|--|--|---|--|
| P12 | | Donepezil GP prescribed Vorazepam for anxiety/restlessness but not helpful. Preventative medicine needed. Bendroflumethiazide; Paracetamol; Simvastatin; | Arthritis. | Significant deterioration from 11/16 (much like P17). Suddenly very agitated and distressed. Not sleeping and wanting to go home. C12 was desperate. Many sleepless nights. Fiddleblanket much loved. | TV, walking | Wife. Entries dated 07/16 and 12/16. Likes and dislikes in food. Documented deterioration. | Needs help with getting dressed; prompted to shower; adapted shower |
| P13 | | | | | | No entries in passport. Daughter is former mental health for older people nurse. | |
| P14 | | | | | | No entries in passport. P14 said she cannot spell, her husband said he is too lazy. | |
| P15 | | | Hearing aids, back-, and leg pain, Diabetes; walking aid. Sleeping problems; occasional falls; | Lives in assisted housing. Visits common room Mon – Fri. | Watching TV, knitting, and wordsearch. | Daughter. Entries dated 08/16 and 09/16. | Carer helps with washing and dressing |
| P16 | | Donepezil; Finasteride; Omeprazole; Simvastatin; Toviaz; Aspirin; Cilostaza; Contiflo; Madopar | Limited mobility (including small motor skills); walking aids. Low blood pressure. Prone to falls. Only drives | (Religion) Problems with concentration. Can no longer follow his hobbies of golf and painting. Does not like to use his walking aids. | Used to paint but due to PK no longer able. Still goes to painting club for tea and chat. | Wife. Entries dated 01/17. | Bathroom adapted (toilet seat, shower seat) |

| | | | | | | | |
|------------|--|---|---|---|--|--|--|
| | | | 1x/week on familiar route. | | | | |
| P17 | | <p>Diazepam had little effect in terms of calming Michael or helping him sleep. Medication not working (Diazepam, Queitapine). Community nurse prescribed Memantin. Sensitive eyes – Lacrilube. 24/7 care required. Cares stay overnight. Zopiclone prescribed. Dr T. prescribed Mirazapine to replace Zopiclone. Did not work for P17, back to Zopiclone – more settled.</p> | <p>Dupuyens constricture on both hands. Very limited; all mobility aids including in shower, etc.</p> | <p>(Religion) Loves going to (Church) but feels no longer confident to do so. Says daily prayers. Can no longer garden due to Dypuytrens. Loves dog walking and football, music, radio. Likes a very structured daily routine. Enjoys his grandchildren. Enjoys going out for meals. Struggles getting out words and follow conversations with lots of people. Deteriorated rapidly from 10/16! Hallucinating, not sleeping, agitation, confusion, wanting to go home, trying to get out, not recognising his wife. Bed downstairs as cannot manage stairs. Re-enablement team on board now as family can no longer manage on their own. Gets on well with carers and befrienders. On waiting list for 1 day/week at a day</p> | <p>Not keen on groups. Loves good food and music. Can no longer garden, paint, or walk any distance, but try to walk their dog. Couple still travel.</p> | <p>Daughter. Many entries – brief life overview, daily routine and food preferences, as well as illness progression and Consultant’s visits. Entries are dated 02/16 and 01/17, others not dated.</p> | <p>Reablement team in place to help with washing, dressing, etc. He needs 24/7 care now (wave 3) and cannot be left alone; cannot do anything by himself.</p> |

| | | | | | | | |
|------------|--|--|--|--|---|--|---|
| | | | | centre. Lack of clarity around diagnosis. HCPs puzzled at rapid decline. | | | |
| P18 | | Donepezil; Pain killers Lactulose; Esomeprazole; Maxitram; Beclometasone; Estradiol; | Depression, vision, hearing; back-, and neck pain | Likes to walk her dogs, and to spend time in their caravan in the summer. | Yes. Walking her dogs, family & friends | Husband. All entries 10/10/16. | |
| P19 | | Tramadol, lbugel | Arthritis; can get anxious due to loneliness (gets irritated and restless). Has glasses which she forgets to wear. | (Religion) Loneliness; sleeps well, loves music and singing, (Religious) TV, socialising, getting out to the beach and to town. Has a sweet tooth but diminished interest in savoury food. | Yes. Getting out with befriender | Niece. Entries are not dated. | Needs prompting and help with showering and washing clothes. |
| P20 | | Donepezil, Mirtazapine | Very limited mobility. Glasses, hearing problems, back pain, dentures, | Diagnosed in 08/15 but noticed changes in memory and ability 2 years before that. Sleeping problems, loss of appetite. Usually gentle and calm but increasingly confused and agitated episodes with low mood. | | Daughter and wife; Consultant, social worker, and OT made entries. No entries made after 3/16! | |
| P21 | | Medication given by carers (NOMAD system). | COPD; Learning difficulties | Was very upset at having her movement restricted by carers | | Key worker (Older Person's Team). Her | Manages independently. |

| | | | | | | | |
|------------|---------------|-------------------------------------|---|---|--|---|--|
| | | Manages on her own in the evenings. | | coming in both morning and night. Changed to only morning now but she still feels she needs to get up earlier than she would like to. | | entries are dated 08/16 and 12/16. | |
| P22 | W | | | | | | |
| P23 | W 2 | | | | | Withdrawn after 2 nd interview. No entries in passport. | |
| P24 | W 2 | | | | | Passport returned at 2 nd interview. | |
| P25 | W | | | | | | |
| P26 | N W | | | | | | |
| P27 | N | | Bypass surgery on leg, 10/15 and repeated 03/16. Heart failure diagnosis 10/16. | Healthcare team have put contact details on passport. | | Wife. Entries purely health related, dated 10/16 and 11/16. Physio, podiatrist, optometrist and out of hours GP entered their details. | |
| P28 | N W | | | | Yes, getting out for walks at the beach | | |
| P29 | N W | | | | | | |
| P30 | N W | | | | Yes. Community engagement, particularly Church | | |

| | | | | | | | | |
|-----|---|---|---|---|--|--|---|--|
| P31 | N | W | | | | Yes. Getting out for social nights | | |
| P32 | | | Prostate cancer – disturbed sleep; severe damage (torn cartilage) to knee joint – v. painful. Limited. Stair rail, shower seat. | (Religion) Goes to (church) weekly. Loves music, singing, and seeing familiar faces. Daily routine very important (wife). Keeps pigeons. Good appetite and sweet tooth. Confusion on holiday, and when out of home environment. Does not want to join groups. Prefers company of his family. Knee increasingly problematic and impairs mobility. Memory has deteriorated and is confused when out of his environment. | Likes to go for a run in the car and seeing grandchildren. Classical music. Enjoys company of brothers and sons. Walking and watching sport. | Wife. Life story and daily routine recorded, and previous health history. Entries dated 06/16; 8/16; and 01/17. | P32 does not like to shower, shave and change his clothes daily (this is not typical of him), so needs cajoling. Handrail on stairs and shower seat. Motion sensor lights. | |
| P33 | | W | | | | | N/A | |
| P34 | | W | | | | | N/A | |

Appendix 6a – HCP Letter



EQulP
Bamford Centre for Mental Health & Well Being
University of Ulster at Coleraine
Cromore Road, Coleraine
BT52 1SA

[GP Name/s and Address]

Dear Dr [Name],

I am writing to inform you that one of your patients, [Name], has agreed to participate in the Evaluation of a Healthcare Passport for People with Memory Loss (EQulP).

[Name] has been fully informed of the nature of the project and has voluntarily consented to take part in up to three qualitative interviews with a named researcher from the Bamford Centre for Mental Health and Well Being over the course of the next 18 months. This consent will be re-negotiated at each interview time point and your patient understands that she has the right to withdraw from the study at any time without repercussion.

As part of the study, [Name] will be using a Healthcare Passport. The Passport has been developed by the Public Health Agency, in association with the Royal College of General Practitioners and voluntary sector organisations. It will be held by the patient, and help to carry significant aspects of his/her life and provide meaningful information between him/her and the health and care services with which she is in contact. The key purposes of the document are: 1) To help people living with memory problems clearly communicate their social, health and spiritual needs to a range of health and social support services in a way that enhances quality and continuity of care; 2) To allow people living with dementia the opportunity (if wished) to consider in some detail the challenges which their illness may bring, and to articulate the preferences about how these challenges might be managed, 3) To improve communication across health and social care providers, patients and their family carers. The Passport aims to embed these views and choices into the patient's documentation, so that it can be accessed and reviewed by them and by their healthcare team, as the course of their memory problems unfold. In order to ensure that all of the key individuals involved in [Name's] care are aware of the Passport and how to use it, training will be provided to you through an informational leaflet, an instructional video, and an opportunity for a brief, interactive live training session.

If at any point during the study the capacity of [Name] to consent to participate should change, the lead clinician associated with the study will contact a previously named "personal consultee" to act as a proxy on behalf of [Name]. Should involvement with the project cause any stress or upset to [Name], appropriate support will be accessed by the professional who referred your patient to the study and support will be provided by the team responsible for their care.

A copy of the Participant Information Sheet is enclosed for your information. Please feel free to contact me if you have any queries or concerns.

Yours sincerely,

Bethany Waterhouse-Bradley

Research Associate, EQUIP Project

Tel: 077 9300 2841 email: b.waterhouse-bradley@ulster.ac.uk

Appendix 6b – HCP Letter II

[GP Practice]

13 June 2018

Dear Dr [Name],

We are contacting you to ask for your help in the evaluation of a **Healthcare Passport**. The passport was developed for people with memory loss by the Public Health Agency in association with the Royal College of General Practitioners. We have full ethical approval from the Northern Ireland Office of Research Ethics. The passport is designed to:

- 1) Help people living with memory problems clearly communicate their social, health and spiritual needs to a range of health and social support services in a way that enhances quality and continuity of care;
- 2) Allow people living with dementia the opportunity to consider the challenges which their illness may bring, and to articulate the preferences about how these challenges might be managed;
- 3) Improve communication across health and social care providers, patients and their family carers.

Some of your patients have agreed to participate in the evaluation and have been equipped with a passport for this purpose.

- ✓ They have been fully informed of the nature of the project.
- ✓ They, and their carers, have consented to take part in the study.
- ✓ They are aware that they can withdraw from the study at any point.
- ✓ They are holding and are encouraged to use, a copy of the Healthcare Passport.
- ✓ This involves bringing the passport to GP consultations and obtaining, in the first instance, a printout of their full medical history, along with a printout of their current medications.
- ✓ It furthermore affords the GP the opportunity to make relevant notes in the passport, or indeed, consult the passport for information provided by other members of the health-, and social care team of the patient.

Your assistance in this evaluation is invaluable and very much appreciated. We will be in touch to talk briefly with you about the passport. In the meantime, please do not hesitate to contact us with any questions.

Sincerely,

Professor Gerard Leavey (Principal Investigator)



The Evaluation of a Healthcare Passport for People with Memory Problems (EQUIP)

Please answer the following questions to the best of your ability. If you are unable to answer the question, please indicate why. Responses to the questionnaire will be anonymous, and participation in the study is wholly voluntary.

1. How many patients do you have currently using a healthcare passport?
2. What, if any, information did you have about a healthcare passport prior to this?
3. Has the patient brought the healthcare passport to an appointment with you?
Yes/No
4. Has the patient discussed the healthcare passport/use of the healthcare passport with you?
Yes/No
5. Do you have experience with using a healthcare passport for any other patient group (ie: people with learning difficulties?). **If so, please describe that experience briefly.**
Yes/No
6. Please briefly outline positive and negative aspects of the passport from the perspective of a General Practitioner.
7. Do you have experience with patients using patient-held notes or records (ie: maternity notes) other than healthcare passports?

Appendix 6d – GPs Follow-up email

Dear Dr,

You have recently received a letter from the Bamford Centre for Mental Health and Wellbeing at Ulster University, along with a copy of the Healthcare Passport designed by the Royal College of General Practitioners together with the Public Health Agency. Some of your patients are currently taking part in a study conducted by the Bamford Centre which aims to evaluate the passport. As part of their participation they are encouraged to bring the passport to their next GP visit, in the first instance for you to supply a printout of their medical history, along with an up-to-date list of their medication for inclusion in the passport.

Here is a link to the website of the Royal College of General Practitioners about the Healthcare Passport (copy it into your browser). At the bottom of the page you will find a link to a short video clip: "View our Healthcare Passport video here":

<http://www.rcgp.org.uk/rcgp-nations/rcgp-northern-ireland/my-healthcare-passport.aspx>

We would really appreciate your co-operation in the study, and would be most grateful if you were able to take part in a very brief (3-5 minutes) telephone survey at a later date.

Dagmar Anna S. Corry, PhD, CPsychol, AFHEA, AFBPsS
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Appendix 7 - Feedback on healthcare passport from patients, carers, GPs, and service user engagement groups

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| <p>Healthcare passport is too big and complex</p> | <p>“But I think, my own personal is... that’s too complicated.” (SU)</p> <p>“I would feel the same. Ah, there’s too much information for a start. But the other thing is, in my perspective of it, and it’s only mine and I can’t compare for anybody else here, but is that I think it’s very big.” (SU)</p> <p>“It’s a very big hard book.” (SU)</p> <p>“I see that and I think what if it was split into two sections, say, about me, about my care and a bit about me...” (SU)</p> <p>“And if there was a way to simplify things, that maybe...” (SU)</p> | <p>“To me, it’s too much information.” (SU)</p> <p>“But I do think if it was simplified and it was stripped down to things like my medical history, my medication, the health team...” (SU)</p> <p>“I think you know a smaller, condensed version of what’s there... With the really important information that needs to be shared amongst GPs and healthcare people.” (SU)</p> <p>“It’s intimidating.” (C19)</p> <p>It’s a great idea, but I think it’s maybe a wee bit daunting, because there’s a lot of information in there or there’s a lot of information required...(SU)</p> | <p>“But coming from, I suppose, a past caring perspective, but now I suppose in the position that I am and seeing the amount of people that I do and things, I suppose that would be my feedback, great to have a resource but maybe less complex, something that’s maybe more enjoyable. Something special. It’s hard enough, living with it, without having to do things like that. Yeah I would agree there... That you’re trying to get over....you know.. It’s hard to live with it.” (SU)</p> <p>That idea is grand, but splitting it up maybe into two smaller books. (SU)</p> <p>“Too bulky!” (Dr M.)</p> | <p>“If it was done easier, because all that c..p there that they have in it needs to be shorter and more... Then it might work, but that will not. There’s just too much.” (C20)</p> <p>“It’s too time consuming.” (C20)</p> <p>“I have found it cumbersome, there’s far too many expectations of the Passport. People think, ‘I won’t bother with it because it is so intense and there’s so much to...’ If it was made smaller and more generalised people would probably fill it in more.” (C13)</p> <p>“Too wordy. Contains a lot of information not relevant to GP care. Too much information for a 10-minute appointment.” (Dr D.)</p> |
| <p>Timing is important</p> | <p>“Actually maybe that’s something that you could do when you are diagnosed, you know, at first diagnosis, you know, so that this is something as you go along or progress.” (SU)</p> | <p>“I can’t even look at that now at the moment. I’ve got too many other problems.” (SU)</p> | <p>“This is what happened to us. Whenever [Name] was diagnosed we got bombarded with everything, which 90% of it was great but there was a couple that we couldn’t just cope with, and that was one of them, you know, it was too much</p> | |

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| | <p>“To put into it, and I think for families who are maybe struggling with the person with the diagnosis or a person who has just been recently diagnosed or is in...you know, in the middle of the illness, that this would maybe be something that wouldn’t ... that they wouldn’t use.” (SU)</p> | | <p>at the time. Probably in time to come it might... It was too soon. And it wasn’t just too soon, it was too much.” (SU)</p> | |
| <p>Paper or electronic platform?</p> | <p>“It’s probably better, because my writing is not very legible and it might be better if it was on something like that, because you’re typing it in and it would be better for somebody to read maybe. “And if you make a mistake you can delete it and write it over again, whereas with that you can’t rub it out, you have to score over it, and it makes it messy looking.” (C16)</p> <p>“I’d prefer to write on paper. I’m not advanced enough on this laptop so I just prefer to write on paper.” (P27)</p> <p>“Clearly all the basic demographic and carer information and social work contacts info is great to have but “paper” is so last century that the concept that a booklet like this is envisaged as an advance of</p> | <p>The thing about the phone is you’re always going to make sure the phone is with you. (C18)</p> <p>“Electronics are not... We have both, my daughter and quite a few people have given up because I couldn’t be bothered with it.” (C20)</p> <p>“I think it might be better, because although there are parts of that that I haven’t used yet, and I don’t know if I will use them, but you will obviously decide what’s useful and what’s not useful, considering all the data that you’re getting. The only thing about the electronics is that the information can be passed very quickly from one place to another.” (C12)</p> | <p>“If the app was along the lines of that medical thing or Facebook where you could put in your name and National Insurance Number and bring up your Passport.” (C18)</p> <p>“They should have it as an app on your phone.” (C19a)</p> <p>“You know yourself, if you had an app everyone could be linked into it and it could be updated by the various social teams. That’s how things will go, I’d imagine, eventually anyway.” (C19a)</p> <p>“Better if electronic and GP/ Patient / other health professionals could both access and make notes.” (Dr M.)</p> | <p>“You can download apps to take your temperature and everything. See that phone there? You can take your blood pressure and everything on that phone there.” (C18)</p> <p>“Definitely both. I keep everything in a notebook but you’re not always going to have that with you, and if the person goes to hospital, you’ll always have your phone.” (C19a)</p> <p>“I don’t mind, either way really, because I use my tablet quite a bit.” (C32)</p> |

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| | <p>patient care is beyond me.” (Dr O.)</p> <p>“GPs do not write on paper any more except to sign prescriptions.” (Dr. O.)</p> <p>“An electronic passport which is updateable through GP computer systems or that allows a service user & provider to have password protected access to essential information via NIECR or equivalent social care networks is the way to go with this type of idea.” (Dr. O.)</p> | | | |
| Patients will forget to bring it to appointments | <p>“When he was rushed into hospital...”</p> <p>“You forgot it.”</p> <p>“I totally forgot it. It was the last thing on my mind.” (SU)</p> | <p>“My fear at the outset, with Dad being a dementia patient, is that he will forget to take it with him.” (C10)</p> | | |
| HSCPs do not have the time | <p>I can see no GP sitting down filling all that because...</p> <p>“I think you scare the life out of them when you produce this...oh my God, do I have to read this now?” (C20)</p> | <p>“I think if you went into hospital, there’s very few hospitals, in fairness, that’s going to take the time to look even through that. No, they won’t have time. Even though it’s a brilliant idea.” (SU)</p> | <p>“Everything is down to money and time. Doctors will say they’re asked to do more, and if you produce that there you’re asking them to do something else.” (C18)</p> | <p>“Sometimes you go into appointments, as I said to you before, you might not have time allocated to produce that there.” (C18)</p> <p>“I never mentioned the book to him after it. They don’t have time to fill it in.” (C3)</p> |
| Helpful for people living on their own | <p>“I would think more particularly, very much more particularly with a person who had no family. It would be a definite necessity.” (P8)</p> | <p>“It must be dreadful to be on your own without any family and I would say in circumstances like that the passport would be invaluable.” (P8)</p> | <p>“If somebody has nobody to look after them, they would need that to give the information.” (C12)</p> | |

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| <p>Helpful for hospital stays and care-home stays</p> | <p>“We actually do have ...just talking about the care home, we actually do, when they come out to us, we actually do fill out something like that, the carers, to see if they like...what their dislikes and likes are.” (SU)</p> <p>“But it's dead handy if you were going to hospital; you take the book with you.” (P3)</p> | <p>“Because a lot of the hospitals, they're not dementia friendly anyway, and I think then to get them hopefully that they're going to read through it, I don't think there's a hope in hell that they're going to do that either.” (SU)</p> <p>“... say you tripped, R., and we needed to get you to hospital or something like that there? I can just hand that there instead of saying "oh I'm not sure..." because if you're under stress, you're not sure, it's all down there very factually.” (C32)</p> | <p>“And my job is activities, so it's to keep them motivated, to keep their interests up and not sit in the corner all day just going... and we know something about their interests before they come in. We have to try and beg families to do this for me now at the minute.” (SU)</p> | <p>“If you're going to A&E you don't need to take a book with you, because they're busy enough without....no matter what, I think even if you go into the hospital, they would have to take time to read that, and if you were in hospital the patient is ill and they don't have time to sit and read that. It takes a lot of time to read.” (C20)</p> |
| <p>HSCPs need to be informed beforehand</p> | <p>“Get the doctors more educated.” (SU)</p> | <p>It was pointed out that really all health and social care professionals involved in the care of the person would need to be aware of and familiar with the passport and its purpose, so they know how they can / should contribute and know which sections of the passport pertain to them and need their input. Equally, so that they know where to find relevant and important information. Everyone involved should be informed and trained appropriately. (SU)</p> | | |
| <p>Public should be informed</p> | <p>The passport logo should be everywhere, e.g., there could be posters up in GP</p> | <p>“You know the way you see men on talking, and women, But it's Still Me, a new ad.</p> | | |

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| | <p>surgeries, with the symbol clearly displayed and a brief description of the passport and what it is for. (SU)</p> | <p>They could have had an ad to say something like "doctors, this is new, you know there is a lot of dementia..." And on Countryfile it said that there's one diagnosed every three minutes, in some countries it's every three seconds, and there's lots of it, and they should have had an ad of maybe you and J. [P3] talking." (C3)</p> | | |
| <p>Will be useful as condition progresses</p> | <p>"The passport, at the moment, I think the Passport will only be coming into usefulness now, because we are getting more people involved [] I can see that it would be useful if there's more going on, so you can keep track of it all." (C12)</p> | <p>"To me, she's not at the stage yet where she can take advantage of this. Nobody takes her anywhere, except me. Nobody takes her to the doctor's, except me. There may come a time where I'm not able to take her here or there, or there's something wrong that I can't, and yes, it will come in handy then, but at the minute, and over the past whatever time she's had it, mammy has had no need for it." (C15)</p> | <p>"No, I just filled in the basic information and that's it. That was all, really. I haven't really used it, because I didn't feel...because she hasn't been to any appointments so at this stage...I would say maybe in the future it will be more relevant but, at the minute, no." (C1)</p> | |
| <p>Can be therapeutic for carer</p> | <p>"I think parts of that might be very therapeutic for somebody, a family member, to write down all the things that you want to [overtalking] That's the people that should be using that." (SU)</p> | <p>"I'll tell you, the thing that did strike me when this was all finished and things had calmed down after Christmas, was that all the stuff that I put on my phone and Messenger and the recording that I did, all those things kept me sane, in a way. It did actually help me, personally, to put it down at the time,</p> | | |

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| | | because it gave me something to do other than panicking. Do you understand what I'm saying?" (C12) | | |
| Good to have all the information in one place | "It's a great idea to have something where somebody can keep all their contacts together, like, say, be it physio, occupational, Alzheimer's Society, your consultant and everything like that there." (SU) | The passport was regarded by the group as essentially a very good resource constituting a concise, whole person information pack, which may prevent wrong diagnoses, and wrong medication. (SU) | "Because it's just handy to have it all down, the information, and then if anything does happen, a crisis or anything else, at least you haven't to rummage round looking for numbers and things like that. Or say I took ill, something happened me, somebody else would know that's the book I need to look at. If T. was here and I wasn't, they could get the information they need." (C16) | "I think it's good, because then everything is in one place and all their names of their team is kept in one bit, because a lot of times you have the problem that the family members don't know the information and it's all just sitting there." (Dr B) |
| Data protection | "There's people would not want to do that. That's personal." (SU) | "No, no, and you know, we don't like to have a document like this lying about the house so that other people, for whom it is not their business, may come across it and see what's going on or what [Name's] drug regime is, because we just feel that the current system, all that is under the Data Protection Act, nobody should be given it without consent and we just feel putting it all down like this is a risk." (C24) | | |

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| <p>Dating and accuracy</p> | <p>The passport is only going to be as good as the information that is put into it, and only as good as its last date. So, care should be taken to include all relevant information, and to update it regularly. (SU)</p> | | | |
| <p>Carers complete</p> | <p>“The person who’s suffering, they wouldn’t have a clue of that. So that means you’ve got to have a carer working at that.” (SU)</p> <p>“If you’re dealing with someone with Alzheimer’s, who you’re living with and trying to support, to sit and do that...” (SU)</p> <p>“No. It’s hard enough for the carers.” (SU)</p> | <p>“And nine out of ten it would be the person ...one of the family would have to fill that in.” (SU)</p> | <p>“I myself, think that people suffering with it would have great difficulty with that there.” (SU)</p> | <p>It will take initially some time to complete all the sections. This may not always be practical, particularly where people with dementia live on their own and may not be able to complete this task by themselves; or where carers are already overwhelmed. Also in cases, where family is unsupportive (“We are dependent on other people.”). (SU)</p> |
| <p>Could help communication</p> | <p>“When she went into hospital, that whole explaining that she had dementia, there was nothing ever written down, you know? You were constantly explaining.” (SU)</p> | <p>“I think it’s good, because my idea is that it’s a communication between us, I think. I think it’s a communication between...medical profession and all, it’s a communication and I think it’s good, that’s my opinion on it.” (P27)</p> | <p>“They usually do write to us but, to be honest, sometimes it’s hard to get the letters on time. There’s a tab here, “My Support Team” quite often I’ll ask people who’s your social worker and what’s their number? I would find that quite useful, to be able open that, because quite often I would write to that social worker directly, and that would be the most useful part of that, me being able to get hold of their social worker if there’s a crisis or things are</p> | |

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| | | | deteriorating, either their psycho geriatrician, especially their social workers, because as you say too, sometimes the letters from the OTs and that, we get letters, you could get a letter three months later, you don't really know what's happening, so from that point of view, yes, that is a good idea.” (CB) | |
| Could help preserve personhood | <p>“It was as if she didn't exist, that is the sad thing, because nobody ever talked to her, they talked to us.” (SU)</p> <p>“It's a great thing to have something where you can put in the likes, for example, of foods and things, because having worked with people, I think, down the line, when people get sick and things like that there and maybe they don't have the capacity to say, it's knowing that you'rehave you ever heard of a situation in alike a nursing home, and everybody gets tea and milk, tea and the same amount of milk, and it's kind of like, well not everybody likes tea with milk; some people don't like tea.” (SU)</p> | <p>The passport should facilitate the inclusion of a name (and photograph) on the cover, so it is personal, and personalised, and confusion can be avoided, should there be more than one passport in a home. (SU)</p> | | |

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