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Acceptability and use of a patient-held communication tool for people living with dementia: a longitudinal qualitative study

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3 **Acceptability and use of a patient-held communication tool for people living with**
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5 **dementia: a longitudinal qualitative study**
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10
11 Professor Gerard Leavey¹ * | g.leavey@ulster.ac.uk (corresponding author)
12

13
14 Phone +44 (0) 7801254924
15

16
17 Dr. Dagmar Corry¹ | d.corry@ulster.ac.uk
18

19
20 Dr. Bethany Waterhouse-Bradley¹ | b.waterhouse-bradley@ulster.ac.uk
21

22
23 Dr. Emma Curran¹ | e.curran@ulster.ac.uk
24

25
26 Dr. Stephen Todd² | stephen.todd@westerntrust.hscni.net
27

28
29 Professor Sonja McIlfatrick³ | sj.mcilfatrick@ulster.ac.uk
30

31
32 Professor Vivien Coates³ | ve.coates@ulster.ac.uk
33

34
35 Dr. Max Watson⁴ | alimaxuk@me.com
36

37
38 Dr. Aine Abbott² | aineabb@gmail.com
39

40
41 ⁶Bernadine McCrory | Bernadine.McCrory@alzheimers.org.uk
42

43
44 ⁵Professor Brendan McCormack | bmccormack@qmu.ac.uk
45

46
47
48 ¹Bamford Centre for Mental Health and Wellbeing, Ulster University, Coleraine

49
50 Campus, Cromore Road, BT52 1 SA, Northern Ireland
51

52
53
54 ²Geriatrics, Altnagelvin Area Hospital (WHSCT) Glenshane Road, BT47 6SB, Northern
55
56 Ireland
57

1
2
3 ³School of Nursing, Ulster University, Jordanstown Campus, Newtownabbey BT37

4
5 OQB

6
7
8 ⁴Adult Services, Northern Ireland Hospice, Whiteabbey Hospital, Doagh Road,

9
10 Newtownabbey BT37 9RH

11
12 ⁵Centre for Person-centred Practice Research, Queen Margaret University, Edinburgh,
13 Musselburgh, EH21 6UU

14
15 ⁶Alzheimer's Society, Northern Ireland, 30 Skegoneill St, Belfast BT15 3JL
16
17

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20
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22

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8 **Abstract:**
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10 **Objectives:** To assess the acceptability and use of a low-cost patient-held communication
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12 tool.
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15 **Design:** Longitudinal Qualitative interviews at three time points over 18 months
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17 **Setting:** Primary and community services
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20 **Participants:** Twenty-eight dyads - People living with dementia in Northern Ireland and their
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22 informal carers, supplemented by focus groups, and content analysis.
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24 Interventions: a patient-held healthcare “passport” for people living with dementia.
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27 **Primary and secondary outcomes:** acceptability and use of the passport – barriers and
28
29 facilitators to successful engagement.
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32 **Results:** There was a qualified appreciation of the healthcare passport and a much more
33
34 nuanced, individualistic or personalised approach to its desirability and use. How people
35
36 perceive it and what they actually do with it, are strongly determined by individual contexts,
37
38 dementia stage and other health problems, social and family needs and capacities. We
39
40 noted concerns about privacy and ambivalence about engaging with health professionals.
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45 **Conclusion:** Such tools may be of use but there is a need for demanding, thoughtful, and
46
47 nuanced programme delivery for future implementation in dementia care. The
48
49 incentivisation and commitment of General Practitioners is crucial. Altering the
50
51 asymmetrical relationship between professionals and patients requires more extensive
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53 attention.
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58 **Article Summary**
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Strengths and limitations of this study

- Our LQR design allowed a consideration and assessment of contextual factors and mechanisms [21] related to use of a patient-held medical communication tool in 'real-world' environments.
- The LQR design was key to building rapport and trust with participants and uncovered various assumptions about caregiving, and aspects of individual and systemic behaviours that determine passport usage.
- 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.

Introduction:

Dementia is increasingly prevalent in Western societies, producing considerable challenges to families, health services and economies [1, 2]. However, as dementia progresses, the appearance of other health problems and disabilities are commonplace, leaving specialist-based healthcare systems to manage the various health and social care problems in a fragmented and inefficient manner. People living with dementia ('PLWD') and family caregivers commonly report dissatisfaction on issues such as multiple and unnecessary appointments and distress at repeating history and current situation (needs and resources), symptoms, treatment and care package [3-5]. Communication with health care professionals in dementia services is often problematic for both the patient and their family members [6], related to various aspects of organizing care and areas of decision-making for

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3 relatives with dementia [7, 8] [9] [10, 11]. Various obstacles deny widespread acceptance
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5 and use of internet-based support [12, 13].
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10 Attempts to address service barriers are generally confined to hospital and hospice settings
11 [14] and/or overly focused on clinical decisions and pathways, to the neglect of person-
12 centred approaches[15, 16]. To address these problems, a consortium of health
13 professionals and people with long-term and life-limiting conditions co-produced a
14
15 “healthcare passport”, an expandable information booklet divided into sections covering
16 key aspects of the person’s life, support, and care. For example, some of the sections
17 covered information on health problems, another contained details of medication, while
18 other sections disclosed salient aspects of the individual’s life – religious or spiritual beliefs
19 and interests. Importantly, the ‘passport’ was to be held by the person with dementia (or
20 their proxy) who completed the personal and social sections, while medical treatment and
21 care were completed by the various and relevant health professionals, and entries could be
22 made by the latter during visits. In brief, the passport was designed as a portable patient-
23 held record of care that could facilitate the cross-transfer of information between patients
24 and a variety of medical and social care professionals. In collaboration with health and social
25 care agencies, statutory and voluntary, we sought to examine how this low-cost
26 communication tool might be acceptable and useful to people living with dementia and
27 their families.
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53 **Aims:** to examine the efficacy of a healthcare passport for people with dementia and their
54 family carers, intended to facilitate communication and decision-making for service users
55 and family caregivers. Additionally, we wanted to explore: (a) how this tool is used over
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3 time; (b) the engagement of relevant service providers; (c) the barriers to information and
4 communication between and among family carers and health and social care professionals
5 ('HSCPs') and how these can be remedied; and (d) how to refine and/or deliver the passport
6 and similar interventions.
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14 **Ethical Approval:** The study was given favourable ethical opinion by the Office for Research
15 Ethics Committees Northern Ireland (ORECNI) on 21 July, 2015. (REC reference 15/NI/0129)
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20 **Method:** adopting a realist evaluation approach to complex interventions, we used
21 Longitudinal Qualitative Research (LQR), focus groups and document content analysis.
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26 **Recruitment**

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29 We aimed to recruit 20-25 people with mild-to-moderate dementia, and their families,
30 sufficient to obtain a range of individual situations and experiences. This was done through
31 the Memory Clinic of the Western Health & Social Care NHS Trust.
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38 **Capacity:** If the lead clinician or centre manager believed absence of capacity, the lead
39 clinician or centre manager helped identify their next of kin, family caregiver or someone
40 close to the person (who does not receive remuneration for this role) who will act as a
41 "personal consultee". Although the capacity of the person with dementia may diminish over
42 the evaluation period, we intended that they are fully involved in using the passport, and
43 any associated decision- making. We held no prior assumptions about participants' current
44 use of health and social care services. The potential participants were approached by
45 clinicians who provided information about the study. Interested service users and their
46 families then contacted the study team for further information and provided written
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3 informed consent. Family GPs were contacted and given information tools about the
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5 passport. Additionally, we ran information sessions for local health professionals within the
6
7 local dementia services.
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10 11 **Interview methodology**

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15 Primarily we used Longitudinal Qualitative Research (LQR) methods [17, 18]. Briefly, this
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17 consisted of three in-depth interviews: (1st) shortly after referral; (2nd) at six months; and
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19 (3rd) at twelve months. The interviews, lasting between 60 and 90 minutes, were
20
21 undertaken in the participants' homes by BWB and EC, females with PhDs with substantial
22
23 training and experience in qualitative research with vulnerable populations; sociologist and
24
25 psychologist, respectively. The researchers met with all participants prior to the study, via
26
27 the memory clinics, and provided a clear overview of the study aims. Neither researcher had
28
29 prior personal experience of dementia or its associated caregiving. We used topic guides to
30
31 help us record and explore change over time, and the processes associated with such
32
33 changes. Thus, the initial interview gathered 'baseline' information about the onset and
34
35 diagnosis, health and social care needs, the context of care and the availability of support.
36
37 We also examined service users' and caregivers' perceptions and expectations of the
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39 passport. Field-notes were not taken during interviews but the team met regularly to
40
41 discuss issues arising from the interviews. The topic guide and analysis were based on the
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43 literature and experts by experience within the Alzheimer's Society. The topic guide was
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45 refined after the initial interviews.
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55 In subsequent meetings, we explored any change to these areas and issues and the passport
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57 usage. Additionally, we did a content analysis of service user and caregiver entries in the
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3 passport and examined General Practitioner's assessment of passport usage. All participants
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5 provided recommendations for future use of the passport.
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9 **Analysis:** The interviews were audiotaped, transcribed and then entered into a qualitative
10 software programme (N-Vivo version 11) for data coding and management. We used
11 *Trajectory analysis* which examines changes over time for participants[19]. We coded and
12 indexed the data, using a spreadsheet in order to generate a matrix into which the data was
13 'charted'. This summarized the data by category from each transcript, building themes with
14 the support of memos and data display. Transcripts were analysed and coded independently
15 by the researcher, 1-2 members of the caregiver participant group, and members of the
16 research team.
17
18

19 Some specific areas covered: (a) a retrospective examination of the experience of people
20 with dementia, family carers, help-seeking and communication needs – prior to using the
21 passport; (b) practical use of the passport, differentiated by different care characteristics
22 and contexts (e.g. dementia stage, social class and social support networks, gender and
23 care-relationship); (c) change in use of the passport over time in response to need; (d) care
24 planning and advance directives for end of life care; (e) joint decision making (family and
25 patient); (f) comprehension and ease of use by stakeholders (professionals and family); and
26 (g) reasons for discontinuation. Additionally, we examined contextual factors of people in
27 the use and maintenance of this type of intervention and how it can be more effective.
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30 Understanding the acceptance and use of the passport over time with a range of people was
31 the main goal and thus, theoretical data saturation was not particularly relevant. While it
32 was not possible to undertake participant checking per se, participants were provided with a
33 synopsis of their previous responses and asked about change.
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3 **Passport Content analysis:** The passports' contents were examined to see how they were
4 used and by whom, in addition to family carers, and the level and quality of the information
5 provided.
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10 Findings

11 Participant recruitment and attrition

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13 Following initial recruitment of 28 patient-carer dyads for the first wave of interviews, two
14 declined; we therefore interviewed 26 PLWDs and carers in wave 1. Participant (patient and
15 carer) characteristics in addition to recruitment and attrition flow are provided in Table 1
16 and Figure 1 below. Advised by the Memory Clinic to expect a high attrition rate in this
17 particular population, we had 16 participating families at wave 3 (48% of total contacted).
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30 We obtained a socially heterogeneous sample from range of occupational backgrounds.

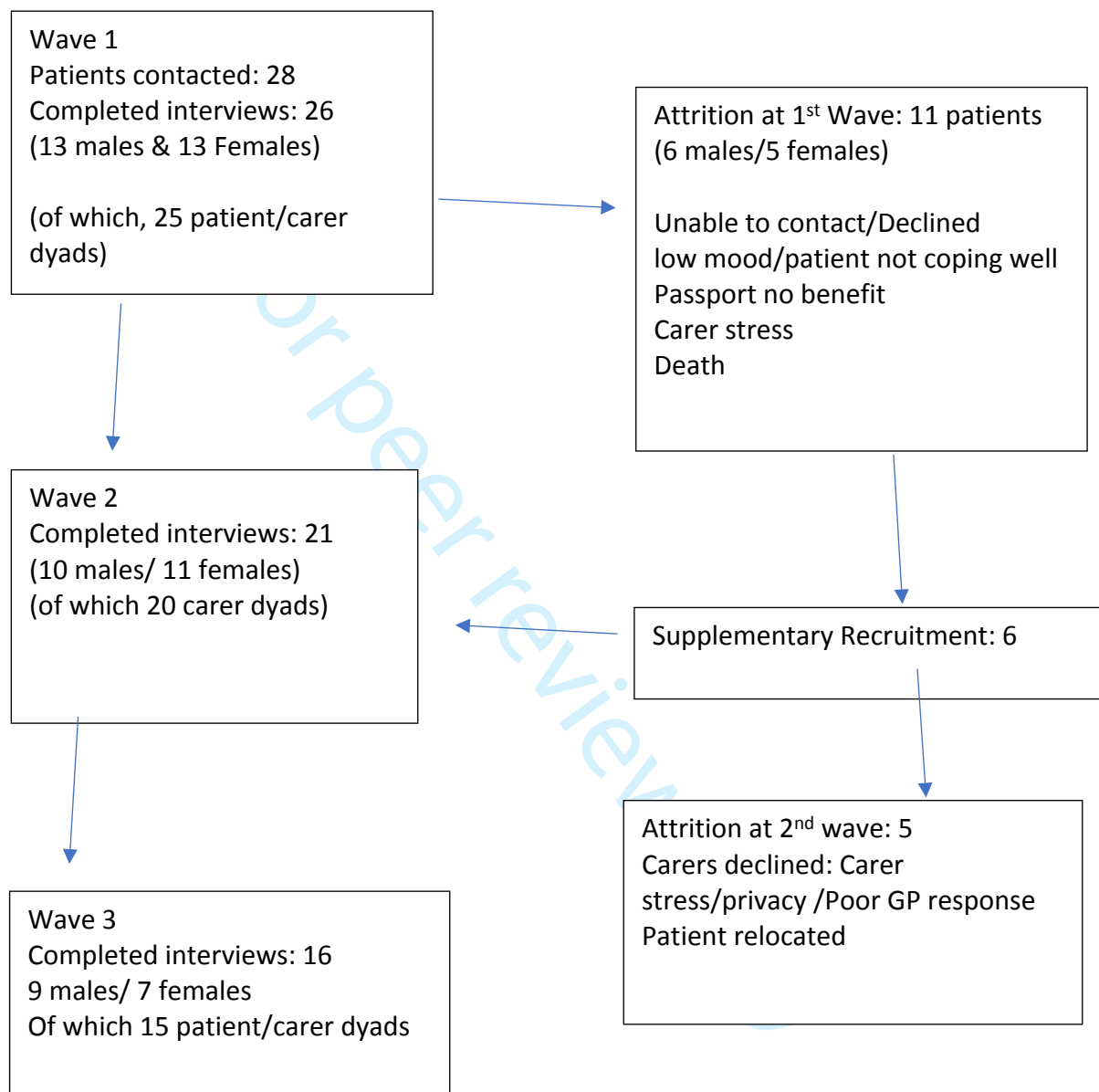
31 However, all 28 patient participants were retired, or not working. Only five patients lived
32 alone in their own home, one lived in residential care (by choice), and 20 lived with either
33 their spouses, or a daughter or son.
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40 We noted various comorbidities (including depression, diabetes, arthritis, COPD, heart
41 problems, hypertension, breast and prostate cancer, hearing, and vision impairments).
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45 Depression (37%), arthritis (30%), diabetes (27%), and cardiac conditions (27%) were the
46 most frequently occurring comorbidities in our final sample. Eighteen participants (60%) had
47 multiple comorbidities, with between two and eight separate conditions in addition to their
48 dementia. The comorbidities reported by the participants may not entirely correspond to
49 their medical records. Some participants may have forgotten to mention particular
50 conditions, or have chosen not to disclose them.
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TABLE 1: RECRUITMENT AND ATTRITION

	Wave 1	Wave 2	Wave 3
Number	26	21	16
Gender	13 females 13 males	11 females 10 males	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

Figure 1: flow chart of Participant Recruitment and Attrition waves 1-3**Carers**

Eighteen of the family caregivers were retired from work and six were still working. Most carers were female, (daughters (N=13), and wives (N=11)). Husbands were the next biggest

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3 group (N=5); others were sons (N=3), brothers (N=1), and sisters (N=1). In some cases
4
5 (N=5), caring was shared between two or more family members. Eight carers (daughters and
6
7 sons) also had their own families to care for; one carer (wife) also cared for a mother with
8
9 Alzheimer's disease and an elderly relative. Thirteen carers had serious health problems
10
11 including diabetes, high blood pressure, arthritis, depression, and epilepsy.
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15 **Contextual Experience of Health and Social Care**

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18 Participants reported limited communication and coordination between departments, and
19
20 individual professionals; miscommunication between health and social care professionals
21
22 (HSCP), considerable variation in information and service provision, and problems when
23
24 formal carers changed. Some families felt intimidated by unfamiliar doctors, while others
25
26 became particularly assertive when they felt the patient was being disadvantaged. Those
27
28 who had worked in healthcare or had family in the healthcare system were more confident,
29
30 and found it easier to get the service they needed. The main health and social care issues
31
32 reported were the difficulty in seeing the same GP every time *"You never see the same*
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34 *doctor twice. They are always booked up, and others don't know your case."* (C16), the short
35
36 consultation time, the importance of the GP taking time to listen, being comfortable with
37
38 the GP, and the attitude of the GP (emphatic and warm versus condescending and
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40 dismissive). Some avoided seeing their GP because they feared another diagnosis, or
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42 because they felt they should not "bother" the GP.
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Attitudes to, and expectations of, Passport use

In the following section, we detail the perceptions and use of the passport over the evaluation period. The key factors in this were: (a) correct completion; (b) timing; (c) privacy; (d) additional burden; and (e) response from Healthcare Professionals.

Correct completion

Most participants were unsure about the potential usefulness of the passport though we noted some scepticism on its usefulness and/or capacity to use it. Some were anxious about writing anything at all in the passport.

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

Importantly, participants worried that there was a ‘right’ way to use the passport, and most wanted guidance on this. Overall, the most common response was ‘we will give it a go’ – a tacit agreement to try it out. In any case, over the study period 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.

Timing

Many participants considered the passport to be unnecessary at this stage of their healthcare, mostly because they had few appointments currently. This was particularly true of care dyads with a diagnosis less than six months prior to interview, and for those with few/no co-morbidities. However, others acknowledged potential usefulness as the illness

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3 progressed, and of particular use if something were to happen to the carer. Few
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5 participants maintained that they could keep track of this information themselves, or
6
7 believed the healthcare professionals would already be sharing/recording the information
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9 without prompting. In each of these cases, the opinion of those individuals did not change
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11 with further explanation of the passport, and so it is unlikely that the response was due to
12
13 poor understanding of the purpose of the passport.
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18 “No, I just filled in the basic information and that's it. That was all, really. I haven't really
19
20 used it, because I didn't feel...because she hasn't been to any appointments so at this
21
22 stage...I would say maybe in the future it will be more relevant but, at the minute, no.” (C1)
23
24

25 26 **Privacy and relationships**

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28 Carers' attitudes to information-sharing with healthcare professionals is complex and the
29
30 concept of promoting 'personhood' in healthcare had limited currency among carers. Thus,
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32 several families were unwilling to share personal details with the doctor beyond medical
33
34 history, and did not acknowledge the significance or relevance of that part of the passport.
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38 “No, no, and you know, we don't like to have a document like this lying about the
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40 house so that other people, for whom it is not their business, may come across it and
41
42 see what's going on or what [P24]'s drug regime is.” (C24)
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46 Such families preferred compartmentalised approaches to care or were suspicious of
47
48 sharing personal information with paid carers in particular. These views seldom changed
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50 over the study period. Participants were also apprehensive about who should have access
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52 to, and make entries in, the passport. Even though it was explained that control over the
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54 use of the passport lay with the family, people remained unsure as to how this could be
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56 decided. We noted warmth between dyads in most of the interviews and this bond appears
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3 to assist in using the passport. However, we also noted that some couples fearing the loss
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5 of their 'old' relationship strove to maintain a 'normality' which, in some instances meant
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7 minimising external intrusion. With implications for the healthcare passport and for care
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9 generally perhaps, several couples suggested that they try and manage things themselves
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11 (e.g., C2, C28/P28, P30). *"We handle things ourselves. As far as we can, we'll do it. Wherever*
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13 *she goes, I go now."* (C2)
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18 19 **Additional burden**

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21 Participants' enthusiasm for the passport centred on its organisational and memory
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23 purposes. However, while carers focussed on keeping track of varied professional
24
25 appointments, patients focussed on medication management. Additionally, while carer
26
27 participants who formed part of family network anticipated its value in cross-
28
29 communication to relatives, unless prompted none indicated its utility in information-
30
31 sharing with health and social care professionals. Again, this suggests that the concerns
32
33 about threats to the personhood of the family member posed by health professionals'
34
35 responses and attitudes does not register significantly with caregivers or was overshadowed
36
37 by healthcare needs. *"It's a new thing, it's very hard to handle, and the last thing on your*
38
39 *mind is this book."* (C3). Others, particularly non-spouse males, were apprehensive that the
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41 passport may become too onerous.
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49 "This is what happened to us. Whenever (Participant) was diagnosed we got bombarded
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51 with everything, which 90% of it was great but there was a couple that we couldn't just cope
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53 with, and that was one of them, you know, it was too much at the time. Probably in time to
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55 come it might..." (C11)
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Ownership of Passport

Most carers indicated that the PLWD would not be able to use the passport, or somehow dissuaded the PLWD from using it. In one case, this was because the PLWD 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.

“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 [...]. Therefore, he wouldn't personally be doing this, it would be me.” (C17)

There was quite a range, however, in the carer's perception of the PLWD's ability to use the passport amongst people with the same/similar memory scores. Carers expressed a number of reasons why the PLWD 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.

Anticipated response from Healthcare Professionals

Some participants, particularly carers, 'self-censored' any exchange with health professionals believing 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.

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2
3 “You'd be taking your life in your hands when you hand them the book and say 'can you fill
4 that in?' They would just tell you that they don't have time and that would be the way like,
5
6 and I wouldn't go back and ask a second time.” (C18)
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10 They were also more likely to relay negative stories about experiences with HSCPs.

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12 However, in contrast, family caregivers who had direct experience working in the healthcare
13 sector, tended to suggest that healthcare staff would find the passport very useful.

14
15 Participants sceptical of professional engagement with the passport nevertheless
16 maintained the value in the passport for their own care dyad. Updating the passport
17 and/or introducing it into healthcare consultations was problematic. *“We weren't good at
18 doing the homework, I have to say. Some of it's done and some of it hasn't been updated.”*
19
20

21 (C32). Thus, some people forgot to bring the passport when attending hospital and general
22 practice appointments –while others were greeted with bemusement by clinicians who
23 appeared to be unaware of its existence. Additionally, other participants consciously
24 neglected it, anticipating that the passport may be perceived by clinicians as a burden and
25 did “not want to bother” them.
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40 “We've tried to use it.” (C20) “When we saw the reaction to it, we don't take it anymore.”

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42 (C20a) “They just look at you as if-“ (C20)
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48 **Healthcare Passport content analysis**

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50 During the 3rd wave of interviews we made copies of the passport entries with the
51 permission of the participants. With one exception (P8), carers had filled in the passport,
52 rather than the PLWD. Most participants opted to keep their HP after the evaluation, except
53 one (P14).
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3 Family caregivers, soon after diagnosis, began incrementally to assume control of various
4 responsibilities in the PLWD's life. Sometimes family intervention is a response to cognitive
5 changes and the diminishing capacity of the person, for others it appears to be a pre-
6 emptive and prematurely unnecessary intervention, prompted by anxiety about risks. In
7 return, the family member with dementia assumed a new identity role which undermined
8 their sense of agency and initiated an erosion of abilities and skills. *"Do you want me to*
9 *write all this down?" (P7) "No, I'll get [wife] to do it for us, Dad."* (C7)

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21 Additionally, some of the PLWD had various co-morbid conditions and/or learning
22 difficulties, which made writing problematic. Each of the passports was completed in a
23 distinctly idiosyncratic style. While this demonstrates the different individuals' personhood,
24 it may also present challenges for HSCPs. In other words, our evidence suggests that the
25 passports may not conform to a standard information collection. For example, in terms of
26 medication and side effects, as well as comorbidities and their impact, and self-care, the
27 level of detail varies considerably between PLWDs, and some do not mention these at all,
28 even when these are a significant aspect of their needs and difficulties. So, HSCPs may be
29 concerned that vital information is not recorded and may consider that, in its current form,
30 the passport is unreliable.

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48 Personal narratives, hobbies, and activities also varied considerably and information was
49 also recorded unsystematically. Thus, carers included details about dementia progression
50 and PLWD deterioration, along with details on religion, likes, and dislikes, and activities. Of
51 the 12 completed passports, four contained only undated entries, two contained partially
52 dated entries only, all but two (P8 self-completed; P21: social worker completed) were

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3 completed by the carer. Those who were overwhelmed (e.g., C13), or coping very well (e.g.,
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6 C13) did not complete the HP.
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10 **GPs feedback**

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12 The general consensus among the GPs was that “... *the fundamental idea is very good.*” (CB)
13
14
15 Some GPs were familiar with maternity notes, about which they noted “... *work well if the*
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18 *patients bring them*” (CB) but said that often they did not. In the current study, few patients
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21 took the passport to their GP, and those who did, reported that the GP appeared to be
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24 unfamiliar with it or unenthusiastic about its use, which deterred them from taking it again.
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26
27 Commonly, GPs felt that the passport created another pressure on GP’s time and also were
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30 concerned about its legal status in the event of medical complications or patient complaints.
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33 Mostly, however, most expressed doubt about the additional bureaucracy.

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

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42 The practicality of and reasoning behind offering the passport in paper format was
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44
45 questioned in the context of ubiquitous digital technology within the healthcare system.
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48 **Discussion**

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51 To our knowledge, this is the first study to evaluate a communication tool in dementia
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54 healthcare [20]. The complexity of dementia, often accompanied by co-morbid disability
55
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57 and illness, create challenges for interventions designed to support relationships in care 4].
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60 Thus, over time, health and social needs can accelerate and informal care networks may be

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3 unpredictable. Additionally, while these factors underpin the rationale for communication
4 tools they also increase evaluation uncertainties about their acceptance and use.
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9 Despite the challenges to its widespread use, the health care passport for people living with
10 dementia was still considered favourably by many participants but requiring a more
11 nuanced approach. As a communication tool it may be determined by the extent of the
12 person with dementia's care needs and the caregiver's role and ability in meeting these.
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18 While the healthcare passport was co-designed and strongly supported by people with
19 dementia, family caregivers and healthcare professionals, its feasibility rested on various
20 assumptions about stakeholder beliefs, values, behaviours within a range of contexts and
21 specific needs. Our evaluation underlined the salience of factors that are seldom
22 acknowledged in the implementation of complex interventions and particularly within the
23 world of dementia care. Prima facie, we found a ready acceptance of the passport by service
24 users and carers who were willing to 'give it a go' and could envisage its benefits. However,
25 a more tacit understanding of cultural attitudes towards health professionals emerged. In
26 many cases, participation was gained simply because families felt an underlying obligation
27 to the dementia services (Memory Clinics). Again, deference to professionals was
28 manifested in the reluctance of service users and carers to 'bother' their GP revealing the
29 asymmetry of this relationship and patient-family insecurities about 'annoying' clinical staff.
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The timing for introducing the passport may influence its uptake and usage. This may prove difficult to gauge. At the very early stages post-diagnosis, patients may have good physical

1
2
3 and mental health and may reject the passport as unnecessary while, nevertheless
4
5 regarding it as potentially helpful as the condition progresses. Others, who appeared to be
6
7 still in shock or depressed for some time after the diagnosis, found the passport as a painful
8
9 reminder and didn't want to use it. It was regarded as a "dementia passport" and associated
10
11 with lack of capacity and decline. For those at a more advanced stage, and/or with
12
13 considerable co-morbidity and thus, service use, often felt overwhelmed by the information
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15 flow that they thought necessary to be inserted.
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23 As noted in other healthcare areas [22, 23], the 'ownership' of communication tools
24
25 presents interesting and challenging dilemmas. Developed as a patient-held communication
26
27 tool but not specifically designed for dementia, cognitive deterioration may alter the
28
29 passport's management, often assumed by the family carers. In some cases, family
30
31 members appear to undertake, and therefore sometimes undermine, the normal activities
32
33 of daily living of the person with dementia. The extent to which the passport is held and
34
35 'owned' by the family caregiver requires further examination.
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43 For people who wished to maintain a sense of 'normality' the passport may have been
44
45 perceived as a threat or an intrusion, in which case people consider what is most at stake
46
47 for them and will try to find ways of protecting this.
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52 Revealing participants' tastes and dispositions within the passport was intended to create a
53
54 sense of personhood and while some people understood and appreciated the concept,
55
56 other participants were anxious about the sharing of personal information, feeling that
57
58 some formal carers or clinicians did not need to know the personal details or specific
59
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3 aspects of a person's life. For others, achieving basic medical and social care services
4
5 appears to be prioritised over non-essential knowledge – suggesting that the two
6
7 information types are balanced in a zero-sum game.
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11
12 Content analysis revealed that each passport was entirely different from others. While this
13
14 is to be expected when it comes to personal narrative, it is not helpful in terms of medical
15
16 information, symptoms, progression, comorbidities, side effects of medication, etc. The
17
18 current non-standardised format of the sections relating to information relating to the
19
20 patient's health may undermine the passport's viability and efficiency. Essential information
21
22 may be missing or not have been updated, or indeed not dated. Many entries were not, or
23
24 only partially dated. As such, the information contained in the passport may not be
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26 regarded as reliable by some professionals.
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34 This evaluation has provided rich, in-depth information about the uptake and use of a
35
36 healthcare passport for people living with dementia. For example, recruitment to studies
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38 such as this may be relatively easy but meaningful participation is more difficult to achieve.
39
40 Thus, a future trial will need to set much stricter parameters for participation including
41
42 much more robust assessment of informed consent rather than a willingness to please
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44 clinicians, complexity of care, disease progression and passport 'ownership'.
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48

49 50 **Recommendations**

51
52
53 HSCPs need to have an awareness of the dynamics in a patient-carer dyad, and the
54
55 particular circumstances of the carer, and devise a care plan fully cognisant of the medical
56
57 and socio-psychological condition of both. Some families require much more in-depth
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3 consultation on the use of the passport and over a longer period of time than the resources
4
5 permitted in the current evaluation. It must be made clear that it is a “health passport”
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7 rather than a “dementia passport”. People living with dementia need to know that it is
8
9 widely used by all patients, so that they do not feel stigmatised by its use.
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14 The degree and exact nature of GP resistance may require further understanding about
15
16 how, if at all, it may be overcome. Alternatively, future design and implementation may
17
18 have to consider which service should take responsibility for the dissemination and
19
20 oversight of the passport.
21
22
23

24 **Patient and Public Involvement**

25
26 This study was developed with the support of the Alzheimer's Society Northern Ireland.
27
28 People living with dementia were involved in various stages of the project except writing for
29
30 publication.
31
32
33

34 **Author contributions:**

35
36 GL, AA, MW, ST, SMcl, BeMcC , BrMcC and VC co-designed the study, EC, BWB and DC
37
38 collected and analysed the data. All authors contributed to the writing of the manuscript. GL
39
40 was the PI on the study.
41
42
43

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45
46
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48
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50
51 possible.
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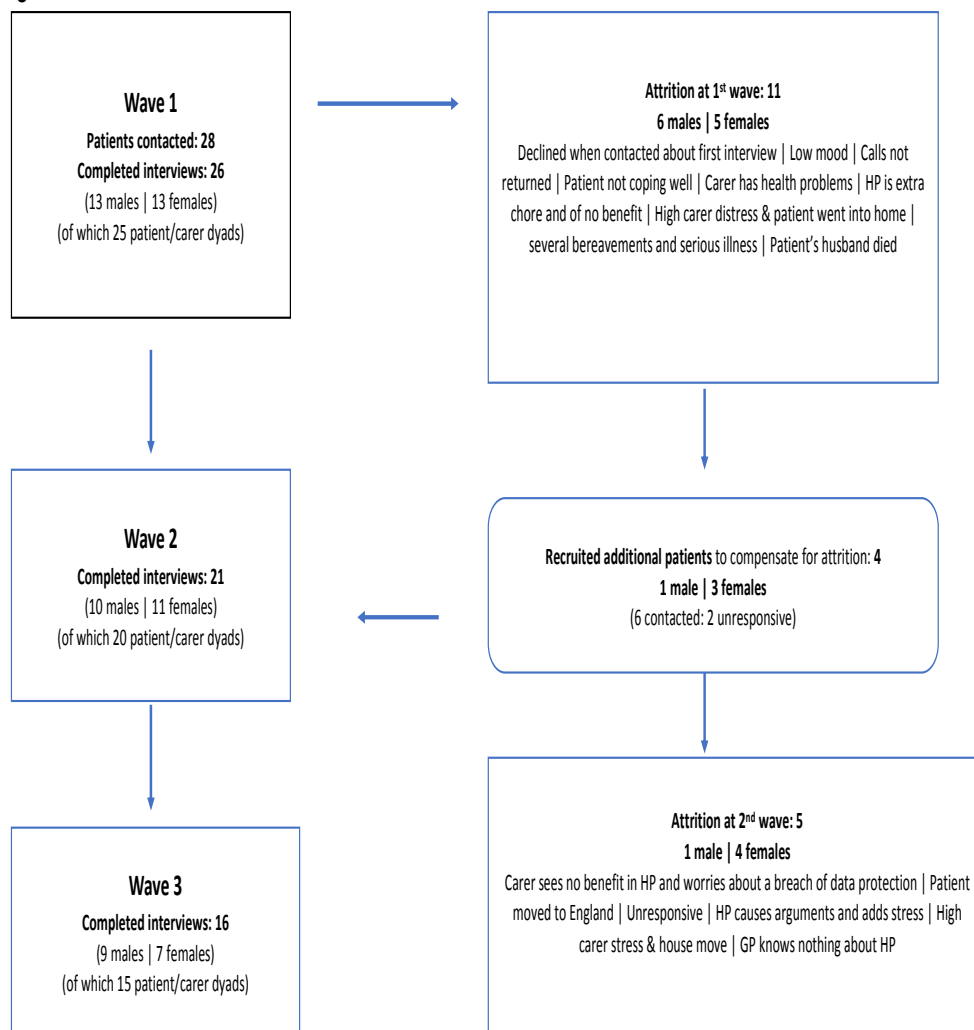
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TABLE 1: RECRUITMENT AND ATTRITION

	Wave 1	Wave 2	Wave 3
Number	26	21	16
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

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

Figure 1 Recruitment and attrition



EQUIP Research Checklist

Consolidated Criteria for reporting qualitative studies (COREQ)

1	Interviewers	Identity provided
2	Credentials	Described
3	Occupation	Described
4	Gender	Described
5	Experience and training	Described
6	Relationship established	Yes
7	Participant knowledge of the interviewer	Described
8	Methodological	Described
9	Orientation and theory	Thematic
10	Sampling	Described
11	Method of approach	Described
12	Sample size	Described
13	Non-participation	Attrition described
14	Setting of data collection	Described
15	Presence of non-participants	Described
16	Description of sample	Described
17	Interview guide	Described
18	Repeat interviews	Described
19	Audio visual recording	Described
20	Field notes	Described
21	Duration	Described
22	Data saturation	Discussed
23	Transcripts returned	Discussed
24	Number of coders	Described
25	Description of the coding tree	Coding discussed/described
26	Derivation of themes	Described
27	Software	Described
28	Participant checking	Discussed
29	Quotations presented	Present
30	Data and findings consistently presented	Yes
31	Clarity of major themes	Described
32	Clarity of minor themes	Described

Person

BMJ Open

Acceptability and use of a patient-held communication tool for people living with dementia: a longitudinal qualitative study

Journal:	<i>BMJ Open</i>
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Complete List of Authors:	<p>Leavey, Gerard; University of Ulster, Psychology Corry , Dagmar; University of Ulster, Psychology Waterhouse-Bradley, Bethany ; University of Ulster, Social Policy Curran, Emma; Ulster University, Bamford Centre for Mental Health and Wellbeing; Ulster University Todd, Stephen; Altnagelvin Hospitals Health and Social Services Trust, Geriatrics McIlpatrick, Sonja; Univ Ulster Coates, Vivien; Western Health and Social Care Trust/University of Ulster, Nursing Research Watson , Max; Whiteabbey Hospital Abbott, Aine; Altnagelvin Area Hospital McCorry, Bernadine ; Alzheimer's Association Northern Ireland McCormack, Brendan; Queen Margaret University, Nursing</p>
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3 **Acceptability and use of a patient-held communication tool for people living with**
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5 **dementia: a longitudinal qualitative study**
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10
11 Professor Gerard Leavey¹ * | g.leavey@ulster.ac.uk (corresponding author)
12

13
14 Phone +44 (0) 7801254924
15

16
17 Dr. Dagmar Corry¹ | d.corry@ulster.ac.uk
18

19
20 Dr. Bethany Waterhouse-Bradley¹ | b.waterhouse-bradley@ulster.ac.uk
21

22
23 Dr. Emma Curran¹ | e.curran@ulster.ac.uk
24

25
26 Dr. Stephen Todd² | stephen.todd@westerntrust.hscni.net
27

28
29 Professor Sonja McIlfatrick³ | sj.mcilfatrick@ulster.ac.uk
30

31
32 Professor Vivien Coates³ | ve.coates@ulster.ac.uk
33

34
35 Dr. Max Watson⁴ | alimaxuk@me.com
36

37
38 Dr. Aine Abbott² | aineabb@gmail.com
39

40
41 ⁶Bernadine McCrory | Bernadine.McCrory@alzheimers.org.uk
42

43
44 ⁵Professor Brendan McCormack | bmccormack@qmu.ac.uk
45
46
47

48
49 ¹Bamford Centre for Mental Health and Wellbeing, Ulster University, Coleraine
50

51
52 Campus, Cromore Road, BT52 1 SA, Northern Ireland
53

54
55 ²Geriatrics, Altnagelvin Area Hospital (WHSCT) Glenshane Road, BT47 6SB, Northern
56
57 Ireland
58
59
60

1
2
3 ³School of Nursing, Ulster University, Jordanstown Campus, Newtownabbey BT37

4
5 OQB

6
7
8 ⁴Adult Services, Northern Ireland Hospice, Whiteabbey Hospital, Doagh Road,
9
10 Newtownabbey BT37 9RH

11
12 ⁵Centre for Person-centred Practice Research, Queen Margaret University, Edinburgh,
13 Musselburgh, EH21 6UU

14
15 ⁶Alzheimer's Society, Northern Ireland, 30 Skegoneill St, Belfast BT15 3JL
16
17

18
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33 authors
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Abstract:

Objectives: To assess the acceptability and use of a low-cost patient-held communication tool.

Design: Longitudinal Qualitative interviews at three time points over 18 months

Setting: Primary and community services

Participants: Twenty-eight dyads - People living with dementia in Northern Ireland and their informal carers, supplemented by focus groups, and content analysis.

Interventions: a patient-held healthcare “passport” for people living with dementia.

Primary and secondary outcomes: acceptability and use of the passport – barriers and facilitators to successful engagement.

Results: There was a qualified appreciation of the healthcare passport 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. We noted concerns about privacy and ambivalence about engaging with health professionals.

Conclusion: Such tools may be of use but there is a need for demanding, thoughtful, and nuanced programme delivery for future implementation in dementia care. The incentivisation and commitment of General Practitioners is crucial. Altering the asymmetrical relationship between professionals and patients requires more extensive attention.

Article Summary**Strengths and limitations of this study**

- Our LQR design allowed a consideration and assessment of contextual factors and mechanisms related to use of a patient-held medical communication tool in ‘real-world’ environments.
- The LQR design was key to building rapport and trust with participants and uncovered various assumptions about caregiving, and aspects of individual and systemic behaviours that determine passport usage.
- 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.

Introduction:

Dementia is increasingly prevalent across the globe, producing considerable challenges to families, health services and economies [1-3] provoking government and philanthropic policy and research initiatives in healthcare and social inclusion[4]. However, as dementia progresses, the appearance of other health problems and disabilities are commonplace, leaving specialist-based healthcare systems to manage the various health and social care problems in a fragmented and inefficient manner. People living with dementia (‘PLWD’) and family caregivers commonly report dissatisfaction on issues such as multiple and unnecessary appointments and distress at repeating history and current situation (needs and resources), symptoms, treatment and care package [5-7]. Communication with health care professionals in dementia services is often problematic for both the patient and their family members [8], related to various aspects of organizing care and areas of decision-

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3 making for relatives with dementia [9, 10] [11] [12, 13]. Various obstacles deny widespread
4 acceptance and use of internet-based support [14, 15].
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10 Attempts to address service barriers are generally confined to hospital and hospice settings
11 [16] with a bias towards clinical decisions and pathways, but neglecting person-centred
12 approaches[17, 18]. A consortium of health professionals, voluntary sector organisations,
13 carer groups and people with long-term and life-limiting conditions met over a two-year
14 period to co-produce a “healthcare passport”. This was an expandable information booklet
15 divided into distinct sections which covered important aspects of the individual's life,
16 support, and care [19]. For example, one section was allocated to information on any health
17 conditions the person had; another allowed for details of any medication they had been
18 prescribed and could be expanded to record changes to medications; Coverage on a
19 person’s social networks and supports was also provided for – allowing the health and social
20 care professionals the opportunity to assess supportive contexts. Other sections disclosed
21 salient aspects of the individual’s life – religious or spiritual beliefs and interests.
22
23 Importantly, the ‘passport’ was to be held by the person with dementia (or their proxy) who
24 completed the personal and social sections, while medical treatment and care were
25 completed by the various and relevant health professionals, and entries could be made by
26 the latter during visits. In brief, the passport was designed as a portable patient-held record
27 of care that could facilitate the cross-transfer of information between patients and a variety
28 of medical and social care professionals. In collaboration with health and social care
29 agencies, statutory and voluntary, we sought to examine how this low-cost communication
30 tool might be acceptable and useful to people living with dementia and their families.
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3 **Aims:** to examine the acceptability and use of a healthcare passport for people with
4 dementia and their family carers, intended to facilitate communication and decision-making
5 for service users and family caregivers. Additionally, we wanted to explore: (a) how this tool
6 is used over time; (b) the engagement of relevant service providers; (c) the barriers to
7 information and communication between and among family carers and health and social
8 care professionals ('HSCPs') and how these can be remedied; and (d) how to refine and/or
9 deliver the passport and similar interventions.
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21 **Ethical Approval:** The study was given favourable ethical opinion by the Office for Research
22 Ethics Committees Northern Ireland (ORECNI) on 21 July, 2015. (REC reference 15/NI/0129)
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27 **Method:** adopting a realist evaluation approach to complex interventions, we used
28 Longitudinal Qualitative Research (LQR) and document content analysis.
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33 **Recruitment**

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37 We aimed to recruit 20-25 people with mild-to-moderate dementia living in the community,
38 and their families, sufficient to obtain a range of individual situations and experiences. This
39 was done through the Memory Clinic of the Western Health & Social Care NHS Trust.
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46 If the lead clinician or centre manager believed absence of capacity, the lead clinician or
47 centre manager helped identify their next of kin, family caregiver or someone close to the
48 person (who does not receive remuneration for this role) who will act as a "personal
49 consultee". Although the capacity of the person with dementia may diminish over the
50 evaluation period, we intended that they are fully involved in using the passport, and any
51 associated decision- making. We held no prior assumptions about participants' current use
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3 of health and social care services. The potential participants were approached by clinicians
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5 who provided information about the study.
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8 9 **Passport Implementation**

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12 Interested service users and their families then contacted the study team for further
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14 information and provided written informed consent. Initially, they were contacted by a staff
15
16 member of the Alzheimer's Society who guided the dyads through the passport contents,
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18 explaining each section and addressing any queries or concerns. Family GPs were contacted
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20 and given information tools about the passport. (CD Rom format and links to the passport
21
22 website). Additionally, we ran information sessions for local health professionals within the
23
24 local dementia services.
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30 31 **Interview methodology**

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34 Primarily we used Longitudinal Qualitative Research (LQR) methods [20, 21]. Briefly, this
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36 consisted of three in-depth interviews: (1st) shortly after referral; (2nd) at six months; and
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38 (3rd) at twelve months. The interviews, conducted with the PLWD and carer together, lasted
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40 between 60 and 90 minutes, and were undertaken in the participants' homes by BWB and
41
42 DC, females with PhDs with substantial training and experience in qualitative research with
43
44 vulnerable populations; sociologist and psychologist, respectively. The researchers met with
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46 all participants prior to the study, via the memory clinics, and provided a clear overview of
47
48 the study aims. Neither researcher had prior personal experience of dementia or its
49
50 associated caregiving. We used topic guides to help us record and explore change over time,
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52 and the processes associated with such changes. Thus, the initial interview gathered
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54 'baseline' information about the onset and diagnosis, health and social care needs, the
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3 context of care and the availability of support. We also examined service users' and
4
5 caregivers' perceptions and expectations of the passport. Field-notes were not taken during
6
7 interviews but the team met regularly to discuss issues arising from the interviews. The
8
9 topic guide and analysis were based on the literature and experts by experience within the
10
11 Alzheimer's Society. The topic guide was refined after the initial interviews. GPs providing
12
13 care for the people with dementia were interviewed by telephone towards the end of the
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15 18-month data collection and addressed issues on acceptability, ease of passport use,
16
17 response to patient participants and recommendations for continued use and adaptation.
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24 In subsequent meetings, we explored any change to these areas and issues and the passport
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26 usage. Additionally, we did a content analysis of service user and caregiver entries in the
27
28 passport and examined General Practitioner's assessment of passport usage. All participants
29
30 provided recommendations for future use of the passport.
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35 **Analysis:** The interviews were audiotaped, transcribed and then entered into a qualitative
36
37 software programme (N-Vivo version 11) for data coding and management. We used
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39 *Trajectory analysis* which examines changes over time for participants[22]. We coded and
40
41 indexed the data, using a spreadsheet in order to generate a matrix into which the data was
42
43 'charted'. This summarized the data by category from each transcript, building themes with
44
45 the support of memos and data display. Transcripts were analysed and coded independently
46
47 by the researcher, 1-2 members of the caregiver participant group, and members of the
48
49 research team. Some specific areas covered: (a) a retrospective examination of the
50
51 experience of people with dementia, family carers, help-seeking and communication needs
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53 – prior to using the passport; (b) practical use of the passport, differentiated by different
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55 care characteristics and contexts (e.g. dementia stage, social class and social support
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3 networks, gender and care-relationship); (c) change in use of the passport over time in
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5 response to need; (d) care planning and advance directives for end of life care; (e) joint
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7 decision making (family and patient); (f) comprehension and ease of use by stakeholders
8
9 (professionals and family); and (g) reasons for discontinuation. Additionally, we examined
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11 contextual factors of people in the use and maintenance of this type of intervention and
12
13 how it can be more effective. Understanding the acceptance and use of the passport over
14
15 time with a range of people was the main goal and thus, theoretical data saturation was not
16
17 particularly relevant. While it was not possible to undertake participant checking per se,
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19 participants were provided with a synopsis of their previous responses and asked about
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21 change.
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27 **Passport Content analysis:** The passports' contents were examined by DC to see how they
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29 were used and by whom, in addition to family carers, and the level and quality of the
30
31 information provided. This was a simple thematic analysis, noting categories of entry and
32
33 overall usage.
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37 Code: P (person living with dementia); C (Caregiver)
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40 Findings

41 Participant recruitment and attrition

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43 Following initial recruitment of 28 patient-carer dyads for the first wave of interviews, two
44
45 declined; we therefore interviewed 26 PLWDs and carers in wave 1. Participant (patient and
46
47 carer) characteristics in addition to recruitment and attrition flow are provided in Table 1
48
49 and Figure 1 below. Advised by the Memory Clinic to expect a high attrition rate in this
50
51 particular population, we had 16 participating families at wave 3 (48% of total contacted).
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We obtained a socially heterogeneous sample from range of occupational backgrounds. However, all 28 patient participants were retired, or not working. 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. We noted various comorbidities (including depression, diabetes, arthritis, COPD, heart problems, hypertension, breast and prostate cancer, hearing, and vision impairments). Depression (37%), arthritis (30%), diabetes (27%), and cardiac conditions (27%) were the most frequently occurring comorbidities in our final sample. Eighteen participants (60%) had multiple comorbidities, with between two and eight separate conditions in addition to their dementia. The comorbidities reported by the participants may not entirely correspond to their medical records. Some participants may have forgotten to mention particular conditions, or have chosen not to disclose them.

TABLE 1: RECRUITMENT AND ATTRITION

	Wave 1	Wave 2	Wave 3
Number	26	21	16
Gender	13 females 13 males	11 females 10 males	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

Figure 1 (here)

Eighteen of the family caregivers were retired from work and six were still working. Most carers were female, (daughters (N=13), and wives (N=11)). Husbands were the next biggest group (N=5); others were sons (N=3), brothers (N=1), and sisters (N=1). 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 Alzheimer's disease and an elderly relative. Thirteen carers had serious health problems including diabetes, high blood pressure, arthritis, depression, and epilepsy.

Contextual Experience of Health and Social Care

Participants reported limited communication and coordination between departments, and individual professionals; miscommunication between health and social care professionals (HSCP), considerable variation in information and service provision, and problems when formal carers changed.

"... 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)

"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)

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3 “It's the same with the carers coming in, and I can't tell them not to because I am
4
5 looking for (help), but because they are swapping and changing faces, he's finding
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7 that....” (C8) “When I saw you this morning, I didn't know ... I said ‘Where did she
8
9 come out of?’” (P8)
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14 Some families felt intimidated by unfamiliar doctors, while others became particularly
15
16 assertive when they felt the patient was being disadvantaged. Those who had worked in
17
18 healthcare or had family in the healthcare system were more confident, and found it easier
19
20 to get the service they needed. The main health and social care issues reported were the
21
22 difficulty in seeing the same GP every time “*You never see the same doctor twice. They are*
23
24 *always booked up, and others don't know your case.*” (C16), the short consultation time, the
25
26 importance of the GP taking time to listen, being comfortable with the GP, and the attitude
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28 of the GP (emphatic and warm versus condescending and dismissive). Some avoided seeing
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30 their GP because they feared another diagnosis, or because they felt they should not
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32 “bother” the GP.
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41 **Attitudes to, and expectations of, Passport use**

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43 In the following section, we detail the perceptions and use of the passport over the
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45 evaluation period. The key factors in this were: (a) correct completion; (b) timing; (c)
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47 privacy; (d) additional burden; and (e) response from Healthcare Professionals.
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50 **Correct completion**

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52 Most participants were unsure about the potential usefulness of the passport though we
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54 noted some scepticism on its usefulness and/or capacity to use it. Some were anxious
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56 about writing anything at all in the passport.
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3 "It's not so much reservations but will it actually really make any difference to (participant)
4 or myself, really? Will it actually make any difference? [] Well, I've only glanced at it but
5 really I don't know." (C17)
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10 Importantly, participants worried that there was a 'right' way to use the passport, and most
11 wanted guidance on this. Overall, the most common response was 'we will give it a go' – a
12 tacit agreement to try it out. In any case, over the study period many people stated simply
13 that they forgot to use the passport which was often put away "for safekeeping". Again,
14 some of this may be due to the uncertainty about using the contents. In the following quote
15 for example, one person queried whether 'objective facts' or more subjective issues were
16 required.
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26 "I wonder about this, the sense of it. There are lots of things. For example, what I
27 would have filled in, or what has been filled in, "All about me"...that's the 7th May, oh
28 whether it is relevant. For instance, "All about me", I'm such and such a height, my weight is
29 such and such...?" (P8)
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37 **Timing**

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40 Many participants considered the passport to be unnecessary at this stage of their
41 healthcare, mostly because they had few appointments currently. This was particularly true
42 of care dyads with a diagnosis less than six months prior to interview, and for those with
43 few/no co-morbidities. However, others acknowledged potential usefulness as the illness
44 progressed, and of particular use if something were to happen to the carer. Few
45 participants maintained that they could keep track of this information themselves, or
46 believed the healthcare professionals would already be sharing/recording the information
47 without prompting. In each of these cases, the opinion of those individuals did not change
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3 with further explanation of the passport, and so it is unlikely that the response was due to
4
5 poor understanding of the purpose of the passport.
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10 “It’ll be some time before I’m going back to see my GP, and I’ll have to wait until F. comes
11
12 back, so there’s really nothing I’ll be doing immediately, and it’ll be some time before I
13
14 would get to use it.” (P30)
15
16
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19 “No, I just filled in the basic information and that’s it. That was all, really. I haven’t really
20
21 used it, because I didn’t feel...because she hasn’t been to any appointments so at this
22
23 stage...I would say maybe in the future it will be more relevant but, at the minute, no.” (C1)
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26

27 **Privacy and relationships**

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29 Carers’ attitudes to information-sharing with healthcare professionals are complex and the
30
31 concept of promoting ‘personhood’ in healthcare had limited currency among carers. Thus,
32
33 several families were unwilling to share personal details with the doctor beyond medical
34
35 history, and did not acknowledge the significance or relevance of that part of the passport.
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38

39 “No, no, and you know, we don’t like to have a document like this lying about the
40
41 house so that other people, for whom it is not their business, may come across it and
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43 see what’s going on or what [P24]’s drug regime is.” (C24)
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47 Such families preferred compartmentalised approaches to care or were suspicious of
48
49 sharing personal information with paid carers in particular. These views seldom changed
50
51 over the study period. Participants were also apprehensive about who should have access
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53 to, and make entries in, the passport. Even though it was explained that control over the
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55 use of the passport lay with the family, people remained unsure as to how this could be
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57 decided. We noted warmth between dyads in most of the interviews and this bond appears
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3 to assist in using the passport. However, we also noted that some couples fearing the loss
4
5 of their 'old' relationship strove to maintain a 'normality' which, in some instances meant
6
7 minimising external intrusion. With implications for the healthcare passport and for care
8
9 generally perhaps, several couples suggested that they try and manage things themselves
10
11 (e.g., C2, C28/P28, P30). *"We handle things ourselves. As far as we can, we'll do it. Wherever*
12
13 *she goes, I go now."* (C2)
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18 19 **Additional burden**

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21 Participants' enthusiasm for the passport centred on its organisational and memory
22
23 purposes. However, while carers focussed on keeping track of varied professional
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25 appointments, patients focussed on medication management. Additionally, while carer
26
27 participants who formed part of family network anticipated its value in cross-
28
29 communication to relatives, unless prompted none indicated its utility in information-
30
31 sharing with health and social care professionals. Again, this suggests that the concerns
32
33 about threats to the personhood of the family member posed by health professionals'
34
35 responses and attitudes does not register significantly with caregivers or was overshadowed
36
37 by healthcare needs. *"It's a new thing, it's very hard to handle, and the last thing on your*
38
39 *mind is this book."* (C3). Others, particularly non-spouse males, were apprehensive that the
40
41 passport may become too onerous.
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49 "This is what happened to us. Whenever (Participant) was diagnosed we got bombarded
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51 with everything, which 90% of it was great but there was a couple that we couldn't just cope
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53 with, and that was one of them, you know, it was too much at the time. Probably in time to
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55 come it might..." (C11)
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Ownership of Passport

Commonly, the family caregivers took responsibility for holding and maintain the passports, commonly indicating that the PLWD would not be able to use the passport and in some instances, they dissuaded the PLWD from using it. For many, caregivers' assumed responsibility for the passport because they provided most of the organisation and management of care. However, in one case, this was because the PLWD 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.

“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 [...]. Therefore, he wouldn't personally be doing this, it would be me.” (C17)

Interestingly, there was quite a range in the carer's perception of the PLWD's ability to use the passport amongst people with the same/similar memory scores. Carers expressed a number of reasons why the PLWD 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.

Anticipated response from Healthcare Professionals

Some participants, particularly carers, 'self-censored' any exchange with health professionals believing 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

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3 doctors being disinterested or pressed for time when discussing their relationships to
4
5 healthcare professionals. Concerns about 'bothering' the health professionals were raised
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7
8 from the outset.
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10 "The doctor wouldn't have any objections whenever I come with that and ask him to fill it
11
12 in?" (P7)
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14

15
16 "You'd be taking your life in your hands when you hand them the book and say 'can you fill
17
18 that in?' They would just tell you that they don't have time and that would be the way like,
19
20 and I wouldn't go back and ask a second time." (C18)
21
22

23 They were also more likely to relay negative stories about experiences with HSCPs.
24
25 However, in contrast, family caregivers who had direct experience working in the healthcare
26
27 sector, tended to suggest that healthcare staff would find the passport very useful.
28
29 Participants sceptical of professional engagement with the passport nevertheless
30
31 maintained the value in the passport for their own care dyad. Updating the passport
32
33 and/or introducing it into healthcare consultations was problematic. *"We weren't good at*
34
35 *doing the homework, I have to say. Some of it's done and some of it hasn't been updated."*
36
37 (C32). Thus, some people forgot to bring the passport when attending hospital and general
38
39 practice appointments –while others were greeted with bemusement by clinicians who
40
41 appeared to be unaware of its existence. Additionally, other participants consciously
42
43 neglected it, anticipating that the passport may be perceived by clinicians as a burden and
44
45 did "not want to bother" them.
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52
53 "We've tried to use it." (C20) "When we saw the reaction to it, we don't take it anymore."
54
55 (C20a) "They just look at you as if-" (C20)
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Healthcare Passport content analysis

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

Family caregivers, soon after diagnosis, began incrementally to assume control of various responsibilities in the PLWD'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 assumed a new identity role which undermined their sense of agency and initiated an erosion of abilities and skills. *"Do you want me to write all this down?" (P7) "No, I'll get [wife] to do it for us, Dad." (C7)*

Additionally, some of the PLWD 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 HSCPs. In other words, our evidence suggests that the passports may not conform to a standard information collection. For example, in terms of medication and side effects, as well as comorbidities and their impact, and self-care, the level of detail varies considerably between PLWDs, 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, in its current form, the passport is unreliable.

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3 Personal narratives, hobbies, and activities also varied considerably and information was
4 also recorded unsystematically. Thus, carers included details about dementia progression
5 and PLWD deterioration, along with details on religion, likes, and dislikes, and activities. Of
6 the 12 completed passports, four contained only undated entries, two contained partially
7 dated entries only, all but two (P8 self-completed; P21: social worker completed) were
8 completed by the carer. Those who were overwhelmed (e.g., C13), or coping very well (e.g.,
9 C13) did not complete the HP.
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23 **GPs feedback**

24
25 The general consensus among the GPs was that “... *the fundamental idea is very good.*” (CB)
26
27 Some GPs were familiar with maternity notes, about which they noted “... *work well if the*
28 *patients bring them*” (CB) but said that often they did not. In the current study, few patients
29 took the passport to their GP, and those who did, reported that the GP appeared to be
30 unfamiliar with it or unenthusiastic about its use, which deterred them from taking it again.
31
32 Commonly, GPs felt that the passport created another pressure on GP’s time and also were
33 concerned about its legal status in the event of medical complications or patient complaints.
34
35 Mostly, however, most expressed doubt about the additional bureaucracy.
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46 “Another form! Will it improve the lives of patients and carers? The others rarely
47
48 do!” (Dr Mc)
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53 The practicality of and reasoning behind offering the passport in paper format was
54 questioned in the context of ubiquitous digital technology within the healthcare system.
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Discussion

There have been welcome developments in internet-based decision-making tools in dementia care [23] much more work is needed in this field, particularly among older people who are less digitally literate or confident in its value. To our knowledge, this is the first study to evaluate a patient-held communication tool in dementia healthcare [24]. The complexity of dementia, often accompanied by co-morbid disability and illness, create challenges for interventions designed to support relationships in care [6]. Thus, over time, health and social needs can accelerate and informal care networks may be unpredictable. Additionally, while these factors underpin the rationale for communication tools they also increase evaluation uncertainties about their acceptance and use.

Despite the challenges to its widespread use, the health care passport for people living with dementia was still considered favourably by many participants but requiring a more nuanced approach. As a communication tool it may be determined by the extent of the person with dementia's care needs and the caregiver's role and ability in meeting these. While the healthcare passport was co-designed and strongly supported by people with dementia, family caregivers and healthcare professionals, its feasibility rested on various assumptions about stakeholder beliefs, values, behaviours within a range of contexts and specific needs. Our evaluation underlined the salience of factors that are seldom acknowledged in the implementation of complex interventions and particularly within the world of dementia care. Prima facie, we found a ready acceptance of the passport by service users and carers who were willing to 'give it a go' and could envisage its benefits. However, a more tacit understanding of cultural attitudes towards health professionals emerged. In many cases, participation was gained simply because families felt an underlying obligation

1
2
3 to the dementia services (Memory Clinics). Again, deference to professionals was
4
5 manifested in the reluctance of service users and carers to 'bother' their GP revealing the
6
7 asymmetry of this relationship and patient-family insecurities about 'annoying' clinical staff.
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10 GPs, mostly, did not engage with the passport, partly because they considered it old
11
12 technology and inefficient. However, this perspective fails to recognise that many older
13
14 people are not familiar with digital technology.
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19 The timing for introducing the passport may influence its uptake and usage. This may prove
20
21 difficult to gauge. At the very early stages post-diagnosis, patients may have good physical
22
23 and mental health and may reject the passport as unnecessary while, nevertheless
24
25 regarding it as potentially helpful as the condition progresses. Others, who appeared to be
26
27 still in shock or depressed for some time after the diagnosis, found the passport as a painful
28
29 reminder and didn't want to use it. It was regarded as a "dementia passport" and associated
30
31 with lack of capacity and decline. For those at a more advanced stage, and/or with
32
33 considerable co-morbidity and thus, service use, often felt overwhelmed by the information
34
35 flow that they thought necessary to be inserted.
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44 As noted in other healthcare areas [25, 26], the 'ownership' of communication tools
45
46 presents interesting and challenging dilemmas. Developed as a patient-held communication
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48 tool but not specifically designed for dementia, cognitive deterioration may alter the
49
50 passport's management, often assumed by the family carers. In some cases, family
51
52 members appear to undertake, and therefore sometimes undermine, the normal activities
53
54 of daily living of the person with dementia. The extent to which the passport is held and
55
56 'owned' by the family caregiver requires further examination.
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1
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3 For people who wished to maintain a sense of 'normality' the passport may have been
4
5 perceived as a threat or an intrusion, in which case people consider what is most at stake
6
7 for them and will try to find ways of protecting this. While not a form of denial, this
8
9 represents a determination to resist labelling as a dementia patient and the sequelae of
10
11 medical and social responses that this may entail.
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18 Revealing participants' tastes and dispositions within the passport was intended to create a
19
20 sense of personhood and while some people understood and appreciated the concept,
21
22 other participants were anxious about the sharing of personal information, feeling that
23
24 some formal carers or clinicians did not need to know the personal details or specific
25
26 aspects of a person's life. For others, achieving basic medical and social care services
27
28 appears to be prioritised over non-essential knowledge – suggesting that the two
29
30 information types are balanced in a zero-sum game.
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38 Content analysis revealed that each passport was entirely different from others. While this
39
40 is to be expected when it comes to personal narrative, it is not helpful in terms of medical
41
42 information, symptoms, progression, comorbidities, side effects of medication, etc. The
43
44 current non-standardised format of the sections relating to information relating to the
45
46 patient's health may undermine the passport's viability and efficiency. Essential information
47
48 may be missing or not have been updated, or indeed not dated. Many entries were not, or
49
50 only partially dated. As such, the information contained in the passport may not be
51
52 regarded as reliable by some professionals.
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3 This evaluation has provided rich, in-depth information about the uptake and use of a
4 healthcare passport for people living with dementia. For example, recruitment to studies
5 such as this may be relatively easy but meaningful participation is more difficult to achieve.
6
7 Thus, a future trial will need to set much stricter parameters for participation including
8 much more robust assessment of informed consent rather than a willingness to please
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Recommendations

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. Some families 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. It must be made clear that it is a “health passport” rather than a “dementia passport”. 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.

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. Digital technology and flexible internet-based platforms which allow for greater flow of exchange between patients, health and social care providers, and caregivers offer much promise for communication and decision-making but again, such platforms need to be shaped and managed according to person-centred needs.

Patient and Public Involvement

This study was developed with the support of the Alzheimer's Society Northern Ireland.

People living with dementia were involved in various stages of the project except writing for publication.

Author contributions:

GL, AA, MW, ST, SMcl, BeMcC , BrMcC and VC co-designed the study, EC, BWB and DC collected and analysed the data. All authors contributed to the writing of the manuscript. GL was the PI on the study.

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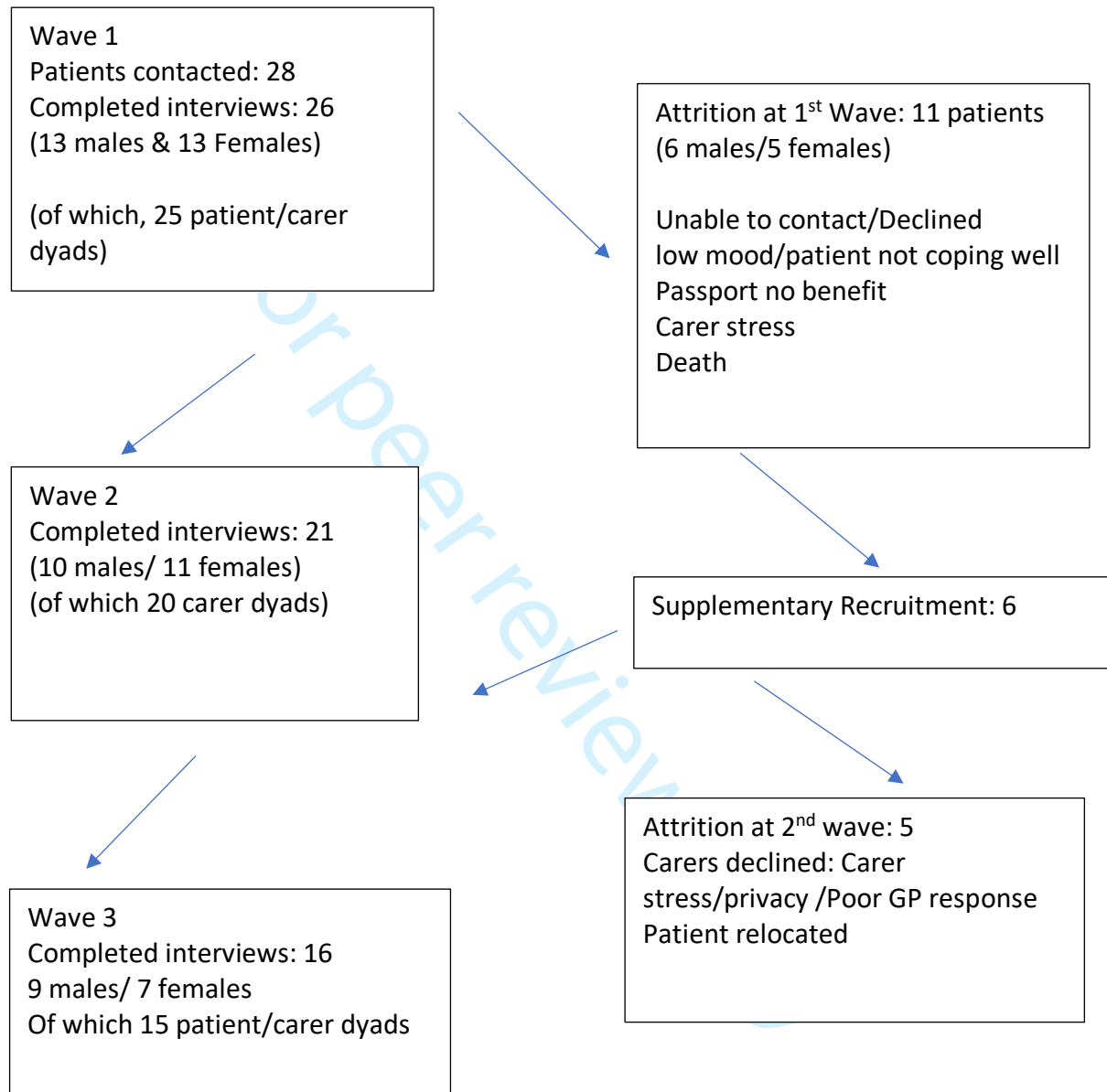
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For peer review only

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

BMJ Open

Acceptability and use of a patient-held communication tool for people living with dementia: a longitudinal qualitative study

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3 **Acceptability and use of a patient-held communication tool for people living with**
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5 **dementia: a longitudinal qualitative study**
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10
11 Professor Gerard Leavey¹ * | g.leavey@ulster.ac.uk (corresponding author)
12

13
14 Phone +44 (0) 7801254924
15

16
17 Dr. Dagmar Corry¹ | d.corry@ulster.ac.uk
18

19
20 Dr. Bethany Waterhouse-Bradley¹ | b.waterhouse-bradley@ulster.ac.uk
21

22
23 Dr. Emma Curran¹ | e.curran@ulster.ac.uk
24

25
26 Dr. Stephen Todd² | stephen.todd@westerntrust.hscni.net
27

28
29 Professor Sonja McIlfatrick³ | sj.mcilfatrick@ulster.ac.uk
30

31
32 Professor Vivien Coates³ | ve.coates@ulster.ac.uk
33

34
35 Dr. Max Watson⁴ | alimaxuk@me.com
36

37
38 Dr. Aine Abbott² | aineabb@gmail.com
39

40
41 ⁶Bernadine McCrory | Bernadine.McCrory@alzheimers.org.uk
42

43
44 ⁵Professor Brendan McCormack | bmccormack@qmu.ac.uk
45

46
47
48 ¹Bamford Centre for Mental Health and Wellbeing, Ulster University, Coleraine
49

50
51 Campus, Cromore Road, BT52 1 SA, Northern Ireland
52

53
54 ²Geriatrics, Altnagelvin Area Hospital (WHSCT) Glenshane Road, BT47 6SB, Northern
55
56 Ireland
57

³School of Nursing, Ulster University, Jordanstown Campus, Newtownabbey BT37

0QB

⁴Adult Services, Northern Ireland Hospice, Whiteabbey Hospital, Doagh Road,

Newtownabbey BT37 9RH

⁵Centre for Person-centred Practice Research, Queen Margaret University, Edinburgh, Musselburgh, EH21 6UU

⁶Alzheimer's Society, Northern Ireland, 30 Skegoneill St, Belfast BT15 3JL

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All of the authors declare that they have no conflict of interest

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Keywords:

Dementia, caregivers, patient-held records, communication, information

Word count: 5536

Abstract:

Objectives: To assess the acceptability and use of a low-cost patient-held communication tool.

Design: Longitudinal Qualitative interviews at three time points over 18 months and document content analysis

Setting: Primary and community services

Participants: Twenty-eight dyads - People living with dementia in Northern Ireland and their informal carers.

Interventions: a patient-held healthcare “passport” for people living with dementia.

Primary and secondary outcomes: acceptability and use of the passport – barriers and facilitators to successful engagement.

Results: There was a qualified appreciation of the healthcare passport 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. We noted concerns about privacy and ambivalence about engaging with health professionals.

Conclusion: Such tools may be of use but there is a need for demanding, thoughtful, and nuanced programme delivery for future implementation in dementia care. The incentivisation and commitment of General Practitioners is crucial. Altering the asymmetrical relationship between professionals and patients requires more extensive attention.

Article Summary**Strengths and limitations of this study**

- Our LQR design allowed a consideration and assessment of contextual factors and mechanisms related to use of a patient-held medical communication tool in ‘real-world’ environments.
- The LQR design was key to building rapport and trust with participants and uncovered various assumptions about caregiving, and aspects of individual and systemic behaviours that determine passport usage.
- 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.

Introduction:

Dementia is increasingly prevalent across the globe, producing considerable challenges to families, health services and economies [1-3] provoking government and philanthropic policy and research initiatives in healthcare and social inclusion[4]. However, as dementia progresses, the appearance of other health problems and disabilities are commonplace, leaving specialist-based healthcare systems to manage the various health and social care problems in a fragmented and inefficient manner. People living with dementia (‘PLWD’) and family caregivers commonly report dissatisfaction on issues such as multiple and unnecessary appointments and distress at repeating history and current situation (needs and resources), symptoms, treatment and care package [5-7]. Communication with health care professionals in dementia services is often problematic for both the patient and their family members [8], related to various aspects of organizing care and areas of decision-

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3 making for relatives with dementia [9, 10] [11 [12, 13]. Various obstacles deny widespread
4 acceptance and use of internet-based supportive tools [14, 15].
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10 Attempts to address service barriers are generally confined to hospital and hospice settings
11 [16] with a bias towards clinical decisions and pathways, but neglecting person-centred
12 approaches[17, 18]. A consortium of health professionals, voluntary sector organisations,
13 carer groups and people with long-term and life-limiting conditions met over a two-year
14 period to co-produce a “healthcare passport”. This was an expandable information booklet
15 divided into distinct sections which covered important aspects of the individual's life,
16 support, and care [19]. For example, one section was allocated to information on any health
17 conditions the person had; another allowed for details of any medication they had been
18 prescribed and could be expanded to record changes to medications; Coverage of a
19 person’s social networks and assistance was also provided for – allowing the health and
20 social care professionals the opportunity to assess supportive contexts. Other sections
21 disclosed salient aspects of the individual’s life – religious or spiritual beliefs and interests.
22
23 Importantly, the ‘passport’ was to be held by the person with dementia (or their proxy) who
24 completed the personal and social sections, while medical treatment and care were
25 completed by the various and relevant health professionals, and entries could be made by
26 the latter during visits. In brief, the passport was designed as a portable patient-held record
27 of care that could facilitate the cross-transfer of information between patients and a variety
28 of medical and social care professionals. In collaboration with health and social care
29 agencies, statutory and voluntary, we sought to examine how this low-cost communication
30 tool might be acceptable and useful to people living with dementia and their families.
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3 **Aims:** to examine the acceptability and use of a healthcare passport for people with
4 dementia and their family carers, intended to facilitate communication and decision-making
5 for service users and family caregivers. Additionally, we wanted to explore: (a) how this tool
6 is used over time; (b) the engagement of relevant service providers; (c) the barriers to
7 information and communication between and among family carers and health and social
8 care professionals ('HSCPs') and how these can be remedied; and (d) how to refine and/or
9 deliver the passport and similar interventions.
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21 **Ethical Approval:** The study was given favourable ethical opinion by the Office for Research
22 Ethics Committees Northern Ireland (ORECNI) on 21 July, 2015. (REC reference 15/NI/0129)
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27 **Method:** adopting a realist evaluation approach to complex interventions, we used
28 Longitudinal Qualitative Research (LQR) and document content analysis.
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33 **Recruitment**

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37 We aimed to recruit 20-25 people with mild-to-moderate dementia living in the community,
38 and their families, sufficient to obtain a range of individual situations and experiences. This
39 was done through the Memory Clinic of the Western Health & Social Care NHS Trust.
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46 If the lead clinician or centre manager believed absence of capacity, the lead clinician or
47 centre manager helped identify their next of kin, family caregiver or someone close to the
48 person (who does not receive remuneration for this role) who will act as a "personal
49 consultee". Although the capacity of the person with dementia may diminish over the
50 evaluation period, we intended that they are fully involved in using the passport, and any
51 associated decision- making. We held no prior assumptions about participants' current use
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3 of health and social care services. The potential participants were approached by clinicians
4
5 who provided information about the study.
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7

8 9 **Passport Implementation**

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11
12 Interested service users and their families then contacted the study team for further
13
14 information and provided written informed consent. Initially, they were contacted by a staff
15
16 member of the Alzheimer's Society who guided the dyads through the passport contents,
17
18 explaining each section and addressing any queries or concerns. Family GPs were contacted
19
20 and given information tools about the passport. (CD Rom format and links to the passport
21
22 website). Additionally, we ran information sessions for local health professionals within the
23
24 local dementia services.
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30 31 **Interview methodology**

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34 Primarily we used Longitudinal Qualitative Research (LQR) methods [20, 21]. Briefly, this
35
36 consisted of three in-depth interviews: (1st) shortly after referral; (2nd) at six months; and
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38 (3rd) at twelve months. The interviews, conducted with the PLWD and carer together, lasted
39
40 between 60 and 90 minutes, and were undertaken in the participants' homes by BWB and
41
42 DC, females with PhDs with substantial training and experience in qualitative research with
43
44 vulnerable populations; sociologist and psychologist, respectively. The researchers met with
45
46 all participants prior to the study, via the memory clinics, and provided a clear overview of
47
48 the study aims. Neither researcher had prior personal experience of dementia or its
49
50 associated caregiving. We used topic guides to help us record and explore change over time,
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52 and the processes associated with such changes. Thus, the initial interview gathered
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54 'baseline' information about the onset and diagnosis, health and social care needs, the
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3 context of care and the availability of support. We also examined service users' and
4
5 caregivers' perceptions and expectations of the passport. Field-notes were not taken during
6
7 interviews but the team met regularly to discuss issues arising from the interviews. The
8
9 topic guide and analysis were based on the literature and experts by experience within the
10
11 Alzheimer's Society. The topic guide was refined after the initial interviews. GPs providing
12
13 care for the people with dementia were interviewed by telephone towards the end of the
14
15 18-month data collection and addressed issues on acceptability, ease of passport use,
16
17 response to patient participants and recommendations for continued use and adaptation.
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24 In subsequent meetings, we explored any change to these areas and issues and the passport
25
26 usage. Additionally, we did a content analysis of service user and caregiver entries in the
27
28 passport and examined General Practitioner's assessment of passport usage. All participants
29
30 provided recommendations for future use of the passport.
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33

34
35 **Analysis:** The interviews were audiotaped, transcribed and then entered into a qualitative
36
37 software programme (N-Vivo version 11) for data coding and management. We used
38
39 *Trajectory analysis* which examines changes over time for participants[22]. We coded and
40
41 indexed the data, using a spreadsheet in order to generate a matrix into which the data was
42
43 'charted'. This summarized the data by category from each transcript, building themes with
44
45 the help of memos and data display. Transcripts were analysed and coded independently by
46
47 the researcher, 1-2 members of the caregiver participant group, and members of the
48
49 research team. Some specific areas covered: **(a)** a retrospective examination of the
50
51 experience of people with dementia, family carers, help-seeking and communication needs
52
53 – prior to using the passport; **(b)** practical use of the passport, differentiated by different
54
55 care characteristics and contexts (e.g. dementia stage, social class and social support
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3 networks, gender and care-relationship); (c) change in use of the passport over time in
4 response to need; (d) care planning and advance directives for end of life care; (e) joint
5 decision making (family and patient); (f) comprehension and ease of use by stakeholders
6 (professionals and family); and (g) reasons for discontinuation. Additionally, we examined
7 contextual factors of people in the use and maintenance of this type of intervention and
8 how it can be more effective. Understanding the acceptance and use of the passport over
9 time with a range of people was the main goal and thus, theoretical data saturation was not
10 particularly relevant. While it was not possible to undertake participant checking per se,
11 participants were provided with a synopsis of their previous responses and asked about
12 change.

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28 **Passport Content analysis:** The passports' contents were examined by DC to see how they
29 were used and by whom, in addition to family carers, and the level and quality of the
30 information provided. This was a simple thematic analysis, noting categories of entry and
31 overall usage.

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37 Code: P (person living with dementia); C (Caregiver)

38 39 40 Findings

41 42 Participant recruitment and attrition

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46 Following initial recruitment of 28 patient-carer dyads for the first wave of interviews, two
47 declined; we therefore interviewed 26 PLWDs and carers in wave 1. Participant (patient and
48 carer) characteristics in addition to recruitment and attrition flow are provided in Table 1
49 and Figure 1 below. Advised by the Memory Clinic to expect a high attrition rate in this
50 particular population, we had 16 participating families at wave 3 (48% of total contacted).

We obtained a socially heterogeneous sample from range of occupational backgrounds. However, all 28 patient participants were retired, or not working. 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. We noted various comorbidities (including depression, diabetes, arthritis, COPD, heart problems, hypertension, breast and prostate cancer, hearing, and vision impairments). Depression (37%), arthritis (30%), diabetes (27%), and cardiac conditions (27%) were the most frequently occurring comorbidities in our final sample. Eighteen participants (60%) had multiple comorbidities, with between two and eight separate conditions in addition to their dementia. The comorbidities reported by the participants may not entirely correspond to their medical records. Some participants may have forgotten to mention particular conditions, or have chosen not to disclose them.

TABLE 1: RECRUITMENT AND ATTRITION

	Wave 1	Wave 2	Wave 3
Number	26	21	16
Gender	13 females 13 males	11 females 10 males	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

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6 **Figure 1:** (Here)

7
8 **Carers**

9
10 Eighteen of the family caregivers were retired from work and six were still working. Most
11 carers were female, (daughters (N=13), and wives (N=11)). Husbands were the next biggest
12 group (N=5); others were sons (N=3), brothers (N=1), and sisters (N=1). In some cases
13 (N=5), caring was shared between two or more family members. Eight carers (daughters and
14 sons) also had their own families to care for; one carer (wife) also cared for a mother with
15 Alzheimer's disease and an elderly relative. Thirteen carers had serious health problems
16 including diabetes, high blood pressure, arthritis, depression, and epilepsy.
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27 **Contextual Experience of Health and Social Care**

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31 Participants reported limited communication and coordination between departments, and
32 individual professionals; miscommunication between health and social care professionals
33 (HSCP), considerable variation in information and service provision, and problems when
34 formal carers changed.
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42 “... but it is frustrating that you're having to go to different professionals that you've
43 to keep regurgitating everything again. Some of them do use the computer systems
44 that have all the information on but, again, I know that they don't have time to read
45 it.” (P27)
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52
53 “Remembering appointments, we always stick the letters up on the fridge so that
54 keeps reminding us about the appointments. We would have to do that or we'd
55 forget. (P14) “There's that many appointments that times you do get mixed up in the
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3 dates." (C14) "You have a lot with diabetics, eye clinic, and different clinics with
4
5 diabetes." (P14)
6
7

8
9 "It's the same with the carers coming in, and I can't tell them not to because I am
10
11 looking for (help), but because they are swapping and changing faces, he's finding
12
13 that...." (C8) "When I saw you this morning, I didn't know ... I said 'Where did she
14
15 come out of?'" (P8)
16
17

18
19
20 Some families felt intimidated by unfamiliar doctors, while others became particularly
21
22 assertive when they felt the patient was being disadvantaged. Those who had worked in
23
24 healthcare or had family in the healthcare system were more confident, and found it easier
25
26 to get the service they needed. The main health and social care issues reported were the
27
28 difficulty in seeing the same GP every time "*You never see the same doctor twice. They are*
29
30 *always booked up, and others don't know your case.*" (C16), the short consultation time, the
31
32 importance of the GP taking time to listen, being comfortable with the GP, and the attitude
33
34 of the GP (emphatic and warm versus condescending and dismissive). Some avoided seeing
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36 their GP because they feared another diagnosis, or because they felt they should not
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38 "bother" the GP.
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47 **Attitudes to, and expectations of, Passport use**

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49 In the following section, we detail the perceptions and use of the passport over the
50
51 evaluation period. The key factors in this were: (a) correct completion; (b) timing; (c) privacy
52
53 and relationships; (d) additional burden; (e) ownership of passport; and (f) anticipated
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55 response from Healthcare Professionals.
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Correct completion

Most participants were unsure about the potential usefulness of the passport though we noted some scepticism on its usefulness and/or capacity to use it. Some were anxious about writing anything at all in the passport.

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

Importantly, participants worried that there was a 'right' way to use the passport, and most wanted guidance on this. Overall, the most common response was 'we will give it a go' – a tacit agreement to try it out. In any case, over the study period 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. In the following quote for example, one person queried whether 'objective facts' or more subjective issues were required.

"I wonder about this, the sense of it. 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)

Timing

Many participants considered the passport to be unnecessary at this stage of their healthcare, mostly because they had few appointments currently. This was particularly true of care dyads with a diagnosis less than six months prior to interview, and for those with few/no co-morbidities. However, others acknowledged potential usefulness as the illness progressed, and of particular use if something were to happen to the carer. Few

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2
3 participants maintained that they could keep track of this information themselves, or
4
5 believed the healthcare professionals would already be sharing/recording the information
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7 without prompting. In each of these cases, the opinion of those individuals did not change
8
9 with further explanation of the passport, and so it is unlikely that the response was due to
10
11 poor understanding of the purpose of the passport.
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18 “It’ll be some time before I’m going back to see my GP, and I’ll have to wait until F. comes
19
20 back, so there’s really nothing I’ll be doing immediately, and it’ll be some time before I
21
22 would get to use it.” (P30)
23
24
25

26
27 “No, I just filled in the basic information and that’s it. That was all, really. I haven’t really
28
29 used it, because I didn’t feel...because she hasn’t been to any appointments so at this
30
31 stage...I would say maybe in the future it will be more relevant but, at the minute, no.” (C1)
32
33

34 **Privacy and relationships**

35
36 Carers’ attitudes to information-sharing with healthcare professionals are complex and the
37
38 concept of promoting ‘personhood’ in healthcare had limited currency among carers. Thus,
39
40 several families were unwilling to share personal details with the doctor beyond medical
41
42 history, and did not acknowledge the significance or relevance of that part of the passport.
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47 “No, no, and you know, we don’t like to have a document like this lying about the
48
49 house so that other people, for whom it is not their business, may come across it and
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51 see what’s going on or what [P24]’s drug regime is.” (C24)
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53

54
55 Such families preferred compartmentalised approaches to care or were suspicious of
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57 sharing personal information with paid carers in particular. These views seldom changed
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59 over the study period. Participants were also apprehensive about who should have access
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3 to, and make entries in, the passport. Even though it was explained that control over the
4 use of the passport lay with the family, people remained unsure as to how this could be
5 decided. We noted warmth between dyads in most of the interviews and this bond appears
6 to assist in using the passport. However, we also noted that some couples fearing the loss
7 of their 'old' relationship strove to maintain a 'normality' which, in some instances meant
8 minimising external intrusion. With implications for the healthcare passport and for care
9 generally perhaps, several couples suggested that they try and manage things themselves
10 (e.g., C2, C28/P28, P30). *"We handle things ourselves. As far as we can, we'll do it. Wherever
11 she goes, I go now."* (C2)

26 **Additional burden**

27
28 Participants' enthusiasm for the passport centred on its organisational and memory
29 purposes. However, while carers focussed on keeping track of varied professional
30 appointments, patients focussed on medication management. Additionally, while carer
31 participants who formed part of family network anticipated its value in cross-
32 communication to relatives, unless prompted none indicated its utility in information-
33 sharing with health and social care professionals. Again, this suggests that the concerns
34 about threats to the personhood of the family member posed by health professionals'
35 responses and attitudes does not register significantly with caregivers or was overshadowed
36 by healthcare needs. *"It's a new thing, it's very hard to handle, and the last thing on your
37 mind is this book."* (C3). Others, particularly non-spouse males, were apprehensive that the
38 passport may become too onerous.

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"This is what happened to us. Whenever (Participant) was diagnosed we got bombarded
with everything, which 90% of it was great but there was a couple that we couldn't just cope

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3 with, and that was one of them, you know, it was too much at the time. Probably in time to
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5 come it might..." (C11)
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12 **Ownership of Passport**

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15 Commonly, the family caregivers took responsibility for holding and maintain the passports,
16
17 commonly indicating that the PLWD would not be able to use the passport and in some
18
19 instances, they dissuaded the PLWD from using it. For many, caregivers' assumed
20
21 responsibility for the passport because they provided most of the organisation and
22
23 management of care. However, in one case, this was because the PLWD did not want to use
24
25 the passport, and in a few cases, this was due to problems with writing as a symptom of the
26
27 condition.
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33 "As regards M., my husband, he won't be able to fill that in because he can't write now
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35 because he has problems with using his fingers and hands [....]. Therefore, he wouldn't
36
37 personally be doing this, it would be me." (C17)
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42 Interestingly, there was quite a range in the carer's perception of the PLWD's ability to use
43
44 the passport amongst people with the same/similar memory scores. Carers expressed a
45
46 number of reasons why the PLWD would not use the passport, including an inability to
47
48 write, forgetting to use it, not understanding how to use it, or not wanting to use it because
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50 it is a reminder of their condition.
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56 **Anticipated response from Healthcare Professionals**

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3 Some participants, particularly carers, 'self-censored' any exchange with health
4 professionals believing that doctors were unlikely to use the passport, or even to read it.
5
6 This was particularly true when people spoke of GPs or Consultants (with the exception of
7 the Memory Clinic staff). People who mentioned this were also more likely to discuss
8 doctors being disinterested or pressed for time when discussing their relationships to
9 healthcare professionals. Concerns about 'bothering' the health professionals were raised
10 from the outset.
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20 "The doctor wouldn't have any objections whenever I come with that and ask him to fill it
21 in?" (P7)
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24 "You'd be taking your life in your hands when you hand them the book and say 'can you fill
25 that in?' They would just tell you that they don't have time and that would be the way like,
26 and I wouldn't go back and ask a second time." (C18)
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33 They were also more likely to relay negative stories about experiences with HSCPs.
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35 However, in contrast, family caregivers who had direct experience working in the healthcare
36 sector, tended to suggest that healthcare staff would find the passport very useful.
37
38 Participants sceptical of professional engagement with the passport nevertheless
39 maintained the value in the passport for their own care dyad. Updating the passport
40 and/or introducing it into healthcare consultations was problematic. *"We weren't good at
41 doing the homework, I have to say. Some of it's done and some of it hasn't been updated."*
42 (C32). Thus, some people forgot to bring the passport when attending hospital and general
43 practice appointments –while others were greeted with bemusement by clinicians who
44 appeared to be unaware of its existence. Additionally, other participants consciously
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3 neglected it, anticipating that the passport may be perceived by clinicians as a burden and
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5 did “not want to bother” them.
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8 “We’ve tried to use it.” (C20) “When we saw the reaction to it, we don’t take it anymore.”
9

10 (C20a) “They just look at you as if-“ (C20)
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17 **Healthcare Passport content analysis**

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20 During the 3rd wave of interviews we made copies of the passport entries with the
21
22 permission of the participants. With one exception (P8), carers had filled in the passport,
23
24 rather than the PLWD. Most participants opted to keep their HP after the evaluation, except
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26 one (P14).
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31 Family caregivers, soon after diagnosis, began incrementally to assume control of various
32
33 responsibilities in the PLWD’s life. Sometimes family intervention is a response to cognitive
34
35 changes and the diminishing capacity of the person, for others it appears to be a pre-
36
37 emptive and prematurely unnecessary intervention, prompted by anxiety about risks. In
38
39 return, the family member with dementia assumed a new identity role which undermined
40
41 their sense of agency and initiated an erosion of abilities and skills. *“Do you want me to*
42
43 *write all this down?” (P7) “No, I’ll get [wife] to do it for us, Dad.” (C7)*
44
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49 Additionally, some of the PLWD had various co-morbid conditions and/or learning
50
51 difficulties, which made writing problematic. Each of the passports was completed in a
52
53 distinctly idiosyncratic style. While this demonstrates the different individuals’ personhood,
54
55 it may also present challenges for HSCPs. In other words, our evidence suggests that the
56
57 passports may not conform to a standard information collection. For example, in terms of
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3 medication and side effects, as well as comorbidities and their impact, and self-care, the
4
5 level of detail varies considerably between PLWDs, and some do not mention these at all,
6
7 even when these are a significant aspect of their needs and difficulties. So, HSCPs may be
8
9 concerned that vital information is not recorded and may consider that, in its current form,
10
11 the passport is unreliable.
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18 Personal narratives, hobbies, and activities also varied considerably and information was
19
20 also recorded unsystematically. Thus, carers included details about dementia progression
21
22 and PLWD deterioration, along with details on religion, likes, and dislikes, and activities. Of
23
24 the 12 completed passports, four contained only undated entries, two contained partially
25
26 dated entries only, all but two (P8 self-completed; P21: social worker completed) were
27
28 completed by the carer. Those who were overwhelmed (e.g., C13), or coping very well (e.g.,
29
30 C13) did not complete the HP.
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38 **GPs feedback**

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40 The general consensus among the GPs was that “... *the fundamental idea is very good.*” (CB)
41
42 Some GPs were familiar with maternity notes, about which they noted “... *work well if the*
43
44 *patients bring them*” (CB) but said that often they did not. In the current study, few patients
45
46 took the passport to their GP, and those who did, reported that the GP appeared to be
47
48 unfamiliar with it or unenthusiastic about its use, which deterred them from taking it again.
49
50 Commonly, GPs felt that the passport created another pressure on GP’s time and also were
51
52 concerned about its legal status in the event of medical complications or patient complaints.
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55 Mostly, however, most expressed doubt about the additional bureaucracy.
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3 “Another form! Will it improve the lives of patients and carers? The others rarely
4
5 do!” (Dr Mc)
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10 The practicality of and reasoning behind offering the passport in paper format was
11
12 questioned in the context of ubiquitous digital technology within the healthcare system.
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14

15 **Discussion**

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19 There have been welcome developments in internet-based decision-making tools in
20
21 dementia care [23] much more work is needed in this field, particularly among older people
22
23 who are less digitally literate or confident in its value [24]. The complexity of dementia,
24
25 often accompanied by co-morbid disability and illness, create challenges for interventions
26
27 designed to support relationships in care[6]. Thus, over time, health and social needs can
28
29 accelerate and informal care networks may be unpredictable. Additionally, while these
30
31 factors underpin the rationale for communication tools they also increase evaluation
32
33 uncertainties about their acceptance and use.
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40 Despite the challenges to its widespread use, the health care passport for people living with
41
42 dementia was still considered favourably by many participants but requiring a more
43
44 nuanced approach. As a communication tool it may be determined by the extent of the
45
46 person with dementia’s care needs and the caregiver’s role and ability in meeting these.
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48

49 While the healthcare passport was co-designed and strongly supported by people with
50
51 dementia, family caregivers and healthcare professionals, its feasibility rested on various
52
53 assumptions about stakeholder beliefs, values, behaviours within a range of contexts and
54
55 specific needs. Our evaluation underlined the salience of factors that are seldom
56
57 acknowledged in the implementation of complex interventions and particularly within the
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3 world of dementia care. Prima facie, we found a ready acceptance of the passport by service
4 users and carers who were willing to 'give it a go' and could envisage its benefits. However,
5 a more tacit understanding of cultural attitudes towards health professionals emerged. In
6 many cases, participation was gained simply because families felt an underlying obligation
7 to the dementia services (Memory Clinics). Again, deference to professionals was
8 manifested in the reluctance of service users and carers to 'bother' their GP revealing the
9 asymmetry of this relationship and patient-family insecurities about 'annoying' clinical staff.
10 GPs, mostly, did not engage with the passport, partly because they considered it old
11 technology and inefficient. However, this perspective fails to recognise that many older
12 people are not familiar with digital technology.

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29 The timing for introducing the passport may influence its uptake and usage. This may prove
30 difficult to gauge. At the very early stages post-diagnosis, patients may have good physical
31 and mental health and may reject the passport as unnecessary while, nevertheless
32 regarding it as potentially helpful as the condition progresses. Others, who appeared to be
33 still in shock or depressed for some time after the diagnosis, found the passport as a painful
34 reminder and didn't want to use it. It was regarded as a "dementia passport" and associated
35 with lack of capacity and decline. For those at a more advanced stage, and/or with
36 considerable co-morbidity and thus, service use, often felt overwhelmed by the information
37 flow that they thought necessary to be inserted.

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54 As noted in other healthcare areas [25, 26], the 'ownership' of communication tools
55 presents interesting and challenging dilemmas. Developed as a patient-held communication
56 tool but not specifically designed for dementia, cognitive deterioration may alter the
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3 passport's management, often assumed by the family carers. In some cases, family
4
5 members appear to undertake, and therefore sometimes undermine, the normal activities
6
7 of daily living of the person with dementia. The extent to which the passport is held and
8
9 'owned' by the family caregiver requires further examination.
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15 For people who wished to maintain a sense of 'normality' the passport may have been
16
17 perceived as a threat or an intrusion, in which case people consider what is most at stake
18
19 for them and will try to find ways of protecting this. While not a form of denial, this
20
21 represents a determination to resist labelling as a dementia patient and the sequelae of
22
23 medical and social responses that this may entail.
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30 Revealing participants' tastes and dispositions within the passport was intended to create a
31
32 sense of personhood and while some people understood and appreciated the concept,
33
34 other participants were anxious about the sharing of personal information, feeling that
35
36 some formal carers or clinicians did not need to know the personal details or specific
37
38 aspects of a person's life. For others, achieving basic medical and social care services
39
40 appears to be prioritised over non-essential knowledge – suggesting that the two
41
42 information types are balanced in a zero-sum game.
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50 Content analysis revealed that each passport was entirely different from others. While this
51
52 is to be expected when it comes to personal narrative, it is not helpful in terms of medical
53
54 information, symptoms, progression, comorbidities, side effects of medication, etc. The
55
56 current non-standardised format of the sections relating to information relating to the
57
58 patient's health may undermine the passport's viability and efficiency. Essential information
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3 may be missing or not have been updated, or indeed not dated. Many entries were not, or
4
5 only partially dated. As such, the information contained in the passport may not be
6
7 regarded as reliable by some professionals.
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11
12 This evaluation has provided rich, in-depth information about the uptake and use of a
13
14 healthcare passport for people living with dementia. For example, recruitment to studies
15
16 such as this may be relatively easy but meaningful participation is more difficult to achieve.
17
18 Thus, a future trial will need to set much stricter parameters for participation including
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20 much more robust assessment of informed consent rather than a willingness to please
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22 clinicians, complexity of care, disease progression and passport 'ownership'.
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26 27 28 **Recommendations**

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31 HSCPs need to have an awareness of the dynamics in a patient-carer dyad, and the
32
33 particular circumstances of the carer, and devise a care plan fully cognisant of the medical
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35 and socio-psychological condition of both. Some families require much more in-depth
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37 consultation on the use of the passport and over a longer period of time than the resources
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39 permitted in the current evaluation. It must be made clear that it is a "health passport"
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41 rather than a "dementia passport". People living with dementia need to know that it is
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43 widely used by all patients, so that they do not feel stigmatised by its use.
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50 The degree and exact nature of GP resistance may require further understanding about
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52 how, if at all, it may be overcome. Alternatively, future design and implementation may
53
54 have to consider which service should take responsibility for the dissemination and
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56 oversight of the passport. Digital technology and flexible internet-based platforms which
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2
3 allow for greater flow of exchange between patients, health and social care providers, and
4
5 caregivers offer much promise for communication and decision-making but again, such
6
7 platforms need to be shaped and managed according to person-centred needs.
8
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10 11 12 13 **Patient and Public Involvement**

14
15 This study was developed with the support of the Alzheimer's Society Northern Ireland.

16
17 People living with dementia were involved in various stages of the project except writing for
18
19 publication.
20
21

22 23 **Author contributions:**

24
25 GL, AA, MW, ST, SMcl, BeMcC , BrMcC and VC co-designed the study, EC, BWB and DC
26
27 collected and analysed the data. All authors contributed to the writing of the manuscript. GL
28
29 was the PI on the study.
30
31

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34
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38
39 possible.
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Figure 1: flow chart of Participant Recruitment and Attrition waves 1-3