


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

Gerard Leavey ^{1,2}, Dagmar Suzanna Corry,^{1,2} Bethany Waterhouse-Bradley,³ Emma Curran,² Stephen Todd,⁴ Sonja McIlfratrick,⁵ Vivien Coates,⁶ Max Watson,⁵ Aine Abbott,⁷ Bernadine McCrory,⁸ Brendan McCormack⁹

To cite: Leavey G, Corry DS, Waterhouse-Bradley B, *et al.* Acceptability and use of a patient-held communication tool for people living with dementia: a longitudinal qualitative study. *BMJ Open* 2020;**10**:e036249. doi:10.1136/bmjopen-2019-036249

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2019-036249>).

Received 09 December 2019
Revised 24 March 2020
Accepted 06 April 2020



© Author(s) (or their employer(s)) 2020. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to
Professor Gerard Leavey;
g.leavey@ulster.ac.uk

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.

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

Strengths and limitations of this study

- Our longitudinal qualitative research (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’ general practitioners (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.

(‘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 healthcare professionals in dementia services is often problematic for both the patient and their family members,⁸ related to various aspects of organising care and areas of decision-making for relatives with dementia.^{9 10 11 12 13} Various obstacles deny widespread acceptance and use of internet-based supportive tools.^{14 15}

Attempts to address service barriers are generally confined to hospital and hospice settings,¹⁶ with a bias towards clinical decisions and pathways, but neglecting person-centred approaches.^{17 18} A consortium of health professionals, voluntary sector

organisations, carer groups and people with long-term and life-limiting conditions met over a 2-year period to coproduce a 'healthcare passport'. This was an expandable information booklet divided into distinct sections which covered important aspects of the individual's life, support and care.¹⁹ For example, one section was allocated to information on any health conditions the person had; another allowed for details of any medication they had been prescribed and could be expanded to record changes to medications; coverage of a person's social networks and assistance was also provided for, allowing the health and social care professionals the opportunity to assess supportive contexts. Other sections disclosed salient aspects of the individual's life—religious or spiritual beliefs and interests. Importantly, the 'passport' was to be held by the person with dementia (or their proxy) who completed the personal and social sections, while medical treatment and care were completed by the various and relevant health professionals, and entries could be made by the latter during visits. In brief, the passport was designed as a portable patient-held record of care that could facilitate the cross-transfer of information between patients and a variety of medical and social care professionals. In collaboration with health and social care agencies, statutory and voluntary, we sought to examine how this low-cost communication tool might be acceptable and useful to PLWD and their families.

AIMS

This study aimed to examine the acceptability and use of a healthcare passport for people with dementia and their family carers, intended to facilitate communication and decision-making for service users and family caregivers. Additionally, we wanted to explore (1) how this tool is used over time; (2) the engagement of relevant service providers; (3) the barriers to information and communication between and among family carers and health and social care professionals ('HSCPs') and how these can be remedied; and (4) how to refine and/or deliver the passport and similar interventions.

Method

Adopting a realist evaluation approach to complex interventions, we used longitudinal qualitative research (LQR) and document content analysis.

Recruitment

We aimed to recruit 20–25 people with mild-to-moderate dementia living in the community, and their families, sufficient to obtain a range of individual situations and experiences. This was done through the Memory Clinic of the Western Health & Social Care NHS Trust.

If the lead clinician or centre manager believed absence of capacity, the lead clinician or centre manager helped identify their next of kin, family caregiver or someone close to the person (who does not receive remuneration for this role) who will act as a 'personal consultee'.

Although the capacity of the person with dementia may diminish over the evaluation period, we intended that they are fully involved in using the passport and any associated decision-making. We held no prior assumptions about participants' current use of health and social care services. The potential participants were approached by clinicians who provided information about the study.

Passport implementation

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

Interview methodology

Primarily we used LQR methods.^{20 21} Briefly, this consisted of three in-depth interviews: (first) shortly after referral; (second) at 6 months; and (third) at 12 months. The interviews, conducted with the PLWD and carer together, lasted between 60 and 90 min, and were undertaken in the participants' homes by BW-B and DSC, females with PhDs with substantial training and experience in qualitative research with vulnerable populations; sociologist and psychologist, respectively. The researchers met with all participants prior to the study, via the memory clinics, and provided a clear overview of the study aims. Neither researcher had prior personal experience of dementia or its associated caregiving. We used topic guides to help us record and explore change over time, and the processes associated with such changes. Thus, the initial interview gathered 'baseline' information about the onset and diagnosis, health and social care needs, the context of care and the availability of support. We also examined service users' and caregivers' perceptions and expectations of the passport. Fieldnotes were not taken during interviews but the team met regularly to discuss issues arising from the interviews. The topic guide and analysis were based on the literature and experts by experience within the Alzheimer's Society. The topic guide was refined after the initial interviews. GPs providing care for the people with dementia were interviewed by telephone towards the end of the 18-month data collection and addressed issues on acceptability, ease of passport use, response to patient participants and recommendations for continued use and adaptation.

In subsequent meetings, we explored any change to these areas and issues and the passport usage. Additionally, we did a content analysis of service user and caregiver entries in the passport and examined GP's assessment of passport usage. All participants provided recommendations for future use of the passport.

ANALYSIS

The interviews were audiotaped, transcribed and then entered into a qualitative software program (N-Vivo V.11) for data coding and management. We used *Trajectory analysis* which examines changes over time for participants.²² We coded and indexed the data, using a spreadsheet in order to generate a matrix into which the data were ‘charted’. This summarised the data by category from each transcript, building themes with the help of memos and data display. Transcripts were analysed and coded independently by the researcher, one to two members of the caregiver participant group, and members of the research team. Some specific areas covered: (1) a retrospective examination of the experience of people with dementia, family carers, help-seeking and communication needs—prior to using the passport; (2) practical use of the passport, differentiated by different care characteristics and contexts (eg, dementia stage, social class and social support networks, gender and care-relationship); (3) change in use of the passport over time in response to need; (4) care planning and advance directives for end of life care; (5) joint decision-making (family and patient); (6) comprehension and ease of use by stakeholders (professionals and family); and (7) reasons for discontinuation. Additionally, we examined contextual factors of people in the use and maintenance of this type of intervention and how it can be more effective. Understanding the acceptance and use of the passport over time with a range of people was the main goal, and thus, theoretical data saturation was not particularly relevant. While it was not possible to undertake participant checking per se, participants were provided with a synopsis of their previous responses and asked about change.

Passport content analysis

The passports’ contents were examined by DSC to see how they were used and by whom, in addition to family carers, and the level and quality of the information provided. This was a simple thematic analysis, noting categories of entry and overall usage.

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

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.

FINDINGS

Participant recruitment and attrition

Following initial recruitment of 28 patient–carer dyads for the first wave of interviews, two declined, we therefore interviewed 26 PLWDs and carers in wave 1. Participant (patient and carer) characteristics, in addition to recruitment and attrition flow, are provided in [table 1](#) and [figure 1](#). As advised by the Memory Clinic to expect a high attrition rate in this particular population, we had 16 participating families at wave 3 (48% of total contacted).

We obtained a socially heterogeneous sample from a 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, Chronic Obstructive Pulmonary Disorder (COPD), heart problems, hypertension, breast and prostate cancer, and 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.

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 group (n=5); others were sons (n=3), brothers (n=1) and sisters (n=1). In some cases (n=5), caring was

Table 1 Recruitment and attrition

	Wave 1	Wave 2	Wave 3
Number	26	21	16
Gender	13 female 13 male	11 female 10 male	7 female 9 male
Carer gender	18 female 8 male	17 female 4 male	12 female 4 male
Age	57–89	57–87	58–88
Stage	Mild-moderate	Mild-moderate	Marked deterioration: 3 male
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 female 6 male	4 female 1 male	N/A

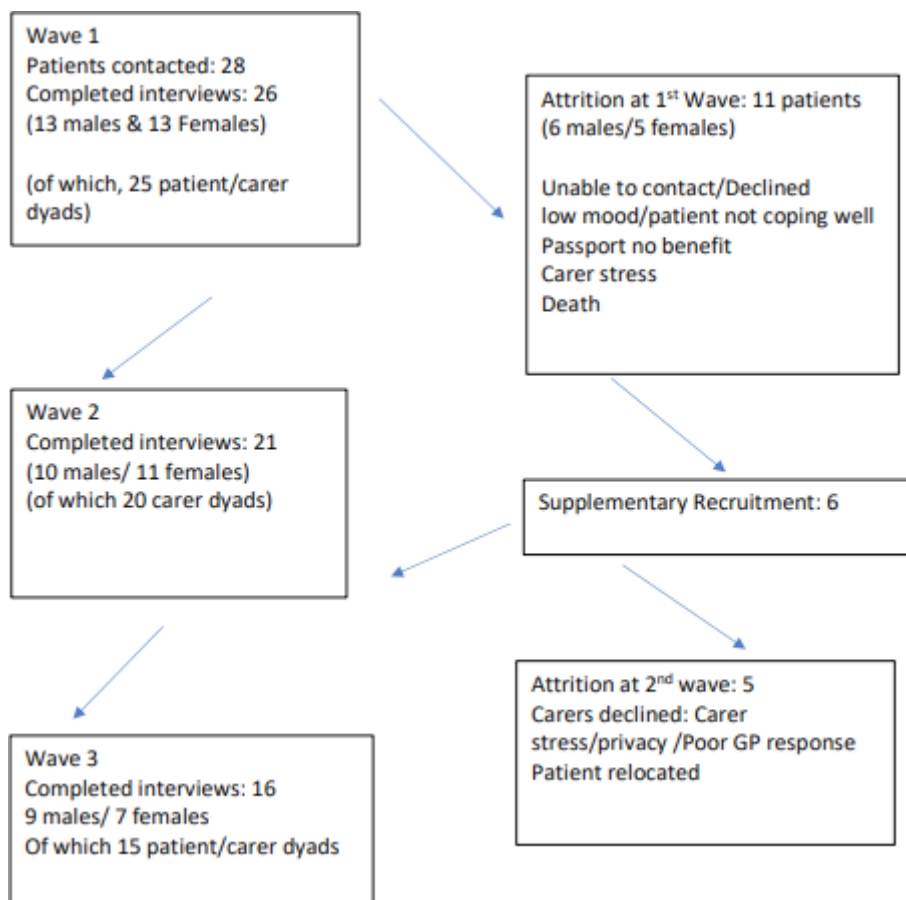


Figure 1 Flowchart of Recruitment and interviews. GP, general practitioner.

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)

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

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

Some families felt intimidated by unfamiliar doctors, while others became particularly assertive when they felt the patient was being disadvantaged. Those who had worked in healthcare or had family in the healthcare system were more confident and found it easier to get the service they needed. The main health and social care issues reported were the difficulty in seeing the same GP every time, "You never see the same doctor twice. They are always booked up, and others don't know your case." (C16), the short consultation time, the importance of the GP taking time to listen, being comfortable with the GP, and the attitude of the GP (emphatic and warm vs condescending and dismissive). Some avoided seeing their GP because they feared another diagnosis or because they felt they should not 'bother' the GP.

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 (1) correct completion, (2) timing, (3) privacy and relationships, (4) additional burden, (5) ownership of passport and (6) anticipated response from healthcare professionals.

Correct completion

Most participants were unsure about the potential usefulness of the passport, although 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 6 months prior to interview and for those with few/no comorbidities. However, others acknowledged potential usefulness as the illness progressed and of particular use if something were to happen to the carer. Few participants maintained that they could keep track of this information themselves, or believed the healthcare professionals would already be sharing/recording the information without prompting. In each of these cases, the opinion of those individuals did not change with further explanation of the passport, and so it is unlikely that the response was due to poor understanding of the purpose of the passport.

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

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

future it will be more relevant but, at the minute, no. (C1)

Privacy and relationships

Carers' attitudes to information sharing with healthcare professionals are complex and the concept of promoting 'personhood' in healthcare had limited currency among carers. Thus, several families were unwilling to share personal details with the doctor beyond medical history and did not acknowledge the significance or relevance of that part of the passport.

No, no, and you know, we don't like to have a document like this lying about the house so that other people, for whom it is not their business, may come across it and see what's going on or what [P24]'s drug regime is. (C24)

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

Additional burden

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

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 with, and that was one of them,

you know, it was too much at the time. Probably in time to come it might... (C11)

Ownership of passport

Commonly, the family caregivers took responsibility for holding and maintaining 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 among 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. Concerns about 'bothering' the health professionals were raised from the outset.

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

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

They were also more likely to relay negative stories about experiences with HSCPs. However, in contrast, family caregivers who had direct experience working in the healthcare sector tended to suggest that healthcare staff would find the passport very useful. Participants sceptical of professional engagement with the passport nevertheless maintained the value in the passport for their own care dyad. Updating the passport and/or introducing it into healthcare consultations was problematic. "We weren't

good at doing the homework, I have to say. Some of it's done and some of it hasn't been updated." (C32) Thus, some people forgot to bring the passport when attending hospital and general practice appointments—while others were greeted with bemusement by clinicians who appeared to be unaware of its existence. Additionally, other participants consciously neglected it, anticipating that the passport may be perceived by clinicians as a burden and did 'not want to bother' them.

We've tried to use it. (C20)

When we saw the reaction to it, we don't take it anymore. (C20a)

They just look at you as if. (C20)

Healthcare passport content analysis

During the third 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 comorbid 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.

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

GPs' feedback

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

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

The practicality of and reasoning behind offering the passport in paper format was questioned in the context of ubiquitous digital technology within the healthcare system.

DISCUSSION

Although 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.²⁴ The complexity of dementia, often accompanied by comorbid disability and illness, creates 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 healthcare 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 code-signed 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 to the dementia services (Memory Clinics). Again, deference to professionals was

manifested in the reluctance of service users and carers to 'bother' their GP revealing the asymmetry of this relationship and patient-family insecurities about 'annoying' clinical staff. GPs, mostly, did not engage with the passport, partly because they considered it old technology and inefficient. However, this perspective fails to recognise that many older people are not familiar with digital technology.

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

As noted in other healthcare areas,^{25 26} the 'ownership' of communication tools presents interesting and challenging dilemmas. Developed as a patient-held communication tool but not specifically designed for dementia, cognitive deterioration may alter the passport's management, often assumed by the family carers. In some cases, family members appear to undertake, and therefore sometimes undermine, the normal activities of daily living of the person with dementia. The extent to which the passport is held and 'owned' by the family caregiver requires further examination.

For people who wished to maintain a sense of 'normality', the passport may have been perceived as a threat or an intrusion, in which case people consider what is most at stake for them and will try to find ways of protecting this. While not a form of denial, this represents a determination to resist labelling as a dementia patient and the sequelae of medical and social responses that this may entail.

Revealing participants' tastes and dispositions within the passport was intended to create a sense of personhood and while some people understood and appreciated the concept, other participants were anxious about the sharing of personal information, feeling that some formal carers or clinicians did not need to know the personal details or specific aspects of a person's life. For others, achieving basic medical and social care services appears to be prioritised over non-essential knowledge, suggesting that the two information types are balanced in a zero-sum game.

Content analysis revealed that each passport was entirely different from others. While this is to be expected when it comes to personal narrative, it is not helpful in terms of medical information, symptoms, progression, comorbidities, side effects of medication, and so on. The current non-standardised format of the sections relating

to information relating to the patient's health may undermine the passport's viability and efficiency. Essential information may be missing or not have been updated, or indeed not dated. Many entries were not, or only partially dated. As such, the information contained in the passport may not be regarded as reliable by some professionals.

This evaluation has provided rich, in-depth information about the uptake and use of a healthcare passport for PLWD. For example, recruitment to studies such as this may be relatively easy but meaningful participation is more difficult to achieve. Thus, a future trial will need to set much stricter parameters for participation including much more robust assessment of informed consent rather than a willingness to please clinicians, complexity of care, disease progression and passport 'ownership'.

Recommendations

HSCPs need to be aware 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 sociopsychological 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'. PLWD 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.

Author affiliations

¹Psychology, Ulster University, Coleraine, UK

²Bamford Centre for Mental Health and Wellbeing, Ulster University, Coleraine Campus, Coleraine, UK

³Social Policy, Ulster University, Belfast, UK

⁴Geriatrics, Altnagelvin Hospitals Health and Social Services Trust, Londonderry, UK

⁵Nursing and Health Sciences, Ulster University, Belfast, UK

⁶Department of Nursing and Health Sciences, Ulster University, Coleraine Campus, Coleraine, UK

⁷Integrated Care Clinic, Western Health & Social Care NHS Trust, Derry, UK

⁸Chief Executive Officer, Alzheimer's Society Northern Ireland, Belfast, UK

⁹Centre for Person-centred Practice Research, Queen Margaret University, Edinburgh, UK

Twitter Brendan McCormack @ProfBrendan

Acknowledgements We are extremely grateful to all the participants in this study and to the clinical staff at the Memory Clinics within the Western Health and Social Care NHS Trust who made this work possible.

Contributors GL, AA, MW, ST, SM, BeMcC, BrMcC and VC codesigned the study. EC, BW-B and DSC collected and analysed the data. All authors contributed to the writing of the manuscript. GL was the principal investigator of the study.

Funding This study was supported by a grant from the R&D Division of the Northern Ireland Public Health Agency & Atlantic Philanthropies COM/5017/14.

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval The study was given favourable ethical opinion by the Office for Research Ethics Committees Northern Ireland (ORECNI) on 21 July 2015 (REC reference 15/NI/0129).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Qualitative data have been stored and may be obtained with permission from the authors.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Gerard Leavey <http://orcid.org/0000-0001-8411-8919>

REFERENCES

- 1 Department of Health. *Living well with dementia: A national dementia strategy*. London: Department of Health., 2009.
- 2 Knapp Met *et al*. *Dementia UK (a report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK 2007)*. London: King's College London and London School of Economics, 2007.
- 3 Sado M, Ninomiya A, Shikimoto R, *et al*. The estimated cost of dementia in Japan, the most aged society in the world. *PLoS One* 2018;13:e0206508.
- 4 *Alzheimer's Disease International publication team, From plan to impact: Progress towards targets of the Global action plan on dementia 2018*
- 5 Beinart N, Weinman J, Wade D, *et al*. Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review. *Dement Geriatr Cogn Dis Extra* 2012;2:638–48.
- 6 Bunn F, Burn A-M, Goodman C, *et al*. Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem). *Health Serv Deliv Res* 2016;4:1–156.
- 7 National Audit Office. *Improving Services and Support for People with Dementia*. London: The Stationery Office, 2007.
- 8 Livingston G, Leavey G, Manela M, *et al*. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ* 2010;341:c4184.
- 9 Leavey G, King M, Cole E, *et al*. First-Onset psychotic illness: patients' and relatives' satisfaction with services. *Br J Psychiatry* 1997;170:53–7.
- 10 Ley P. Satisfaction, compliance and communication. *Br J Clin Psychol* 1982;21 (Pt 4):241–54.
- 11 Livingston G, Leavey G, Manela M, *et al*. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ* 2010;310:c4184.
- 12 Klodnicka Kouri K, Ducharme FC, Giroux F. A psycho-educational intervention focused on communication for caregivers of a family member in the early stage of Alzheimer's disease: Results of an experimental study. *Dementia* 2011;10:435–53.
- 13 Schneider J, Murray J, Banerjee S, *et al*. EURO CARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: I--Factors associated with carer burden. *Int J Geriatr Psychiatry* 1999;14:651–61.
- 14 Parker D, Mills S, Abbey J. Effectiveness of interventions that assist caregivers to support people with dementia living in the community. *Int J Evid Based Healthc* 2008;6:137–72.
- 15 Bharucha AJ, Anand V, Forlizzi J, *et al*. Intelligent assistive technology applications to dementia care: current capabilities, limitations, and future challenges. *Am J Geriatr Psychiatry* 2009;17:88–104.
- 16 Boyd K, Mason B, Kendall M, *et al*. Advance care planning for cancer patients in primary care: a feasibility study. *Br J Gen Pract* 2010;60:e449–58.
- 17 McCormack B. *McCance, person-centred nursing: theory, models and methods*. Oxford: Blackwell publishing, 2010.
- 18 Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000;51:1087–110.

- 19 Leavey Get *et al.* *Evaluation of a Healthcare Passport to improve Quality of Care and Communication for People with Dementia (EQUIP)*. Belfast: Ulster University, 2018.
- 20 Snelgrove SR. Conducting qualitative longitudinal research using interpretative phenomenological analysis. *Nurse Res* 2014;22:20–5.
- 21 Saldana J. *Longitudinal Qualitative Research: Analysing Change Through Time*. Walnut Creek CA.: AltaMira Press, 2003.
- 22 Grosseohme D, Lipstein E. Analyzing longitudinal qualitative data: the application of trajectory and recurrent cross-sectional approaches. *BMC Res Notes* 2016;9:136.
- 23 Span Met *et al.* Developing an interactive web tool, the decide guide, to facilitate shared decision-making in dementia-care networks: lessons learned. *Frontiers in Aging Neuroscience* 2015;7.
- 24 Ko Het *et al.* Quality safety in health care. Patient-held medical records for patients with chronic disease: a systematic review 2010;19.
- 25 Atkinson J, GARNER H, PATRICK H, *et al.* Issues in the development of advance directives in mental health care. *J Ment Health* 2003;12:463–74.
- 26 Nicaise P, Lorant V, Dubois V. Psychiatric advance directives as a complex and multistage intervention: a realist systematic review. *Health Soc Care Community* 2013;21:1–14.