



**Report on the Evaluation of the Implementation
and use of a Patient Healthcare Passport in
Specialist Palliative Care Contexts**

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Abbreviations

Com	Community
DH	Day Hospice
DHSSPS	Department of Health, Social Services and Public Safety
DOH	Department of Health
EAPC	European Association of Palliative Care
GPs	General Practitioners
HCP	Healthcare Professional
HSC	Health and Social Care
Mal	Malignant disease
NI	Northern Ireland
NM	Non-malignant disease
ORECNI	Office of Research Ethics Committees of Northern Ireland
PHA	Public Health Agency
PHR	Patient Held Records
RCGP	Royal College of General Practitioners

Executive Summary

Introduction

In 2011, in response to recommendations contained in the regional palliative care strategy for Northern Ireland (NI) (DHSPSSNI, 2010), the Royal College of General Practitioners (RCGPs) in NI were commissioned by the Public Health Agency (PHA) to create a Patient Held Record (PHR) for use by patients with progressive, life-limiting illness and by their families and carers. Following a pilot process, the Passport was entitled, 'What I Need You to Know: A Health and Care Record for Me, My Family and Carers: My Healthcare Passport' and was launched in January 2014. In order to know whether or not it should be used in patients with specialist palliative care needs, there is a need to understand if it is acceptable and useful for people with these needs.

Methods

A prospective longitudinal cohort study using a mixed methods model was undertaken through the NI Hospice community service. The study involved two phases:

Phase 1: Patients: Patients were given a questionnaire at the time they were given a passport and a further questionnaire was sent to them after 4-6 weeks.

Phase 2: Healthcare professionals: This involved NI Hospice HCPs who had been trained in the use of the passport and occurred 8 months following the commencement of the study. Data was collected by both questionnaire and a focus group.

Results

From Sept 2016- June 2017, 550 patients were screened, 347 (63.1%) of these patients were offered a passport to use and 259 accepted a passport (74.6% of those offered). 238 patients accepted a research pack, with 105 returning questionnaire 1 (44.1% response rate), and 26 returning questionnaire 2 (24.8% of initial respondents).

Questionnaire 1 for patients – 40% of patients found it difficult or burdensome to repeat information about themselves to each HCP they met, and almost 70% said they would be interested in carrying a record to cut down on the need to repeat information. Twenty percent

of respondents stated they would like to talk to their family more than they already do about their day-to-day care and 13% felt they would like to talk to their healthcare staff about this more than they already did. The majority (72%) found it easy to talk to their family about their wishes for future care, with 36% indicating that they would like to talk to their family more about this than they already did, and 28% stating they would like to talk to healthcare staff more about their wishes than they already do.

Questionnaire 2 for patients - Of the 26 respondents, when asked about ease of use of the passport, 74% found it either very or quite easy to use, but only a few actually used it regularly. Over 40% felt the passport had helped them talk to their family about their day-to-day care, with over 50% feeling that it had helped them talk about this to their HCPs. In relation to future care, 55.6% felt it had helped them talk to their family, and 23.5% with HCPs about this, but few had recorded these wishes in the passport. When asked to score their overall impression of the passport, 8 (36.4%) stated it was 'very useful', 7 (31.8%) 'quite useful', 4 (18.2%) stated it 'was not very useful', and 3 (13.6%) were unsure. Fourteen (63.6%) would recommend using the passport to others, 3 (13.6%) would not, and 5 (22.7%) were unsure.

Questionnaire with Hospice Nurses - Eighteen HCPs replied to the questionnaire. When asked about who they had noticed writing in the passports, it was mainly patients and relatives, with very little input in writing from non-palliative care HCPs. Half felt the passport was initially well received, but only 4 (22%) felt it was used regularly by patients or their families. More found it useful to talk about future care or advance care planning (9) compared with talking about day-to-day care (6). In general it was not seen as helpful in talking to other HCPs. Half found it generally useful for patients and families, with fewer (8, 44.4%) thinking the passport should continue to be offered to patients in this context.

Focus Group with Hospice Nurses –this confirmed that for some the passport was useful but many patients did not use the passport.

Conclusions and Recommendations

This study looked at the use of a patient held passport in the specialist palliative care setting. While initial uptake of the passport was high, use appeared low and due to a very low response rate to questionnaires it is difficult to draw firm conclusions on its usefulness. From this evaluation several recommendations can be made:

1. The passport is not well used by all palliative care patients and therefore should not be given to all. This evaluation does not support widespread use in this setting.

2. The passport was felt to be useful by some palliative care patients in that it facilitated communication with their families and HCPs about their day-to-day care and future care, and therefore should be considered for use with some patients. Due to a high attrition rate it was not possible in this evaluation to determine if there were groups of patients who were more likely to use it than others. HCPs should use their judgement in determining if the passport should be offered to individuals in the absence of evidence.

3. The passport may be more useful earlier in a patient's disease trajectory and studies looking at its use from the point of diagnosis of a palliative condition should be considered to compare with the use of the passport in this population with a shorter prognosis.

Acknowledgements

This project could not have been completed without the enthusiastic support and commitment of all the NI Hospice HCPs who were involved in offering the passports to patients and informing them about the research study. Their commitment to improving patient care is outstanding, and the evaluation of the passport in the specialist palliative care setting would not have been possible without their expert involvement. We are particularly indebted to all the patients who so willingly gave of their time to complete questionnaires when they have many more pressing issues to deal with.

Many people were involved in various stages of the evaluation whose support we are most grateful for- Dr Aine Abbott (RCGP), Corina Grimes (Public Health Agency), George Kernohan (Ulster University), and Sue Foster (NI Hospice) who helped in the original design of the project. Administration support was provided by Jennifer Stewart, and Charlotte Pollock helped input and analyse some of the data- both these people were invaluable in the project.

Our sincere thanks also go to the Belfast Charitable Society for funding this study, to the Public Health Agency for supporting the printing of the passports and to Barbara Watson and the Senior Management Team at the Northern Ireland Hospice for having the vision to invest in trying the passport as a new way of working.

Contributors to the report

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Introduction

Palliative care is provided across various settings such as in hospital, in hospice inpatient units, through attendance at day hospice and also in the family home. It is also provided at different levels, which include using a palliative approach, providing generalist palliative care and providing specialist palliative care (EAPC, 2009). In the course of the palliative stage of an illness, patients and their families may encounter numerous health care professionals (HCPs), from various clinical specialities, who input into their palliative care (Bliss and While, 2003; Waldrop, 2006).

Communication between these HCPs, the patients, and their family members, is crucial to decision-making in palliative and end of life care (Forsyth et al, 2011) and necessary in order to achieve high quality supportive and palliative care delivery which is based on patients' and families' identified preferences and needs (DHSSPSNI, 2010). Yet empirical studies and systematic review evidence indicate that patients and families may experience significant communication challenges during this time due to many factors (Hickman, 2002). Factors related to the impact of disease mean that patients may struggle to absorb and retain clinical information (Gaston and Mitchell, 2005), and differences in knowledge and social or professional status can make it difficult for patients to express themselves and often fail to provide their preferences (Fine et al, 2010). Differences in perception of information, education, personal characteristics and pre-existing cognitive issues can all contribute to difficulty with communication (Hancock et al, 2007). How patients develop and express preferences is subject to a variety of cultural and societal influences (Ballard-Reisch and Letner 2003), as well as being mediated by family and HCP views (Forsyth et al, 2011). Poor communication around palliative and end-of-life care is associated with failure to achieve end-of-life decision-making and advance care planning (Chang and Sambamoorthi, 2008) and contributes to "discontinuity of care" at the end of life (Leydon et al, 2013); decision regret (Connolly and Reb, 2005); patient and family distress, dissatisfaction with care and an increased incidence of complaints (DOH, 2013).

In response, UK healthcare policy has moved to improve communication between patients, families and HCPs (DoH, 2011). Since 2003, the NHS Choices programme has promoted initiatives aimed to promote patient-centred, collaborative communication which have included the use of Patient Held Records (PHRs). Designed to empower individuals to have a better knowledge of their own needs, support the communication of personal preferences for care and record the services received (Turk et al, 2010), PHRs are structured records which remain with the patient through the course of their illness, in order to enable continuity and quality of care (Gysels et al, 2007). Although formats vary, PHRs typically include

patient and healthcare information, plus blank sections to enable notes or information to be added (Ko et al, 2010).

First developed in child health and maternity services, PHRs are now used in a variety of settings and by various patient groups such as those with chronic diseases (Ko et al, 2010). Debate exists about their effectiveness (Laughame and Henderson, 2004), but findings from studies in general healthcare settings, associate use of PHRs with benefits such as improved retention of information (Ngiuyen et al, 2004); increased patient satisfaction with communication (Jefferis et al, 1994; Tobacman and Nolan, 1996); patient empowerment (Spencer et al, 2011) and sense of control in decisions (Turk et al, 2009). However, studies tend to be cross-sectional and limited research exists which has considered the long term impact of PHRs (Nguyen et al, 2014).

More recently PHRs have been introduced for use by cancer patients, and they are well aligned with the person-centred objectives of palliative care (World Palliative Care Alliance, 2014). A systematic review of their effectiveness in studies with cancer patients indicates that they are generally well received by patients (Gysels et al, 2010), yet studies relating to the use of PHRs in palliative care settings are limited (Latimer et al, 1998). This highlights a gap in knowledge about how PHRs might contribute to the experience of patients and families at the end of life.

The Patient Healthcare Passport

In 2011, in response to recommendations contained in the regional palliative care strategy for Northern Ireland (NI) (DHSPSSNI, 2010), the Royal College of General Practitioners (RCGPs) in NI were commissioned by the Public Health Agency (PHA) in NI to create a PHR for use by patients with progressive, life-limiting illness and by their families and carers.

Developed collaboratively by RCGPs (NI) and 41 stakeholder groups throughout NI, the Patient Healthcare Passport aimed to:

- Promote patient resilience and self-care ability through access to and ownership of evolving information about their own condition.
- Help patients and families to build a support network of HCPs, know how to access them and understand when that would be appropriate.
- Provide a resource through which patients and families might consider and communicate their preferences and evolving needs for care and to promote their

engagement in anticipatory and collaborative care and support planning with family and HCPs.

Following a pilot process, the Passport was entitled, 'What I Need You to Know: A Health and Care Record for Me, My Family and Carers: My Healthcare Passport' and was launched in January 2014. In order to know whether or not it should be used in patients with specialist palliative care needs, there is a need to understand if it is acceptable and useful for people with these needs.

Aims and Objectives

The **research aim** is to evaluate how palliative patients, their families and specialist palliative care professionals, use and experience using the Patient Healthcare Passport in specialist palliative care settings.

The **objectives** were:

1. To discover patient experience of using the Passport document in specialist palliative care contexts, specifically in relation to:
 - Comprehension and ease of use;
 - Perceived impact of the Passport on communication, decision-making and planning for everyday and future care, both with each other and with HCPs.
2. To understand the experience of hospice staff involved in implementing and using the Passport with patients and families.

Methods

A prospective longitudinal cohort study using a mixed methods model was used.

Study population: The study was undertaken through the NI Hospice community service, in adult patients in two cohorts:

1. Those under specialist nurse review in the community;
2. Those attending the day hospice service.

Responding to the aims and objectives, the study involved two phases:

Phase 1: Patients: To participate in the study patients must have accepted to use a passport. Patients known to the hospice team meeting eligibility criteria were offered a passport by their hospice nurse who was trained in its introduction and use.

Inclusion criteria for passport introduction and the study: Adult patients (>18years), who are currently or newly in receipt of specialist palliative care services from the Hospice, across two settings (day hospice and community).

Exclusion criteria: Those identified by staff to be within the last days of life or patients whose physical, mental or emotional capacity would preclude participation.

All patients offered the Passport were given an identifier code which linked their responses and ensured anonymity. All patients who accepted to use the passport were invited to participate in the evaluation. Patients who indicated initial interest to staff received a study pack which included study information and Questionnaire 1.

Questionnaire 1: Patients were asked to complete and return the first questionnaire to the research team using a SAE within 7 days if possible. In questionnaire 1, patients were asked to indicate their willingness to participate in a second questionnaire in 4-6 weeks' time. This short timeframe was based on statistics generated by the NI Hospice in relation to a weighted mean time of 86 days from admission to death, calculated across the inpatient unit, day hospice and community settings and over a period of four months between June and September 2015.

Questionnaire 2: Patients returning questionnaire 1 and indicating their willingness to be sent the second questionnaire were sent the second Questionnaire 4-6 weeks following the return of questionnaire 1.

Consent to both questionnaires was implied by its return, and descriptive statistics were used to analyse the data from both questionnaires.

Sample size: The outcome measure of determining use of the passport for advanced care planning was used to ascertain sample size. This measure was estimated using the final proportion who answered the following question at 4-6 weeks "has using the passport helped you talk about your wishes for your future care?" In order to detect this proportion within +/- 5% (a 10% margin of error) with 95% confidence, the number required in the sample was N=96. Taking attrition as an anticipated 50% would lead to recruitment of 192 participants.

Phase 2: Healthcare professionals: The second phase, involving NI Hospice HCPs who had been trained in the use of the passport, occurred 8 months following the commencement of the study. Data was collected by both questionnaire and a focus group.

1. Questionnaire: An anonymous online questionnaire was distributed using Survey Monkey™ and via hard copy for staff who preferred this method to all potential participants who had been trained in the use of the passport. This elicited HCP views on using the passport in the palliative care setting, its usefulness in their experience and about the timing of introduction of the passport to patients. Consent was implied on return of the questionnaire and data was analysed using descriptive statistics.

2. Focus group: To develop insight into HCPs experience of implementing and using the passport, and to reflect on how factors have impacted the use of the passport over-time, a focus group was conducted by an independent facilitator. From the existing sample of those staff trained in passport use who were involved in introducing and using it, a purposive selection were invited to the focus group. Written consent was taken and discussion was facilitated around a topic guide, audio-recorded with permission and key themes analysed using a framework of thematic content analysis. Participants were also given the opportunity to comment on any other issues that had not been addressed within the topic guide.

Ethics: Ethical approval was obtained from the Office of Research Ethics Committees Northern Ireland (ORECNI).

Results

Recruitment

From Sept 2016- 2 June 2017, 550 patients were screened, 347 (63.1%) of these patients were offered a passport to use and 259 accepted a passport (74.6% of those offered). 238 patients accepted a research pack, with 105 returning questionnaire 1 (44.1% response rate), and 26 returning questionnaire 2 (24.8% of initial respondents). Demographic data is shown in table 1.

Table 1 – Demographic data (Com- community, DH- day hospice, Mal- malignant disease, NM- non-malignant disease)

	Patients screened	Patients accepted passport	Patients returned Q1	Patients returned Q2
Total	550	259	105	26
Community or day hospice	530 Com 20 DH	240 Com 19 DH	101 Com 4 DH	26 Com 0 DH
Primary Palliative diagnosis	NM- 70 Mal- 373 Unanswered- 7	NM- 22 Mal – 232 Unanswered- 5	NM – 6 Mal – 94 Unanswered- 5	NM- 3 Mal – 22 Unanswered- 1
Gender- female	259	136	53	13
Age				
20-39	6	5	1	0
40-59	88	52	22	8
60-79	307	150	59	15
80+	127	39	17	3
Unanswered	22	13	6	0

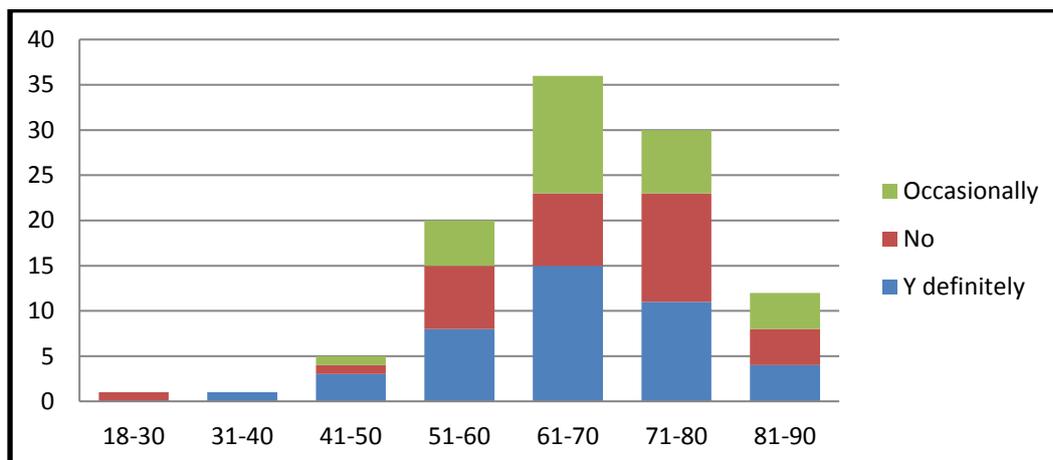
Questionnaire 1

Demographic data relating to those who responded to questionnaire 1 is shown in table 2. There was a wide range of responses to the number of different HCPs patients estimated they saw in a typical week - between 1 and over 30 different HCPs. When asked if they found it difficult or burdensome to repeat information about themselves to each HCP they met, 42 (40%) said yes, 30 (28.6%) said occasionally and 33 (31.4%) said no. Graph 1 shows the difference in age ranges for the responses.

Table 2 Demographic data of those who responded to questionnaire 1 (missing data - 2)

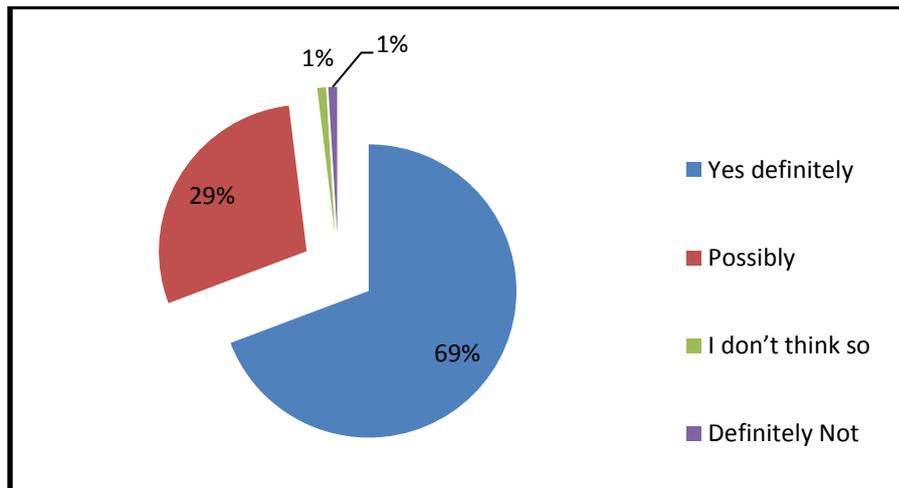
Age	F	M	Total
18-30	1		1
31-40	1		1
41-50	3	2	5
51-60	9	9	18
61-70	18	18	36
71-80	11	19	30
81-90	5	7	12
Grand Total	48	55	103

Graph 1 Questionnaire 1- Number of patients who find it difficult or burdensome repeating information to each healthcare staff

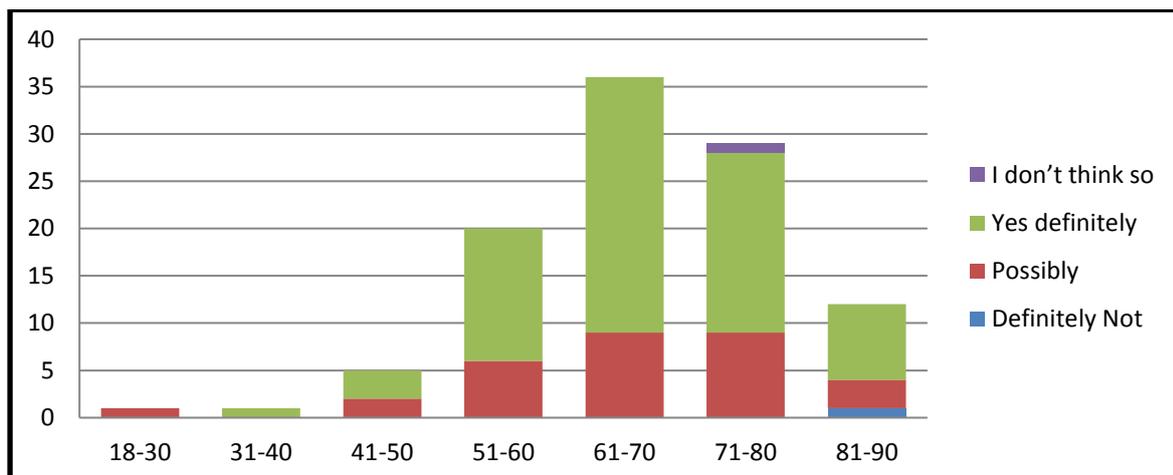


When asked (N=104) if they would be interested in carrying a record to cut down on the need to repeat information 72 (69.2%) said yes definitely, 30 (28.8%) possibly, and 2 (1.9%) gave a negative response (graph 2). Both negative responses were aged over 80 years old (graph 3).

Graph 2 Questionnaire 1 – Percentage of respondents interested in carrying a record to cut down on the need to repeat information



Graph 3- Questionnaire 1 - Are you interested in carrying a record to cut down on the need to repeat information?



Day-to-day care - When asked about 'day-to-day care' which was defined to participants as "covering many things including where they would want to be cared for, how they could be supported at night, or who do they want to help with personal care", 83% found it easy to talk to their family about this, 13% did not, and 4% were unsure. Twenty percent of respondents stated they would like to talk to their family more than they already do about their day-to-day care (69% would not, 11% were unsure). The majority (78%) found it easy to talk to their healthcare staff about day-to-day care (11% did not, 10% were unsure), and only 13% felt they would like to talk to their healthcare staff about this more than they already did (71% said no, 16% were unsure).

Future Care- Participants were asked about their views on ease of communication about their future care, which was defined as "covering decisions such as what they would want to happen if they became very unwell, where they would want to be, or how they would want to be cared for if they couldn't communicate". The majority (72%) found it easy to talk to their family about these wishes (16% did not with 12% unsure), with 36% indicating that they would like to talk to their family more about this than they already did (49% would not, 15% unsure). In relation to discussing their wishes for future care with healthcare staff, 68% found this easy and 14% did not (18% were unsure), with 28% stating they would like to talk to healthcare staff more about their wishes than they already do (56% did not, 16% were unsure).

Questionnaire 2

Of the 26 respondents, when asked about ease of use of the passport, 17 (65%) stated they found it either very or quite easy to use, with only 3 (12%) stating it was either very or quite difficult, and 3 (12%) finding it neither easy nor difficult to use. Two people (7.7%) stated they had used the passport 'a lot', 2 (7.7%) 'quite a lot', 13 (50%) 'a little' and 6 (23%) 'not at all'. For those who hadn't used it, one respondent reported having forgotten about it, one found it too difficult to complete, one felt it would have been more useful at diagnosis, and two didn't think HCPs would look at it. Of those who had used it, the ways they did so are shown in table 3. Five respondents had not shown the passport to any HCPs, with six indicating they had shown it to a range of 1-7 HCPs (15 did not respond to this question). Reasons given for not showing it to HCPs were 'I forget' (2), 'I didn't think they would be interested in it' (2), 'I didn't think they would have time to look at it' (1), 'I haven't filled it in' (1), or 'I haven't seen any' (2). Several people did not respond to some the questions.

Table 3 How did you use the passport?

	Frequency
Read through it	11
Written in it	10
Shown it to my family	11
Shown it to nurses in the community	7
Shown it to my carers	9
Shown it to Hospice Nurse	3
Shown it to nurses in the hospital	2
Shown it to my GP	2
Don't think it is useful for me	1
Too difficult to complete	1

Day-to-day care- When asked if the passport had helped people talk to their family about their day-to-day care, 7 (41.2%) agreed, 2 (11.8%) disagreed, and 8 (47.1%) neither agreed nor disagreed. The responses were similar in relation to talking to HCPs (N=15) – 8 (53.3%) agreed it had helped, 2 (13.3%) disagreed, and 5 (33.3%) neither agreed nor disagreed. When asked if the passport helped them cut down the number of times participants had to repeat themselves (N=16), 7(43.75%) agreed, 4 (25%) disagreed, and 5 (31.25%) neither agreed nor disagreed.

Future Care – When asked if the passport had helped participants talk to their family about their future care (N=18), 10 (55.6%) agreed that it did, 1 (5.6%) disagreed, 6 (33.3%) neither agreed nor disagreed, and 1 (5.6%) stated they didn't want to discuss future care with their family. When asked if they had recorded their wishes in their passport (N=18], only 2 (11.1%) had, with 3 (16.7%) stating they had partially recorded them, and 12 (66.7%) had not recorded them. One (5.6%) stated that he/she had not discussed future care with his / her family. When asked about whether or not the passport had helped participants talk about their future care with healthcare staff (N=17), 4 (23.5%) agreed that it had, 1 (5.9%) stated that it had not, 10 (58.8%) neither agreed not disagreed, and 2 (11.8%) stated they did not want to discuss future care with HCPs. Of those who had discussed future care with HCPs (N=13), only 1 (7.7%) stated he/she had partially recorded these wishes in his/her passport, with 12 (92.3%) stating they had not recorded them.

Overall impression – When asked to score their overall impression of the passport (N=22), 8 (36.4%) stated it was ‘very useful’, 7 (31.8%) ‘quite useful’, 4 (18.2%) stated it ‘was not very useful’, and 3 (13.6%) were unsure. Fourteen (63.6%) would recommend using the passport to others, 3 (13.6%) would not, and 5 (22.7%) were unsure.

Some participants wrote comments on their questionnaires which included:

‘I think this is a great idea, when I get around to filling it in as when I am asked "What tablets I am taking" (new ones) I always forget what they are and what they do. By using the passport I only have to show them and it gives a clear reading of what's been happening to my care and health and the insight in to medications I have been given along with what I am taking now. Going to fill it in this weekend.’

‘I find it difficult to use and my husband finds it difficult to understand.’

‘Perhaps a page where you can jot down things that happen on a daily basis like a diary.’

‘I am not sure what I should be writing in it. I also think that it is adding additional workload to my healthcare professionals who are already filling in a multitude of forms.’

‘This passport should be given out at the start when first diagnosed. This would help with health care workers.’

‘One healthcare professional indicated that perhaps some of the sections were unnecessary but some kind of history of illness would be of help. One consultant I handed it to agreed but then placed it to one side.’

‘Early days yet for me. Just getting used to it.’

Questionnaire with Hospice Nurses

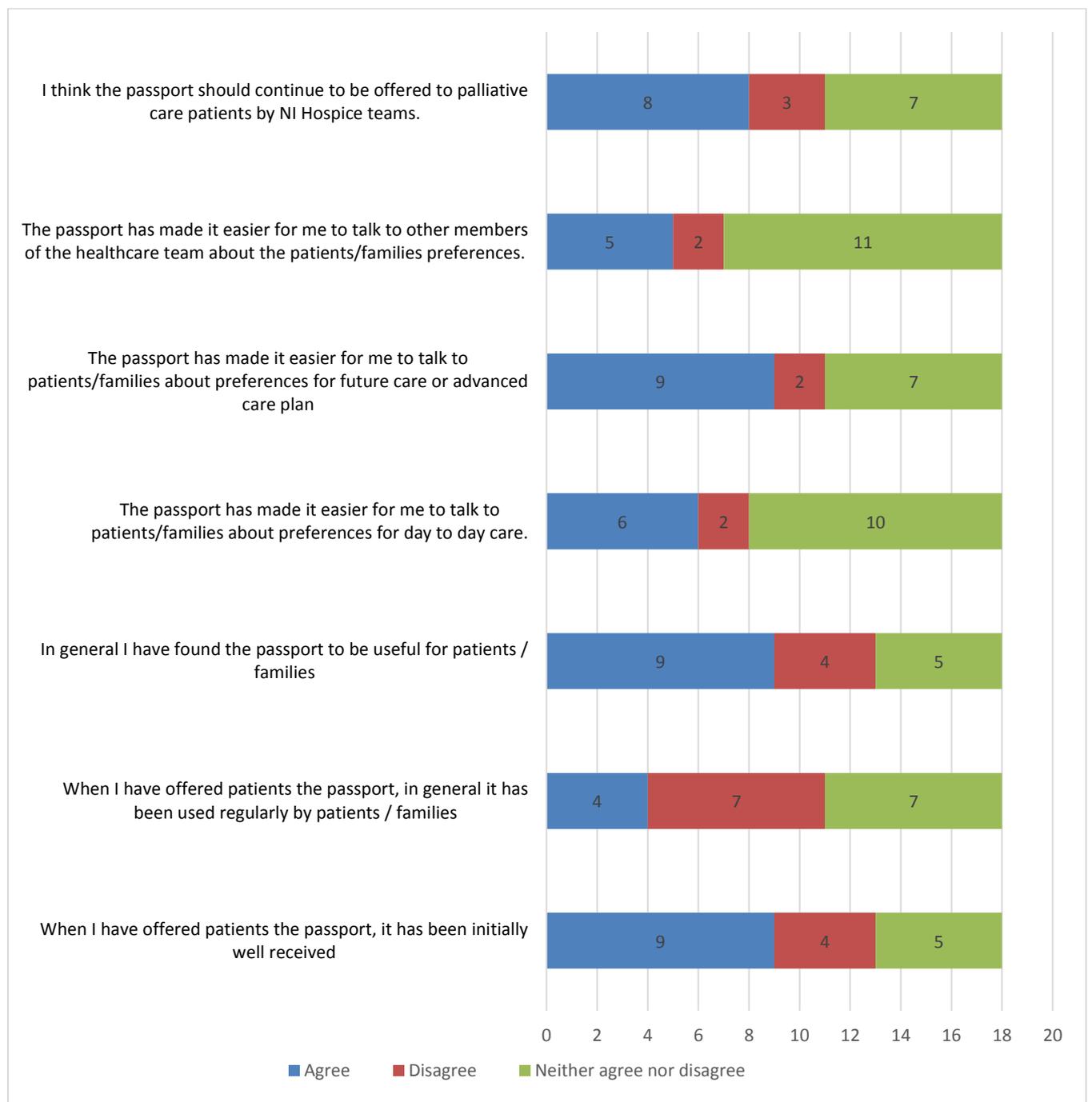
Eighteen HCPs replied to the questionnaire – twelve band 7 specialist nurses, four band 6 specialist nurses, one band 5 nurse and one ‘other’. Respondents had a wide range of experience working in palliative care, ranging from 2 years to over 25 years. Two respondents worked in the day hospice setting, with the other 16 working as community hospice specialist nurses. Participants were asked about their use of passports with patients, and results are shown in table 4. There was a wide range in responses between HCPs in terms of how many passports they had offered to patients and the uptake of those passports. Passports were offered to patients at different stages from becoming known to the HCP, with half feeling that the first consultation was the ideal time to offer the passport. When asked about who they had noticed writing in the passports, it was mainly patients and relatives, with very little input in writing from non-palliative care HCPs.

Table 4 Hospice HCP use of passports with patients

	Response Options	Frequency (%)
Approximately how many passports have you personally offered to patients? (N=17]	0	0
	1-5	1 (5.9)
	6-10	3 (17.7)
	11-20	9 (52.9)
	21-50	3 (17.7)
	51-100	0
	101+	1 (5.9)
Approximately what percentage of patients have accepted the passports you have offered to them? (N=17)	0-10%	3 (17.7)
	20-40%	2 (11.8)
	50%	4 (23.5)
	60-80%	5 (29.4)
	90-100%	3 (17.7)
When have you offered passports to patients?(N=18)	At first consultation	17 (94.4)
	At second Consultation	13 (72.2)
	After > 2 consultations	10 (55.6)
In your view, what was the best time to offer the passport to patients? (N=18)	At first consultation	9 (50)
	At second Consultation	7 (38.9)
	After > 2 consultations	2 (11.1)

Graph 4 shows HCP views on how useful they felt the passport was for palliative care patients. Half (9, 50%) felt the passport was initially well received, but only 4 (22%) felt it was used regularly by patients or their families. More (50%) found it useful to talk about future care or advance care plan (9) compared with talking about day-to-day care (6, 33%). In general it was not seen as helpful in talking to other HCPs. Half (9, 50%) found it generally useful for patients and families, with fewer (8, 44.4%) thinking the passport should continue to be offered to patients in this context.

Graph 4 HCP views of the passport



Focus Group with Hospice Nurses

Seven hospice nurses participated in the focus group.

Participant feedback in terms of describing the general look of the Passport was positive. The consensus was that it looked, “quite professional”, “laid out well”, “the sections are good.” Other comments included: “It’s a good size for patients to transport... it’s user-friendly as well... with the colours marked out with the sections.”

INTRODUCTION / TIMING OF THE PASSPORT

The general consensus amongst participants was that the Passport needed to be introduced earlier to the patient. As one of the participants explained:

“I think it depends on where the patient is in their diagnosis. For some patients, I felt that it was too late to bring the Passport out. I felt that maybe it should be introduced early on, maybe at a clinic... Sometimes, depending on where the patient was on your visit, it wasn’t always appropriate to use it.”

A number of participants expressed the view that they did not feel that it was always appropriate to introduce the passport when first meeting a patient; this meant waiting until they felt the time was right.

“If you were out with somebody who maybe just came to terms with their diagnosis and the family were very anxious... and were thinking of pro-active treatments... it wasn’t always appropriate, they had enough on their plate to discuss their diagnosis, what they thought was supposed to be happening, without introducing the passport on your first visit. So it maybe meant you had to wait until you developed a sort of a good relationship with the family so that you felt comfortable to introduce the passport.”

“In subsequent visits you might have brought it up then... I think if they had of been given it at clinics earlier on in their diagnosis, whenever they are going back and forward more to Oncology it would have been more benefit to them then for documenting things in.”

A number of participants also felt that the passport needed to be introduced earlier because of the fact that, *“our patients were so weak and fatigued that it wasn’t appropriate to introduce the passport at that stage.”*

Some of the participants felt that parts of the passport would benefit some people more than others.

“Sections of it probably, but not all of it... there is bits in it I suppose they can use and other bits they can choose not to use.”

“I suppose the bits that are probably more important for them using... changes in medication and things like that... every few days their painkillers or their anti-emetics are changing, so they should know what they have taken in the past... Less useful... ‘Useful Resources’ might not be very much use to them if they are housebound, if they’re not able to get out and about.”

One of the participants summed up a general feeling that:

“I think for the patient... towards their end of life, it’s more their family that actually would use it more-so than the patient. It depends how the family feel about using it. ...some family members were keen to use it, others were not keen to fill-in the passport at all... I think they were so stressed out with their patient’s condition, getting so weak, and maybe other symptoms that they felt that they had enough on their plate without completing this passport.”

When considering if there were any groups that it was more appropriate for, only one participant stated that they felt it was more appropriate to use the passport with young people; as he / she explained,

“...young people benefitted a lot from it, just because they generally have a lot going on... appointments and complications and treatment... so yeah if they got it early enough.”

PASSPORT USE

The general feeling amongst the group was that patients did not like or use the passport, the consensus being that families use it more. As one person explained,

“the ten pilot ones that I gave out, there was only one patient that was actively engaged in using it... it was more the relatives.”

“I had one family in particular... there were a lot of sons and daughters who were inputting into the father’s care and they found it very useful just as a track of communication for the family so they knew when the patient was given... the person coming behind knew what time the last dose was given... and they found it very helpful from that point of view.”

For some families the passport functioned as a tool-kit to use in bringing up awkward or difficult conversation. As one participant explained,

“It gave the families an opportunity to talk to the patient maybe about some of the questions that were in the passport, which the patient may not necessarily want to talk about... you know... advanced care planning and the likes of DNR... it gave them the opportunity to open-up that conversation.”

Participants confirmed that they had used the passport with patients and had written in them, with a range of examples were given of the type of information they had added to the passport, these included:

“I was using writing in it maybe if the patient was going up to see the Oncologist and I wanted to give details of what I had discussed with patient and family before they were going up to see the Oncologist.”

“I was writing in just helping them talk through their practicals... you could write down like any advanced care plans they wanted... write it in for what they wanted to say.”

“In one other instance I wrote in... because the patient was adamant that he wanted to stay at home, so we were able to put in the preferred place of care was home but obviously that information was then relayed on to GPs/nurse etc as well, but it was documented.”

“Useful contact numbers I put in for them... the district nurse’s number... so they were all under the one spot for them, that if the family did need to contact someone

quickly they weren't chasing around the house trying to find different telephone numbers."

All of the participants felt that it was easy to use the passport. One person also explained that it was easy for patients / families to use it too. As he / she put it:

"It's very straight forward, I think it's quite easy for them to use and I know patients or any relatives that have fed back to me said they found it quite straight forward and I think the fact it is laid out in sections was very good."

None of the participants described finding any of the sections of the passport difficult to use but in the majority of cases, participants felt that few other healthcare professionals used the passport, in particular, GPs, district nurses and OTs were described as being either too busy or reluctant because of duplication. Some of the comments made included:

"Anytime I read it, It was always just either myself writing in it or the relative or the patient writing in it."

"I had a patient who had the Marie Curie support team involved as well and actually the first day that I was introducing the passport; the Marie Curie nurse happened to be there and she certainly then engaged with it and she did weekly sits and would have put some information into it as well, but other than that... I didn't see any GPs writing in or any other notes from any other health professional... and I encouraged the patients to try and leave the district nurse the notes so that other professionals would see them."

"Certainly OT, if they come out to do an assessment for example, I had one patient who had a respiratory nurse involved as well, but again there was no other follow-ups from other health professionals that I could see."

"I think Oncologists would be good if they could write in it, especially when patients are going to clinics and finding out more about their illness and their 'chemos' that they are going through and the side-effects of their 'chemos' and stuff."

"I did have one Oncologist did write in it which was excellent. But as regards district nurses and other professionals they were very wary about doing it, they said they

had their own notes and they wanted to write in any information on those notes... They thought it was creating more work for them because it was duplication and they had enough to write-up... their own notes."

"I had a lady went to day therapy up at ... (another hospice) and they actually wrote in it just to say a change in medication and that, so they had written in it about what they had done, the medication list change... so that was very helpful too."

LEVEL OF INVOLVEMENT - COMMUNICATING TOGETHER

Mixed views were expressed with regard to the perceived impact the passport had on the communication of preferences and plans for care between staff, the patient and family members. Whilst it was recognized that the passport did serve a positive function in enabling families to better communicate with the patient, participants felt that their own personal involvement in the situation played a significant role and that this needed to be taken into consideration and weighed against the perception that the passport by itself was a catalyst in instigating impact. Again, some of the views expressed included:

"It raises some issues in some houses that maybe wouldn't have been raised, but I think as well maybe, you know, the issues would have been raised anyway because of the families that you are dealing with. I don't know that the passport influenced that."

"I'm going to sit on the fence with that one because I think because of our input with patients as well and because we talk to patients about the future and things, I don't know, I couldn't one hundred percent put it down to the passport doing that to be honest with you."

"I don't think it had any major influence on the issues that we would have been raising anyway."

The general consensus expressed by participants was that other health care professionals viewed the passport as duplication. As some of the participants explained:

"Obviously there's more documentation... the likes of the district nurses have their own notes. GPs really probably weren't that terribly interested and wouldn't have had time probably to write in it, so I just think, just another bit of documentation."

“I agree with you, the district nurses especially have their own notes which are left in the patients’ houses so why would they want to duplicate their notes?”

“I think they thought it was useful for the patient as opposed to for them; I think they felt that it was useful for the patient to have as a documentation of their journey but not for them to write in it.”

DECIDING TOGETHER

Mixed views were expressed by participants as to the impact the passport had on their decision-making with patients, family and health care professionals. One of the participants described how:

“I can actually honestly say, I don’t think it made any difference you know with regard to decision making overall. A lot of my patients actually weren’t seeing Oncologists at that time... there were some of them that were in the last three months of life, so I can’t say it influenced any decision making.”

Another participant reiterated that whilst the passport did not impact decision-making, it was of benefit to the family:

“No I didn’t feel it made any impact or... changed or influenced any decision making or anything like that... it was more benefit to the family.”

One of the participants described having been slightly influenced by the passport with regards to decision-making; as he / she put it:

“The only decision-making it influenced for me was whenever... wrote down whatever medication the patient was taking, so if they had taken lots of PRNs then you could track what they had been taking and when they had been taking it. So I suppose it was useful from that point of view. Like, you know, if you hadn’t seen a patient for a few days the relatives were writing down how much of the break-through medication they were taking, so then you were able to see was there a pattern for pain and things like that. So I suppose maybe slightly would have influenced.”

ACTING TOGETHER

The consensus amongst the group was that the passport had not helped them to form more supportive partnerships with patients, family and other healthcare professionals. As a number of the participants explained:

“I wouldn’t have thought so to be honest with you, because I think we have a very good relationship with our other health care professionals that we work with in the community... so to be honest with you, I don’t think the passport would have made any difference to that. As for the patients probably not... the ones that I’d given it out to I had got to know over a period of time and so they already had that support in place with myself anyway so I don’t think the passport made a lot of difference that way.”

“I didn’t see any difference at all, you know obviously we do have a good relationship with our patients and families so the passport didn’t really make much difference as such.”

“I think the fact that you already had a good relationship helped let you be able to get the passport out.”

“It was not that the passport itself as a document helped our relationship with other health care professionals... I don’t feel it did.”

“I didn’t see any big influence in that supportive relationship... and I agree... the fact we knew patients/families well... I think a lot of them actually took the passport as a good gesture and I did see some just sitting on the bedside table and a few of them never opened but they certainly readily accepted it because we were giving it to them.”

RECOMMENDATIONS FOR FUTURE DEVELOPMENT

Whilst participants indicated that the passport is a useful tool for patients and family use in the future they felt that it needed to be given out *“in a more timely fashion.”* When asked if it was useful for them as healthcare professionals, the view expressed was summed up by one participant who stated:

“I don’t see it as a tool for us, it really should be a tool for the patient and the families to use with our support... I don’t think it added to our assessment skills of the patient because hopefully we do that anyway.”

The following suggestions were made by participants to improve the passport, or to help people to use it more effectively:

“Give it out earlier at the initial clinics would be better because they would be able to map their journey with it.”

“One family did say to me about getting more inserts for it. That was one thing that they found they didn’t have enough of the wee inserts... I just opened another passport, took the inserts out and gave them to them.”

“It was well laid out so I can’t see any need for any changes with it... it’s probably timing more than anything, it’s a fair enough document, so you want to get your use out of it.”

Discussion

The initial interest in the passport was positive, with 74.6% of those offered it accepting and using it. While the majority of these people accepted a research pack (92%), only 44.1% responded to the initial questionnaire, with just under 25% of these respondents returning a further questionnaire in 4-6 weeks. A low response rate to questionnaires and a high attrition rate has been seen in many palliative care studies (Hui et, 2013; Jordhoy et al, 1999; McWhinney et al, 1994), and has meant that the intended statistical analysis in this study was not possible, including trying to identify if any particular groups of patients were more likely to use the passport than others. The original sample size calculation was based on a 50% attrition rate, and when the attrition rate was seen to be higher than this, recruitment was continued until more than initially were targeted accepted research packs. However, due to a very low ongoing response to questionnaire 2 the study had to be closed before the required number were achieved. The attrition rate from research packs given out to questionnaire 2 returned was almost 90%. Of those who did respond after having had the passport for 4-6 weeks, approximately two-thirds stated it was 'very useful' or 'quite useful' and would recommend the passport to others. However, due to the low response rates this could be a very biased sample, and it is not possible to draw conclusions about the usefulness of such a document in general in the palliative care setting from just the patient responses.

While the initial intention with this study was to interview patients and their families, and review used passport documents in addition to the patient questionnaires, it was not possible due to research staffing challenges and the low response rates to the two questionnaires. Hospice HCPs who had seen how the passport was used by patients were identified as potential surrogates who could provide information on if and how the passport was used, and their impressions of how useful it was in the palliative care context. A questionnaire was used to elicit a wide range of opinions, and then a focus group to seek more insight into a variety of issues was carried out. A range of Hospice HCPs (mainly nurses who were the professionals involved in the implementation of the passport) participated in the questionnaire- they had a wide range of years' experience working in the speciality and included both those who had given out a lot of passports and those who had given out only a few. The HCPs involved perceived a varied range of uptake of the passport by patients, and it may be that this and the numbers of passports distributed are linked to the enthusiasm of the HCP for the passport and how they portrayed it to patients.

When respondents were asked initially if they found repeating information about themselves to multiple HCPs burdensome, 40% stated that it was and almost 70% were interested in a document that may cut down the need to repeat such information. However, when given such a document to try, only 4 respondents stated they had used it 'a lot' or 'quite a lot', and only 10 (38.5%) respondents stated that they had actually written in it. While half of the HCPs felt the passport was initially well received by patients, only 22.2% perceived that the passport was used regularly by patients and their families. This lack of use did not appear to be due to its ease of use, as 65% of patients stated they found it 'very' or 'quite' easy to use, and this was confirmed by the focus group of HCPs- that it was easy for both patients and HCPs to use. It was also reported as looking quite professional, well laid out and user friendly, suggesting the design of the passport was adequate for the purpose for which it was intended. This lower than anticipated use has also been shown in the use of a personal health record in adults with learning disabilities – while 92% liked their passport, only 63% of these patients and 55% of carers reported passport usage (Turk et al, 2010).

Almost 44% of respondents felt the passport helped them cut down the number of times they had to repeat themselves, but only about half of patients who responded stated they had shown it to their HCPs- some stated they felt their HCPs either would not be interested or would not have time to look at it. The focus group confirmed this, with the consensus being that in the palliative context the passport was used more by families than patients, and that while occasionally the palliative HCP used it to communicate with other HCPs, it was perhaps more useful for communication amongst family members. They observed occasional use by other HCPs, but felt it often led to duplication of the work of these HCPs e.g. GPs and district nurses.

Before the passport was introduced, approximately 80% of respondents stated that they found it easy to talk to their families and HCPs about their day-to-day care, with only a few keen to talk more about this (20% to family, 13% to HCPs). Fewer (approximately 70%) found it easy to talk to family and HCPs about their future care, and more felt they would like to talk more about this (36% to family, 28% to HCPs). After 4-6 weeks of having the passport, approximately half felt the passport had helped them talk more to their families (41.2%) and HCPs (53.3%) about their day-to-day care. Over 55% felt the passport had helped them talk more to their families about their future care needs, but only 4 patients (23.5%) felt it had helped them discuss these needs with their HCPs. Very few respondents had actually recorded their future care wishes in the passport. The focus group of HCPs confirmed that the passport had helped facilitate some discussions with patients about these issues, more-so future care rather than day-to-day care, but also raised the issue that this may have reflected the hospice HCPs involvement and them initiating these conversations

rather than the passport itself. The HCPs did not feel the passport itself helped much in facilitating decisions or forming partnerships with patients, families and HCPs. These palliative HCPs did not find the passport helped facilitate conversations with other HCPs, reflecting what it was designed for- a tool for discussion with patients, not between HCPs.

At the training for passport initiation there was a concern about when the passport should be introduced to patients- would the first consultation be too overwhelming for patients and would it be better introduced after a relationship with the patient was formed? On reflection, after trying the different times of distributing the passport, half of the HCPs felt it was best used at the initial consultation, with almost 40% feeling that the second consultation was more appropriate, and just over 10% feeling it was better offering it to patients after more than two consultations. It may be that different timings would be appropriate for different patients, depending on the issues raised at each consultation, rather than a blanket policy for a prescriptive time frame for HCPs offering its use to patients. This was confirmed at the focus groups, with individualised time of initiation confirmed as being most appropriate. The focus group participants also felt that it may be that when they were seeing the patients the passport was less useful than it would have been earlier in the patients disease trajectory, and it may be that if the passport was distributed at an earlier stage e.g. in oncology clinics when the patient was still undergoing more active treatment, that it may have been more beneficial and hence better used, than when patients became weaker and frailer and it was perhaps more burdensome for them. More research in this area is needed. Due to the low response rates it was not possible to determine if a patient's prognosis affected their use of the passport.

Despite the low passport use, half of the HCPs felt it was useful for palliative care patients, and 44.4% thought it should continue to be offered to patients for use in this context. It may be that it is useful for some patients in the palliative care setting but definitely not all, and those that it is useful for should be offered the opportunity to use it.

Strengths of this study include that it was used in a specialist palliative care population across a large geographical area, with many patients with a wide range of conditions at different stages of their illness considered for inclusion in the study. It included all those known to the specialist palliative care team, including those with malignant and non-malignant palliative conditions. High numbers of patients were offered the use of the passport in a very pragmatic setting within the context of day-to-day care by the patient's own palliative HCP, rather than by an independent researcher, which reflects daily practice.

Weaknesses include the low response rates of patients to the questionnaires, and a very high attrition rate, meaning statistical analysis was restricted. This has also been an issue in other studies in this population. In order to not put patients under undue pressure, there was no follow up to the questionnaires if the patient did not return them. The respondents are perhaps a biased cohort as it may be they were more comfortable completing paper work, and hence more likely to use the passport. It was not within the scope of this study to assess this. The initial intention was to interview patients and review passport documentation, but due to the low uptake of use and staffing issues this was not possible.

Conclusions and Recommendations

This study looked at the use of a patient held passport in the specialist palliative care setting. While initial uptake of the passport was high, use appeared low and due to a very low response rate to questionnaires it is difficult to draw firm conclusions on its usefulness. From this evaluation a number of recommendations can be made:

1. The passport is not well used by all palliative care patients and therefore should not be given to all; this evaluation does not support widespread use in this setting.
2. The passport was felt to be useful by some palliative care patients in that it facilitated communication with their families and HCPs about their day-to-day care and future care, and therefore should be considered for use in some patients. Due to a high attrition rate it was not possible in this evaluation to determine if there were groups of patients who were more likely to use it than others. HCPs should use their judgement in determining if the passport should be offered to individuals in the absence of evidence.
3. The passport may be more useful earlier in a patient's disease trajectory and studies looking at its use from the point of diagnosis of a palliative condition should be considered to compare with the use of the passport in this population with a shorter prognosis.

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