



Public Health
Agency

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**Evaluation of the Regional Hospital
Passport for People with Learning
Disabilities**

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Executive Summary

Following the introduction of Guidelines and Audit Implementation Network's (GAIN) guidelines, the PHA developed the Regional Hospital Passport for Individuals with Learning Disabilities (RHPLD). The RHPLD provides information that will help hospital staff to make reasonable adjustments to provide safe and effective care.

Evaluation of the RHPLD has included interviews regarding distribution processes and experiences of using the RHPLD, surveys regarding awareness of the RHPLD among the C&V sector, and desktop analysis of downloads of the RHPLD and guidance notes from the PHA website.

Key findings from the evaluation are as follows:

Distribution

- Distribution intentions were to ensure the RHPLD would be easily accessible for people with learning disabilities (PWLD). To this end, the RHPLD was distributed to a wide range of services/departments, and approaches varied widely between organisations.
- In addition to distribution of hardcopies, on average there have been 61 copies of the RHPLD and 11 copies of the associated guidance notes downloaded per month.
- The top-down distribution approaches were reported to cause initial delays in circulation of the passport documents and processes for reordering were unclear.
- A more targeted distribution approach may be effective going forward making greater use individuals working with PWLD.

Awareness, reach and uptake

- Evidence of best practice with a word of mouth approach (eg in staff meetings, induction for new staff, general discussion, awareness raising sessions) to raising awareness being championed as effective. This approach meant that questions could be answered and fears about potential burden on workload could be quickly addressed which ultimately increases buy-in to the process.
- PWLD championing the RHPLD was considered an important element of promotion amongst others with learning difficulties, helping to make the passport more relatable.
- Awareness among individuals responding to an online survey distributed via C&V organisations was high, with three quarters being aware of the RHPLD, and two thirds were aware of how to find copies of the passport within their organisations.

- However, there are gains to be made in promoting the RHPLD documents and how they should be used. A communications strategy may help with developing a systematic targeted approach. Whilst greater use of individuals/services working with PWLD, resources to raise awareness within organisations will need to be considered.

Usage and reasonable adjustments

- The introduction of a completed RHPLD when a PWLD was attending hospital was reported to open dialogue between hospital staff and the passport holder. Improved communication was reported to have reduced anxiety and stress among PWLD, their carers and hospital staff. This eased the admission processes and ensured treatment was provided more quickly and with greater adherence.
- Examples of reasonable adjustments included speaking more slowly, allowing more time for appointments, adapting behaviour, ensuring consistent care and providing regular updates if delays were experienced. Using reasonable adjustments when providing care were reported to improve communication, reduce distress and make the hospital experience less confusing for PWLD.
- Some concerns remain about the confidentiality of the RHPLD. Concerns are centred on visibility of the document due to its size and secure storage when PWLD are admitted to hospital. These issues warrant further consideration.

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Glossary of terms

ARC	Association for Real Change
C&V	Community and Voluntary sector
ED	Emergency Department
HSC	Health and Social Care
HSCT	Health and Social Care Trust
NHSCT	Northern Health and Social Care Trust
PHA	Public Health Agency
PWLD	People with Learning Disabilities
RHPLD	Regional Hospital Passport for people with Learning Disabilities

1. Introduction

Going into hospital can be a stressful experience for anyone but particularly so for people with learning disabilities^{1,2,3,4}. Difficulties can be encountered with respect of communication (e.g. expressing pain, feelings of discomfort, etc.) anxiety and self-management. Alongside this, hospital staff may have a limited knowledge of the additional health needs of those with learning disabilities (such as increased risks of choking, sensory impairment, mental health issues, etc.). Taken together these issues have the potential to impact the level of care those with learning difficulties receive^{1,5}.

A lack of effective two-way communication acts as a barrier to safe and effective care of people with learning disabilities (PWLD) when they go to hospital (either inpatient or outpatient)^{6,7}. Poor communication between PWLD and hospital staff can result in staff failing to receive and/or provide key information their treatment⁸. Ineffective communication results in delayed diagnoses and treatment, causes distress for PWLD and their carers, and has been a contributing factor in avoidable deaths among PWLD⁵. To help improve the healthcare of PWLD when they attend hospital, the Guidelines and Audit Implementation Network's (GAIN)⁵ produced guidelines for best practice within Northern Ireland. The use of the regional hospital passport was recommended within their guidelines as a way forward. Recently, the guidelines have been updated by The Regulation and Quality Improvement Authority (RQIA)¹.

1.1. The Regional Hospital Passport for individuals with learning disabilities

Following on from the GAIN recommendations, the Public Health Agency (PHA) developed a single regional hospital passport with guidance notes to be used in Northern Ireland. This work was taken forward by the PHA's learning disability health and well-being improvement group, who worked with a range of key stakeholders (including HSC Trusts, education providers, PWLD and their families/carers). The purpose of the RHPLD is to provide vital information about the person with a learning disability. This includes their personal information, details of the key people caring or providing support to them, their communication preferences, medical history, tips on how to provide care, and how to keep them safe. The idea is that this information will help hospital staff to make reasonable adjustments¹ to provide safe and effective care.

¹ Examples of reasonable adjustments include adapting communication styles (e.g. speaking slower, using clear simple language, repeating important pieces of information) to ensure an individual with a learning disability fully understands what is happening, the treatments they are to follow, help with setting up appointments, and help with managing identified issues. The level and number of adjustments needed may vary and there is no 'one size fits all' approach.

The RHPLD was piloted in August 2016, with feedback from HSC staff, PWLD and their families/carers. Feedback was taken on board and the final version of the RHPLD and guidance notes were formally launched in May 2017. Hardcopies of the RHPLD were sent to each of the five HSC Trusts and five community and voluntary organisations for wider distribution. A PDF of the RHPLD was also available for download from the PHA's website.

2. Evaluation approach and methodology

Evaluation of the RHPLD has been ongoing from March to September 2018 with a central aim:

To evaluate awareness and usage of the Regional Hospital Passport for individuals with learning disabilities to aid communication and positive experience within hospital settings for individuals with learning disabilities, and to make reasonable adjustments to ensure safe and effective care.

Seven objectives presented in Table 1 were devised to meet the aim of the evaluation. The approach and methodology used to evaluate the Regional hospital passport are outlined against each of the objectives in Table 1.

Table 1: Overview of evaluation approach

Objective	Approach	Data sources:
To describe the distribution processes of the Regional Hospital Passport in relation to accessibility for individuals with learning disabilities, their carers and HSC staff	<ul style="list-style-type: none"> • Analysis of downloads of the RHPLD and associated documentation • Staff interviews regarding distribution, records keeping, & awareness 	<ul style="list-style-type: none"> • Google analytics • Staff interviews (HSC and C&V)
To examine awareness, reach and uptake of the Regional Hospital Passport among individuals with learning disabilities and their carers	<ul style="list-style-type: none"> • Feedback regarding awareness, expected benefits, identification of gaps • Feedback from awareness raising sessions and ideas on how to best promote • Stakeholder feedback on uptake • Identification of areas of demand 	<ul style="list-style-type: none"> • Staff interviews (HSC and C&V) • Staff feedback survey for awareness sessions (NHSCT only) • Interviews with individuals with learning disabilities • C&V awareness survey
To explore how the Hospital Passport is used for the benefit of individuals with learning disabilities, their carers and staff	<ul style="list-style-type: none"> • Stakeholder feedback on experiences of usage and impact on healthcare provided • Feedback on reasonable adjustments made for individuals attending hospital and assessment of impact 	<ul style="list-style-type: none"> • HSC staff interviews • Interviews with individuals with learning disabilities and their carers • C&V awareness survey
To obtain any wider feedback from stakeholders about the HP	<ul style="list-style-type: none"> • All feedback and comments that can be used to improve distribution, awareness and usage of the RHPLD 	<ul style="list-style-type: none"> • Staff interviews (HSC and C&V) • Staff feedback survey for awareness sessions (NHSCT only) • C&V awareness survey • Interviews with individuals with learning disabilities and their carers

2.1. Methodology

The methodology used to evaluate the hospital passport included (Figure 1):

- 9 telephone interviews about the distribution processes (5 HSC & 4 C&V). The majority of interviewees were female (n=4) and included nurses, healthcare facilitators, speech and language therapists, operational staff, campaigns officers, mental health professionals, and staff from the C&V sector;
- 42 responses to a HSC staff awareness survey for staff who attended sessions designed to promote the RHPLD in the Northern HSCT early in 2018 (response rate 81%). Awareness sessions were advertised by promotional flyers and were scheduled for break times to encourage attendance. Sessions lasted 30 minutes and introduced attendees to the RHPLD and provided tips on using it to communicate more effectively with PWLD. At the end of the session, all attendees were asked to complete a brief feedback survey. Anonymous survey responses were returned to PHA for analysis
- 5 interviews about experiences of using the passport (3 HSC & 2 C&V). Interviews were conducted face-to-face (n=4) or by telephone (n=1) to suit interviewees and all interviewees were female. Interviews lasted 20 minutes and covered how the passport has been used, the impact of this and any other feedback;
- 71 responses to an awareness survey among the C&V sector. A link to an online survey was distributed via Association for Real Change (ARC) and fieldwork took place between 19th July and 31st August 2018. Participants were female (n=64, male n=7) and worked in supported living/residential care (n=19), residential managers/team leaders (n=28) with other roles including behavioural therapist, clinical psychologist, psychiatrist, employment and recruitment, researcher, social worker, administrative, speech and language therapist, nursing, and carer. Participants had more than two years' experience working in their professions and all had daily contact caring for PWLD in paid or unpaid capacity. They reported helping PWLD to attend the GP (n=59) or hospital appointments (n=66, including out-patient appointments n=58 or attendance at emergency departments n=57).
- Desktop analysis of Google Analytics to monitor downloads of the RHPLD from the PHA's website (May-17 to Jun-18).

Figure 1: Evaluation approach

Google analytics	Interviews regarding distribution processes	Interviews regarding experience of using the RHPLD
Desktop analysis of downloads of the RHPLD and guidance notes (May '17–Jun '18)	HSC staff (n=5) C&V staff (n=4)	HSC staff (n=3) C&V staff (n=2)
Feedback from awareness raising sessions (NHSCT only)		Awareness survey of the RHPLD
Hospital staff (n=42)		C&V sector organisations (n=72)

3. Distributing the Regional Hospital Passport

In March 2017, Chief Executives within the HSC and C&V sectors received hardcopies of the RHPLD, its associated guidance notes and cover letter. The cover letter detailed the background of the RHPLD, its intended role in supporting the delivery of services to PWLD, and closed with the request that a PDF version of the RHPLD would be made accessible on their organisations website in addition to the distribution and wider circulation of the RHLD across relevant key staff within their organisation.

These key individuals took part in interviews to find out how the RHPLD was distributed, promoted and how awareness was raised within their organisations. The following section discusses four key areas of the distribution process; the rationale and location of where passports were distributed, challenges encountered during distribution, what went well, and suggestions from staff as to how they think the process could be refined in future.

3.1. Distributing the Hospital Passport

There was intention among those who were responsible for distributing the passport that it was sent to appropriate departments and/or individuals to ensure that they were easily accessible by PWLD:

“We distribute them throughout the acute hospital and get them distributed to the likes of residents at home and clients living in the community.” HSC

“When we received the passport, we distributed it to every service user and asked if they wanted to use it. With consent, we incorporated it into the care and support plan, so if they were admitted to hospital their details were handy and up to date.” C&V Organisation

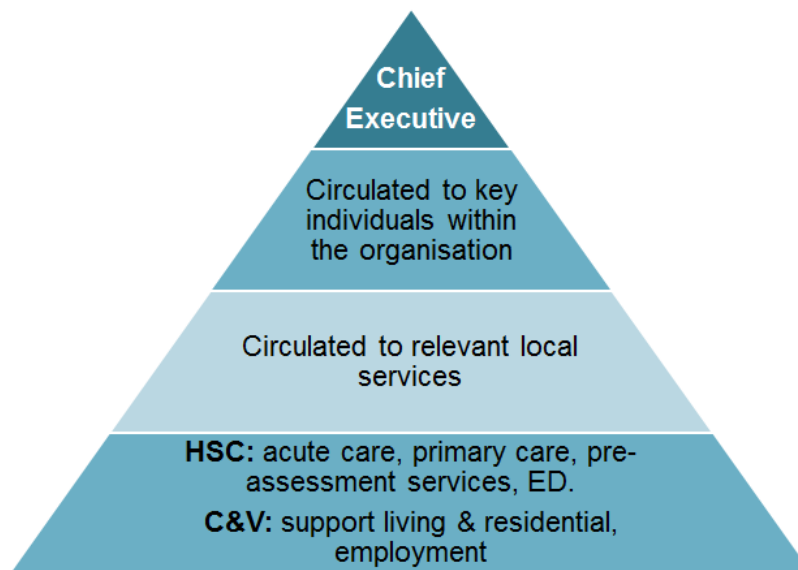
Efforts to ensure the passport reached PWLD in the community involved targeting groups, services and individuals who had frequent contact with these individuals:

“For us, it would be to complete them with our clients of learning disability who we know our frequent users of hospitals and who may have poor physical health and have to have frequent admissions to hospitals or anybody who has planned hospital admissions as well that we know in advance.” HSC

The range of departments that the RHPLD was distributed to was varied across the organisations, with none following the same process. This included primary and acute care settings such as Emergency Department, out-patient and pre-assessment units. Outside of

hospital, the passport was sent to GP surgeries, supported living and residential care, community nurses and learning disability services (Figure 2).

Figure 2: Distribution Process



Whilst the passport was distributed widely, there were limited records maintained by stakeholders regarding the number of passports received and where they were distributed. Whilst some stakeholders were aware of the numbers or types of copies received, others were unclear:

“I think I only got one box of 100 but I think they had come through the divisional office and I am not sure where they all went to.” HSC

One C&V distribution stakeholder had kept a detailed record of the number of passports they had received from their chief executive. This record included the names of other organisations they had distributed the passport to and the numbers sent.

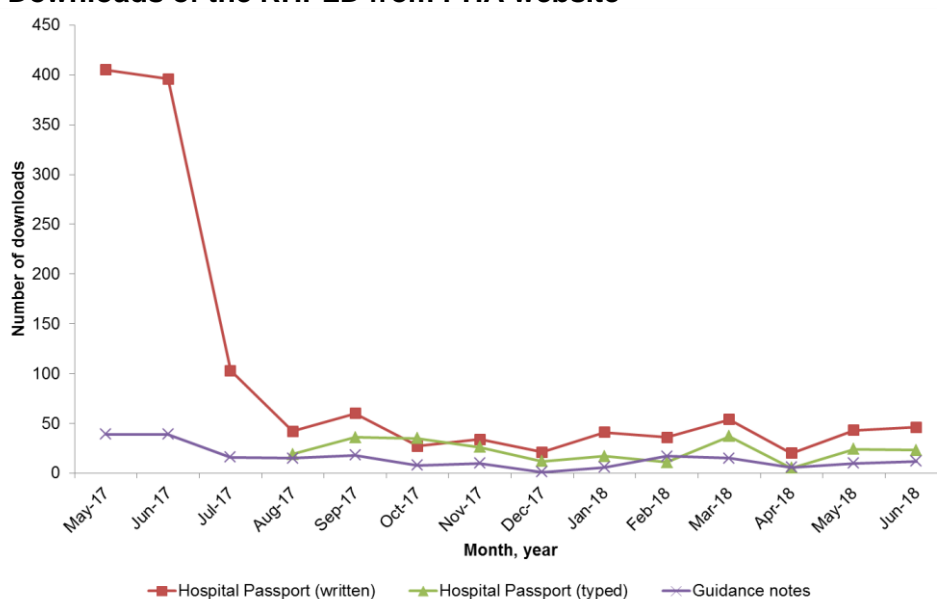
In addition to the hardcopies circulated via the Chief Executives within HSC and C&V organisations, it was also possible to download the RHPLD from the PHA’s website. Interviewees described how they circulated the RHPLD by embedding a link in their own organisation’s intranet or downloaded the PDF and stored this locally or circulated via email. This electronic version was considered particularly accessible and useful in an emergency situation:

“It’s quick and if somebody needs it in an emergency situation...it is useful to have the electronic one there for the person going in to get the carer to write it up.” HSC

Analysis indicated that following an initial peak of download activity when the RHPLD and guidance notes were launched, downloads have remained relatively stable since August 2017. Analysis of online activity between May 2017 and June 2018 shows (Figure 3):

- A printable copy of the RHPLD that can be written on has been downloaded 1,348 times by 988 unique users and a version that can be typed on has been downloaded 251 times by 185 unique users since being introduced in Aug-17.
- The guidance notes have been downloaded on 220 occasions by 175 unique users.
- On average from August 2017, there have been 61 copies of the RHPLD (39 written version & 22 typed version) and 11 copies of the associated guidance notes downloaded per month².

Figure 3: Downloads of the RHPLD from PHA website



3.2. Distribution challenges and suggestions for going forward

There main challenge around distributing the RHPLD was the top-down distribution approach which was described by staff as causing delays in it being made available. It was suggested that greater use of staff with an interest in working with PWLD would be more effective. This included staff working as healthcare facilitators, learning disability nurses etc. It was felt that these staff would be already bought in to the process. These staff may be better aware of where to target when distributing the passport. Their interest in working with PWLD would mean that they are more enthusiastic and driven when promoting the RHPLD:

“Like everything that’s new has to come from the top down. But I feel that the momentum can get lost in all the tiers of management because we are there on

² **Please note:** these figures may not fully reflect the usage of the RHPLD as blank copies can be downloaded and stored on individual’s machines for repeated usage. Saving blank copies on machines may make it easier for individuals to access blank copies.

the ground delivering the care plus being on the creative team behind it we are maybe more driven to give it out.” HSC

The top-down distribution approach also caused confusion about the processes for re-ordering the RHPLD. Some interviewees were unaware of how to get additional copies when their current stock was depleted.

“Nobody knew how to get them [additional copies of the RHPLD] and nobody knew where to get them from...how do we get more copies in the future?” HSC

Although the electronic copy of the RHPLD was considered useful for distribution, this version was often printed in black and white, often on poor quality paper. Consequently, interviewees felt printed copies were less appealing to use:

“It’s [printed on] just normal A4 [paper]...it’s a bit more flimsy. Most clinical areas only have access to a black and white printer so when you print it out on black and white rather than colour it doesn’t have the same affect so it’s maybe not as pleasing on the eye to read and to work through.” C&V Organisation

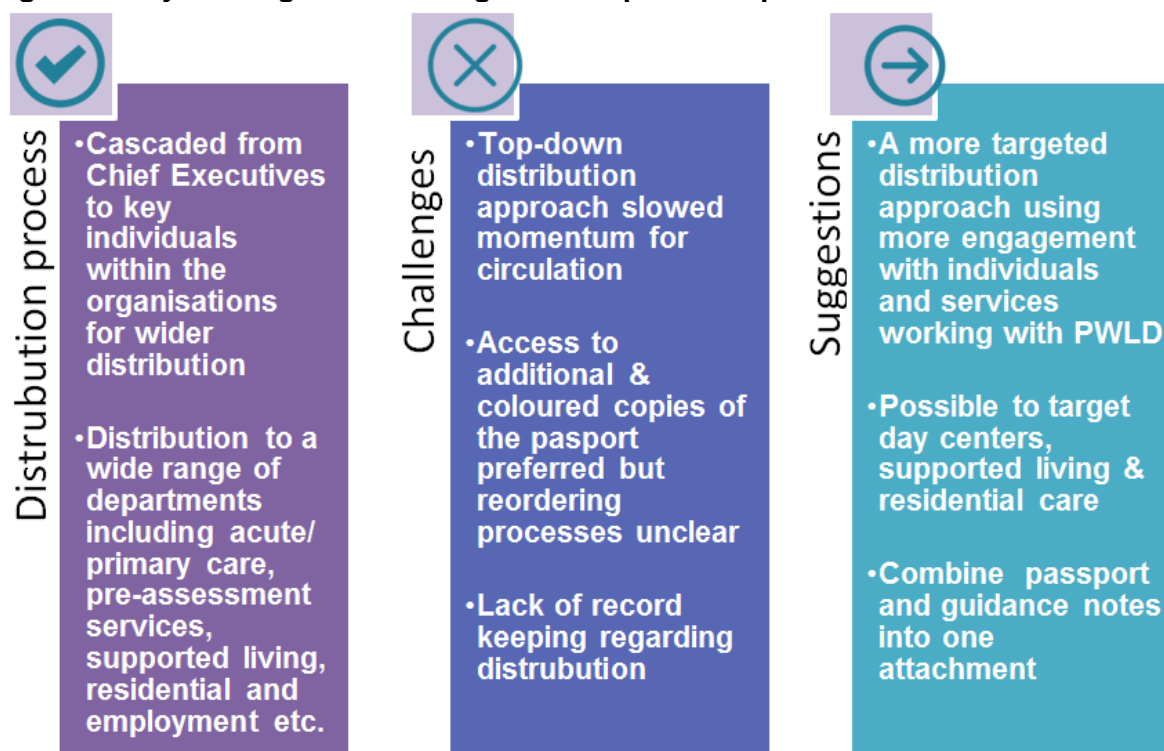
“I think the hardcopy is better, just due to the colour of the document. I think people prefer having that document, it looks a bit more professional than the printed-out sheets.” HSC

Interviewees suggested that distribution could be improved by targeting day centres, supported living and residential units where PWLD live or regularly visit:

“[The RHPLD should be distributed to] the residential homes that would have clients or other day centres or stuff like that. I think it would be very good to encourage the use of them because they would be well up with [knowledge about] their clients and if they were due to come in to hospital and they use our secondary services.” HSC

3.3. Summary regarding distribution

Figure 4: Key messages for the Regional Hospital Passport Distribution



4. Awareness, reach and uptake

When the RHPLD was distributed, a covering letter requested that awareness of the document was raised with staff in each of the organisations. Encouraging awareness and usage of the RHPLD was recognised by interviewees as an important factor for success.

“You need to have an awareness amongst staff to be able to ask for it and we need to evaluate the effectiveness of it so we can really bring back to staff the impact of this and then as they hear those stories and hear that data I think then staff are more encouraged to make it part of the generic care pathways.” C&V

4.1. Evidence of best practice

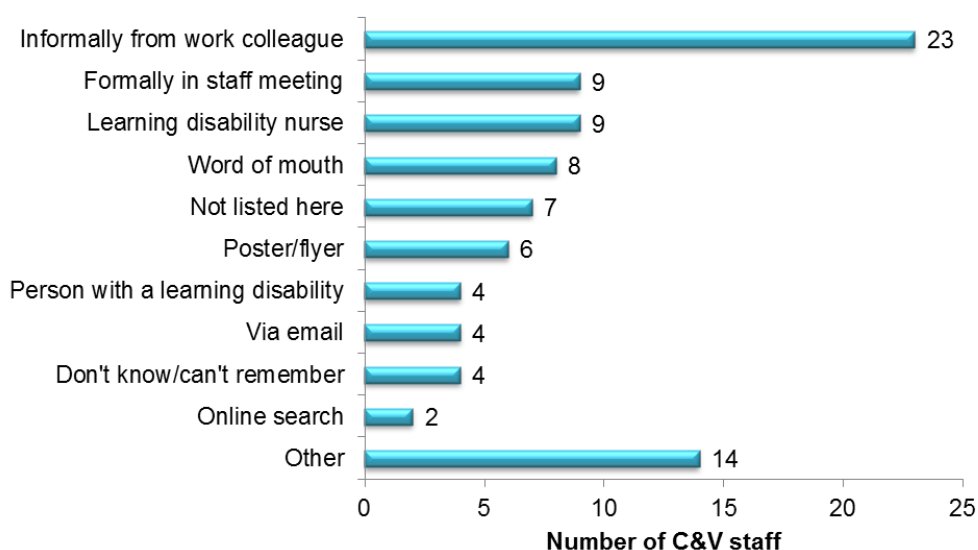
There was evidence that raising awareness of the RHPLD was best achieved via word of mouth. This included being raised during team meetings and when inducting new staff, holding specially tailored awareness raising sessions with staff, and having PWLD championing the passport.

Awareness was predominately raised by managers cascading information about the RHPLD at staff meetings and to key individuals. Interviewees reported that word of mouth promotion allowed the targeting of specific departments that interact most often with PWLD.

“I think it [sic word of mouth] worked well in our organisation because it was talked about and distributed at a meeting were all of the service managers where together.” HSC

Within C&V sector organisations, awareness was frequently raised informally during discussions between work colleagues (Figure 5).

Figure 5: How C&V staff had been made Aware of the RHPLD (n=54)



Having individuals raise awareness of the RHPLD via word of mouth meant that someone was available to describe how the passport could be used, answer queries and allay fears regarding perceived burden as a result of using the passport. When the RHPLD was fully explained to staff, its value was recognised and staff were enthusiastic about using it:

“Some of the staff were wondering ‘is this more work for us to fill in?’ but when it was explained to them ‘no, it is for the client and the carers to fill in and be in their possession’.” HSC

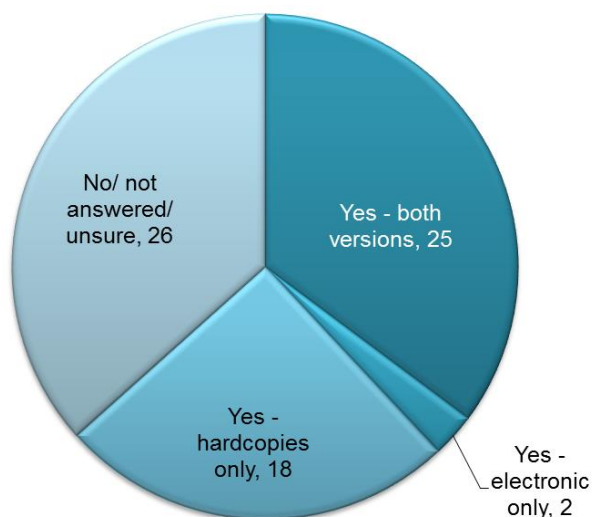
“Once they found out that it’s to help them provide the care and it is not to be completed by them as such, they can complete it but it’s really for the carers to complete along with the clients and they were happy.” HSC

The RHPLD was also added into induction processes for new staff members in some HSC Trust areas:

4.2. Levels of awareness

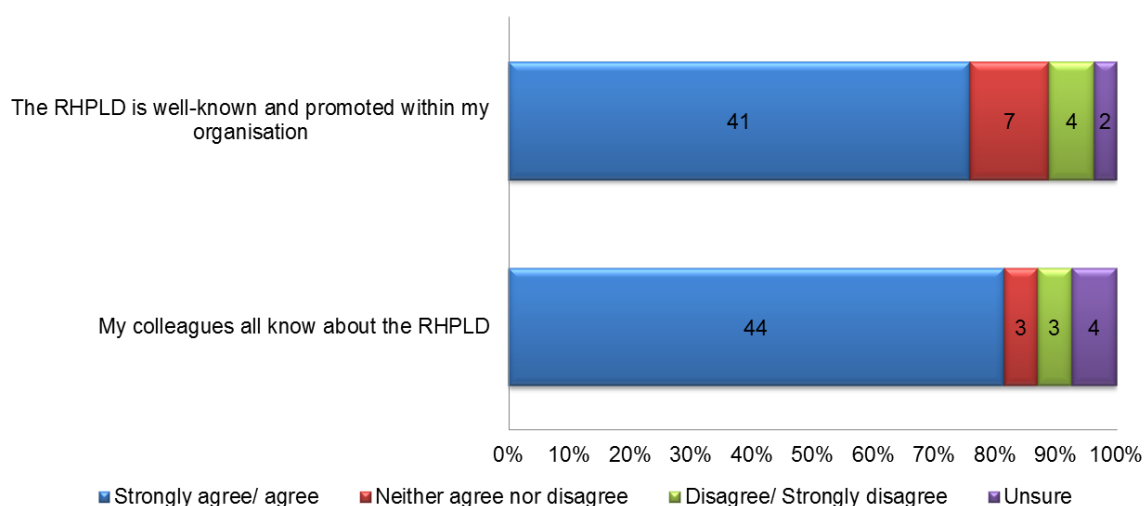
It was encouraging that three quarters of staff in C&V sector organisations who replied to an online survey were aware of the RHPLD. Furthermore, approximately two thirds were aware of how to find copies of the RHPLD within their organisations (45 out of 71 individuals). Awareness of where to access hardcopies was generally higher than the electronic copies (n=18 vs 2, respectively; Figure 7).

Figure 7: Access to a copy of the RHPLD in C&V workplaces (n=71)



In addition to C&V sector staff being aware of the RHPLD, these individuals also felt that the passport was well promoted and known among their colleagues (Figure 8).

Figure 8: Awareness of the RHPLD among the C&V sector

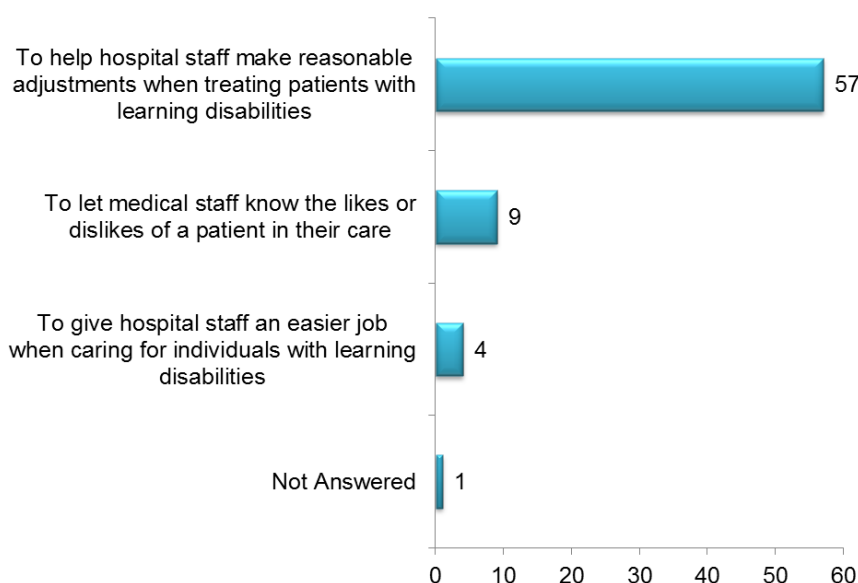


4.3. Understanding about the Hospital Passport

It is important that, along with awareness of the RHPLD, individuals understand how the passport should be used. Understanding about the RHPLD was obtained from individuals working in C&V organisations.

The majority of individuals in C&V organisations (n=57 out of 71) were aware that the RHPLD is designed to enable hospital staff to make reasonable adjustments when providing care to patients with learning disabilities. Nine felt the key purpose was to let medical staff know patients' likes and dislikes and four thought it was to give hospital staff an easier job when working with PWLD (Figure 9).

Figure 9: Understanding of the key purpose of the Hospital Passport among C&V sector



There was uncertainty about who should complete the RHPLD. Seventeen (out of 71) thought the document should only be completed by the individual who owns it. A further 21 said disagreed with this indicating that anyone can complete the document and seven were unsure. This uncertainty highlights a need to increase awareness around who can help complete the document.

There also seemed to be some uncertainty around information recorded in the RHPLD. Suggestions on improving the document included noting the passport holder's interests and how they like to spend their free time, or including information on pain relief. However, these sections are already included in the passport:

"I think another thing there to is maybe something where common interests, if you have a complete stranger coming into you and you are saying you are wanting to

do personal care or something, I think if you had something in it that you could use for conversation.” C &V Organisation

“I really wish there really was something, a heading in the hospital passport that mentioned somewhere about your pain relief”. C&V Organisation

Importantly, 66 (out of 71) individuals working in C&V organisations agreed that PWLD should bring the RHPLD with them when attending hospital. This is important given that staff within C&V organisations may help to prepare PWLD for attending hospital.

4.4. Barriers to raising awareness and suggested improvements

Despite a number of strengths in terms of awareness of the RHPLD, there were a number of challenges noted relating to the resources available to undertake this work. In each of the organisations, the number of individuals working or having an interest in learning disability services is limited. Whilst there was a keen interest in promoting the RHPLD, some stakeholders noted that their ability to raise awareness was impacted by staff turnover or sickness:

“We haven’t done a lot of promotion, it is slowly transcending through word of mouth whereas actually it needs to be celebrated and really embedded the importance of what this is used for.” C&V Organisation

“I believe one of the other Trusts had done [sic] a very good poster campaign... unfortunately due to sickness I haven’t been able to.” HSC

As part of the feedback from staff attending awareness sessions in the NHSCT, staff made suggestions on how they felt the RHPLD could be better promoted within HSC. Four staff (out of 42) highlighted that it was important for copies of the RHPLD to be available in all wards, departments and staff rooms. One person suggested that the status as a person with a learning disability should be held on the patient’s electronic care records. Another suggestion was to include information about the RHPLD on HSC screen savers. These suggestions may address concerns about staff being available to promote the RHPLD.

In addition to work undertaken in this evaluation, a survey of PWLD was undertaken by the *Telling It Like It Is* (TILII) group (see Appendix B for a full copy of their report). Nearly two thirds of individuals surveyed were unaware of the RHPLD, indicating that more needs to be done to raise awareness among PWLD. This was reiterated by interviewees who noted that awareness needed to be raised among this group:

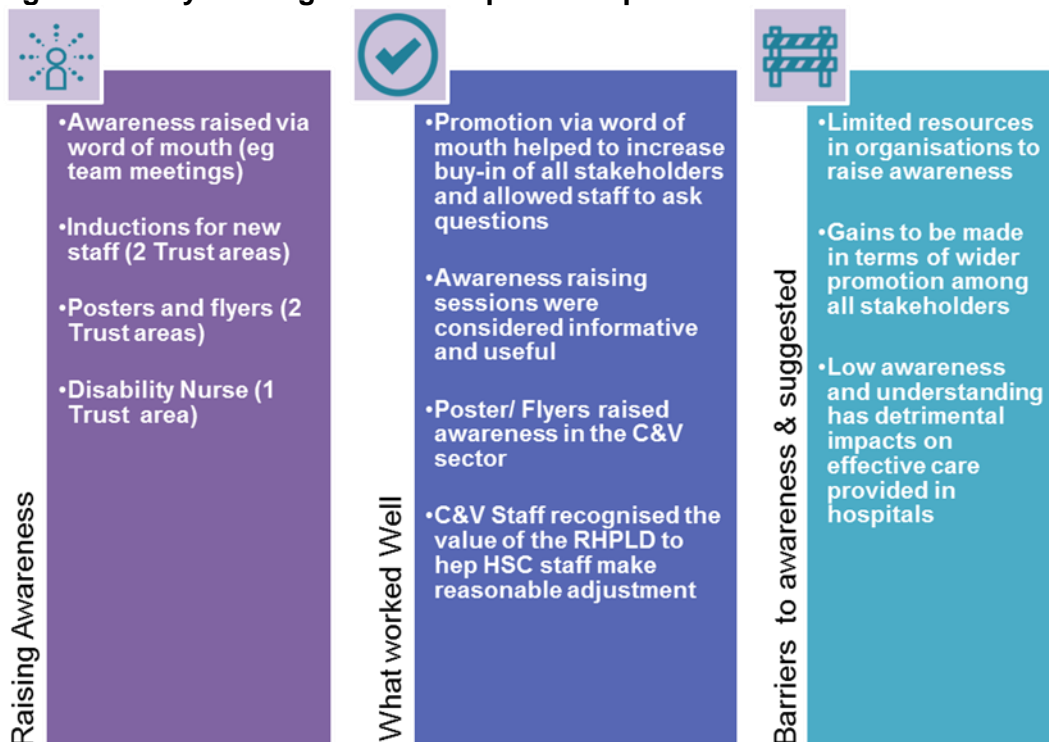
“Maybe more awareness needs to be raised with the service users about them [the Hospital Passport] because by the nature of some of the people we support, maybe the retention of memory isn’t that good or their focus... what I am afraid of... is that somebody gets it [the RHPLD] and then it goes in the drawer and everybody forgets.” **C&V Organisation**

The impact of low awareness of the RHPLD was described by one interviewee. On this occasion, when the RHPLD was presented to hospital staff, they returned it to the PWLD:

“There was uproar because the service user went to hospital and the hospital gave the passport back, they didn’t even bother opening it.” **C&V Organisation**

4.5. Summary regarding awareness, reach and uptake

Figure 10: Key messages from Hospital Passport awareness



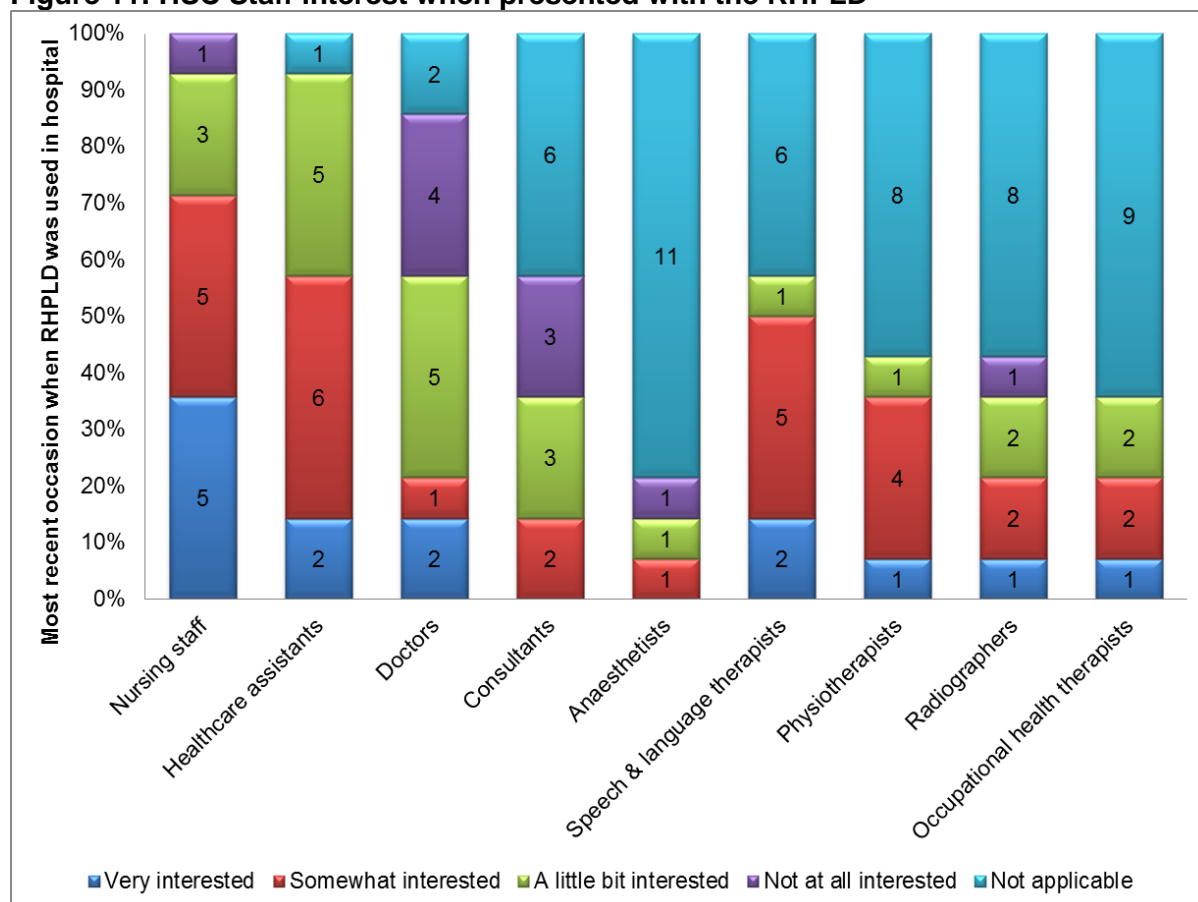
5. The Hospital Passport in practice – usage and reasonable adjustments

5.1. Presenting the RHPLD at hospital

Among C&V organisations, 49 (out of 71) individuals said they had attended hospital with someone in their care. An additional 20 said they knew someone in their care who had gone to hospital but they did not go with them. The majority of these hospital visits were emergency visits (48 out of 69, 20 planned and one unsure). Fourteen reported that the RHPLD had been used during the hospital visit, three of which by the PWLD and 10 by their family/carer³.

Figure 11 shows the interest of hospital staff in looking at the RHPLD as perceived by staff in C&V organisations. There was less engagement by PWLD for more specialist hospital staff (anaesthetists, occupational health, speech and language therapists, physiotherapists, radiographers, consultants). Staff that had more engagement with PWLD attending hospitals included nursing staff, healthcare assistants and doctors. Based on the perceptions of C&V sector staff, nursing staff and healthcare assistance had the greatest interest in the RHPLD.

Figure 11: HSC Staff interest when presented with the RHPLD



³ In one instance, who introduced the RHPLD was not reported.

5.2. Improving communication

A key fundamental purpose of the RHPLD is to improve communication between PWLD, their families/carers and hospital staff. It was therefore encouraging that HSC interviewees reported that the RHPLD helped them open a dialogue with the PWLD. Interviewees felt this was especially useful in situations where there were communication barriers and helped staff provide better care for PWLD in their care. Given the benefits of having the passport, staff reported feeling more at ease during admission and when providing treatment:

“The passport is quite useful because with somebody who they don’t know very well, it gives that person a starting point to talk to them...and that makes me feel comfortable.” **C&V Organisation**

“The information on it [the passport] was fantastic, [hospital staff] would have never known because they were treating the very ill patient who was very heavily sedated so they needed to ... wean him off the sedation and be able to deal with his behavioural issues.” **HSC**

HSC interviewees reported that using the RHPLD helped them to provide comfort and reassurance to the PWLD and their family/carer. Staff felt the RHPLD provided them with a better understanding of the patient’s needs and helped to make admission easier and help to minimise the patient’s fear and anxiety:

“You want to cut out that anxiety and you want to try and minimise any fear that they have and if you have as much information as you can be going in it is going to be so much easier for the person.” **HSC**

“At least with that it is giving a bit of communication about what I know about the individual and what will make their journey hopefully easier.” **HSC**

In addition to minimising patient’s fears and anxieties, staff in C&V organisations reported that having a RHPLD also improved their confidence in attending hospital with someone in their care. For instance, if a staff member did not know an individual in their care, the hospital passport provides all relevant information about the PWLD which reduces the burden on paid carers:

“[Staff] feel more comfortable when you go to the hospital with a service user so you have that information there with you encase you have forgotten anything, there is a sense of ease and security having the passport.” **C&V Organisation**

“Even for the staff member themselves, if you are being asked for information and you haven’t got it, it makes you feel stupid so if you have it to hand and you are very confident.” **C&V Organisation**

“It has been vital and if you are working with agency staff too, they don’t know the person at all so all the information is here.” **C&V Organisation**

However, one HSC interviewee was concerned that the existence of a completed passport would increase expectations but may actually be ‘*filed away*’ with the implication that it is not used. This concern emphasises that good awareness of the benefits of the passport are crucial:

“[The passport] helps. I would say not so much the communication but it helps the individual with their confidence in going to the hospital. They see that as a wee guarantee, it is down here, the nurses will read it and that is then my fear, in giving them that false hope that if it is filed away.” **HSC**

5.3. Reasonable adjustments

Ultimately, the RHPLD is expected to provide hospital staff with information about a PWLD so that they can use to tailor their care by making reasonable adjustments. This purpose was reiterated by interviewees:

“It’s just giving [hospital staff] a very brief overview but it is enough for them to maybe take note and say ‘okay maybe I need to do things a bit differently here’.” **C&V Organisation**

“I think it is an instant way to ensure you capture reasonable adjustment and I think that is one of the best parts of the passport. That people recognise and acknowledge that this person, regardless of what is wrong with them, they have a learning disability and that comes with some reasonable adjustment requirements and that that is done and managed respectfully.” **C&V Organisation**

HSC interviewees with experience using the RHPLD were asked if they could recall any examples of reasonable adjustments made in response to information contained within the document. A summary of reasonable adjustments made are in Figure 12.

Figure 12: Reasonable Adjustment made as a result of the RHPLD



Adapting communication approach and style was the most frequently described reasonable adjustment staff could recall. For instance, the passport offered detailed information on PWLD (e.g. likes and dislikes, their hobbies etc.), which helped staff to build a rapport with PWLD. Building rapport and establishing a connection with the patient then improved acquiescence in compiling with treatment:

“From the medic’s point of view the pressure on their time....[the passport] was of immense value and it saved a lot of time on relationship building and they were able to get the bloods taken and all of that, it made it much easier.” HSC

“For one of the people who was in hospital, what worked well was the staff started to ask her about her dog and that really calmed her down, a very simple thing but the nurse definitely wouldn’t have known to ask that if she didn’t have it in her hospital passport.” C&V Organisation

Simple information contained within the RHPLD was reported as beneficial in helping staff make reasonable adjustments. For example, having the PWLD’s preferred name or explanations of key phrases the individual may use was reported to be useful:

“[The passport is] fantastic. So the patient’s name, what they preferred [to be called] was not on his hospital records.” HSC

“We had a guy who went into hospital at one stage and he would have different sayings and we would have put his wee sayings in [the passport] and what they actually mean because it wouldn’t have maybe been understandable to the person in hospital but it may have been understandable to the person working with him every day.” HSC

In addition to improved communication, hospital staff improved their monitoring and observation of PWLD. This helped staff respond more appropriately to PWLD to minimise their emotional responses to hospital experiences (e.g. fear, anxiety, nervousness etc.):

“[The section on the RHPLD] ‘What to do when I am afraid’ and [the PWLD] said they didn’t want anyone coming in he just wanted to be on his own. If somebody is afraid or nervous you would assume that they wanted company but he said ‘no’ he wants to be alone. If he was getting anxious and wanting to hit out he would say no just leave me alone and I will come round. So that was really good.” HSC

Information about how the medication needs and preferences of PWLD was also considered a beneficial aspect of the RHPLD. One HSC interviewee described how they made reasonable adjustments for a patient by arranging for their carer to be available to administer medication. This ensured the patient’s adherence to treatment:

“The carer came in at medication times to help with that because apparently he was very very specific [about] who gives it.” HSC

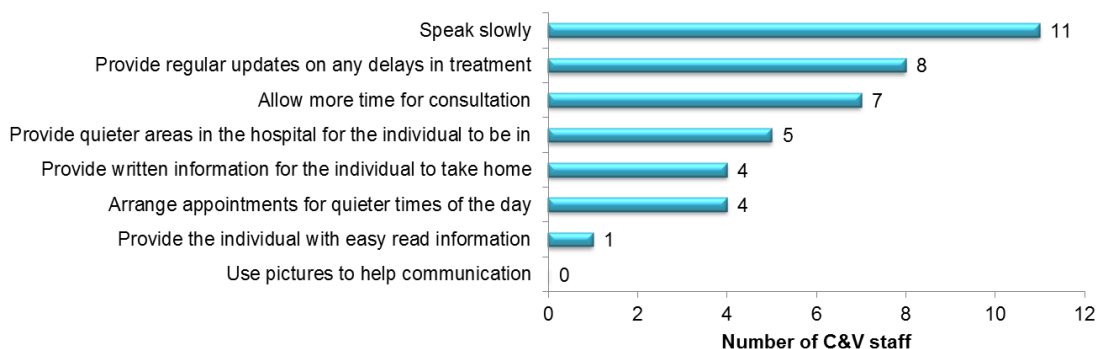
Other information that could be used to inform reasonable adjustments included information on the PWLD’s key worker, how staff could respond when the PWLD became anxious or worried, and details of eating, sleeping and personal hygiene preferences:

“One specific thing is my key worker [section on the RHPLD], that is very useful if there is something they are unaware of in the hospital.” HSC

“We went through what is your favourite thing to do? He would say ‘I like T.V. I like EastEnders’ things like that and it was great, went down to the food and down to the sleeping pattern, when do you get up and so much in the personal care and when we asked what do you like doing whenever you are at home and that sort of thing.” HSC

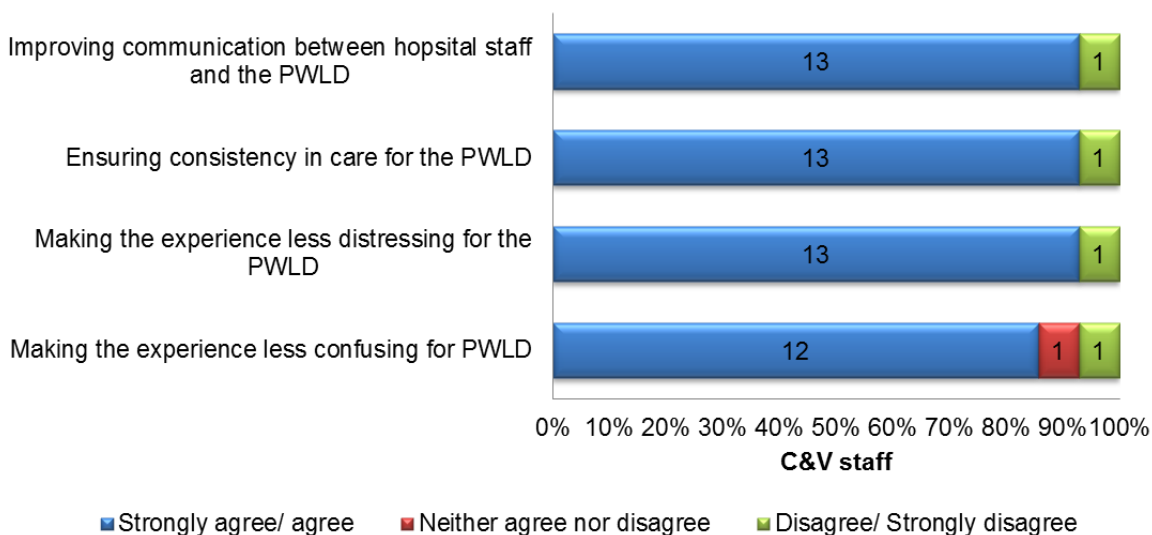
Fourteen staff in C&V organisations reported attending hospital with a PWLD when a RHPLD was used. Reasonable adjustments that they report hospital staff using are presented in Figure 13. Six (out of 14) individuals felt the reasonable adjustments were made in direct response to the presence of the passport.

Figure 13: Adjustments made by hospital staff after reading the Hospital Passport (n=14)



Feedback about the impact of using the RHPLD was positive among the 14 staff in C&V organisations that had attended hospital with a PWLD when the passport was used (Figure 14).

Figure 13: Impacts of using the RHPLD



Positive impacts were also noted by other stakeholders who noted the RHPLD improved the efficiency by which PWLD were admitted and treated in hospital. This contradicts the fears reported to be prevalent among people who have not used the passport:

“I think it has lessened the length of time that [PWLD] need to be in a hospital environment, I am thinking specifically for the times that they are coming in for assessment.” HSC

“For me it has very much reduced time, reduced the amount of questions and a lot of the questions are much more appropriate if you are going in the wards.”

HSC

5.4. Concerns about using the Hospital Passport

Concerns about using the RHPLD centred on the RHPLD not being used as envisaged. One HSC interviewee recalled an occasion where there was a perception that the passport was not given appropriate attention by hospital staff:

“When I handed it over, I handed it over to the staff and I could see they never even flicked as if they were interested at all.” **HSC**

In this instance, there was a subsequent breakdown in communication which resulted in pain not being managed. The experience of pain by the PWLD led to their behaviour becoming more challenging and their healthcare needs became more complex. This example highlights the necessity of the effective use of the RHPLD:

“[The PWLD] are sitting there and their pain threshold is quite high and they are in an awful lot of pain and that has knock on effects...[they became] agitated and presenting in a really difficult way and needing to go on a one to one [care by hospital staff]... it didn't go well for [the PWLD, they ended] in a care home in excruciating pain and ended up quite some time in nursing care when he probably could have went back home..” **HSC**

There were concerns that the size of the RHPLD increases its visibility and this was felt to breach confidentiality. One interviewee commented that some carers would not go to hospital carrying the RHPLD but might reconsider if it was re-designed. For example, being available via a mobile phone app might make it more accessible and ensure the PWLD has access to it when required.

“Some of the families and some of the adults we talk to said they don't actually want to go in carrying it and if they had a way of doing that that was a wee bit more personal.” **C&V Organisation**

“That if it is done correctly smartphones are used a lot wider and sort of having the information stored on a smart phone would be a better resource because everybody has a phone.” **C&V Organisation**

There were also confidentiality concerns about where and how the passport is stored when a PWLD is in admitted into hospital:

“I know initially in the hospitals there is the issue of where you keep them? Do you keep them at the bedside or in the client notes so that it is visible to everyone that is involved?” HSC

“My worry is that is an awful lot of data on one person to be floating around. So, where does your Data Protection come into play there?” C&V Organisation

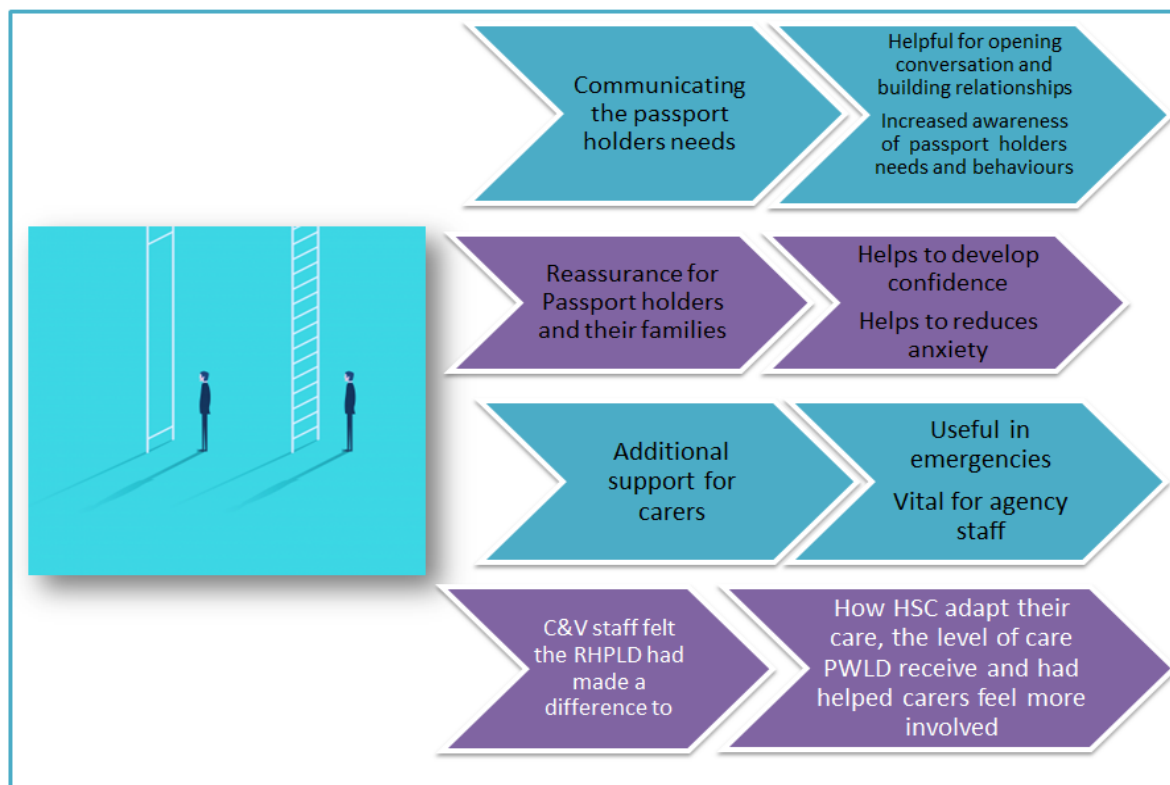
This concern was reiterated by survey participants as seventeen (out of 71) did not think that the RHPLD should be stored a bedside locker when a PWLD was admitted to hospital. A further eight individuals were unsure about where it should be stored.

Another concern raised was that the information on a RHPLD may not be regularly updated or may contain inaccurate information. In particular, this related to medication which may change frequently. However, it should be noted that hospital staff use the patient’s Electronic Care Record to obtain the most relevant information and this is also emphasised within the guidance notes:

“There was [sic] issues around that from the people who were filling them in, you know how do we fill this in and that’s changed and then I’m giving the wrong medication, that was a big issue.” HSC

5.5. Summary of using the Hospital Passport

Figure 14: Key RHPLD usage



6. Feedback about the Hospital Passport

Feedback about the RHPLD was positive with many interviewees reporting enthusiasm about the introduction of a RHPLD. The importance of having a single, regional passport was reiterated as interviewees noted that this may encourage uptake and understanding about its purpose:

"We had devised something [another passport] prior to this [regional passport] because we felt that we needed something...it was actually really good to see the passport being rolled out." **C&V Organisation**

"I think it's a fantastic tool for relationship building and it will reduce anxiety for people with learning disability going into a really strange environment and we have a lot of people with a lot of challenging behaviour. It's a really wonderful tool and I'm very proud of it. It's a great initiative." **HSC**

"I just think it is a very useful document because we find that service users when they are going into hospital they find that a very anxious time and people who have communication difficulties anyway it saves them trying to repeat and repeat information although we do staff support them but that's not the thing." **HSC**

6.1. The Hospital Passport document

The RHPLD document was completed by 31 (out of 71) staff in the C&V sector and with the exception of three individuals, the document was considered to be easy to complete.

Twenty-six felt the document was the right size. Of the three who had reported difficulties in completing the document, these difficulties were in completing the sections: keeping the individual safe, how to look after the individual, caregiver information, and medical history. Reasons for difficulties included finding it difficult to get the information from the PWLD or their family/carer, and not having enough room on the document to write in the relevant information.

Staff with experience using the RHPLD had a number of suggestions of details they would like to see added to the RHPLD in future. Staff felt these suggestions could help improve the document and benefit staff, PWLD and their families/carers. One suggestion was that the size of the document could be reduced to allow it to fit into a folder or diary, and be more hard wearing:

“They’d quite like a smaller one, this is really from the users and they would like a smaller version, like an A5 version but that is something that they would be holding and keeping so they want a wee book” **C&V Organisation**

“It may be an idea to have it more robust - in a Journal format - with hard back”
C&V Organisation

“It could really be made into a double sided A4 page and laminated, only have concise details about the service user and how best to support them.” **C&V Organisation**

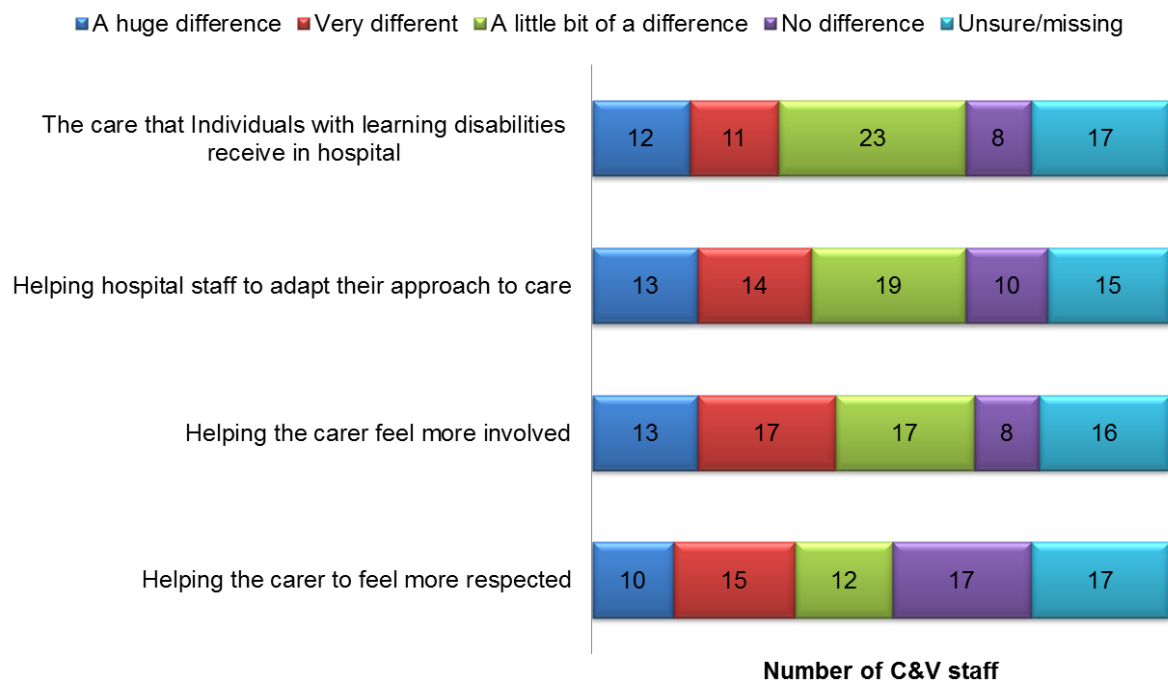
Further suggestions made by stakeholders to improve the RHPLD included:

- Having space for a photograph of the PWLD;
- Making the RHPLD available on the Electronic Care Record, or a patient’s bed notes;
- Having an app or other electronic version of the document;
- Having a larger area available to write information about medication needs.

6.2. The difference made by the Hospital Passport

The RHPLD was reported by staff in C&V organisations to make a difference by helping HSC staff adapt their approach when caring for PWLD, and the care they receive in hospital (n=45). The majority also felt that the RHPLD made at least a little bit of a difference to benefit carers who felt more involved and respected (Figure 16).

Figure 15: The difference made by the Hospital Passport (n=71)



7. Issues for consideration

The Regional Hospital Passport for individuals with learning disabilities was considered by all stakeholders as an important tool that can be used to improve health care provided to PWLD when they attend hospital. When used effectively, the RHPLD reduced anxiety and stress not only among PWLD but also carers (paid/unpaid) and hospital staff. Being able to make reasonable adjustments based on information contained within a person's passport resulted in better care being provided.

However, there are improvements that can be made to improve awareness and understanding of the RHPLD, how it can be used and how it can benefit stakeholders.

Consideration should be given to the distribution processes as top-down distribution from Chief Executives to staff on the ground led to delays in circulation and confusion about how to order additional copies of the documents. Stakeholders suggested that better use of on-the-ground staff with an interest in learning disability work may be more effective. Such staff are likely to be already aware of the value of the RHPLD and may more enthusiastically promote the documents to the most appropriate people.

Distribution of the RHPLD may also benefit from a more targeted approach. The RHPLD distribution in supported living/residential care appeared to be beneficial as staff incorporated the document into personal care plans. These plans were regularly updated and held on file and easily accessible for planned/unplanned hospital visits. Staff working directly with individuals with learning disabilities (e.g. learning disability nurses, healthcare facilitators, social workers, GPs etc.) may also be able to assist or provide guidance on the best approaches for distribution.

In considering distribution processes, it is recommended that the electronic copies of the passport and guidance notes are combined into one document. This will avoid confusion about how to complete the passport document if it is circulated to end-users electronically.

Awareness of the RHPLD can be improved among all stakeholders and may benefit from a formal communications strategy. Promotion of the RHPLD and its value may benefit from input from those working directly with PWLD. However, suggested approaches to improving awareness included a wider roll-out of awareness sessions, increased use of posters/flyers advertising the passport, screen savers on all hospital based computers, and individuals who can champion the use of the passport.

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Appendix A: Survey findings from promotional sessions in NHSCT (figures)

Figure 16: Summary of feedback from NHSCT awareness sessions (n=42)

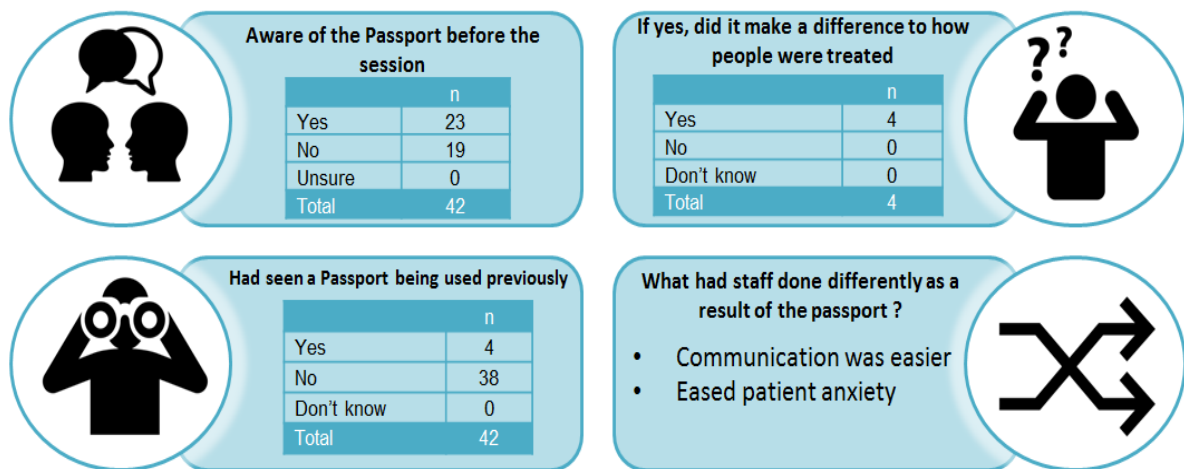
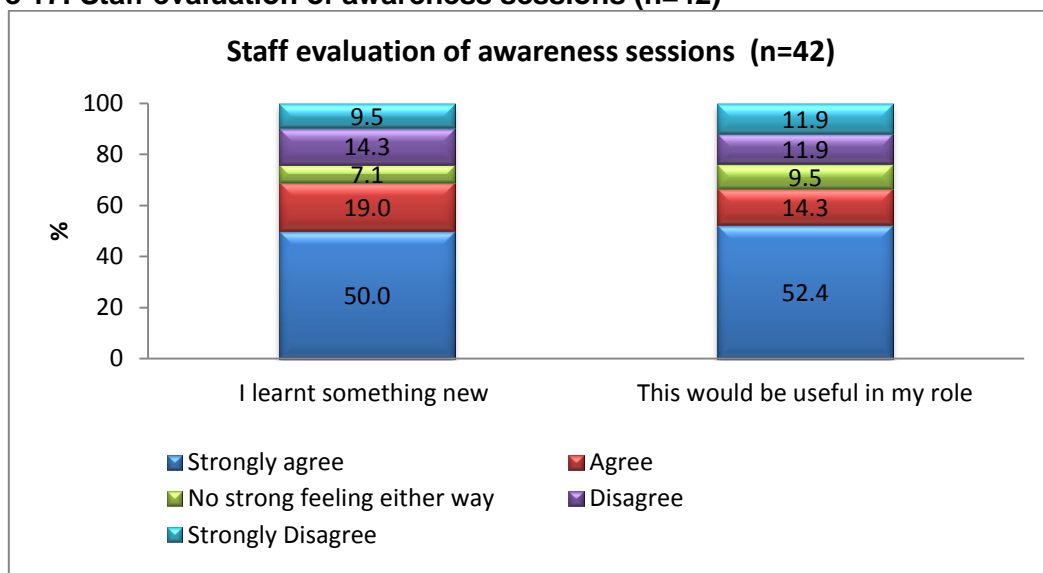


Figure 17: Staff evaluation of awareness sessions (n=42)



Appendix B: Telling It Like It Is – Survey of PWLD



Hospital Passport Evaluation

We know that visiting the hospital can be stressful for people with a learning disability and their family. From the basics of quickly informing treating clinicians how best to take blood, to the complexities of treatment and drug interactions – the learning disability Hospital Passport was designed to help make stays in hospital as stress free as possible. For people with a learning disability it explains their wants, needs and communication preferences which is crucial to alleviating anxiety.

TILII have been involved with the learning disability Hospital Passport and were pleased to complete a Roving Report to highlight its launch in May 2017. One year on they have been working alongside the PHA to evaluate the Passport and to analyse its impact. TILII's role was to interview their peers to find out if the Passport had made a difference to their lives.

TILII designed an evaluation form using the Appreciative Inquiry Method which looks at leading with the positives. We asked positive questions to find out the strengths of the Passport and by encouraging conversations, we identified areas for improvement to help us to move towards the dream phase of having the Passport embedded into every day practice. This would make sure that each individual gets the care and support they need when going into hospital, and that it is not only of a high standard but actually fitting to their individual needs.

We wanted to cover a wider geographical area than Belfast so we also took our evaluations to Downpatrick, Bangor, Lisburn and Muckamore Abbey Hospital to make sure we had a good overview.



150 people were reached:



52 people had heard of the Passport

- ❖ 36 people through TILII
- ❖ 1 through the residential home they lived in
- ❖ 1 through their Sister
- ❖ 6 through their named nurses
- ❖ 5 through their Community Nurse
- ❖ 2 through their Mum
- ❖ 1 through Ulster Hospital



98 people had not heard of the passport (so TILII were able to give them a copy of their own Passport!)



Out of the 52 people who had heard of the Passport only three people had been admitted to hospital;

- ❖ One person who used the Passport had a less than positive response. The hospital staff did not use the Passport and returned it to the patient. This upset the person and in return, angered the parents who had spent a lot of time supporting their loved one to fill the Passport in. They did this, believing that it would provide positive support and ensure their loved one would receive the appropriate care to meet their individual need. This negative experience has deflated them and as a result the Passport was destroyed.
- ❖ A staff member also gave a personal reflection on an incident where they felt if a particular service user had a Passport, their experience may have led to a better outcome
- ❖ Two patients had received a positive response to the Passport by the staff in the hospital, who had used the information to influence their practice. The staff took note of the individual needs of the patient to



ensure they gave the appropriate care, which led to their positive experience in hospital.

Positive Story

Mr A, a middle aged male with moderate learning disabilities used the Passport on admission to hospital for an operation. Mr A is able to communicate verbally but when anxious can find it difficult to articulate how he feels, or about his needs. The parent explained that the more anxious Mr A becomes the more likely he is to present behaviour that can challenge, by disengaging and refusing to interact. This has in the past made the situation difficult for everyone involved, however the Passport enabled the staff member to understand how important it was to take the time to engage with the patient, and this helped to alleviate MR A's anxiety. The staff member sat with Mr A, going through the Passport and the parent felt that this not only allowed the staff to understand the needs of Mr A but also helped him to feel valued. The parent also felt it helped Mr A to feel comfortable as it broke the ice and allowed him to start building a relationship with the staff member. Mr A was keen to talk about himself and showed pleasure that the staff member was interested in him as a person. The parent felt the Passport helped to create a positive experience and also allowed her, the parent, to feel more comfortable about the whole situation.

When filling in the evaluation question 'did it help make your stay in hospital better', Mr A picked a smiley face. When asked 'how did it help make your stay in hospital better?', Mr A answered "It helped me, it did. It helped staff to understand me, fix me and make friends. They cared for me well and understood what I like and don't like".

In conclusion

TILII members recognised that 98 people with a learning disability had not been aware of the Hospital Passport and this needs to change.

Though outside of the remit of work for the PHA, one of the TILII members decided to visit three hospitals to see if staff had heard about the Hospital Passport. These were only brief visits. By going into the main reception and



asking staff if they had heard about the Hospital Passport for people with a learning disability, the answer was no. There was only one student nurse who said they had heard of it. Whilst this is not a fair evaluation as only five members of staff, over the three hospitals were asked, it shows a trend towards lack of awareness of the Hospital Passport, similar with TILII's peers (people with a learning disability). This needs to improve.

Recommendations



Recommendations

Awareness needs to be raised throughout hospitals, health and social care services and most importantly staff. This could be addressed by staff training, a service which TILII provide by creating bespoke training delivered by people with a learning disability to ensure staff understand the importance of the Passport as a communication method. This could be face to face, eLearning, or a video clip produced on a DVD.

Awareness for our peers is also crucial. This could be done by regular updates in day centres/day opportunities services, doctors surgeries, dentists, community centres, announcement on the radio, advert in newspapers. TILII recognise this would incur costs but feel that it is important that the Hospital Passport is out there and being used to improve health and social care services for people with a learning disability. TILII's peers are already often disadvantaged and less able to access the services they need.

Belfast Day Centres are currently having WIFI installed for service users. TILII wondered if could this be used to advertise the Hospital Passport and raise awareness?

People with a learning disability and hospital staff should be encouraged to use the Passport and to keep it in high on everyone's radar. One way TILII thought this could be achieved is to introduce a hospital visa stamp. When the Passport is used in a hospital, it is stamped when a person is discharged - (TILII suggested this as it mirrored how a passport is used when a person travels from country to country and no one would go on holiday without their passport).



HOSPITAL PASSPORT EVALUATION



Do you know about the Hospital Passport?



How did you hear about the Hospital Passport?



Have you used the Hospital Passport?



Did it help make your stay in Hospital better?



How did it help make your stay in Hospital better?



How could we make sure everyone knows about the Hospital Passport?

Name _____

Hospital Passport Received