

# **Evaluation of the Useability of the Once for Wales Health Profile**

## **Final Report**

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## 1. Introduction

In 2022 Improvement Cymru commissioned the Unit for Development in Intellectual and Developmental Disabilities (UDIDD) at the University of South Wales to evaluate the useability of the Once for Wales Health Profile. This report presents the findings of this evaluation and makes recommendations for future development.

## 2. Background

People with learning disabilities can experience many barriers to timely, appropriate, and equitable healthcare. Whilst many factors contribute to this, communication barriers are often cited as having a significant impact. These barriers can arise due to healthcare staff lacking the confidence, competence, and knowledge to communicate effectively with people with learning disabilities. Also, people with learning disabilities themselves may experience challenges with communicating their needs, signs, and symptoms in ways that health professionals can understand.

One solution to addressing communication barriers has been the implementation of communication tools often referred to as ‘communication passports’, ‘hospital passports’ or ‘traffic light’ documents. These documents contain vital information about the focus individual such as their health needs, communication preferences, and support needs. The aim is to provide healthcare staff with the information they require to provide appropriate care. In Wales, the use of a hospital passport was included as a key element of the Learning Disability Acute Care Bundle (Bowness, 2014).

A review of 60 such documents, however, found that they varied in terms of appearance, length, structure, and content (Northway et al, 2017). This was assessed as a patient safety risk since the variability of documents meant that they might not be easily recognised (and therefore used) by clinicians and that the information they contain might not be easily accessible in an emergency. A single, uniform tool was thus recommended (Northway et al, 2017).

In 2019, Improvement Cymru commissioned the Unit for Development in Intellectual and Developmental Disabilities (UDIDD) at the University of South Wales to undertake work to develop a single, uniform health communication tool for use in Wales. The resulting tool (The Health Profile) was created based on the views of people with learning disabilities, their families and carers, and health professionals in Wales. Key recommendations arising from this project were that the document should be no more than four pages long, and that broad headings (rather than a list of very specific questions) should be used to enable information most pertinent to the individual to be included. Furthermore, there was an identified need to develop additional guidance to assist individuals in completing the Health Profile. To promote an appropriate balance between patient safety and flexibility to tailor the information provided to the specific needs of the focus individual the guidance documents for people with learning disabilities and their families/ paid carers provide prompts as to what should be included in each section. An additional guidance document for health professionals was also

developed to stress the relevance of the Health Profile to their role and their role in supporting completion of the document. Finally, it was felt that the term ‘hospital passport’ should be dropped and the term ‘Health Profile’ adopted to reinforce that the new documentation could be used when attending a range of health and social care settings, not just during hospital admission.

The Health Profile was launched in 2020 along with guidance documents. Given the timing of this launch (amid the COVID-19 pandemic) and the possibility for individuals with learning disabilities to be hospitalised without family or caregiver support, it was important to make the tool available as quickly as possible. The initial launch was, therefore, held online to try and maximise awareness at a time when it was not possible to bring people together physically. Since 2020, however, there has been a drive to promote its use through the website ([The Once for Wales Health Profile - Public Health Wales \(nhs.wales\)](https://www.nhs.uk/health-profile)) which provides access to the documentation and promotional animations, and through various other events and conferences. A children’s version of the Health Profile has also been developed and the tool reformatted to improve accessibility and completion online.

In 2022 it was agreed that, having been in use for two years, it would be timely to undertake a review of the usability of the Health Profile.

### 3. Aims

The aim of this evaluation is to gather feedback concerning the usability of the Once for Wales Health Profile from the perspective of a range of stakeholders namely:

- People who have a learning disability
- Those who support people to complete a Health Profile, including family and unpaid carers and paid care staff.
- Those who use the tool to inform the care they deliver (health professionals)

### 4. Method

#### 4.1 Participants and recruitment

Information regarding the study (participant information sheets, consent forms) was circulated to self-advocacy groups who had agreed to support the evaluation through distributing this information to members. Those interested in participating were asked to contact the research team and return their consent forms after which an interview would be arranged. The target number for recruitment was set at 20 – 30 people with learning disabilities.

Recruitment to the on-line surveys used a range of approaches that included posting of adverts on social media, distribution of information by third sector organisations, and posting of adverts on Blackboard (on-line platform used within USW for communication with students). No target figure was set for recruitment of the two target groups (families/carers and health professionals), the aim being to secure responses from as many people as possible.

#### 4.2 Data collection

To try and maximise participation, whilst also ensuring accessibility, two methods of data collection were utilised.

First people with learning disabilities were invited to participate in semi-structured on-line or telephone interviews that were, with the permission of participants, recorded. Second, two on-line surveys were developed to seek the views of (1) families and carers and (2) health professionals. The survey was developed and distributed using the JISC On-Line software and comprised both fixed response and open questions.

#### 4.3 Data analysis

Data from the interviews were transcribed and analysed to identify recurring themes. Quantitative data from the on-line surveys were exported into Excel to support analysis using descriptive statistics and qualitative data were exported into Word to enable thematic analysis. The thematic analysis was undertaken by one team member and then independently checked by another team member to promote rigor.

#### 4.4 Ethical considerations

Participation in the evaluation was voluntary and prior to participation individuals were provided with full information regarding what was entailed and given the opportunity to ask questions. Participants in the interviews provided written consent and submission of a response to the on-line survey was taken as consent. Responses to the survey were anonymous and interview participants assigned a participant number to ensure anonymity.

Ethical approval for both elements of the evaluation was obtained from the Faculty of Life Sciences and Education Ethics Committee, University of South Wales.

## 5. Results

The results will be presented here in relation to each of the three key stakeholder groups.

### 5.1 People with Learning Disabilities

A total of 20 **people with learning disabilities** were interviewed regarding their experiences of using the Health Profile. The aim had been to recruit participants who had a Health Profile but when some interviews commenced, it became apparent that they did not have such a

document. The potential for this to occur had been anticipated when planning the interviews and hence it was decided to continue with such interviews since they would also provide some useful insights into how the Health Profile is being utilised (or not).

Table 1 (below) sets out the themes that emerged from analysis of the interviews. Most of these themes were deductive in that they encompass key areas explored within the interview schedule. However, others (alternative tools used, ownership and responsibility, and awareness raising) were inductive since they emerged as key issues from discussion with participants.

<b>Theme</b>	<b>Focus</b>
Awareness of Health Profile	Whether individuals are aware of the tool and how they became aware
Support to complete the Health Profile	Whether individuals completed the document independently or with support.
Use of the guidance document	Whether individuals used the guidance document when completing the Health Profile.
Use of the Health Profile	How and where individuals have used the Health Profile.
Positive aspects of the Health Profile	What individuals feel are the positive aspects of the Health Profile
Changes needed to the Health Profile	Areas where individuals feel changes to the Health Profile might be helpful
Alternative tools used	Where individuals use a tool other than the Health Profile to communicate their health needs.
Ownership and responsibility in relation to the Health Profile.	Who individuals feel the Health Profile belongs to and who has responsibility for it.
Updating of the Health Profile	Issues individuals identify in relation to updating of their Health Profile.
Use of the Health Profile by health staff	How individuals feel their Health Profile has (of has not) been used by health professionals
Awareness raising	Individuals' perceptions of the need to raise awareness and actions taken to do this.

**Table 1: Themes emerging from thematic analysis of interviews with people with learning disabilities**

#### 5.1.1. Awareness of Health Profile

Some participants reported not being aware of the Health Profile and/ or not being sure whether they had one:

*'I didn't know all this before' (p5)*

*'No I haven't what is it about... no one told me anything... I don't have one or maybe my mum would know, I don't know' (p7)*

*'I mean not sure I know what a Health Profile is no' (p8)*

Where participants indicated that they had a Health Profile, they had been made aware via a variety of sources including the University of South Wales, People First, support staff and peers:

*'I heard about it with TRAC. They were talking about it and the student helped me to fill one in.' (p2)*

*'From staff here at people first' (p10)*

*'I should have one all of us here have one, so we all have a Health Profile here somewhere' (p11)*

*'Yes, I have one... From a public health Wales event and I think it was a colleague who told me. And yeah, through having a one-to-one session with public health Wales. My colleagues and me, and yeah, it's just like more of a one-to-one session of built up and then within a few weeks or months of it.' (p14)*

*'I have a Health Profile, I had it ages now. I can't remember how long I had it, but I have used many times... my girlfriend told me about it. Yeah, she works like with ... People First and she works with NHS and stuff.' (p18)*

#### 5.1.2 Support to complete the Health Profile

Some participants reported that they had completed their Health Profile independently:

*'I filled it in myself.' (p4)*

*'Did it by myself' (p13)*

*'I did it by myself... I have filled it all myself. I kept it confidentially until we handed it over to our admin to type up and they typed it and they made into a booklet.' (p16)*

Others indicated that they had had support and that this had come from a range of sources:

*'I would need some help... My mum can help and staff at People First too' (p5)'*

*'Yes I had help, my girlfriend helped me out with all the details and stuff. So yeah' (p18)*

*'Yes I had support from other people. I think they were people from the people first. Yeah, I think staff at people first helped me.' (p19)*

*'It was effort between myself and my support colleague or family member, if I felt the details weren't accessible, or if I felt overwhelmed with details, potentially the structure is accessible. But there are days when even accessible information to*

*me gets overwhelming because when you have one of those off days, even basic information is a bit overwhelming for you. ... So I would say it was a 50/50 where I did some and got support from others.’ (p14)*

The final comment above raises some important issues in terms of support being available even where individuals have the capacity to complete some or all of the document themselves. The potential to feel overwhelmed when filling out the Health Profile needs to be acknowledged and there may be a need to break down this task into a number of shorter sessions.

#### 5.1.3 Use of the guidance document

Awareness of the guidance document to support completion of the Health Profile appeared variable with some participants indicating that they were not aware of it and hence had not used it. Others indicated they did not think it was needed :

*‘No not that I can remember but I know we didn’t’ (p11)*

*‘I didn’t know there was any guidance notes with it.’ (p13)*

*‘I just didn’t think I need to read it.’ (p15)*

However, where it was used, it was felt to be helpful:

*‘Yeah, very helpful cause it’s great. Like I referred back to it most times, but then it also helps to reintroduce to the person to the family or colleagues assisting me or if it’s one of my colleagues. So yes, that note is a good idea. Especially for the people with disability who need reminders or helpful hints, helpful for me.’ (p14)*

This was particularly the case where participants were assisting their peers to complete their Health Profile over the telephone during the Covid 19 pandemic:

*‘Yes, I use the notes for myself, filling in mine, and I use the notes when I filled in other peoples... because when we filled the other peoples, we were doing them over the telephone, so we needed help to fill them in, so the guidance notes are very common way to do this and very useful. And then we checked it with the authorities and they, they said use the notes because the notes are to give you more details.’ (p16)*

#### 5.1.4 Use of the Health Profile

Those participants who had a Health Profile often viewed it as something that could be used when they visit, or are admitted to, hospital:

*‘I know where it is if I want to go and get it to go to the hospital’ (p1)*

*‘I always remember with the hospital as I go on hospital transport, and I have to pack my bag the night before, so I remember to put it in. I have to go early and pick loads of people up even if my appointment is not till late’ (p2)*

*'When I go, if I do go well, I got a grab file. And that's in my grab file. The health passport. See when I need it see.'* (p4)

It is interesting to note here that participant 4 refers to the 'hospital passport' rather than the 'Health Profile'. This could be a legacy of still using older terminology or could potentially indicate that they are using one of the older tools.

However, some also referred to using the Health Profile in the context of primary care and other healthcare settings such as the dentist:

*'When I go to the doctors I don't need to take it but when I go for my annual health check I might take it with me... So doctors know and are not just talking to staff'* (p1)

*'And so when I obviously first moved out, it was the new doctors and dentist I've always been with the same dentist, so I didn't need to worry about that. And then the hospital because I got taken in twice to A&E. So we have to have obviously all the information which they didn't obviously use because I got stuck out.'* (p11)

*'Yeah, I took it to out of hours doctors and that was very helpful to them to know what all the medication am on from the Health Profile. And I took it to my dentist, and they didn't know what it was at the dentist. I mean they had no clue.'* (p16)

*'I used it twice at Specsavers, at Heath hospital, take it to my Dentist too and one appointment but can't remember. I'll tell you if I remember'* (p20)

Some participants did not appear to know that it could be used in a range of settings:

*'I didn't know I could use it for anything else. What other things can I use it for?'* (p2)

From the above responses it is interesting to note the tendency to view the Health Profile as something that can be taken to appointments and/ or during admissions rather than as a document that accompanies the individual at all times in case an emergency should arise.

#### 5.1.5 Positive aspects of the Health Profile

Participants identified several aspects of the Health Profile that they felt were positive. For example, as an aid to communication some felt that it was helpful in terms of situations where individuals could not communicate some of their key health and support needs. They also felt it spare people with learning disabilities from repeatedly having to convey the same information to numerous health professionals:

*'some people who have not got the confidence to talk about themselves, or to tell people about them. It stops people from asking you the same questions again and again'* (p2)

*'It's basically, I'm not having to explain myself again and again which beforehand before I moved out here. Do that or explain it on every single appointment or*

*every single whatever visit I was going on to do with me, you'd have to really explain everything and you have to say like, right, I've got disabilities. This how I need to be spoken to, ... Whereas now I'm able to say right, this is what I want. It's about me.'* (p11)

*'I love it as it is. I love that you can let the doctor know about yourself in a quick time. And as I said, yeah, at the allergy question, but also the medication question because then you can just have all the spellings of it on the paper and then you can show it to your doctor cause if you verbally tell him what tablet you're on, you might not be able to pronounce it. So, you might not be able to say it if it's a long word, you might not be able to say everything like you want to, but if written down it may be easier.'* (p16)

Some also recognised the key role that the Health Profile could play in emergency situations and keeping them safe:

*'for me is very good because I know that I have the form with my information... Just keep me safe... I can tell doctors what I need because it is there on the form... At least now people can know what I need and they can provide me with it.'* (p10)

*"I absolutely love the questions on it like the allergy question. I always say it could save a life because if you're allergic to something like strawberry flavour and they won't give you Calpol. And so, even something simple like a couple of painkillers. If you can't take real tablet, it could save a life and some people can't swallow no more painkillers. So, something like a syringe can be used to give Calpol or a meltable med easy to swallow. I even use Calpol and I'm like 36. I use the meltable ones, and it's included on my profile. So, something like that it could save a life...'* (p16)

Participant 16 (above) clearly recognises the role that the Health Profile can play in promoting patient safety.

When the Health Profile was being developed key considerations were the length and format of the document. Participants commented favourably on both aspects:

*'Everything I'll say yes ... but I think it's good as it is because they make it like it's so compact so you can carry it in the smaller bag and there's plenty of room for each category to fill in your details. I mean you have pretty much how it's been designed and look how; how convenient it is to carry. It's easy to maintain like you just write down what you need to and then just pull back on the folder.'* (p14)

*'I think it's more how is set out. So, it's great how it's all set out like and with like how to best communicate, medication etc. So, it's great as well for that person with learning disability such as myself, who's able to go back into that booklet and say oh, this is what I got and need.'* (p15)

*'My thing is that it's just the appropriate information on it. So, it's kind of got like the proper details staff need to help you. I think it's just like short, you know, it's just a short medical record rather than just like a long, tight piece of paper.'* (p18)

#### 5.1.6 Changes needed to the Health Profile

Participants were asked about negative aspects of the Health Profile but, rather than identifying anything negative, they instead spoke more in terms of areas that they felt could perhaps be changed / improved.

Some participants suggested that, in addition to the paper version of the Health Profile, there should also be digital version:

*'I think that's the way to go yep because people have got all smartphones now, while those people have got smartphones. I mean if west Wales can then expand it to the wider Wales. So yeah, I think so because then you've got your that information on you. (p13)*

*'I was thinking too in that, you know, where people say it should possibly be more of a digital, not a hard copy. I think it would be a good idea, you know. So, people who would like to have it on their phones or whatever like an app for example, can have it. For example, like Health Profile app or something like that. Like people have their phones on them so they can literally just like take it everywhere because technology is literally improving and stuff like that will help them.'* (p18)

However, others recognised that there would still be a need to maintain a paper version:

*'it could be a mixed because some people don't like using the phones some people with disabilities don't. So I think it could be it is dependent on what that person would prefer. You know, if that person prefers it on their phone, then they've got it. But if some want it on a paper, then they've got in the same way, then it's just obviously different format.'* (p11)

Some participants suggested that some minor changes in terms of presentation and contents might be helpful:

*'I think it is good. I am happy with the book so no change for me... I can't think now but I think you should make the font bigger for blind people and those with eyes problem. I think they call it Braille where they can touch and feel the letters on the actual book (Health Profile) and understand what it is. Braille, they call it and when they touch with their hands, they can read it then and understand, it's brilliant for people like that. May be more photos too would help make things better.'* (p17)

*'I think we should use more little pictures, little symbols and I also think people don't know what they can use it for. I thought only able to take to appointments with doctor. I didn't know I could take it to the clubs that I go to, too.'* (p2)

Whilst some suggested that the inclusion of further information would be helpful, they also recognised the value in keeping the document brief:

*'You know, the font needs to be made bigger. Some people said they need more photos. Some even said it's too short because it doesn't accommodate other medical record. Although the reason it is short is to make sure that in emergency people can look and get what they want. Am I right?.. I think the photos and stuff is right and just the right size for it. I think it's about keeping the right balance between people who like use it, they need to understand it quite well and between having to read it.'* (p18)

*'I know some people at work said about need to make it bigger. Some said to put in more photos but for me the small ones are better cause if you make it bigger it will be too much information I reckon. And I don't think there should be too much information.'* (p20)

#### 5.1.7 Alternative tools used

Whilst the focus in this project was the Health Profile some participants reported that they used app which (whilst it is not primarily a health app) does contain key health/ medical information instead:

*'I have something different, but I would like to have the Health Profile or passport... I do have an app on my phone called access My life, I got it from a company called (organisation name) here in West Wales, they put it together... that's to do with information about your house and transport and a bit of that fun'* (p12)

The reason they gave for using this alternative tool was their preference for a digital tool since in an emergency they knew they would always have their phone with them. Another participant also reported using this app:

*'I've actually downloaded it and it's really good app. And then you just put in your information, you just put information of what support you need and how much support you need and what medication you need, what help you need and that kind of thing. Really good app.'* (p13)

One participant noted that there are several similar tools currently in use and that there is a need to raise awareness of the Health Profile:

*'There's also the National Autistic Society Health passport. I know that's big work but working together and making a difference is the way. You know all these big words, you know but yeah, there is a one at different National Autistic Society health passport and so on. So yeah, it's good to raise the awareness for people to know more about it I mean the once for Wales profile for general population.'* (p16)

#### 5.1.8 Ownership and responsibility in relation to the Health Profile

Whilst the Health Profile is designed to be used by health professionals to inform care delivery the document is owned by the individual on whom it focuses. Some participants clearly felt that they had ownership of the document:

*'It's easy for me to take everywhere, easy to read, it's mine and it is personal to doctors and myself and I can do everything I want with it like change my information when I have to.'* (p17)

However, another participant reported that their peers seemed not to view it in this way with ownership instead being with carers:

*'at the moment some who spoke to me and my colleagues said it is with their staff or carer or in the house. And I'm thinking it cannot be because it is for them, it is their document, you know. But then it's only because people don't know. You can only claim to own something when you know yourself about it.'* (p15)

This was reflected in the comments of other participants:

*'the staff have got one for all of us up on the block'* (p1)

*'but they got that in my file, my medical file. If they want it ... and the hospital want all my details, then they can need it.'* (p4)

*'I haven't seen it.'* (p9)

Some also felt that the Health Profile was for the benefit of support and healthcare staff rather than for them:

*'it's for when the staff, when I need to go to health appointments. So the staff and others doctors, nurses know a bit more about me, how I like to be called yeah.'* (p8)

*'We we've got one in our folders most probably because obviously it changes I mean the staff change and going out and stuff and then for when the new staff come in, they get to know that person through their paper.'* (p11)

One participant recognised that the Health Profile belonged to them but they described accessing their document as being 'allowed' by staff:

*'I'm the only one here who is allowed to go into their folders so I'm allowed to go in and look at my information.... Because I was as if it's about me. So I'm allowed to go in and say, like, OK, this is correct'* (p11)

### 5.1.9 Updating of the Health Profile

It is important that the information contained in the Health Profile is current and this means that it requires regular review and updating. Some participants recognised the need for this to occur but were unsure as to how it could / should be achieved:

*'I wouldn't know what to do it too. I would have to ask.'* (p2)

*'I'm thinking it is a personal form with your information so at the moment I can't update it either because things change over the years. You might be on different medication, or you might end up having another illness or something, or etcetera. It's really hard to keep it updated if you haven't got it on you.'* (p13)

However, another participant both recognised the need to update the tool and how they would achieve this:

*'We need to maybe update this cause. Like obviously with things changing all the time and the person's body, especially mine, I'm able to go in and obviously talk to staff and say, yeah, this is not right. We need to update it.'* (p11)

### 5.1.10 Use of the Health Profile by health professionals

If the Health Profile is to promote patient safety and aid communication then it is essential that it is recognised, read, and used by health professionals to inform care provision. Participants were asked as to whether health professionals asked to see their Health Profile and whether they read and used it. Sadly, none of the participants reported that health professionals had requested sight of their Health Profile.

Only one participant reported that their Health Profile was used by health professionals to plan their care, and this was in the context of a private hospital:

*'So I had my Health Profile and my one page profile ... and it was a private hospital so I had my own room with my family and she (the nurse) sat on my bed and my stepdad said (name) would like to show you some documents before we talk about the operation... she sat down and asked me questions and she took time. She took time to read and so did the doctor. The doctor sat down and read and seen as well. ... He was the consultant that done my eyes so... they done the adjustments for me and they also put me to sleep as well because they knew that I couldn't be awake..'* (p3)

Most reported that they had had to offer their Health Profile to the healthcare staff due to not being asked for it:

*'No, no one asked, I just show it to them'* (p10)

*'So we took it in but obviously they didn't look at it.... We gave it to them they didn't ask'* (p11)

*'They did not ask for it. I took it in and told them I've got my Health Profile. It is helpful to you, you know, like and as I said to the dentist, when they didn't know what it was. So, I ask do you know what it is all about?.'* (p16)

Participant 16 raises an important issue here namely that even where the Health Profile is offered to health staff they may not know about it and how it can assist them to provide care. This suggests that health professionals are not always aware of the document and the accompanying guidance. Hence, even where the Health Profile was offered to healthcare staff it was not always read or used:

*'No, they didn't ask, but I gave it to them anyway, but they weren't interested even when I said I have it on me. It was like not today yeah maybe next time you attend your appointment it would help... I gave it to them anyway and said all they need about me is there, so they took it.'* (p14)

*'I showed it to them because they didn't know what a Health Profile was, so when I gave it to him, they were like, what's this? So, I said, well, it's a booklet to do with me and to help health professionals such as yourselves to understand my needs...: I think they just briefed it. They were just like they just looked at it and that's all... Like I said, I don't think they know much about it, and I suggest we need to raise awareness on it as well.'* (p15)

*'No, they didn't ask me to see it. Even when I'm at doctors as well no one ask to see it... No, nobody did until I show it to them or ask them to see and look at my information. One thing is clear they don't know anything about the Health Profile...'* (p20)

Some participants did, however, take the opportunity to educate health professionals:

*'So, I told him a little bit about it. I think that's really nice because we found that many people, they don't really know much about it, which means they are not using it to support people like me you know.'* (p16)

#### 5.1.11 Awareness raising

Some participants suggested that change was needed in relation to awareness of the Health Profile amongst health professionals:

*'All your nurses (need to know) how to use them. Basically paramedics like the ones who rush you in and through. Whoever knows was on that shift can know if they gonna have the passport or not or they got disability.'* (p4)

*'It needs to be more out there like I know it's in the hospitals, but I don't think it's spoken about enough. So that's my personal view.'* (p15)

Leading on from the comments above regarding a lack of awareness regarding the Health Profile some participants commented more broadly regarding the need to raise awareness:

*'Some people who live with their family haven't got one' (p1)*

*'making it more of awareness of the Health Profile and making sure people with a learning disability understands what our Health Profile is as well. Yeah, have the right information because like if that person can go, needs to go in an ambulance and he is diabetic, that person could be diabetic. Uh, that healthcare staff needs to understand like he might need an EPI pen or something like that just to be aware and again, it's about communication and being aware.'* (p15)

*'I think not many people in society knows about it not even the doctors too. Only if you're in a learning disability capacity. Only if you like, say you might have been an advocacy group or something, or some sort of supported living house, or somewhere where it's learning disability or all about it. But I don't think the general population knows about it enough.'* (p16)

*(re healthcare staff) 'Seriously something really needs to be done because they don't know till I show them. And these are the people you need to be aware about it so they can use it to help us but I always show it when I am there. It is the same when I went to dentist, they didn't know nothing at all.'* (p20)

Positively, however, participants reported how they have been involved in raising awareness:

*'as a team, we made a lot of people's Health Profiles and help them to know about it and the use for them. We help some people do it on phones...I use mine to help with training student nurses. Like they've seen the front cover, but not inside cause its confidential, obviously. But it's got my picture on it and then we have a pretend one as well. I've got a pretend one for training.'* (p16)

*'...we have done work about the Health Profile for Public Health Wales.'* (p20)

### 5.3 Families and Paid Carers

Twenty-four responses were received to the **family and paid carer** survey. Of these 3 identified as family carers, 19 as paid carers and 2 as 'other'. Those who identified as 'other' were both community learning disability nurses who had chosen to complete this survey rather than the health professional survey. These responses have been included since it is likely that they will have been involved in supporting individuals to complete and use their forms rather than receiving a Health Profile to inform care.

It is important to note that feedback was received from a self-advocacy organisation assisting with recruitment, that most of their members living with families seemed not to have Health Profiles. In addition, one response was received via social media from a parent indicating that neither they nor the other parents in their support group were aware of the Health Profile. In this instance the opportunity was taken to forward the relevant link to the web page for further information and downloading of the tool. The issue of awareness will be revisited in the subsequent discussion section of this report.

Despite the limited response rate, responses were received from people living / working within 6 of the 7 health boards in Wales. Nine participants had supported individuals to complete their own Health Profile whilst 21 had completed the tool on behalf of individuals they support (some had done both). Only one participant had supported completion of the children’s version of the Health Profile with all others using the adult version.

### 5.3.1 Use of the Health Profile

Table 2 below details how long participants reported it took to complete the Health Profile and Table 3 details how easy they found this process:

<b>Time taken</b>	<b>Number of responses</b>
Less than 30 minutes	5 (20.8%)
30 minutes to 1 hour	9 (37.5%)
More than an hour	7 (29.2%)
Cannot remember	3 (12.5%)

**Table 2: Time taken by family and paid carers to complete Health Profile**

<b>Ease of completion</b>	<b>Number of responses</b>
Very easy	18 (75%)
Easy	4 (16.7%)
Difficult	2 (8.3%)
Very difficult	0

**Table 3: Ease of completion reported by family and paid carers**

Participants were also asked about whether they used the guidance document to assist them with completing the Health Profile. Eleven (45.8%) indicated that they were not aware of the guidance document, 2 (8.3%) that they were unsure, 1 (4.2%) that they did not use the information and only 10 (41.7%) that they had used it. Of those who had used the document 3 (12.5% of total response) said that they found it very helpful whilst 7 (29.2% of total sample) found it helpful.

Table 4 below sets out the settings in which participants had used the Health Profile. Since participants had used the document in more than one setting the total number of responses is more than 24.

Setting in which Health Profile used	Number of responses
Attending Accident and Emergency	15 (62.5%)
Admission to acute care hospital	12 (50%)
GP surgery (general visits)	9 (37.5%)
Community Learning Disability Team	8 (33.3%)
Out patients appointment at hospital	6 (25%)
GP surgery (annual health check)	5 (20.8%)
Admission to a learning disability assessment and treatment unit	5 (20.8%)
Ambulance	4 (16.6%)
Dentist	3 (12.5%)
Admission to a mental health setting	2 (8.3%)
Optician	2 (8.3%)
Pharmacy	2 (8.3%)
District nurses	1 (4.2%)
Practice nurses	1 (4.2%)
Other healthcare setting	1 (4.2%)
Other non-healthcare setting	1 (4.2%)

**Table 4: Settings in which families and paid carers reporting use of the Health Profile**

Unfortunately, in relation to ‘other’ healthcare and non-healthcare settings the participants did not detail the nature of these settings.

### 5.3.2 Family and paid carer reported use of the Health Profile by health professionals

Participants were asked whether, when the Health Profile was offered to health professionals, these professionals read it. Only 12 (50%) reported that it had been read whilst 8 (33.3%) said they were unsure and 4 (16.7%) that it had not been read.

They were also asked whether, if read, the Health Profile had been used to inform the care provided. Nine (37.5%) reported that it had been used whilst the other 3 (12.5% reported that it had not.

Participants were also invited to comment on how the Health Profile had been used. Some felt it had been used in a positive manner to improve care:

*‘It is very helpful for staff supporting as this has all information of diagnosed health conditions and medications included- especially for complex health needs’ (Participant ID 1520)*

*‘It was used to make sure my son knew what was going to happen and why. It was also used postoperative, so that staff knew how to make him feel comfortable.’ (Participant ID 6282)*

However, others reported that staff had to be reminded to refer to the tool and/ or did not use it to proactively inform care:

*'Handed over to hospital staff but then had to continually verbally tell them things about the person I support that were in the document as they seemed to not take notice.'* (Participant ID 3867)

*'Sometimes is used by health staff reactively (reading it if there is an issues or if the person won't take medication) rather than reading the information and working proactively'* (Participant ID 2915)

*'Due to such high turnover of staff in hospital it was not read by all staff. Support staff having to tell nursing staff all the time about SALT guidelines.'* (Participant ID 4358)

### 5.3.3 Experience of using Health Profile

Participants were asked to rate their overall experience of using the Health Profile. Table 5 below details their responses:

Rating	Number of responses
Very positive	3 (12.5%)
Positive	18 (75%)
Negative	3 (12.5%)
Very negative	0

**Table 5: Family and paid carer overall rating of using the Health Profile**

Participants were also asked to comment as to why they gave the rating they did. As would be expected the comments reflected both negative and positive aspects:

*'Had to continually reinforce details that were in the profile.'* (Participant ID 3867)

*'the Profile is so useful for people supported who find it a challenge to communicate, but it needs to actually be read'* (Participant ID 4358)

*'As I am unsure of whether the health professional read the Health Profile'* (Participant ID 4304)

*'when someone supported needed to go to hospital, we used the Health Profile as an a easy read guide for nurses/doctors'* (Participant ID 4851)

What is interesting to note from these comments is that where negative aspects were noted these relate more to its use (or non-use) by health professionals rather than to the document per se. Two participants, however, made an identical comment suggesting that they preferred the previous hospital passport format:

*'Very basic document. Doesn't stand out enough as an important document. Needs the green, red and Amber added so people can go direct to green-positive supporting, amber-things to be aware of and red-must know and important information.'* (Participant IDs 7275 and 8159)

#### 5.3.4 What is positive, what is not working so well and what needs to change?

Open questions inviting free text responses were asked in relation to the above areas. In terms of what is positive, comments included the following:

*'It is good to have on hand for the staff supporting the person as they have all relevant details to hand, it's easy format, good layout with important information to hand.'* (Participant ID 3867)

*'The Health Profile enhances person-centred care - likes, dislikes and wishes whilst supported in healthcare services. The profile enables health professionals to have insight to the support needs of the person...The Health Profile raises awareness of the unique needs of people with learning disabilities and provides them with a voice whilst in hospital or accessing health services.'* (Participant ID 1316)

*'Person supported is more involved. Its not a long document so it's a easy read document for professionals to read through'* (Participant ID 4316)

*'They are a consistent document used and so when providing these to A&E and assessment unit they are a familiar document'* (Participant ID 1520)

In relation to the question of what is not working so well 22 participants took the opportunity to comment. Of these 9 indicated that they did could not identify any problematic areas. In terms of those who commented on areas of difficulty these seemed to focus on aspects relating to its use (or non-use), its appearance, and information included (or not included):

*'It's still not fully utilised by both the LD community and health care settings.'* (Participant ID 9212)

*'Hospital staff not having the time to read or remembering what's in it.'* (Participant ID 3867)

It is interesting to note that participant 9212 suggests the Health Profile is not yet fully used in learning disability and community settings. This may be due to previous hospital passport documents being focused primarily on use in an acute hospital setting and reflects a need to raise awareness of the broader potential use of the Health Profile.

The comments relating to the context seemed to focus primarily on concerns regarding the medication section:

*'The "tablets or medicines that I take" element may not include updated information and may lead to confusion when transitioning between service.'* (Participant ID 1316)

*'The section around medication could lead to errors and miscommunication of important changes. I feel that a list of uptodate medication should be attached from prescription or a medication chart but listing the Medication onto the document may not always be updated effectively. Some people could have*

*frequent changes to medication, and it may not be feasible in certain settings to frequently update the profile.’ (Participant ID 3143)*

Some also felt that the document was not as comprehensive as previous hospital passports but did recognise that there is the potential to append additional information:

*‘They are less detailed than plans that we had in place previously, although additional information has been added to ensure individuals are supported in the right way there are less sections/prompts to ensure this is included’ (Participant ID 1520)*

Two participants again made an identical comment in relation to the appearance of the document:

*‘Document is too plain and does not stand out enough for people to take notice and use like a bible to stick to’ (Participant IDs 7275 and 8159)*

It appears here that they attribute healthcare staff’s lack of use of the document to its appearance and a perception that it fails to ‘stand out’ from other documentation.

Participants were also invited to offer suggestions as to what (if anything) needs to change in relation to the Health Profile. Eighteen took the opportunity to respond to this but 8 indicated that no changes were required. As with previous questions Participant IDs 7275 and 8159 provided identical responses reiterating the point they made (see above) regarding the document needing to stand out more. Others indicated that additional information (as with the old hospital passport) should be included:

*‘Previously there were sections to say, Before I go in to Hospital you should, Whilst I am in Hospital you should and When I leave Hospital you should as well as heading to include individual sections around eating/drinking, Sight & Hearing, going to the toilet, moving around, Personal Care, Keeping me safe and pain- These specific headings/prompts were helpful to not only complete but also to follow’ (Participant ID 1520)*

One participant indicated that they had not seen the guidance document whilst another drew attention to the different ways in which the document is completed:

*‘I have observed many different approaches to how the Health Profile is completed. Some use a meaningful meeting with the individual and families to gather or the necessary information where others have completed it within an office based on information they gather from existing files. I believe the latter is less meaningful and runs the risk of another “tick box” exercise and as a result the quality of the Health Profile will be poor. This isn’t so much as a change, more so an area I feel needs to be highlighted more and embedded into the process.’ (Participant ID 3143)*

Such variations in the manner of completion have the potential to affect the quality of the information included and hence its potential to positively inform person centred care delivery.

One participant also commented on the need to change how the document is used rather than the document itself:

*'It should be requested on arrival to hospital rather than it be the patient or their carers responsibility to hand it over' (Participant ID 6282)*

This reflects comments made by people with learning disabilities in the previous section of the results regarding they (or their families and paid carers) needing to offer the Health Profile to health professionals rather than being asked for it.

#### 5.4 Health Professionals

Fifty-eight responses to the **health professional** survey were received. A further three surveys were returned via email from one health board where those responding had not used the online survey but had instead accessed a Word version. In each instance the respondent indicated that they had not been aware of the Health Profile and did not, therefore, fully complete the survey. These responses have not been added into the electronic survey data but are noted here since they further underline issues with awareness of the Health Profile.

The professional background of the 58 participants is detailed in Table 6 below.

<b>Professional background</b>	<b>Number of participants</b>
Allied health professional (hospital based)	2 (3.4%)
Allied health professional (learning disability specialist)	1 (1.7%)
Acute hospital based nurse	7 (12.1%)
Learning disability nurse (residential)	1 (1.7%)
Community learning disability nurse	14 (24.1%)
Children's nurse	2 (3.4%)
Student nurse	12 (20.7%)
Learning disability acute care liaison nurse	12 (20.7%)
Other	7 (12.1%)

**Table 6: Professional background of participants in the health professional survey**

Of those who indicated 'other' in relation to their professional background 2 were learning disability primary care liaison nurses, 1 was a retired learning disability acute care liaison nurse, 1 was a student midwife, one identified as a student nurse and learning disability support worker, and 2 were clinical nurse specialists. It should be noted, therefore, that the majority of participants (n = 32, 55%) indicated that they had a professional background in learning disability services. This figure is likely to be higher since the student nurses were not asked to indicate their field of practice.

Responses were received from all seven health boards in Wales with the number of responses per board ranging from 4 – 13.

#### 5.4.1 Use of the Health Profile in practice

Participants were asked whether, when providing care for people with a learning disability in the past two years they had been provided with a copy of the individual’s Health Profile. They were also asked whether they would ask to see an individual’s Health Profile if it hadn’t been presented. Table 7 below shows the responses to these questions:

Question	Always	Sometimes	Never	Unsure
In the past two years, when you have provided care for individuals with learning disabilities how often have they provided you with a copy of their Health Profile?	4 (6.9%)	38 (65.5%)	14 (24.1%)	2 (3.4%)
If an individual with a learning disability does not provide you with a copy of their Health Profile do you ask them if they have one?	41 (70.7%)	8 (13.8%)	6 (10.3%)	3 (5.2%)

**Table 7: Presentation of Health Profile to health professionals and health professionals requesting Health Profile**

Participants were also asked whether they had ever completed a Health Profile on behalf of an individual with learning disabilities or supported an individual to complete their own document. Forty-one participants (70.7) indicated that they had done this whilst 17 (29.3%) said no. They were also asked how easy or otherwise they found this process and Table 8 below details their responses:

Question	Very easy	Easy	Difficult	Very difficult	Unsure	Not applicable (had not completed Health Profile)
How easy did you find completion of the Health Profile?	14 (24.1%)	25 (43.1%)	3 (5.2%)	0	0	16 (27.6%)

**Table 8: Health professionals reported ease of completion of Health Profile**

Guidance notes have been produced to assist health professionals in using the Health Profile (these include prompting them to ask for the Health Profile if it is not offered and completing/supporting completion if the individual does not have a Health Profile). Participants were asked if they had read this guidance document and 39 (67.2%) said yes, 8 (13.8%) said no, and 11 (19%) indicated that they were not aware of the document. Of those who had read the guidance document, 10 (17.2%) indicated that they had found it very helpful, 26 (44.8%)

helpful, 2 (3.4%) unhelpful and 20 (34.5%) indicated that the question was not applicable as they had not read the document.

#### 5.4.2 Using the Health Profile to inform care planning and delivery

Participants were asked an open question that invited them to detail how, if an individual with a learning disability had provided a Health Profile, they had used it to inform care delivery. Nine participants indicated that this question did not apply to them, 1 that they had not received the document, and 1 mentioned they had not received training on the use of the Health Profile. From the responses to the other questions, however, a number of themes emerged the first of which related to supporting the provision of person-centred, holistic care:

*'Look for best methods to provide care and support in the most person centred way, creating a pleasant experience for both individual and care team. Utilise the document to understand the individual.'* (Participant ID 7125)

*'Person centred care is enabled.'* (Participant ID 5365)

*'I would use the Health Profile to ensure they receive personalised care to their personal needs'* (Participant ID 7169)

As part of care delivery some participants identified that the Health Profile is helpful in terms of raising awareness of health conditions and medication:

*'Medical history information and allergies. What direct care needs they require. How they take their medications.'* (Participant ID 6755)

*'Assessing their medical history, what they would like to be known as and any assistance that is needed for the individual'* (Participant ID 0717)

Some referred specifically to the document assisting communication:

*'Understanding their communication method'* (Participant ID 4515)

*'I will communicate to the service user in the way that is described on the Health Profile. I will ensure that my care is person centred. I am able to understand there needs with the Health Profile'* (Participant ID 6061)

A further key theme that emerged was how the Health Profile supported the provision of reasonable adjustments:

*'Ensuring all care needs are met. Facilitate reasonable adjustments. Placed where all can read'* (Participant ID 7349)

*'We also use them to recommend reasonable adjustments to care and treatment.'* (Participant ID 0066)

*'Able to create a positive experience from the likes/interests and making reasonable adjustments to reduce anxieties from any known fears/barriers that may delay treatment.'* (Participant ID 7158)

It was also positive to note that the Health Profile assisted professionals to know the 'baseline' for an individual and hence to identify when they were off baseline and intervention was required or to identify when their condition improved:

*'By knowing the person's baseline abilities and what is normal for them, it is easier to monitor recovery.'* (Participant ID 6381)

*'Health passports are very helpful in a environment to assist in having a greater understanding of the individuals baseline presentation and management of other comorbidities such as epilepsy and dysphagia.'* (Participant ID 0066)

One of the key aims of the Health Profile is to improve patient safety. This was only explicitly referred to by one participant whilst another referred instead to assessment of risk:

*'Also enhances patient safety.'* (Participant ID 3633)

*'Used it to help communicate to ward staff the patient's needs and to complete our rapid risk assessment to identify any necessary reasonable adjustments'* (Participant ID 7815)

A final theme that emerged was that some participants recognised the importance of making colleagues aware of the Health Profile to ensure that appropriate care is delivered:

*'My experience has been providing a Health Profile on behalf of an individual when admitted to hospital so that the nurses in the hospital have access to information on how best to support that person.'* (Participant ID 0202)

*'Read the Profile myself then ensure it is shared with ward staff and discussed in hand-overs. Copies then placed in hospital notes and also at bed side.'* (Participant ID 0285)

*'Read through and noted anything that may support that person within the environment e.g ward - I then share the document with the ward - request it is put at bedside/front of notes - request it is put in handover that all staff supporting should familiarise themselves including dr's - give education around importance of document and how it can support them to provide best care for the pt'* (Participant ID 2525)

### 5.4.3 Overall experience of the Health Profile, positives, what is not working so well, and what needs to change

Participants were asked to rate their overall experience of using the Health Profile and Table 9 below details their responses:

Question	Very positive	Positive	Negative	Very negative
Overall, how would you rate your experience of using the Health Profile?	15 (25.9%)	36 (62.1%)	6 (10.3%)	1 (1.7%)

**Table 9: Health professionals’ overall rating of using the Health Profile**

Open questions were posed relating to what participants view as the positive aspects of the Health Profile, what is not working so well and what, if anything, they feel needs to change. Positive comments tended to reflect those made in relation to how it informs care with participants noting the support it provides for holistic care, communication, reasonable adjustments, and safety:

*‘It gives you a understanding of the patients lives and dislikes which can help in the decisions of making reasonable adjustments. If there was no carer or family present it should be able to give enough information to help care for the patient with a LD.’ (Participant 4722)*

*‘The descriptions of the support a person needs in communication, mobility, personal care, etc. Also, the inclusion of a photograph of the person.’ (Participant ID 6381)*

*‘The information provided helps in ensuring people received safe and person centred care. It enables the wards to make reasonable adjustments. Information with the document is extremely helpful in understanding the individuals base line presentation which is used to ensure that they are safe to return home. This is particularly evident with the therapy departments i.e Speech and language, physio, nutritional support and OT’ (Participant ID 0066)*

The usefulness of including a photo of the individual was also noted:

*‘Photograph on front page. Also headings as a guide to completion.’ (Participant ID 0285)*

*‘the photo section , the how best to communication and health needs section .Having an electronic copy is always handy , as people move wards and dept and things can get lost ! also easier to make electronic changes to keep up to date’ (Participant ID 2166)*

As with comments received from individuals with learning disabilities one participant noted that it avoids people with learning disabilities having to constantly repeat information and that it is easier for them to self-complete:

*'That service users don't have to keep answering the same questions in medical appointments and that hopefully, health care providers read the profile to facilitate the process' (Participant ID 4430)*

*'More user friendly for individuals to complete themselves or read if they are able. Welsh language option available' (Participant ID 7815)*

Some comments were also made in relation to the format and length of the document which were viewed positively:

*'Its a 4 page document, it can provide immediate information.'* (Participant ID 6755)

*'They are short and include the important and necessary information required'* (Participant ID 0202)

*'It is brief so you're not spending an age trying to locate the relevant information. It provides all the key information you that must know to support the individual well - providing it has been completed and completed well.'* (Participant ID 1828)

Finally positive comments were also made in relation to it being designed for use across settings and also that it was a pan Wales document.

In terms of what participants felt is **not working well** in relation to the Health Profile some key themes emerged. Some comments related to the format and contents of the document with some feeling that additional information needs to be included:

*"Pain or unwell' section could include prompts of assessments that are in place.'* (Participant ID 6755)

*'it all works well but does not capture all of the information needed to support the client'* (Participant ID 2110)

*'It would be helpful to have more prompts to aid the person completing it. For example, some headings for communication, etc. It would also be helpful to include GP details'* (Participant ID 6381)

*'no address, allergies, free flow text'* (Participant ID 2116)

In analysing the latter two comments, however, it is important to note earlier comments regarding participants not being aware of the guidance document since the prompts for completion are contained in that document. Furthermore, the Health Profile does contain a specific section relating to allergies and the guidance notes for health professionals do make reference to specialist pain assessments.

When discussing areas they deemed as not working well, some participants drew comparisons between the Health Profile and previous documents:

*'Traffic light forms had been recognised and I am concerned that all the hard work that went into that has now gone as healthcare staff don't recognise the profile in the same way as the passport. The health passport also had more*

*prompts so more information included. Staff on ward may sometimes look only at the red but at least it stood out. I don't think the profiles are as effective.'* (Participant ID 4389)

*'Not as detailed as the hospital passport'* (Participant ID 7815)

*'How I need you to support me section Pg.3. Sometimes information provided on here is a little sparse. People don't always know what to include. I would like to see more headings as a guide (more like the old Traffic Light).'* (Participant ID 0285)

Interestingly, however, one participant suggested that the fact that other documents are still being used is giving rise to inconsistency and hence confusion:

*'It's use is inconsistent. At times, it has not been recognisable on the wards as there are still variations of other similar documents such as the health passport being utilised.'* (Participant ID 0128)

Whereas (as noted earlier) some participants felt that the Health Profile is not comprehensive enough some participants, in relation to this question, suggested that it is too long:

*'Very large document.'* (Participant ID 9207)

*'It's a lengthy document work like a grab sheet to go with it'* (Participant ID 4515)

Some participants identified that some areas of awareness raising and implementation are not working well:

*'Still not all patients with a LD living in care homes have these completed.'* (Participant ID 4722)

*'Education needs to be improved especially with agency nurses. Some nurses have said they do not know what one is...I think staff need to know the importance of it and why it has been implemented. I feel this would be best done with a face to face training session.'* (Participant ID 0202)

*'I feel that not everyone is aware of it - so staff who are presented with it see it as another piece of work/document - they feel they do not have the time - more education is needed around benefits'* (Participant ID 2525)

As with the views expressed by people with learning disabilities some health professionals suggested there is a need for an electronic version of the Health Profile:

*'a digital copy may be beneficial as some clinical areas are paper free'* (Participant ID 4827)

*'Giving these to people there is no guarantee they will be filled in and returned. possibly there's a way to hold an electronic copy?'* (Participant ID 9023)

One participant also raised the issue of updating and specifically raised concerns in relation to medication:

*'Medication section could potentially cause confusion when people's meds are changed and the profile is not updated. I've been advised to leave this blank and write see meds chart/ask carers.'* (Participant ID 8095)

The Health Profile is available in both English and Welsh versions. However, some participants indicated that this was not working well and that a fully bilingual version is required:

*'The Profile needs to be bilingual. Often there isn't access to translators and within a very busy A & E department key information could be missed if there are no Welsh speakers and the person is unaccompanied.'* (Participant ID 5830)

*'Separate Welsh and English documents does not work well as this can mean they need 2 documents.'* (Participant ID 0066)

The final part of the survey invited participants to identify what, if **any changes are needed** to the Health Profile. Unsurprisingly, most of these comments reflected those made in relation to areas where they felt the Health Profile was not working well namely the need for more sub-headings, a preference amongst some for the old 'traffic light' hospital passport, the need for a digital version and the need to raise awareness. However, there was some expansion on issues relating to how the Health Profile is completed and the role of the guidance documents:

*'I think it would be helpful to have some prompts on the document itself so that important areas are not overlooked whilst completing it. Rarely do we find that the guidance documents are used alongside the HP, and they are quite lengthy in themselves which I think puts people off using the guidance. Families have commented that they overlook things that are important about their loved one, because they are so familiar with them. So, important details can be missed here. Some specific prompt to encourage people to think about how the person copes with being in hospital and interventions would be helpful - what has worked previously, and what has not worked'* (Participant ID 1744)

*'Further elaboration on communicating pain/illness. Sometimes this is completed with a wealth of information, other times this is not, as individuals often do not attend hospital with a disDAT. Prompts in this section such as details on body language, vocalisations, and facial expression would be beneficial'* (Participant ID 1828)

*'Perhaps there needs to be a link to the Guidance in the Profile and people asked to read that'* (Participant ID 1573)

Some participants suggested the need for a longer document whilst others suggested it should be shorter. One identified the tension between these two points of view:

*'I realise it's a balance between quantity (as acute staff are just so busy) and quality of info.'* (Participant ID 1573)

Finally, one participant noted that the Health Profile is as good as the information that is included in it:

*'They are as good as the information that is put in them. Would be beneficial if the Health Profile was completed with the individual and part of an MDT. I believe key information is missed for someone in a secondary care environment. For example, how someone may want their observations taken or how they would manage with cannulation.'* (Participant ID 7158)

## 6. Discussion

The results of surveys and interviews have been presented above in relation to each of the three key stakeholder groups. In discussing the results, however, the focus will be on exploring common themes across the three groups.

### 6.1 Recruitment

First, it is important to comment on the challenges encountered in relation to recruitment to the study. Challenges were experienced in relation to each of the groups and these included the fact that, at the time of this survey, there were other surveys in circulation to both families and paid carers and health professionals. One of these surveys related to the work commissioned by Improvement Cymru in terms of evaluating the learning disability acute care bundle, whilst others were being circulated by other learning disability organisations. This meant that, in some instances, there was 'survey fatigue' and/ or confusion with potential participants thinking they had already responded (when they had complete done of the other surveys).

A lack of awareness of the Health Profile also meant that recruitment from key groups (most notably families and paid carers) was difficult. As previously noted, some responded to social media invitations to participate indicated they were not aware of the Health Profile. Feedback from partners also indicated that adults with a learning disability living with their families tend not to have Health Profiles further suggesting a lack of awareness.

Finally, whilst one advocacy organisation initially indicated that they would assist with recruitment for the interviews they later said that it was not possible since, having asked their members, they found that the Health Profile was not being used. The group supporter suggested that members were still using the 'Traffic Light Hospital Passport' and felt this was because they found it easier to use. This meant that whilst participation was sought from North Wales, in practice it was only possible to recruit people with learning disabilities from South and West Wales.

Despite these limitations however, it was possible to gain views from each of the stakeholder groups, from across all health boards in Wales, and concerning use of the tool in various healthcare settings. In addition, some common themes were evident across the three

stakeholder groups suggesting some consensus from which recommendations for future development can be made.

## 6.2 Usefulness of the Health Profile

The key aim of this evaluation was to assess the useability of the Health Profile. It is pleasing to note, therefore, that people with learning disabilities who were interviewed and who had a Health Profile seemed to view it as helpful. Similarly, most families and paid carers (87.5%) and health professionals (88%) rated their overall experience of using the Health Profile as either positive or very positive.

Whilst the main setting in which the Health Profile seemed to be used was when attending acute hospital settings, it was positive to note that it had also been used in primary care, learning disability services, opticians, and dentists. There would thus appear to be some movement away from regarding it just as a tool to be used in hospital settings although this view was still evident from some responses and hence further awareness raising may be needed.

The aim of the Health Profile is to improve patient safety and communication and hence to promote person centred, timely and appropriate care. Participants in this study identified several contributions they felt had been made through use of the tool. These included enhancing communication especially where the individual with learning disabilities is nonverbal or are too nervous to communicate in a healthcare setting. Some participants with a learning disability felt that it enhanced their confidence and avoided them having to constantly repeat the same information to different professionals. Several participants reported that it supported the delivery of person-centred care, enabled reasonable adjustments to be made, and provided an important overview of the individual's health and support needs. Some health professionals reported that it provided an important 'baseline' in terms of what is normal for an individual thus enabling them to recognise signs of illness and/ or distress, and hence to act.

Overall, then, when it is used appropriately the Health Profile appears to be making a positive difference. However, this difference can only be made if all stakeholders are aware of its existence and that people with learning disabilities are supported to have an up-to-date Health Profile and that this is then used appropriately in practice. The results of this study suggested that these are areas that both require improvement and hence the discussion will now turn to these.

## 6.2 Awareness of the Health Profile and guidance documents

As has been noted above, the challenges encountered in relation to recruitment to this study revealed that there is still work to be undertaken in terms of ensuring that all stakeholders (people with learning disabilities, their families and paid carers, and health professionals) are aware of the Health Profile. Similarly, participants also reported a lack of awareness of both the Health Profile and the guidance documents.

In relation to the guidance documents almost half (45.8%) of the family and paid carer group indicated that they were not aware of the document and of the health professionals approximately a third (33%) indicated that they had either not read the document or were not aware of its existence. This lack of awareness may, in part, explain the comments received regarding the Health Profile not including as many specific headings / questions as the previous hospital passport.

When consulting to develop the Health Profile the research undertaken with people with learning disabilities indicated that they felt some of the headings traditionally included in the hospital passport were not necessarily relevant to them as individuals. In addition, that research also indicated that over 70% of participants felt that the new document should be no longer than 4 pages. To keep the profile as concise as possible, whilst also allowing the potential to personalise the information more, the decision was therefore taken to include broad headings in the document itself whilst using the guidance document to identify areas that those completing the document might wish to consider in each of these areas. However, if the guidance document is not used then there is the potential for some information to be overlooked.

When the guidance document is used, however, participants reported that they found it useful. Thirty-nine health professionals indicated that they were aware of the guidance document and, of these, 36 rated it as either helpful or very helpful. Amongst the family and paid carer responses, 10 indicated that they had used the guidance document, and all rated them as either helpful or very helpful. Some participants with learning disabilities indicated that they had used the guidance document either to self-complete the document or when working with a supporter to complete it. Interestingly, some participants reported that they had supported their peers to complete a Health Profile over the phone during the Covid pandemic and, in this context, the guidance document had been helpful to structure the discussion and gain the information required.

A further dimension of awareness in relation to the Health Profile that emerged from this study is awareness of who the document 'belongs' to. For some people with learning disabilities there was a view that the document is for the staff, belongs to the staff and (in one instance) that they were 'allowed' to access it. There may thus be a need to support people with learning disabilities that this is their personal document even though others may assist through taking care of it.

In terms of raising awareness regarding the Health Profile it was positive to note the role that people with a learning disability are playing both in terms of peer education and in relation to the education of health professionals whether on an individual basis during a health appointment or on a more formal basis in training sessions. Other key routes for gaining information regarding the Health Profile appear to be via People First groups, groups such as TRAC at the University of South Wales and the work undertaken by Improvement Cymru.

### 6.3 Use of the Health Profile in practice

A key aim of developing a 'Once for Wales' Health Profile was to promote consistency across services and settings. The rationale being that a consistent and easily identifiable document would be more likely to be recognised (and hence used) by health professionals. In addition, in emergency situations, greater safety would be ensured since practitioners, familiar with the document, would know exactly where to look in the document for key information such as allergies. The research underpinning the Health Profile also suggested that the document should be recognisable as an NHS document to ensure that practitioners would know that it should be used.

However, it is evident from both the findings of this study and the feedback gained during recruitment, that different tools appear to be still in use. There are some geographical influences on this (West and North Wales) which may impact on consistency of approach and reduced awareness amongst health professionals.

Whilst having a Health Profile is positive, its usefulness will only be realised if it is read by health professionals and used to inform care planning and delivery. It was, therefore, disappointing to see that neither people with learning disabilities or the family and paid carers reported that health professionals had asked to look at their Health Profile. In contrast, however, 84% of the health professionals reported that, if they were not offered a Health Profile by a patient with learning disabilities or their family / paid carers, they would ask if they had one. This difference in perception might, however, be accounted for by the composition of the health professional groups where at least a half of participants were from a learning disability background and who might, therefore, be more aware of the document. Alternatively, despite it being an anonymous survey, respondents may have wished to give a socially acceptable answer. Whatever the reason, opportunities to promote the use of the document may be missed by health professionals and there is a need to 'make every contact count' through asking individuals if they have a Health Profile. The inclusion of a question in the Welsh Digital Nursing Records asking whether an individual has a Health Profile may assist in addressing this issue.

Several responses from both people with learning disabilities and their families / paid carers, indicated that where they were not asked for their Health Profile, they then offered this to health professionals. Disappointingly, several participants reported that even when they did this the Health Profile was not read and hence not used to inform care. Others spoke of having to remind health professionals to refer to the tool. There thus appears to be a reluctance on the part of some health professionals to use the Health Profile and additional awareness raising is required. Whilst the reasons for this reluctance are unclear perhaps the patient safety message needs reinforcing as well as the fact that whilst reading the Health Profile may take time, it may end up saving time in the longer term and assist health professionals to do their work more effectively.

### 6.4 Changes needed

Whilst overall participant experiences of the Health Profile appear positive, they were invited to identify areas where they felt it was not working well and where change might be needed. Some common themes were evident across the stakeholder groups.

As has already been noted, when the research to underpin development of the Health Profile was undertaken, over 70% of respondents indicated that the document should be more than four pages long. This was, therefore, the length of the document developed. In this evaluation, however, a couple of participants suggested that the Health Profile is too long whilst others that it is not long enough. In relation to the latter, such comments were sometimes linked to those which indicated a preference for the old 'hospital passport' or 'traffic light' documents indicating that they contained more information. Given that the Health Profile is designed to be a brief document containing the key information regarding an individual whilst remaining brief enough to be read by busy health professionals and, given that the majority of participants in the original research indicated it should be no more than four pages, increasing the length of the document does not seem to be justified.

The Health Profile does not preclude additional information being appended to the document and the reader being referred to this in the main document. The guidance documents highlight this but as noted earlier, there seems to be a lack of awareness in relation to the guidance. Rather than altering the Health Profile, therefore, it may be more appropriate to focus on increasing awareness and use of the guidance documents. One way of supporting this could be to add a QR code to the Health Profile which would give direct access to the guidance documents. In addition, stakeholders could be encouraged to view the Health Profile as being equivalent to the 'red' section of the previous traffic light documents to which other (amber and green) information can be appended.

There were, nonetheless, some suggestions for further development that may be worthy of consideration. First, across all stakeholder groups, there was the suggestion that it would be helpful to develop a digital version of the Health Profile. The reasoning for this was twofold – first, some people with a learning disability felt that it would be helpful as they always have their phones with them. Second, some health professionals felt that a digital version would be helpful since their records are all digital. Whilst there would appear to be merit to consideration of this proposal it is likely that there would still be a need for a paper version since not everyone will have a smart phone or tablet. In addition, if health professionals are reluctant to read a paper document when handed to them the likelihood of them reading a version on a phone or tablet that they would not have continuing access to is even more limited. For the information to be easily transferred to health care IT systems would require that systems are compatible but, if that could be achieved, it would support the updating of the document when (for example) needs change during a hospital admission.

Some concerns were raised in relation to updating of information contained in the Health Profile and this would seem to be an important part of the process to consider particularly as some people with a learning disability said they did not know how they would update their profile. Most concerns regarding updating related to the medication section where changes may occur frequently and, if not recorded, could potentially, constitute a patient safety issue. This therefore appears an important area to reconsider.

Some other minor changes to the document were suggested such as the addition of contact details for the individual's GP, a larger font, the addition of some more pictures / colour, and the need for a braille version. In considering any of these modifications there would need,

however, to be balance potential benefits against the potential for them to increase the length of the document.

A final issue raised was the need for a bilingual version of the Health Profile. At present there are English and Welsh versions, but some participants indicated there should be a bilingual document to avoid the need for translation that might not be available in an emergency. Once again, however, this would be likely to increase the length of the document and hence would need to be carefully considered.

## 7 Conclusion and Recommendations

Whilst recognising the limitations of this study in terms of sample size, some consistent themes were identifiable across the three stakeholder groups who participated. Based on these, conclusions can be drawn, and recommendations made.

First, when the Health Profile is used appropriately it appears to be helpful in promoting safe and person-centred care, ensuring that reasonable adjustments are in place, ensuring effective communication and providing reassurance for people with learning disabilities. However, there is a need to further build awareness across the stakeholder groups and particularly amongst families. This relates to both the Health Profile and the accompanying guidance documents and, in turn, limits the potential of the document due to limited use in practice. There is also a need to raise awareness of the range of settings in which the Health Profile can be used.

Second, whilst some suggestions were made for development/ improvement of the document generally the length and content appear to be acceptable. Suggestions for change include development of a digital version and the potential to add additional sections. In relation to the latter, however, the addition of any further sections would increase the length of the document and that would be contrary to the strong view expressed in the original research that it should be no more than four pages long.

One possible way to address this issue would be to encourage stakeholders to view the Health Profile as equivalent to the 'red' section of previous 'traffic light' hospital passports, and to stress that additional (amber and green) information can be appended if desired. This would keep the document brief for health professionals, address the concerns expressed by some participants, and potentially also assist the process of change management from previous systems to the Health Profile.

Third, the need to regularly update an individual's Health Profile needs to be considered and further thought given as to how this might best be supported. This is particularly important in relation to the information regarding medication and this section of the Health Profile may require further consideration.

The following recommendations are therefore made:

- That further work is undertaken to raise awareness of the Health Profile and the guidance documents. This is important across stakeholder groups but a particular focus needs to be on raising family awareness.

- That consideration be given to encouraging stakeholders to view the Health Profile as equivalent to the 'red' section of previous traffic light hospital passports to which they can append additional information they feel might be helpful.
- In relation to health professionals then there needs to be a focus on promoting how it can assist them in their work, on them requesting to see an individual's Health Profile, and on using the information it contains to inform care delivery.
- In relation to raising awareness of the guidance documents then consideration should be given to including a QR code on the Health Profile that links directly to the guidance documents.
- That a digital version of the Health Profile be developed to complement the paper version.
- That further consideration be given as to how regular updating of an individual's Health Profile can best be supported.

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