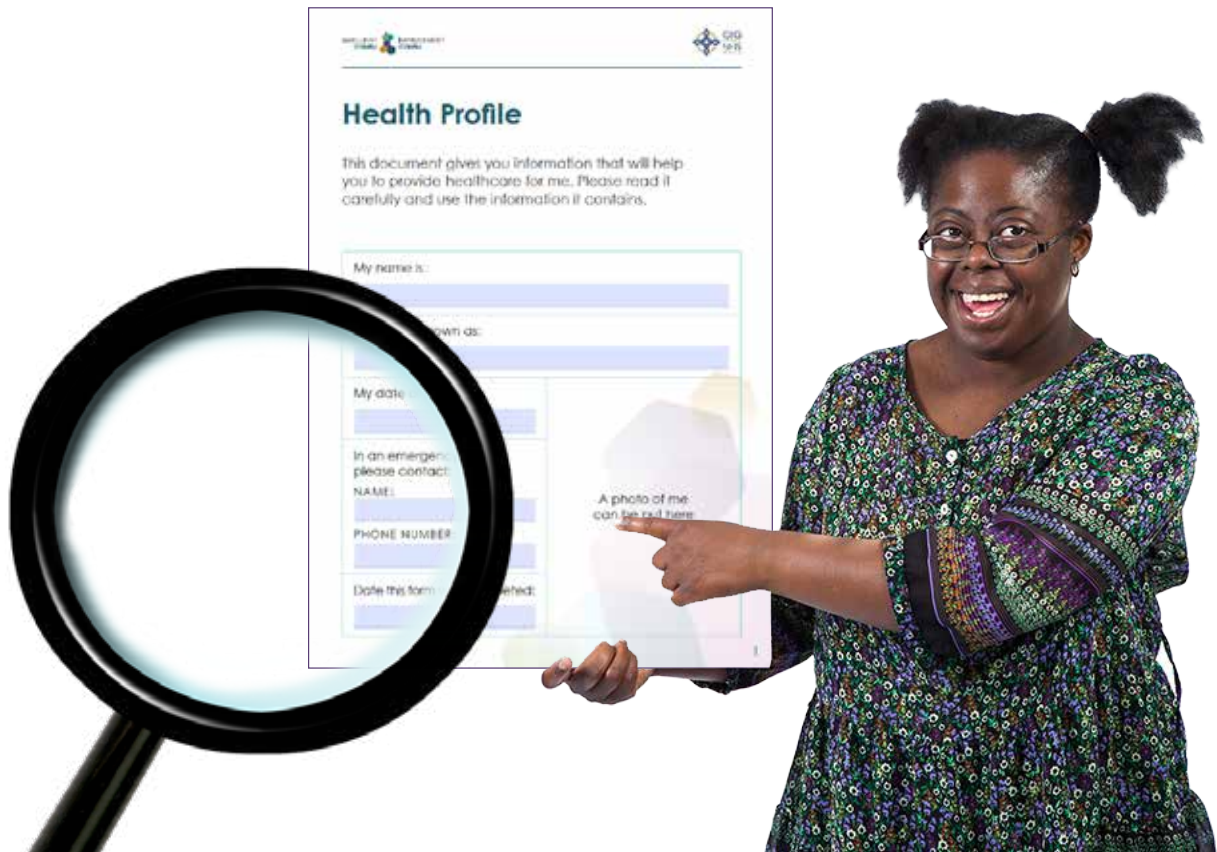


Checking how easy the Once for Wales Health Profile is to use

A report by the University of South Wales



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This is an easy read version of 'Evaluation of the Useability of the Once for Wales Health Profile – Executive Summary'.

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How to use this report



This is an easy read document. You may still need support to read it. Ask someone you know to help you.



Words in **bold blue writing** may be hard to understand. You can check what the words in blue mean on **page 22**.



Where the document says **we**, this means the **Unit for Development in Intellectual and Developmental Disabilities (UDIDD)** at the **University of South Wales**. For more information contact:

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About this report

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Prifysgol
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We are the **Unit for Development in Intellectual and Developmental Disabilities (UDIDD)** at the **University of South Wales**.



In 2022, **Improvement Cymru** asked us to check how easy the **Once for Wales Health Profile** is to use. In this report we share what we found and suggest ways to make it better.

Background



People with a learning disability can find it hard to get the right healthcare. One big problem is communication.



To help, there were documents like **communication passports** and **hospital passports**. These had important information for health workers.



When we say health workers we mean doctors, nurses and other health staff.



We looked at 60 of these documents and saw they were all very different in look, length, and content. This could be unsafe as health workers may not know what they are or how to use them.



The important information might not be easy for the health workers to find. There should be 1 type of document that everyone uses.



In 2019, **Improvement Cymru** asked us to create 1 document for everyone in Wales to use. We made the Once for Wales Health Profile.



We asked people with a learning disability, their families and carers, and health workers to help us make the Health Profile.



We launched the Health Profile in 2020. 1 for adults and 1 for children.



We made guides to help people fill it out.



The Health Profile is 4 pages long.



We updated it to be easier to use and to complete online.

Our goals for this report



We wanted to find out how easy the **Once for Wales Health Profile** is to use by getting feedback from:



- People with a learning disability.



- Family, friends and care staff, who help people fill it out.



- Health workers who use it to provide care.

How we got feedback

We used 2 ways:



1. We asked 20 people with a learning disability about their experiences with the Health Profile.



2. We sent online surveys to families, paid carers, and health workers.



We got 24 replies from families and paid carers.



We got 58 replies from health workers.



We looked at the interview notes and survey answers to see what people talked about most.

What people told us

People with a learning disability



People with a learning disability knew different amounts about the Health Profile. Some filled it out on their own. Others had help.



Many did not know about the guide that can help you with filling it out. Those who used it found it helpful.



The Health Profile was useful for hospital visits. And other places like GP doctors and dentists.



People said it was good as they do not have to repeat the same information.



People said it was important for emergencies and safety.



Most people found its length and look was OK.



Some people said having an online version of the Health Profile would be helpful. But we should keep a paper version because not everyone can fill it out online.



Some people thought adding more pictures and extra sections could be useful. But this would make the document longer. Most agreed it should stay at 4 pages.



The Health Profile is yours. The information is about you. Some people thought it was their own document. Others thought it was more to help staff.



Some worried about getting help to update the Health Profile when needed.



It was worrying that only 1 person said health workers used their Health Profile to guide their care.



Most people had to offer their Health Profile themselves. Even then, it was not always read or used by staff.



People felt that more people need to know about and use the Health Profile.

Family and Carers



Feedback from family groups on social media showed that many families did not know about the Health Profile.



Most people said the Health Profile was easy to complete.



Less than half used the guide when filling out the Health Profile.



Those who used it found it helpful.



People used the Health Profile in many places. They used it most for emergency and planned hospital visits.



People also used it in learning disability and mental health centres, GP doctors, opticians, and pharmacies.



Half of the people said that health workers read the Health Profile when it was given to them.



1 in 4 of these said health workers did not use it to plan care. Staff needed to be reminded to read it.



Most people said their experience using the Health Profile was very good.



People liked that the Health Profile helps provide **person-centred** care.

Person-centred means focusing on what each person wants and needs.



They also thought its length and look was OK.



Some said it is not being used fully and that health staff often do not have time to read it.



Some people think it has less information than earlier versions.



Some said that keeping the medication part updated is very important.

Health workers



Most health workers said people with a learning disability they were caring for had given them a Health Profile.



When they helped someone to complete a Health Profile, they found it easy to do.



There is a guide for health workers on how to use the Health Profile.



Most knew about it, but about 1 in 3 either did not use it or did not know about it.

Health workers used the Health Profile in many ways:

- to provide **person-centred** care





- share medical history and allergies



- understand communication needs



- notice changes in a person's condition



- ensure patient safety



- make **reasonable adjustments**.

Reasonable adjustments are changes made to make things easier for someone.



Most people said their experience with the document was very good. They said the photo was helpful. People had mixed ideas on the length.



Some thought adding extra sections would be useful. This would be the same as the previous Health Passports. This would make the Health Profile longer. Others thought the current length is long.



Some people worried that not everyone with a learning disability has a Health Profile. They said more people need to know about and use them.



Some said an online version would be helpful.



Some said it is important to find better ways to keep medication information updated. People said to add links from the Health Profile to the guidance documents.

Our main findings



Though the review was not a big one, we spoke to lots of different people.



There were 3 important areas:

1. The Health Profile helps



It supports safe and **person-centred** care when used correctly.



It helps health workers make any changes needed and improves communication.



More people, including families, need to know about and use the Health Profile and its guides.

2.Length and content are OK



Most people think the length and content of the Health Profile are fine. Some people want an online version as well.



Some want extra sections to add more details. Most people think it should stay at 4 pages.

3.Update often



Everyone needs to keep the Health Profile updated.



This is most important if medication changes. We need to find the best way to do this.

Ways the Health Profile can be better



Raise awareness

Tell more people, especially families, about the Health Profile and guides.



Use it like the old Red Section

Encourage people to use the Health Profile like the red section in old traffic light hospital passports. Adding any extra useful information.



Help health workers

Make sure health workers know how the Health Profile can help them. They should ask for the Health Profile and use it to provide better care and patient safety.

Add a QR Code



Put a QR code and link on the Health Profile that goes to the guidance documents. A QR code is a square you can scan with a phone, and it goes to a web page.



Create an online version

Make an online version to go with the paper one.



Support regular updating

Find ways to help keep the Health Profile updated.

Hard words

Person-centred

Person-centred means focusing on what each person wants and needs.

Reasonable adjustments

Reasonable adjustments are changes made to make things easier for someone.