Easy read report

Llywodraeth Cymru
Welsh Government

Continuing NHS Healthcare

What people said about the changes we want to make

This document was written by **Welsh Government**. It is an easy read version of: **Continuing NHS Healthcare: The National Framework for Wales. Consultation Report.**

December 2019

How to use this document

This is an easy read version. The words and their meaning are easy to read and understand.

You may need support to read and understand this document. Ask someone you know to help you.

Words in **bold blue writing** may be hard to understand. They have been explained in a box below the word.

If the hard word is used again it is in normal blue writing. You can check what all the words in blue mean on **page 29**.

Where the document says **we**, this means the **Welsh Government**. For more information contact:

Address: Complex, Unscheduled Care and Disability Branch
Partnership and Cooperation Division
Welsh Government
4th Floor, North Cathays Park
Cardiff, CF10 3NQ

Website:
https://gov.wales/draft-national-framework-continuing-nhs-healthcare

E-mail: CHCFramework.Consultation@gov.uk

This document was made into easy read by **Easy Read Wales** using **Photosymbols**.

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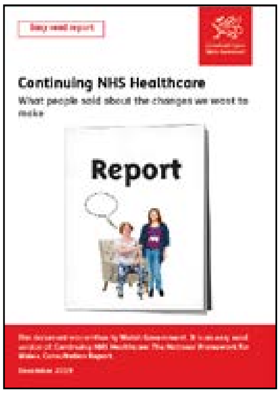
Introduction

We want to make changes to the guide that explains how to provide **Continuing NHS Healthcare.** We want to make it better.

Continuing NHS Healthcare is care and support for people who have extra needs because of their health. We call it **CHC** for short.

We asked people what they thought about our ideas for changes to the guide. This happened between May and August 2019.



Continuing NHS Healthcare
What people said about the changes we want to make

Report

This report is about what people said.

Health boards and councils must work together to provide **CHC**. They must obey the guide. The guide says:

- Who can get **CHC**.
- How to decide if someone should get **CHC**.
- What health boards must do.
- What councils must do.

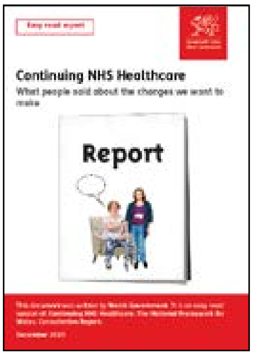
You can see more information about this here: https://gov.wales/draft-national-framework-continuing-nhs-healthcare

What people said

We got answers from:

- Members of the public.
- Local Health Boards – providing health services across Wales.
- Councils.
- Public Services Boards – working across all services in each council.
- Groups that speak up for patients.
- Inspectors – people who check how good services are.

We got 58 responses in total. We asked 11 questions. But not everyone answered every question.



Continuing NHS Healthcare

What people said about the changes we want to make

Report

This is what people said to each question.

Question 1

We are changing the guide for providing CHC. Are there any problems you think we need to deal with to make sure it is used properly?

There were 49 answers to this question. People said:

- We should give training on the new guide to health boards and councils. And have ongoing training for all staff.

- Having time to get used to the new guide is a good idea. But some thought this did not help when we changed the guide in 2014. They said we need better ways to keep checking the guide is used properly.

- We should have examples of the best ways of working put on our website that is called **Complex Care Information and Support Site**: www.cciss.org.uk.

- We should help make issues between **CHC** and the **Mental Health Act** clearer.

Some people liked the idea of having a checklist to help decide who should have **CHC**. They said:

- Staff should get training so they all use the checklist in the same way.

- We should check how useful the checklist is.

- We need to make it clearer who should use the checklist. And what to do if someone is not happy with the decision made after using the checklist.

What we will do

We will work with health boards and councils to write training.

We will work with partners to improve how we check how **CHC** is provided.

We will make sure all **CHC** staff can use the website. And can get all the information they need to provide **CHC**. We will keep the website updated.

We are working to make issues around the **Mental Health Act** clearer.

We will think about re-writing the instructions for using the checklist.

Question 2

The guide is for staff who run services. Should we make an easier guide for staff and people who use services?

There were 44 answers to this question. People said:

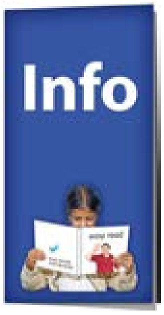
- An easier guide would be useful for staff. But this would be a big job.

- An easier guide would be very useful for the public. Because they would not have to rely on staff to explain **CHC** to them.

- New parts about carers are good. We should write something in the guide to remind carers they can get a **carer's assessment**.

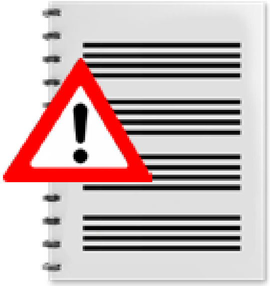
A **carer's assessment** is when you are asked about your care responsibilities and what support you need.

- The public do not know about **CHC**. We should do work to tell more people about **CHC** when we launch the new guide.



Some people said we did not need an easier guide because:

- we already have leaflets about **CHC** for the public



- an easier version may miss out important details.

What we will do

Instead of an easier guide for staff we think it would be best to write:

- examples of the best ways to work
- frequently asked questions (FAQs)

We will write a booklet all about **CHC** for the public.

We will work with patient groups and individuals to write the booklet about **CHC**.

The booklet will have all the information people need to understand:

- What will happen when they go through the **CHC** process.

- Their rights.

- Who is responsible for their care and support needs.

- Where to get advice and support.

We will get the booklet ready by April 2020 and send it out with the new guide. We will use the booklet to tell more people about **CHC**.

Question 3

Do the changes we want help make it clear how CHC should be organised?

There were 42 answers to this question. People said:

- The new guide is clearer. But some things are still not clear enough. For example the checklist, the money to pay for **CHC** and **Direct payments**.

A **Direct Payment** is when you get money to buy your own support and services.

You cannot use Direct Payments to pay for **CHC**.

- Everyone should know who is responsible if a decision is late. It would be good to have an extra guide to say who was in charge of what.

Councils said they want us to look into how we check **CHC**. And that we should check all decisions whether they decide to give someone **CHC** or not. They also want to see all the reports written by health boards on **CHC**.

What we will do

We will work with health boards and councils to make all the areas talked about clearer.

We have already started looking into how we check **CHC**. The new way of checking will be ready in April 2020 with the new guide.

Question 4

How can we make sure organisations like health boards and councils work well together?

There were 44 answers to this question. People said:

- The guide will help people work well together to provide care and support and manage money. And all CHC staff from health boards and councils will get training together.

- Councils want to be involved more in making decisions about **CHC**. Not just at the **Decision Support Tool** meeting.

They think this will help stop delays because of arguments over who should pay for care and support. Councils should be at all important **CHC** meetings.

The **Decision Support Tool** helps us decide who needs **CHC**.

What we will do

We will talk about how councils could be involved in making decisions after the Decision Support Tool meeting.

We think it is important for councils to be at important meetings about **CHC**.

Question 5

Do you think the new guide for how we provide CHC will be clearer?

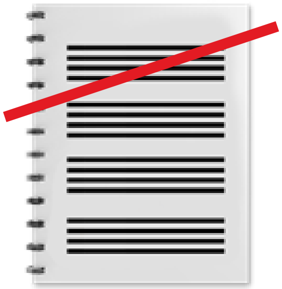
There were 39 answers to this question. People said:

- Some parts of the guide are still not clear enough.

- There is a team of people that make decisions about who is **eligible** for **CHC**.

Eligible means you have the right to get **CHC** because of your health needs.

The new guide says health boards can ask the team to give more proof about the decision if they do not agree.



Some people think this should be taken out. Health boards should only be able to do this in special situations.

Most people said it was still not clear what should happen when someone who gets Direct Payments becomes eligible for **CHC**. They said there needs to be examples of the best way to deal with this.

What we will do

We will look into making the guide clearer where needed. Including parts about the health board getting more proof from the decision making team.

We will work with partners to find a way to deal with the problem with **CHC** and Direct Payments.

Question 6

We want to make changes to:

- **Assessments**
- **Deciding if someone is eligible for CHC**
- **Using a checklist and Decision Support Tool.**

Do you agree with the changes we want to make to these areas?

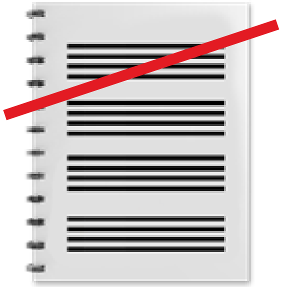
An **assessment** is when someone looks at your care and support needs and how they can be met.

There were 48 answers to this question. People said:

- The new guide and the Decision Support Tool is set out well.

- We should have a flowchart in the guide. To show how **CHC** should work. And how long everything should take.

- We should not change the Decision Support Tool. Because this might change who gets **CHC**. We should explain why we suggested changes to the Decision Support Tool.



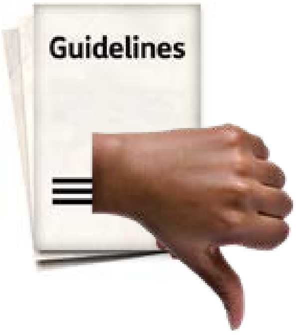
- We should not say ‘scoring’. We should say ‘assessing levels of need’ instead. This is to keep the focus on people’s needs.

- people from the decision making team must be involved in:

    - Decision Support Tool

    - Assessment

    - Providing care and support



The new guide only says this should happen when possible.

What we will do

We will add a flowchart to the guide. And we will also put it in the booklet about **CHC**.

We will look into what happens after the checklist. We will either change the guide to make this clearer, or give training on the checklist.

We want the decision making team being involved when possible rather than at all times. This is to help stop decisions and support being delayed. We will make the guide clearer on this.

We will not change the rules about who is eligible for **CHC**. We will make sure the Decision Support Tool does not change who is eligible for **CHC**.

We will change 'scoring' to 'levels of need' in all documents about **CHC**.

Question 7

Do you think people and their families are involved enough in assessments?

There were 43 answers to this question. People said:

- It is good that the guide talks about people and families being involved. But this needs to happen more often, all over Wales. **CHC** staff should get training on listening to family, friends and carers.

What we will do

We want to make sure people and families are fully involved. We need to do more so it really happens. We agree that people need to be able to talk with the decision making teams. And that **CHC** staff should get training.

We think the booklet about **CHC** will also help. The booklet will give people and their families the information they need to have a voice and control.

Question 8

Do you think the new guide will work well with other health and social services rules?

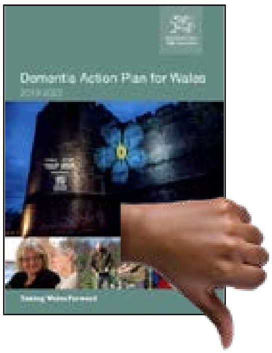
There were 44 answers to this question. People said:

- It is not clear how the guide links to rules like:

  - **Code of Practice on the Delivery of Autism Services**

  - **Additional Learning Needs and Education Tribunal Act**

  - **Loneliness and Isolation**



- The guide does link with the **National Dementia Action Plan**. But we need to make sure this happens. The guide should say all assessments will be joined up with any other assessments a person is having.

- There is not enough focus in the guide on the **Social Model**.

The **Social Model** focuses on how we can make changes to support people. Rather than just treating them because there is something wrong with them.

- We need to do more to make sure children moving to adult services are supported. There is not enough in the guide about this.

What we will do

We will do more work on linking the guide with other rules.

Health boards and councils must make sure families know about changes to care and support when a child moves to adult services.

There is information in the guide about this. And there are very good resources on the website to support **CHC** staff with this. We will work with partners to make sure these resources work.

Question 9

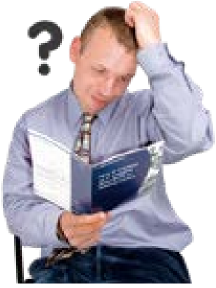
We talked about retrospective reviews. And said there should be 2 stages to this. Do you agree with what we want to change?

There were 43 answers to this question. People said:

- The changes in the new guide will help to deal with **retrospective reviews**.

A **retrospective review** is when someone asks for the care they have had to be checked. For example, when they have paid towards their care but think this was wrong.

Some people did not agree because:



- It is not clear how long you have after a decision is made to **appeal**.

An **appeal** is when you ask for a decision to be changed.

- People do not have enough time to appeal. The guide says people have 28 days. But this should be 6 months.

- Providers have too much time to show the records needed for a review. Health boards said there should be useful tools on the website to help them deal with reviews quicker.

What we will do

We will work on making the words clearer about how long you have to appeal.

We agree that 28 days is not enough time to get everything ready. We will make it clearer that you have 28 days to tell the health board that you want to appeal.

We will change the time you have to make an appeal to either 6 or 12 months. This will only count for decisions that are made after the new guide is brought out.

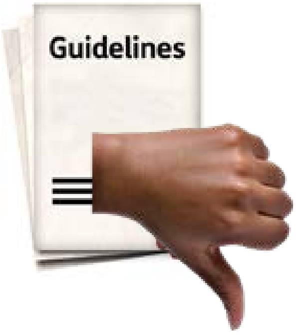
We will make sure that there are useful tools on the website to help deal with appeals quicker.

Question 10

Do you think the Welsh language will be used the same as English in the new guide?

People said:

- The new guide should be available in Welsh.



- The guide does not do enough to make sure people can get services in Welsh.

- It is important that people with **Dementia** can get services in their 1st language. Which might be Welsh.

Dementia is a condition where people have problems with memory and can be confused.

- Finding Welsh speakers to go to assessment meetings can cause delays.

- The **Welsh Language Commissioner** said we must plan to provide CHC services in Welsh. And this should be added to the guide.

What we will do

We will offer people the choice to get **CHC** services in Welsh. They should not have to ask for it.

Health Boards and councils must make sure their staff have Welsh language skills.

We will write a strong rule in the guide about making sure **CHC** services are available in Welsh.

Question 11

Is there anything else you would like to say?

Most answers to this question talked about issues with how to make sure the guide is used properly. And we have talked about this under question 1.

What we will do next

We will write training on the new guide for **CHC** staff.

We will work on the **Complex Care Information Services Site** website to make sure it offers the best support for **CHC** staff.

We will work with the public and patient groups to write a booklet about **CHC**. We will get this ready by April 2020.

We will work with partners on other rules to help clear up certain things in the guide.

Hard words

Assessment
An assessment is when someone looks at your care and support needs and how they can be met.

Appeal
An appeal is when you ask for a decision to be changed.

Carer’s assessment
A carer’s assessment looks at your care responsibilities and what support you need.

Decision Support Tool
The Decision Support Tool helps us decide who needs CHC.

Dementia
Dementia is a condition where people have problems with memory and can be confused.

Direct Payment
A Direct Payment is when you get money to buy your own support and services.

Eligible
Eligible means you have the right to get CHC because of your health needs.

Retrospective review
A retrospective review is when someone asks for the care they have had to be checked. For example, when they have paid towards their care but think this was wrong.

Social Model
The Social Model focuses more on how we can make changes to support people. Rather than just treating them because there is something wrong with them.