

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC34: Ymateb gan: | Response from:

David Proud; Clinical Dietetic Lead Cystic Fibrosis Service

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# Supporting people with chronic conditions: consultation

29 March to 25 May 2023

This document has been prepared in Microsoft Word. An explainer document is available in **Microsoft Word format** if you need any help to use the 'Read aloud' function, or to change the page background colours, text sizes or text colours.

## 1. Introduction

The Health and Social Care Committee is holding an inquiry into supporting people with chronic conditions.

## 2. Background

The term 'chronic conditions' (also known as 'long term conditions' or 'longstanding illnesses') includes a broad range of health conditions which cannot be cured but can be managed with the right support and treatment. Many people also live with multimorbidity (two or more chronic conditions). People from different backgrounds, who belong to different groups or communities, or who live in different parts of Wales may also experience inequalities in relation to their conditions or their access to services or support.

## 3. A two-stage approach

Because of the complexity of these issues and the wide range of chronic conditions people may experience, we are approaching our work in two stages. During stage 1 we would like you to help us by identifying the key themes and issues we should focus on when we move into the second stage of our work.

### Stage 1

During the first stage of our work, we are considering the following broad areas:



### NHS and social care services

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- Please note as I have worked exclusively in the All Wales tertiary specialist area of adult cystic fibrosis my experience is limited to this area. This response relates to patients with Cystic Fibrosis
- The readiness of local NHS and social care services to treat people with chronic conditions within the community.
- Due to recent improvements in CF pharmacological management our adult CF population are now expected to live much longer (current median survival 51y and expected to increase). As a consequence of improved health our patients suffer significant fewer acute exacerbations of CF and therefore our MDT is shifting to supporting in the community.
- However, with an ageing population of People with CF (PwCF) there is a recognised trend of increasing overweight and obesity. Consequently, there is concern that risk of CVD, T2DM will increase. Traditional model of nutritional care in CF has focused on nutritional support, with particular focus on ONS and ETF. Consequently, there is a lack of CF appropriate healthy eating and living resources. Previous discussions with traditional C&V UHB weight management services for the general population are unsuitable as our PwCF are deemed 'complex'. Consequently, we are working with Cardiff Met Health Psychology dept in a bid to develop appropriate resources for our patient group.
- Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.
- See comment above re inability to access current traditional weight management services as our patient group are deemed complex.
- Currently our WHSSC funding model does not take into account the needs of an ageing population (with CF). There is evidence that although PwCF are living longer they may be more frail compared to non CF peers. Therefore, there is a potential that we will need to access or develop relevant services going forward in relation to OT support (current WHSSC funded CF model of care does not include OT).

- As stated our PwCF are generally more well and therefore require less admissions. Therefore, future care may require a focus towards home visits? Currently, our dietetic resources are unable to cater for this aspect of care.
- Support available to enable effective self-management where appropriate, including mental health support.
- Our CF MDT includes a Psycho-social team of Psychologists, social worker and youth worker.
- Our centre is exploring patient leadership programme. Also exploring Patient initiated follow-up (PIFU) service.
- Currently we utilise the virtual platform BEAM providing online exercise and nutritional advice resources for patients.
- PREMS & PROMS digital: Trial in our CF service where patients are able to complete surveys / questionnaires (eg QOL's) digitally (PREMS), but also have the capacity to track their own progress by accessing trend in results (PROMS)
- We utilise and encourage use of tele-health for our PwCF. They have the option to receive Bluetooth spirometers, weighing scales and fit bits linked up to the Project Breather platform which is accessible remotely by our MDT.

### Multiple conditions

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- The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.

Our patients are at risk of developing multiple co-morbidities, including CF related liver disease, diabetes, bone disease and arthropathy. We currently have established links with hepatobiliary care and diabetes.

- The interaction between mental health conditions and long-term physical health conditions.
- Our CF MDT includes a Psycho-social team of Psychologists, social worker and youth worker.

### Impact of additional factors

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- The impact of the pandemic on quality of care across chronic conditions.
- Throughout the pandemic our AWACFC continues to function fully offering inpatient and outpatient support. However, this period also enabled us to access effective virtual technology allowing more equitable care for our all Wales patients, regardless of geographical location.
- We utilise and encourage use of tele-health for our PwCF. They have the option to receive Bluetooth spirometers, weighing scales and fit bits linked up to the Project Breather platform which is accessible remotely by our MDT.
- The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.
- We have seen a rise in the number of PwCF under our care reporting they are struggling more with cost of living. Consequently, we have recently begun to register relevant members of our CF MDT eg Dietitians, Youth Worker, Social Worker as Food Bank referrers.
- We continue to utilise Attend Anywhere in hybrid clinics (virtual and F2F) for patients who are generally stable and well reducing the need for our patients to travel.
- The extent to which services will have the capacity to meet future demand with an ageing population.
- See previous comments.

## Prevention and lifestyle

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- Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).
- See previous comments re Healthy Eating, Exercise and Living resources appropriate for PwCF under development.
- Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.

- See previous comments re Healthy Eating, Exercise and Living resources appropriate for PwCF under development.
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David Proud. Clinical Dietetic Lead Cystic Fibrosis Service

You are welcome to comment generally or specifically about a certain condition.

## 4. How to share your views

### Evidence gathering

We want to make sure that our work is informed by experiences, needs, and views that reflect the diversity of the people and communities affected by these issues.

We encourage anyone with expertise or experience of these issues to share your views, with the full knowledge that your views will be welcomed and valued.

The closing date for submissions is **Thursday 25 May 2023**.

### **Along with your submission, you should provide the following information:**

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- Your name and contact details as the person, or organisation, submitting the evidence.
- Whether your evidence is submitted as an individual, or on behalf of an organisation.
- If you are submitting evidence as an individual, confirmation that you are over 18 years old.
- If you are under 13 years old, your parent or guardian's agreement that you can participate (this can be provided via email).
- Confirmation of whether you would prefer that your name is not published alongside your evidence (names of individuals under 18 years old will not be published).
- Confirmation of whether you would like the Committee to treat any or all of your written evidence as confidential, with reasons for the request.

- If you have referred to a third party in your evidence, such as a parent, spouse or relative, confirmation that they have agreed that you can share information that may be used to identify them and that they understand that it will be published.

### How to share your views

To share your views electronically, please send to [SeneddHealth@senedd.wales](mailto:SeneddHealth@senedd.wales), or by post to Health and Social Care Committee, Welsh Parliament, Cardiff, CF99 1SN.

### Providing Written Evidence

The Senedd has two official languages, Welsh and English.

In line with the [Senedd's Official Languages Scheme](#), the Committee welcomes contributions in both or either of our official languages, and we ask organisations that are subject to Welsh Language standards or schemes to respond in line with their own obligations. Please inform the Committee when submitting responses if you intend to provide a translation at a later date.

Please see [guidance for those providing evidence for committees](#).

### Disclosure of information

Please ensure that you have considered the Senedd's [policy on disclosure of information](#) before submitting information to the Committee.