



Russell George
Chair, Senedd Health and Social Care Committee

13 January 2022

Dear Russell,

Health and Social Care Committee inquiry into the impact of the waiting times backlog on people in Wales

Thank you for your correspondence dated November 22nd seeking information on the patient surveys that NHS organisations in Wales undertake.

We have engaged with the Local Health Boards to develop our response to the two questions that you posed.

1. Whether Health Boards in Wales have undertaken, or plan to undertake, local, national or regional surveys of patients similar to the national survey being undertaken in England by Healthwatch.

From correspondence received from the Local Health Boards they have not undertaken, or intend to undertake, patient surveys in the way that Healthwatch England has commenced. However, as an equivalent to Healthwatch England, the [Board of Community Health Councils](#) (CHC) has undertaken a number of all-Wales surveys and reports. Local CHCs have also engaged with Local Health Boards, with some publishing individual reports and surveys.

‘Feeling Forgotten’

The Board of Community Health Councils is the independent watchdog of the NHS in Wales which represents the collective voice of the 7 CHCs in Wales, with a similar remit to Healthwatch in England. Each of the 7 CHCs in Wales represents the “Patient voice” within their respective geographical areas.

CHCs hear from the public in many different ways. Before the pandemic, CHCs regularly visited NHS services to hear from patients while they were receiving care and treatment. CHCs also heard from people at local community events and by talking to community representatives and groups. Since the pandemic, CHCs have had to change the ways they engaged with the public and patients. CHCs use public and patient surveys, social media and videoconferencing apps to hear from people directly about their views and experiences of NHS services. CHCs also continue to hear from people through enquiries and their complaints advocacy service.

Throughout the pandemic, CHCs have heard from many people whose care and treatment has been delayed because of the pandemic. As a result, the Board of CHCs published a national report in November 2020, [‘Feeling Forgotten: Hearing from people waiting for NHS](#)

[care and treatment during the Coronavirus pandemic](#)'. This followed a public national survey, during which the Board of CHCs heard from around 1,150 people across Wales.

The report showed continuing and widespread appreciation for NHS workers, while revealing that more still needs to be done to help people whose care and treatment has been delayed because of the pandemic. The feedback shared with CHCs identifies a number of common themes, including people experiencing physical and mental pain, worsening conditions, employment and income worries, feelings of isolation and loss of trust in service providers.

The report identified six areas that NHS bodies needed to respond to, including making sure:

1. healthcare staff keep in regular touch with people waiting for care and treatment;
2. Patients need to know how to get advice and support while they are waiting;
3. Healthcare staff involve people in discussions about the benefits and risks of treatment during the pandemic;
4. Staff explain clearly when changes must be made to the way services are provided during the pandemic, and what this means for those attending care and treatment;
5. Provide up to date, clear and simple information about how local NHS services have changed during the pandemic, and what the plans are to reintroduce services;
6. Reach more people who may not be able to find things out by looking on-line.

Since the publication of the report, individual Health Boards have been working closely with their local CHCs to consider the report's themes and recommendations, providing feedback to the Board of CHCS on the actions and approaches they are undertaking to address the issues raised. In addition, individual Health Boards have undertaken engagement surveys and validation exercises to gather patient views, which address concerns and issues raised with them by patients waiting for treatment.

The Board of CHCs currently has a number of open surveys asking for national [feedback](#), including on NHS care during the Coronavirus pandemic, and [local CHCs](#) are also undertaking surveys.

2. If any such surveys have been undertaken, or are planned, whether the findings and any resulting action plans will be published.

Aneurin Bevan University Health Board (ABUHB)

ABUHB Executive Team considered the Feeling Forgotten Report in January 2021, along with the actions required to respond to the recommendations raised by the Board of CHCs. ABUHB's Quality, Patient Safety and Outcomes Group has continued to provide oversight of progress during 2021/22.

In addition, ABUHB has been proactively contacting patients who have been waiting over 52-week for a new outpatient appointment in some specialities via letter/questionnaire to understand whether the referral remains appropriate and an appointment was still required. For example, some patients' symptoms may have improved or deteriorated, or services may have been accessed elsewhere. This approach will soon be rolled out to patients who have waited 36-52 weeks for a new outpatient appointment. ABUHB is also working to commence an engagement process with patients waiting for follow-up outpatient appointments.

Aneurin Bevan CHC has live surveys listed on their [website](#), including on “Winter Patient Experience Survey 2021-2022” and “Is the NHS getting better after COVID and what has it meant for you?”. The Health Board will continue to engage with the CHC on future reports and feedback received from patients.

Betsi Cadwaladr University Health Board (BCUHB)

During the pandemic BCUHB has been keeping in touch with patients and seeking to offer support while they wait to access services and receive treatment.

As part of BCUHB’s commitment to keeping in touch with patients, the Health Board has been contacting patients to find out whether they still feel they need their treatment, and importantly whether their symptoms have changed. This has followed a two-stage model which is recognised as good practice across the NHS. Where a change in symptoms is reported, BCUHB is arranging for a remote clinical review to ensure patients are treated according to the most up to date view of their clinical urgency.

There are examples across North Wales where BCUHB works in partnership with other organisations to support patients on waiting lists. Some of these focus on practical issues such as pain management, diet or exercise, whilst others have a broader aspect to support mental health and wellbeing, such as outdoor and indoor activities like walking and yoga. In January 2022, the Health Board will commence work with a technology partner to establish a home-based prehabilitation programme for orthopaedic patients with an initial focus on knee arthroplasty. The programme will focus on the longest waiters (52 weeks +) and provide support to enable self -management in the home environment, including education and exercise programmes.

BCUHB recognises that patients can often feel unsupported whilst on long waiting lists and the absence of information regarding likely waiting time to treatment can exacerbate this. A communication strategy is being developed to help keep patients more informed regarding their waiting time. This strategy will include the extended use of social media, as well as more traditional communication channels.

The Health Board will continue to discuss their proposed plans with the CHC locally to ensure that they put in place arrangements that can offer the type of support patients will find most beneficial, whilst seeking to reduce waiting times as rapidly as possible.

Cardiff and Vale University Health Board (CVUHB)

Following the Board of CHCs report, CVUHB wrote to the South Glamorgan CHC outlining some of the steps they are taking to address the concerns highlighted in the report.

The Health Board is focusing on areas such as supporting patients mental and physical health whilst waiting for treatment and are developing a web page with information for patients on how services are progressing with returning to normal capacity.

CVUHB has been undertaking a validation exercise, gradually working its way through contacting patients who have been waiting excessively long times for diagnosis and treatment. Initially, the Health Board has contacted patients who have waited more than 52

weeks for a new outpatient appointment, and CVUHB will commence validation of patients who are waiting for a follow-up appointment in January and those who are waiting for treatment in April. The validation exercise asks patients to confirm if they wish to remain on a waiting list for diagnosis or treatment but also asks patients to notify the Health Board if their condition has deteriorated since they were added to the list so they can be escalated to the specialty team looking after them for urgent review.

CVUHB has also piloted a 'nudging' approach for patients whilst they are waiting for surgery. The concept was to provide self-management advice to educate and support patients to ensure they are optimised prior to surgery and includes general health and wellbeing advice for patients.

Cwm Taf Morgannwg University Health Board (CTMUHB)

To ensure patient experience is captured, CTMUHB is launching the Civica patient feedback system on the 13th January 2022 to the public. The system was launched with Health Board staff on the 6th January and was well received. The Health Board has received a number of enquiries from different specialities as to how they can utilise the system to engage with patient's, families and unpaid carers to gain feedback around services provided.

CTMUHB has created a survey replicating the 'Have your say' format, and an optional more detailed survey for patients to complete. Posters with a QR code have been distributed across CTMUHB sites, the QR code and e-link will also be launched via social media pages and stakeholders. The surveys allows people to inform CTMUHB on how services are working and if any improvements could be made. This will allow CTMUHB to use this data to inform and shape the services they currently provide to their local population. These will enable patients, families and unpaid carers to have a voice in how the Health Board supports its communities to achieve better health outcomes for all.

In addition, in the summer of 2021 CTMUHB set up a patient phone line to support patient waiting list validation. This service was then expanded to form a helpline for patients for a variety of queries and to ensure correct signposting to the right services, including waiting list support.

Hywel Dda University Health Board (H DUHB)

Due to the significance of the global pandemic, H DUHB undertook a six-week engagement exercise in May/June 2021 ([Building a healthier future after COVID-19](#)). This engagement exercise provided significant relevant feedback and learning about how the COVID-19 pandemic has affected people's health and care, access to services, and the implications of these experiences in relation to the Health Boards long-term strategy.

Feedback received highlighted a significant number of people concerned about the impact of the pandemic on waiting lists and delays in diagnosing certain conditions due to the inability or reluctance to see a doctor. The impact of the pandemic on the mental health and wellbeing of staff, patients and the wider public of all ages, became a recurrent theme throughout the questionnaire responses. Concerns ranged from the impact of isolation and loneliness exacerbated by lockdown to the difficulty in accessing mental health services and support. Many felt the pandemic highlighted the importance of more services being available

at a local level, such as in the community. This feedback is being shared across the organisation, so it can inform service delivery now and in the future.

Powys Teaching Health Board (PTHB)

In PTHB, one of its Renewal Programmes relates to Diagnostics, Ambulatory Care and Planned Care. A key stream of this work is the 'Advice, Support and Prehabilitation' element, where people on waiting lists can access help and support. Survey work undertaken by the local CHC in relation to accessing primary care has influenced the importance of first interactions which leads to assessment and onward referral. This has influenced the need for the Health Board to ensure support is provided following a referral from the general practice consultation and not only once patients have been seen by secondary care and are awaiting an 'intervention'.

In relation to specific surveys, the Health Board has asked the Wales Cancer Network to enable the inclusion of information on patients being treated in cross-border English hospitals in the Wales Cancer Experience Surveys. The Wales Cancer Network is currently in discussion with NHS England to explore how the results of the Cancer Patient Experience Survey in England can be shared for Welsh patients. The findings of this work will contribute to the Cancer Renewal Programme that the Health Board has established.

Swansea Bay University Health Board (SBUHB)

Following the publication of the Board of CHCs report, Swansea Bay CHC, published a report in September 2021, [Is my life worth living? Lived experiences of patients waiting in pain for elective orthopaedic surgery.](#)

Between December 2020 and May 2021, Swansea CHC asked people across the SBUHB area to share their lived experiences of waiting times for elective orthopaedic, joint replacement and spinal surgery. In December 2020, Swansea Bay UHB agreed to send the questionnaire directly to a random sample of 2,000 patients across all waiting lists for elective orthopaedic, joint replacement and spinal surgery, receiving a postal response rate of around a third (32.35%). The CHC received feedback from 948 people.

The report noted the actions taken within NHS Wales in response to the pandemic in March 2020 and the prioritisation of treatment for people with COVID-19 over other non-urgent NHS care. 92% (827) of people who contributed to the report agreed the length of time they had been waiting for surgery had seen their condition worsen and 74% (654 people) agreed the length of time they have been waiting for surgery had affected their mental health and well-being. 63% of people rated their experience as 'good, very good or excellent', 19% rated their experience as 'fair', and 18% rated their experience as 'poor' or 'very poor'.

In November 2021, SBUHBs [Quality and Safety Committee](#) considered the Board of CHCs and Swansea Bay CHC reports and actions being undertaken by the Health Board in response to the report's findings. The Committee noted the areas of work that have been improved or progressed to address the long-term delivery of orthopaedic services within the Health Board. The Committee report also provides information about the Health Boards programme of regular direct validation of patients who have been assessed and are now waiting for an operation, which commenced in May 2021. It noted that the Health Board was surprised at the volume of responses where patients have notified that they no longer

require surgery, usually for conditions which are low level and low impact on everyday living or in conditions which can improve over a period of time.

The Health Board has been able to offer an Exercise and Lifestyle Programme to around 100 orthopaedic patients awaiting knee replacements, based on information gained from completed assessment forms used across a range of specialties, including orthopaedics and spinal surgery, and other communication. The Health Board has plans to extend this prehabilitation service to a wider cohort of orthopaedics patients and expand the range of services available to include emotional wellbeing and pain management.

Other national and local surveys and reports

Wales Cancer Experience Survey

Funded by Macmillan Cancer Support and the Wales Cancer Network, the latest Wales Cancer Experience Survey asked cancer patients their views of cancer care during the pandemic, including questions around waiting times and referrals. From the 20 October, more than 11,000 people were asked to share their views through a survey. The survey results are due to be published around May 2022, with a national report and accompanying Local Health Board and NHS Trust reports. The survey's results will help to shape future cancer care in Wales, including pinpointing what is working well and where improvements can be made. The seven Local Health Boards and Velindre University NHS Trust supported the survey through raising awareness of it through their communication channels and providing full lists of all eligible patients. Previous Wales Cancer Experience Surveys were conducted in 2013 and 2016.

Public Health Wales NHS Trust

Public Health Wales NHS Trust, as the national public health agency in Wales, is leading on gathering data and evidence on the impact that winter pressures and waiting times are having on patient health and wellbeing and the need to take an equitable approach to respond to these challenges. Research by Public Health Wales, and analysis of the NHS waiting time backlog in England conducted by [The King's Fund and Healthwatch England](#), highlighted that healthcare needs are not equal across the population, and the greatest burden of disease is closely linked to socio-economic disadvantage. [Recent analysis](#) on hospital utilisation conducted by Public Health Wales reveals that people living in more deprived parts of Wales are more likely to require use of hospital services, especially in an emergency. Consequently, any immediate or longer-term response to managing the waiting times backlog needs to avoid focusing on a one-size-fits-all approach and take deprivation into consideration to avoid generating further health inequity.

I hope this information has been helpful for the Committees inquiry.

Yours sincerely,



Nesta Lloyd – Jones
Assistant Director, Welsh NHS Confederation