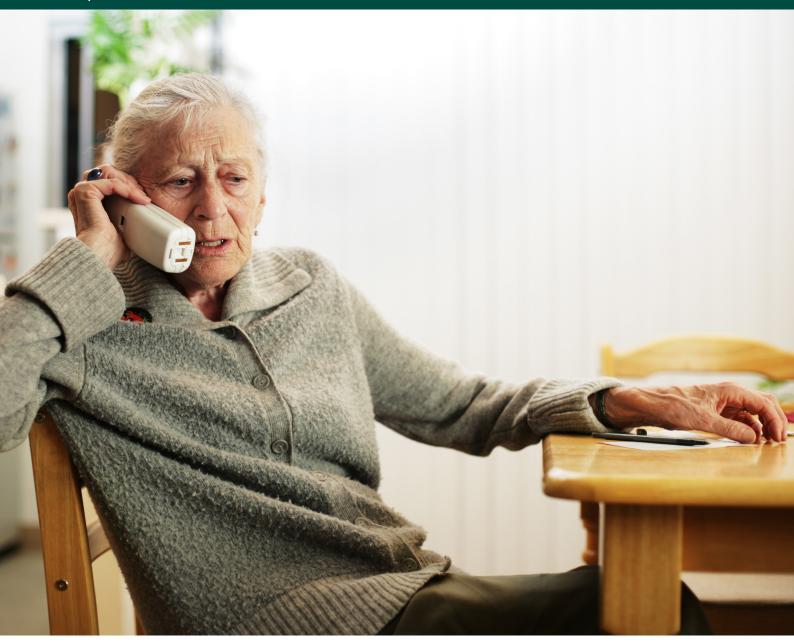
Waiting well?

The impact of the waiting times backlog on people in Wales

April 2022





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The impact of the waiting times backlog on people in Wales

April 2022



About the Committee

The Committee was established on 23 June 2021. Its remit can be found at: www.senedd.wales/SeneddHealth

Current Committee membership:



Committee Chair: Russell George MS Welsh Conservatives



Rhun ap Iorwerth MS Plaid Cymru



Gareth Davies MSWelsh Conservatives



Mike Hedges MSWelsh Labour



Jack Sargeant MS Welsh Labour



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Chair's foreword

People were already waiting too long for diagnosis, care and treatment before the pandemic. COVID-19 has undoubtedly made the problem worse across all specialties and all stages of the pathway, including outpatients, diagnostics, therapy services, mental health support, pain relief and treatment.

It is frequently said that the equivalent of 1 in 5 people in Wales are currently on a waiting list for diagnosis or treatment. That is a shocking statistic, with implications both for the performance of our health service and levels of ill health in Wales. Behind those numbers are individuals whose daily lives—and potentially those of their families, friends or carers—are being affected adversely by delayed diagnosis or care. People may experience pain, distress, discomfort or anxiety. Their needs may become more complex. Some people may deteriorate and need acute or emergency care. Against a backdrop of rising costs of living, people who are unable to work or whose outgoings have increased as a result of their condition may face increasing financial uncertainty. Others may be unable to undertake their usual caring responsibilities.

Our inquiry has taken place in a complex and evolving context, as Wales has responded to the omicron wave of the COVID-19 pandemic. This has added to the pressures facing our health and social care sectors, and we thank the health and social care workforce, including unpaid carers and volunteers, for all that they have done during this time.

However, it is crucial that the Welsh Government and health boards put in place robust plans to tackle the backlog, and to ensure that people receive the care and treatment they need as soon as possible. This must include arrangements to support people who are waiting, and to communicate with them effectively so that no one feels forgotten.

And, importantly, we cannot simply aim to return to where we were in March 2020. We must look to the future, with a renewed focus on innovation, on genuine and sustainable service transformation, and on prevention and tackling health inequalities, so that no one is left behind.

Russell George MS

Chair of the Health and Social Care Committee

Recommendations

addressed, the Minister for Health and Social Services must ensure that the planned care recovery plan includes a focus on supporting patients to wait	Welsh Government's well
Recommendation 2. The Minister for Health and Social Services should the Welsh Government has taken to ensure that health services provide parand appropriate information about their level of clinical need and the degree which they need to receive treatment.	tients with adequate ee of urgency with
Recommendation 3. The Minister for Health and Social Services should and third sector organisations to develop and deliver a national campaign months to raise awareness of cancer symptoms, and to encourage people services if they have any concerns. The campaign should also encourage prinvitations to participate in cancer screening programmes.	within the next 12 to access health eople to take up
Recommendation 4. The Minister for Health and Social Services should information about the role, membership and work of the national steering and how it will ensure that regional partnership boards and dementia service accountable for reducing waiting times.	group on dementia, ces are held
Recommendation 5. When she shares the findings of the neurodevelop capacity and demand review with us, the Minister for Health and Social Serout how and when any recommendations made by the review will be implestheir impact will be monitored.	vices should also set emented and how
Recommendation 6. The Minister for Health and Social Services should autumn 2022 on what action has been taken to identify and address any dilength of time taken in Wales to diagnose females and males with neurode conditions such as autism.	fferences in the velopmental
Recommendation 7. The Minister for Health and Social Services should consideration the Welsh Government has given to supporting health board commission private healthcare on an ongoing basis as a means of addressi backlog, including what role the Welsh Government has in ensuring that the collaboration across providers and systems, and fair sharing of resources as health boards.	Is across Wales to ng the waiting times ere is effective nd capacity across

Recommendation 8. The Minister for Health and Social Services should confirm whether the	9
return to multiyear Welsh Government budgets is expected to result in longer-term funding	
certainty for services commissioned from third sector organisations	44
Recommendation 9. The Minister for Health and Social Services should set out what action	is
being taken to ensure that health boards are providing suitable venues for the delivery of	
services such as pain management, physiotherapy and occupational therapy both in hospitals,	
on the primary care estate, and in the communityPage 4	44
Recommendation 10. The Minister for Health and Social Services should provide an update	Š
on the appointment of the national clinical leads for pain management. This should include	
nformation about their role in ensuring the appropriate use of pain medication in the	
management of people on waiting lists, including their contribution to managing the risks	
associated with the prescription of opiatesPage 4	45
Recommendation 11. The Minister for Health and Social Services should provide an update	Š
n autumn 2022 on the Waiting Well support service pilot, including details of elements which	
are proving effective and what plans there are to roll them out to the other three health board	S,
and elements which have not worked as intended and have therefore been withdrawn or	
stopped	45
Recommendation 12. The Minister for Health and Social Services should ensure that the pla	an
for the recovery of planned care includes clarity about how health services should be	
communicating with people who are waiting. This should include potential communication	
approaches, assurance that there is sufficient clinical and administrative resource to deliver it,	
and details of how communication will be evaluated and how best practice and innovation will	
be sharedPage 5	52
Recommendation 13. The Minister for Health and Social Services should provide an update	Š
on progress made on the implementation of recommendation 37 in the <i>Into sharp relief:</i>	
inequality and the pandemic report published by the Fifth Senedd Equality, Local Government	
and Communities Committee in August 2020. The recommendation, which was accepted by th	าе
Welsh Government on 23 September 2020, called for the appointment of an accessibility lead	
within the Welsh Government to oversee the production of all key public health and other	
nformation in accessible formatsPage 5	52

Recommendation 14. The Minister for Health and Social Services should work with health
boards and community health councils to evaluate the recent standard communication
campaign and waiting list validation exercise, and implement any lessons arising when planning
future waiting list validation exercises. The outcome of the evaluation should be published. Page 53
Recommendation 15. The Minister for Health and Social Services should set out how priority theme 4 (promoting financial resilience) in the Welsh Government's unpaid carers delivery plan
will be delivered. This should include details of actions that will be taken to promote and
support carers in accessing a range of welfare benefits, financial support information and services, and how the impact of these actions will be assessed
Recommendation 16. The Minister for Health and Social Services should outline her
expectations for the involvement of carers and families in care and treatment planning, and how any reduction of their involvement during the pandemic will be reversed
Recommendation 17. The Minister for Health and Social Services should require health
boards to routinely publish waiting times data disaggregated by specialty and hospital. The
publication of such data should be accompanied by clear information for patients and the
public to ensure that they understand that the waiting times indicated by the data may be subject to changePage 60
Recommendation 18. The Minister for Health and Social Services and Digital Health and
Care Wales should work with health and social care services, including primary and community
services, to ensure that all health and social services have appropriate access to shared patient records
Recommendation 19. The Minister for Health and Social Services and Digital Health and
Care Wales should outline the approach that is being taken to ensure that ICT systems used within health and social care services are compatible in order to facilitate effective
communication and information sharingPage 63
Recommendation 20. The Minister for Health and Social Services should outline what actions
the Welsh Government and NHS Wales are taking to deliver targeted support and signposting
to people living in more deprived areas in order to reduce the health inequalities gap, and ow the impact of these actions will be assessedPage 68

Recommendation 21. The Minister for Health and Social Services should provide details of the work being undertaken with the Royal College of GPs to develop solutions to address health inequalities in Wales. This should include details of the proposed scope of the project, the anticipated timescales, how it will be resourced, and how the project will be evaluated to ensure that learning is rolled out across the health service where appropriate
Recommendation 22. The Minister for Health and Social Services should outline what contribution the new community pharmacy contract will make to tackling health inequalities, including what scope it provides for pharmacy teams to refer patients into other health services and how it will contribute to raising awareness of the services and support community pharmacies can provide
Recommendation 23. The Minister for Health and Social Services should require all health data collected and published in Wales to be disaggregated on the basis of diversity characteristics
Recommendation 24. The Minister for Health and Social Services and Health Education and Improvement Wales should provide an update on what consideration has been given to reducing the length of medical training placements, including what assessment has been made of the impact on patient safety and the number of training places that can be provided. Page 74
Recommendation 25. The Minister for Health and Social Services should set out what consideration she has given to the twelve recommendations made in December 2021 by the Academy of Medical Royal Colleges ('A dozen things the NHS could do tomorrow to help the medical workforce crisis') to alleviate the medical workforce crisis in the short term, and what actions have been taken by the Welsh Government or the NHS in Wales as a result Page 74
Recommendation 26. The Minister for Health and Social Services should outline how the Welsh Government will provide national oversight and leadership for the delivery of its planned recovery plan, including how it will hold health boards to account for the detailed actions to tackle the waiting times backlog set out in their integrated medium term plans
Recommendation 27. The Minister for Health and Social Services should outline the actions the Welsh Government will take to promote awareness among people who are waiting for care or treatment of the support that may be available to them from alternative primary and community care services

1. Introduction

Background

- **1.** On 13 March 2020, the Welsh Government announced the suspension of all outpatient and routine planned care activity in hospitals in Wales in order to redeploy staff and free up bed capacity and equipment to deal with the COVID-19 pandemic.¹
- 2. Outpatient and some routine planned care restarted in summer 2020, but infection control requirements including social distancing substantially reduced service activity, causing waiting times to increase. Throughout the pandemic, the NHS has continued to treat the most urgent patients, but hospital waiting lists have grown substantially as more people have been referred for diagnosis and treatment. Subsequent surges in the pandemic have resulted in further suspensions of planned care and treatment, particularly during winter 2021-22.
- **3.** The Minister for Health and Social Services ("the Minister") said in June 2021 that it would "probably take the whole length of this Senedd term [until 2026] to get us back to prepandemic levels".²
- **4.** The Board of Community Health Councils in Wales ("the Board of CHCs") represents the voice of patients and the public. It said in December 2021 that:

"People appreciate that staff have worked tirelessly to keep people safe and provide the best possible care, treatment and support in very difficult circumstances.

But it is also true that as the pandemic continues to have such an impact on our NHS services—and the people who deliver and receive those services—we are seeing and hearing more anxiety and frustration. Everyone's resilience is being tested like never before."³

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¹ Welsh Government, *Written statement: Coronavirus (COVID-19)*, 13 March 2020

² BBC News, <u>Covid: Welsh NHS warns waiting list backlog could take years to clear</u>, 26 September 2021

³ WT04 Board of Community Health Councils in Wales

Statistical context

- **5.** The Welsh Government publishes monthly data on referral to treatment ("RTT") waiting times. RTT is the time from referral by a GP to a hospital for treatment, and includes time spent waiting for any hospital appointments, tests or scans that may be needed.
- 6. As at January 2022, there were 688,836 patient pathways⁴ in Wales waiting to start treatment. This is an increase of 51 per cent on March 2020 (when 456,809 pathways were waiting).⁵ The Welsh Government's targets for RTT are that 95 per cent of patients referred for planned hospital treatment should be seen within 26 weeks, and 100 per cent within 36 weeks. The percentage of patient pathways waiting more than 36 weeks increased from 6 per cent (28,294) in March 2020 to 36 per cent (250,892) in January 2022. 170,238 patient pathways (25 per cent) had been waiting over one year, and 56,515 (8 per cent) had been waiting over two years.
- 7. There is some variation in the length of waiting times across health boards, but the number of patient pathways waiting to start treatment has increased across all health boards apart from Powys Teaching Health Board since March 2020. In January 2022, Betsi Cadwaladr University Health Board (UHB) had the largest number of patient pathways waiting to start treatment (148,884) and Powys Teaching Health Board had the smallest (5,679).⁶ Cwm Taf Morgannwg UHB had 43 per cent of its patient pathways waiting over 36 weeks compared to Powys Teaching Health Board with 4 per cent.
- **8.** There is also variation in the extent of the waiting times backlog across different specialties and treatment functions. As at January 2022, the specialties with the highest number of patient pathways awaiting treatment were:
 - Trauma and orthopaedic (98,389). The number of patient pathways waiting to start trauma and orthopaedic treatment in Wales had increased by 20 per cent on the figure of 82,014 in January 2021. Across Wales, 56 per cent had been waiting more than 36 weeks.

⁴ The term 'patient pathways' is used in the statistics to reflect that one person can be on multiple waiting lists.

⁵ Analysis by Senedd Research using data from Stats Wales, <u>Patient pathways waiting to start treatment by month,</u> grouped weeks and stage of pathway

⁶ There are no district general hospitals in the Powys Teaching Health Board area.

- General surgery (85,400). The number of patient pathways waiting to start general surgery in Wales had increased by 35 per cent on the figure of 63,430 in January 2021. Across Wales, 40 per cent had been waiting more than 36 weeks.
- Ophthalmology (83,168). The number of patient pathways waiting to start ophthalmological treatment in Wales had increased by 33 per cent on the figure of 62,378 in January 2021. Across Wales, 45 per cent had been waiting more than 36 weeks.

Our inquiry

- **9.** Tackling the waiting times backlog must be a priority for the Welsh Government and the NHS. However, the scale of the challenge means long waits are likely to continue for some time to come. We therefore decided to focus on the impact of the backlog on people who are waiting, including:
 - The services in place for people who are waiting for diagnostics and treatment, particularly pain management support.
 - Access to psychological therapies and emotional support for those who may be experiencing anxiety or distress as a result of long waiting times.
 - The contribution the third sector can make in providing peer support and information to patients waiting on an NHS waiting list.
 - The effectiveness of messaging and engagement with the public about the demands on the service and the importance of seeking care promptly.
 - The extent to which inequalities exist in the elective backlog, with deprived areas facing disproportionately large waiting lists per head of population compared to least deprived areas.
 - Plans to fully restore planned NHS care in Wales.

Listening to lived experience

10. Behind the statistics are people who are living day-to-day with the uncertainties of delayed diagnoses, or discomfort, pain or distress resulting from delayed treatments. We know long waits for care and treatment have a profound impact on people and their families, sometimes with debilitating or life-changing effects. People's mobility may be reduced, with corresponding

implications for their independence, or their ability to work or care for others. Others will be experiencing chronic pain, or may have become isolated, anxious or depressed.

- **11.** To make sure people with lived experience had a voice in our work we held interviews and focus groups with people who are waiting for diagnosis or treatment, or caring for people who are. The resulting report powerfully demonstrates the impact of delayed care and treatment.⁷
- **12.** We are grateful to everyone who shared their experience, and to the organisations who worked with us to identify and support those who took part.
- **13.** We also gathered evidence in writing⁸ and by holding oral evidence sessions with stakeholders, including the Minister and the Chief Executive of NHS Wales.⁹

⁷ Senedd Citizen Engagement Team, <u>Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings</u>, January 2022

⁸ Health and Social Care Committee, <u>Consultation: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u> [accessed March 2022]

⁹ Health and Social Care Committee, <u>Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u> [accessed March 2022]

2. Waiting for NHS care and treatment

14. We have explored how the waiting times backlog affects different conditions and services. We recognise that there are issues relating to other conditions and services too, and that people waiting for diagnosis, care and treatment will all have their own experiences. In one inquiry we cannot look in detail at all specialties or conditions, but it is clear that there are common themes arising that will need to be taken into account as the backlog is tackled.

Diagnostics

- **15.** Welsh Government targets state that no one should wait longer than eight weeks for diagnostic services like x-rays, imaging or endoscopy. However, as at January 2022, 46 per cent of patients (48,701) had been waiting longer than eight weeks, compared to 7,964 patients in March 2020.¹⁰
- **16.** The Deputy Chief Medical Officer ("Deputy CMO") described diagnosis as "a critical point in nearly all of our clinical pathways" which could move people along the right pathway, enable prioritisation on waiting lists and provide reassurance for those able to leave the clinical pathway. There is some evidence that diagnostic services may be recovering at a faster rate than outpatient and inpatient procedures. The Minister said:

"So, if we just take cancer, for example, I think about 92 per cent of the people, or even more of the people who are suspected with cancer are taken off fairly quickly, and, of course, that gives great comfort not just to those who are told that they haven't got cancer, but also it means that we can crack on then with treating the people who do have cancer. So, in November, for example, 1,700 people started that cancer treatment following that diagnostic service, and 12,400 people were given the comfort of knowing that they haven't got cancer, and I think it's really important to understand the importance of diagnosis within the pathway that we set out for people who are suffering." 12

¹⁰ Analysis by Senedd Research using data from Stats Wales, Waiting times by month

¹¹ RoP [para 205], 10 February 2022

¹² RoP [para 203], 10 February 2022

Trauma and orthopaedics

- **17.** Elective orthopaedic care has been completely suspended in some units since March 2020, and capacity elsewhere is still significantly reduced. This was described by the British Orthopaedic Association ("BOA") as "unacceptable" and "untenable for patients" as people may deteriorate clinically, suffer harm, and experience disability, isolation, loss of independence, and anxiety or depression.¹³
- **18.** The Deputy CMO explained orthopaedic services had not been prioritised during the pandemic because "it's not life-threatening or life-saving surgery". However, many stakeholders told us the term 'elective care' is misleading, as it implies that care is a choice. They said restoring planned care was an urgent priority. Is
- **19.** During our interviews, Participant D, a 65 year-old female, recalled being told about the wait for hip surgery:

"I was told then that the waiting time at that point was 3 years...most likely 5. It was at this point, (and I don't cry easily) that I burst into tears. I am 65 and can barely walk now so what am I going to be like by the time I get an operation. The feeling I got then was that they were happy to leave me for 3 years and just let me rot away in the corner."¹⁶

20. Participant E, an 83 year-old male, also waiting for hip surgery, described the impact on his quality of life:

"I have to say that since Christmas, my hopes and aspirations have taken a nosedive. I know my condition has deteriorated, I now have to walk across the house with a walking stick. The pain is constant and getting to the point where even making a cup of tea is a physical and mental effort.

It might sound melodramatic, but I am 83 now and in two years time I will be 85—I don't think I want to go on as I am. I am on my own, I am weary of it all—if I reach 85

¹³ WT26 British Orthopaedic Association

¹⁴ RoP [paras 238-239], 10 February 2022

¹⁵ RoP [para 255-6], 2 December 2021

¹⁶ Senedd Citizen Engagement Team, <u>Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings</u>, January 2022

and nothing will have been done then I don't know if I will be able to go on. I have lost my confidence to go out of the door.

It's not just a physical problem that I have, it's a mental one as well. I'm taking a step back from everything. I'm in here and the world is out there, and I get angry with myself, I get cross with the situation as it stands."

17

21. In written evidence, the Welsh Government said that orthopaedic patients will be contacted to join the 'Living Well' programme, which can provide advice on pain management through medication and health and wellbeing advice. It explained that the National Orthopaedic Clinical Board was also developing a long-term orthopaedic clinical strategy.¹⁸

Eye care

- **22.** The national eye care measures are that 95 per cent of Health Risk Factor 1 ("HRF1") patients are seen within their clinical waiting time or within a defined period afterwards. ¹⁹ RNIB Cymru told us that "more than 70 per cent of the patients in the system are HRF1 patients". ²⁰ However, data shows that in Cardiff and Vale UHB 33 per cent of patients are waiting beyond their clinical target, while in Cwm Taf Morgannwg UHB 63 per cent are over target. ²¹
- **23.** We heard powerful evidence about the impact of the backlog, including from an individual who has lost all sight in one eye as a result of delayed appointments, and has had to seek support from his local optician in the absence of NHS care.²² RNIB Cymru highlighted the emotional toll as people may struggle to come to terms with a visual impairment, and said that its own counselling service currently has a waiting time of nine months.²³
- **24.** The Welsh Government has been encouraging health boards to move more services into the community, but RNIB Cymru argues that change needs to happen at pace, and that health boards must have "clear plans and deadlines for improvement against the eye care measures".²⁴

¹⁷ Senedd Citizen Engagement Team, *Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings*, January 2022

¹⁸ Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

¹⁹ HRF1 patients are those whose health risk factor is risk of irreversible harm or significant patient adverse outcome if the target date is missed.

²⁰ RoP [para 197], 2 December 2021

²¹ WT01 RNIB Cymru

²² WT02 William Evans

²³ WT01 RNIB Cymru

²⁴ WT01 RNIB Cymru

25. The Minister said that planned legislation to increase general ophthalmic services' ability to carry out eye healthcare could reduce hospital waiting lists by around a third. On 10 February 2022 she told us that the Bill would be introduced in September 2022 following a consultation in the spring²⁵, but she subsequently wrote to clarify that an announcement on the Welsh Government's legislative programme would be made by the First Minister in the summer.²⁶

Cancer care

- **26.** Early diagnosis and swift treatment are key to increasing the chance of survival for people with cancer. A new suspected cancer pathway target was introduced on 1 December 2020.²⁷ However, waiting times data for January 2022shows that just 53 per cent of patients received their first treatment within 62 days of being suspected of having cancer, well below the target of 75 per cent.²⁸
- **27.** The Minister acknowledged that cancer targets were being missed, but stressed that cancer had remained a priority throughout the pandemic.²⁹
- **28.** Macmillan Cancer Support has estimated that, in addition to those already on waiting lists for cancer diagnosis or treatment, around 4,000 people might have suspected cancer but have not presented themselves to health services.³⁰ We were told that third sector organisations have sought funding for campaigns to encourage people to access health services if they have any concerns, but that this should be led by the Welsh Government and NHS Wales as a national campaign rather than being left to charities.³¹
- **29.** Tenovus Cancer Care has seen significant increases in the number of people eligible for end-of-life welfare benefit support, which it said suggested that people were presenting to health services later or being diagnosed later.³² Richard Pugh of the Wales Cancer Alliance agreed:

²⁵ RoP [para 244], 10 February 2022

²⁶ Letter from the Minister for Health and Social Services, 28 February 2022

²⁷ The pathway starts at the point of suspicion (i.e. when the GP makes a referral) and is closed when the patient starts their first definitive treatment, is told that they do not have cancer, chooses not to have treatment, or dies.

²⁸ Analysis by Senedd Research using data from Stats Wales, <u>Suspected cancer pathway (closed pathways): The number of patients starting their first definitive treatment and those informed they do not have cancer by local health board, tumour site, age group, sex, measure and month</u>

²⁹ RoP [para 246], 10 February 2022

³⁰ RoP [para 119], 2 December 2021

³¹ RoP [paras 128-130], 2 December 2021

³² WT03 Tenovus Cancer Care

"So, what we're seeing is that the backlog is here. It's not around the corner; it's actually impacting now. So, people are presenting later, people are presenting with more severe cancers, people's outlooks and outcomes are going to be more severe. [...] the picture out there isn't a good one. COVID has had a dramatic impact on cancer, and the statistics and the backlog—we're actually seeing what that is bringing to us now and, unfortunately, the impact on patients is huge."³³

30. The Board of CHCs told us that delays meant that people waiting for cancer care were worried that they might die before getting the treatment they needed.³⁴ This was reflected in our women's health focus group, when one participant said:

"I had a breast cancer scare that ended in me going private. After initial diagnosis I rang them back after 2 weeks, unfortunately I was told there was a backlog of 4 weeks due to Covid, after 4 weeks I rang back and was told now 6-8 weeks...this was untenable. It wore down my mind and mental health, 2 weeks is long enough with a cancer scare, especially as the prognosis gets worse and worse. I eventually spoke to a manager who said it was now 12 weeks, the time just kept increasing. My husband put his foot down and said we were going private". 35

- **31.** Target Ovarian Cancer said that many women have experienced problems accessing GP appointments, resulting in slower diagnosis as urgent referrals for suspected cancer are delayed. Others have had their treatment disrupted.³⁶ Bowel Cancer UK similarly raised concerns about delayed diagnoses, and a "bottleneck" within the diagnostic pathway.³⁷
- **32.** The Welsh Government has invested in new imaging equipment to replace ageing equipment and boost diagnostic capacity, but the Wales Cancer Alliance said that Wales still lacks equipment such as MRI units and CT scanners needed to manage rising demand.³⁸ In addition, cancer charities have concerns about whether there is sufficient diagnostic workforce capacity to reduce waits and improve cancer outcomes.³⁹

³³ RoP [para 119], 2 December 2021

³⁴ WT04 Board of Community Health Councils in Wales

³⁵ Senedd Citizen Engagement Team, *Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings*, January 2022

³⁶ WT18 Target Ovarian Cancer

³⁷ WT30 Bowel Cancer UK

³⁸ Letter from the Wales Cancer Alliance, 11 January 2022

³⁹ RoP [para 134], 2 December 2021

- **33.** The Wales Cancer Network funded two pilots in 2018—in Cwm Taf Morgannwg UHB and Swansea Bay UHB—to test how Rapid Diagnostic Clinics ("RDCs") can help reduce the time to diagnosis for patients. The results were positive; diagnosing cases of cancer and other diseases within a matter of days. But full roll out has been slow. The Wales Cancer Alliance highlighted that "four years on from the initial pilot we still do not have RDCs in every Health Board". It added that "RDCs are no longer the most innovative pathway". Dowel Cancer UK agreed that effective solutions need to be "scaled-up" at pace to help increase capacity, and called for more innovation through "the accelerated adoption of new technologies" such as Colon Capsule Endoscopy and "changing clinical practice in terms of how patients are diagnosed, managed and treated" such as increased use of virtual clinics. All
- **34.** Specific concerns were also raised about access to clinical nurse specialists, described by Target Ovarian Cancer as a vital source of support and information to women diagnosed with ovarian cancer, particularly when they are waiting for treatment to begin.⁴² The Deputy CMO said that health boards had tried to "minimise, at all times, the impact on cancer care", but acknowledged that some clinical nurse specialists had been redeployed as part of the pandemic response.⁴³

Mental health services

- **35.** Mental health services were already severely stretched before the pandemic. The Royal College of Psychiatrists ("RCPsych") said that pre-pandemic waiting times and barriers to access would have been "unacceptable in any other area of medicine". It added that the pandemic had intensified the impact of underlying issues such as workforce shortages, the mental health estate, and the need to develop technology and digital infrastructure.⁴⁴
- **36.** While the mental health core dataset is not yet available,⁴⁵ data which has been published shows significant difficulties in mental health services:
 - Specialist child and adolescent mental health support services ("CAMHS")

 In March 2020, 489 children and young people were waiting for their first specialist

 CAMHS appointment. By January 2022, there were 534 children and young people

 waiting, an increase of 9 per cent. Of these, 34 per cent (180) had been waiting up to

⁴⁰ Letter from the Wales Cancer Alliance, 11 January 2022

⁴¹ WT30 Bowel Cancer UK

⁴² WT18 Target Ovarian Cancer

⁴³ RoP [para 247], 10 February 2022

⁴⁴ WT32 Royal College of Psychiatrists

⁴⁵ We explore issues relating to data, including the mental health core dataset, further in chapter 7.

four weeks for a first appointment (the target time). Waiting times have grown significantly with 31 per cent (151) waiting over four weeks in March 2020 compared to 66 per cent (354) waiting over four weeks in January 2022. As at January 2022, 68 per cent of all children and young people waiting for specialist CAMHS treatment come under the Cardiff and Vale UHB. Of the 363 children and young people waiting for a first appointment in the Cardiff and Vale UHB area, 91 per cent (331) had been waiting over four weeks.⁴⁶ Mind Cymru has called for children and young people's mental health services to be prioritised.⁴⁷

Local primary mental health support services ("LPMHSS")

The number of referrals for LPMHSS assessments increased for all age groups from 5,266 in March 2020 to 5,711 in December 2021. The percentage of LPMHSS assessments undertaken within 28 days of referral decreased from 82 per cent in March 2020 to 67 per cent in December 2021. The Welsh Government target is for 80 per cent of people to receive an assessment within 28 days. 48 In written evidence, Mind Cymru said that children and young people were "significantly less likely than adults to receive an LPMHSS assessment within 28 days". 49

- **37.** Delays in treatment for mental health conditions, including eating disorders, can not only intensify the suffering of individuals, they can also result in more complex needs and higher costs when people do receive treatment. Stakeholders were particularly concerned about specialist CAMHS services, where substantial waits can have significant consequences for children, young people and their families. Mind Cymru added that an insufficient response historically to mild to moderate mental health problems has resulted in people's conditions escalating until they require CAMHS services, further adding to waiting times and the pressure on specialist services. S1
- **38.** Adferiad Recovery (a Welsh charity that speaks for people with a serious mental illness, such as schizophrenia, bipolar disorder or psychosis, and people affected by addiction) said the priority for mental health services must be to 'catch up' in terms of treatment and care for those

 $^{^{46}}$ Analysis by Senedd Research using data from Stats Wales, <u>sCAMHS patient pathways waiting for a first appointment by month and grouped weeks</u>

⁴⁷ WT25 Mind Cymru

⁴⁸ Analysis by Senedd Research using data from Stats Wales, <u>Referrals for a LPMHSS assessment, by LHB, age and month</u>

⁴⁹ WT25 Mind Cymru

⁵⁰ WT04 Board of Community Health Councils in Wales

⁵¹ RoP [para 233], 18 November 2021

most in need. It called in particular for a focus on people with serious and enduring mental illness 52

39. Participant C in our interviews is a 21 year-old female who initially received CAMHS services while in school and has subsequently transitioned to adult mental health services. She said that mental health services have changed in recent years, and she now increasingly relies on support from third sector organisations:

"I hardly see my mental health therapists anymore. I get no communication, only the odd letter about blood tests. I used to have weekly therapy support and then it disappeared and went non-existent. I feel sorry for anyone coming into this system during the last 2 years.

Communication has been dreadful in the last few years; I was introduced to different therapy and emotional support when I was younger and in all honesty, I couldn't fault them. Now it feels very different. Covid has had a huge impact on Mental Health services—you are the one doing the chasing all the time. I just feel like garbage!

The health board needs to sort out their working system. The communication between therapists and doctors seems horrendous—you end up getting promised referrals and then nothing happens. You end up thinking—why are they lying to you?"53

- **40.** The Welsh Government target for people waiting to start psychological therapy is 26 weeks, with the expectation that 80 per cent of people will have been seen within that time. Mind Cymru said that 26 weeks is too long—especially as targets for primary care mental health services are more ambitious—but that, in any case, Freedom of Information requests show that:
 - The target for 80 per cent of people to be seen within 26 weeks was not met in any of the 17 months to August 2020.
 - In each month from April 2019 to August 2020, thousands of people across Wales were waiting longer than 26 weeks to access psychological therapy. Hundreds were waiting longer than a year.⁵⁴

⁵² WT17 Adferiad Recovery

⁵³ Senedd Citizen Engagement Team, *Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings*, January 2022

⁵⁴ WT25 Mind Cymru

- **41.** Simon Jones of Mind Cymru emphasised the importance of patient choice in respect of the treatment of mental health conditions. He agreed with Professor Euan Hails of Adferiad Recovery that greater access to psychological interventions could avoid "such a fall-back on medicine"55, but said that some patients may prefer medication, and/or may need medication in order to be able to access psychological therapies.56
- **42.** Professor Peter Saul of the Royal College of GPs ("RCGPs") said that backlogs had resulted in the prescription of drugs such as antidepressants when other treatment approaches might have been more appropriate. Noting that GPs and their teams can feel "a bit helpless", he suggested that solutions could include increasing both online services and the numbers of mental health workers embedded in primary care teams.⁵⁷
- **43.** In written evidence, the Welsh Government stated that investment in mental health across Government was being prioritised, including an additional £100m across the next three years. ⁵⁸ The Minister explained that the cross-Government approach included the whole-system approach in schools, working with the police (for example in relation to crisis care), and non-clinical tier 0 and tier 1 support. ⁵⁹

Dementia care

- **44.** Delays in receiving dementia diagnoses can be devastating, affecting not only individuals, but also their eligibility for support services. Delays can increase pressures on already-stretched unpaid carers, and can also mean that by the time a person does receive a diagnosis they need more substantial intervention, or to go into residential care rather than being supported in the community.⁶⁰ There is no concrete data on the increase in the numbers waiting for memory assessment services across Wales, but Alzheimer's Society Cymru told us that in late 2021 there were around 4,000 people waiting for a memory assessment service appointment.⁶¹
- **45.** In written evidence, the Welsh Government said that an additional £3m has been allocated to regional partnership boards ("RPBs"), on top of the £9m initially allocated through the

⁵⁵ RoP [para 244], 18 November 2021

⁵⁶ RoP [para 243], 18 November 2021

⁵⁷ RoP [para 163], 18 November 2021

⁵⁸ Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

⁵⁹ RoP [para 221], 13 February 2022

⁶⁰ RoP [paras 310-11], 2 December 2021

⁶¹ WT29 Alzheimer's Society Cymru

dementia action plan.⁶² The Minister acknowledged there had been "a little bit of backtracking", but said that progress was being monitored. She added that a national steering group had been convened to "hold people's feet to the fire".⁶³

Neurodevelopmental services

46. The NHS Delivery Framework includes a target of 80 per cent of children and young people waiting less than 26 weeks to start an assessment. However, Freedom of Information requests show that in September 2021 more than 4,100 children and 2,300 adults in Wales were waiting for a neurodevelopmental assessment. The National Autistic Society described this as "unacceptable". The wait varied across health boards, from an average of 32 weeks for some health boards, up to an average of 130 weeks for others, with the longest recorded waits being up to 200 weeks. The National Autistic Society added that waiting times for the seven integrated autism services have also increased, and that:

"Demand for assessments is far outstripping capacity to deliver them and it shows little sign of subsiding. Over the past two years, for roughly every two children or adults referred for an assessment, only one was undertaken".⁶⁴

- **47.** Hywel Dda UHB explained that recruitment challenges before the pandemic had affected service capacity. It acknowledged that it had not met the 26 week target for several years, and told us that the combination of the pandemic and the suspension of key pathways in March 2020 had further contributed to a year-end breach position of 750 patients waiting more than 26 weeks for an assessment. While pathways have now been re-established, it said that waiting times continue to be affected by reduced staffing availability and a significant re-emergence of demand after the initial wave of the pandemic. It told us that the application of virtual and other innovative approaches to delivery of clinically based services has limited effectiveness for patients awaiting neurodevelopmental assessments, and by the end of November 2021, the number of patients waiting more than 26 weeks had increased to 1,467 patients.⁶⁵
- **48.** Dai Davies of the Royal College of Occupational Therapists ("RCOT") said he was hopeful the Welsh Government's neurodevelopmental services demand and capacity review could address the issues. However, he highlighted the scale of the challenge, and emphasised that

⁶² Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

⁶³ RoP [para 228], 10 February 2022

⁶⁴ WT27 National Autistic Society

⁶⁵ WT41 Hywel Dda University Health Board

assessment is not enough; if they are diagnosed, people also need appropriate aftercare and interventions 66

49. The Minister told us that she understood the pressures. She confirmed the demand and capacity review would be completed in March 2022, and committed to sharing the findings with us. She added that the statutory code of practice on the delivery of autism services had come into effect in September 2021, providing greater clarity on what people can expect.⁶⁷

Chronic or existing health conditions

- **50.** Many stakeholders were concerned about the disruption of routine services for people with chronic conditions and ongoing health needs. This includes, for example:
 - People with a history of mental health problems, who, we were told, may now be presenting with worsening symptoms, or additional issues such as substance misuse.⁶⁸
 - People living with conditions such as diabetes who have not always been able to access the "routine maintenance-type appointments that help them stay healthy".⁶⁹
- **51.** Participant I in our interviews, a 49 year-old female, told us:

"The nature of diabetes is that it gets worse—it's a progressive condition. It can attack nerve endings, in ears/eyes/fingers/toes. It is important that regular checks take place. During the pandemic everything stopped and diabetic specialist nurses were deployed to the front line, nothing there for you. You could try to ring, and the phone just kept ringing and ringing, you felt abandoned. There was no communication. Care is now mostly through hospital, but annual check is at the doctor and is supposed to be once a year minimum, it's regularly cancelled." ⁷⁰

52. Kate Young of the Wales Carers Alliance told us that, even before the pandemic exacerbated the waiting times backlog, "an awful lot of families and carers were living in a pretty precarious situation". She said that unless regular reviews and routine appointments were

⁶⁶ RoP [para 98], 2 December 2021

⁶⁷ RoP [paras 230-233], 10 February 2022

⁶⁸ RoP [para 239], 18 November 2021

⁶⁹ RoP [para 313], 2 December 2021

⁷⁰ Senedd Citizen Engagement Team, *Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings*, January 2022

reinstated, people were at risk of reaching "a critical and crisis point", resulting in increased pressure on NHS services and other partners, including social services, as people's conditions deteriorated and they needed more significant interventions.⁷¹

53. In written evidence, the Welsh Government stated that health boards' plans include "collaborative action between GP practices and community health and care teams to undertake regular reviews and checks for people living with long-term health conditions, such as asthma and diabetes, to help them stay well".⁷²

Social care and community services

- **54.** Stakeholders highlighted the interaction between health service waiting lists and social care or community services. Carers in particular may rely on such services, which are often delivered in partnership by social care or third sector organisations. The suspension of such services during the pandemic had led, according to Kate Young of the Wales Carers Alliance, to "an already stressed therapies regime being reduced even further".⁷³
- **55.** Concerns about the availability of necessary social care were raised by Age Cymru, the Chartered Society of Physiotherapy ("CSP") and RNIB Cymru, among others. There are clear links between waiting lists for social care packages and orthopaedic waiting lists. People unable to access the care packages they need may be more likely to require urgent care following falls, or may experience delayed discharge. Appropriate social care packages are also vital for effective rehabilitation, for supporting people to stay in their own homes, and to help people access information and advice, including support in reading leaflets or finding information online. In contrast, the contrast of the contrast
- **56.** The significant shortages in the social care workforce have knock on implications for health services, including delaying discharge.⁷⁶ The Minister told us she was making efforts to address these issues, including a commitment to the real living wage, additional recognition payments for social care workers, and efforts to increase recruitment.⁷⁷

⁷¹ RoP [para 353-354], 2 December 2021

⁷² Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

⁷³ RoP [paras 334-336], 2 December 2021

⁷⁴ RoP [para 11], 2 December 2021

⁷⁵ RoP [paras 91, 301 and 364], 2 December 2021

⁷⁶ RoP [paras 277and 342], 13 January 2022

⁷⁷ RoP [para 218], 10 February 2022

Our view

- **57.** It is clear from the evidence we have heard that a wide range of services and conditions are affected by the backlog, with significant implications for people facing long waits for diagnosis or treatment. However, it is also clear that for many of these services, the pandemic has exacerbated underlying issues, or intensified pressures or struggles that were already being experienced.
- **58.** We support the Minister's focus on decreasing waiting times for diagnostic services—without diagnosis people who have health conditions will be unable to access the care, treatment and support they need. It is positive to see that diagnostic services are recovering, but sustained improvement in this area will require the right workforce, equipment and space to be available.
- **59.** As at January 2022, trauma and orthopaedic services was the specialty with the highest number of patient pathways awaiting treatment (98,389). This represented an increase of 20 per cent on the figure of 82,014 in January 2021. And, across Wales, over half of the patient pathways (54,621, 56 per cent) have been waiting more than 36 weeks. With people facing waits of this nature, consideration must be given to ensuring they are properly supported. The evidence we have heard suggests that there is variation in the availability of support services across Wales, and that the services that are available in the community or from third sector organisations may themselves have long waiting lists—we explore these issues further in chapter 4.

Recommendation 1. In addition to setting out how the waiting times backlog will be addressed, the Minister for Health and Social Services must ensure that the Welsh Government's planned care recovery plan includes a focus on supporting patients to wait well.

- **60.** We welcome the indication from the Minister that she is exploring ways to shift eye care away from secondary care and into the community and high street optometrists. It is right in principle that the skills and abilities of all health professionals should be harnessed to their fullest in order to enable people to access care and treatment more rapidly and closer to home. We look forward to scrutinising the Minister's legislative proposals in due course.
- **61.** It is worrying to hear from RNIB Cymru that poor communication means that some patients waiting for eye care are unaware of their level of clinical need, or the degree of urgency with which they need to be seen. This is especially concerning as eye conditions resulting in

sight loss do not always cause pain, and people may not be aware of the potential impact waiting for treatment could have.⁷⁸

Recommendation 2. The Minister for Health and Social Services should set out what action the Welsh Government has taken to ensure that health services provide patients with adequate and appropriate information about their level of clinical need and the degree of urgency with which they need to receive treatment.

62. We are deeply concerned that, in addition to those already waiting for diagnosis of a suspected cancer or treatment, there are an estimated 4,000 people in Wales who may have cancer, but who have not presented for diagnosis. We all—health services, the third sector, Welsh Government, and Members of the Senedd—have a role to play in getting the message out that if people have any concerns about potential symptoms they should access health services without delay.

Recommendation 3. The Minister for Health and Social Services should work with NHS Wales and third sector organisations to develop and deliver a national campaign within the next 12 months to raise awareness of cancer symptoms, and to encourage people to access health services if they have any concerns. The campaign should also encourage people to take up invitations to participate in cancer screening programmes.

- **63.** We recognise that such a campaign would, by its nature, result in more people presenting themselves to health services, and that people are already experiencing difficulties in getting GP appointments. We explore issues relating to the role of GPs and alternative primary and community care settings in chapter 11.
- **64.** While we understand that health boards have been faced with difficult decisions during the pandemic, we are concerned that patients' access to their key workers and clinical nurse specialists has been disrupted. These roles provide crucial support to people who have received a cancer diagnosis, and it is vital that they continue to be available.
- **65.** In respect of mental health services, we share the concerns of stakeholders that children and young people with mild to moderate mental health problems—the missing middle—may not get the care and treatment they need without effective investment in services to meet their needs, especially in the context of long waiting times for CAMHS services. The Fifth Senedd Children, Young People and Education Committee took a close interest in matters relating to children and young people's emotional wellbeing and mental health, including specialist

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⁷⁸ RoP [para 201], 2 December 2021

CAMHS.⁷⁹ As part of our work on mental health inequalities,⁸⁰ we have agreed to coordinate with the current Children, Young People and Education Committee to seek a progress update on the Fifth Senedd Committee's recommendations

- **66.** In the meantime, we welcome the indication from the Deputy Minister for Mental Health and Wellbeing in Plenary on 2 March 2022 that eating disorder services will be prioritised within the additional £50m allocation in the 2022-23 budget, and that the Welsh Government plans to strengthen the national clinical leadership for such services. However, it will be important to ensure that progress is made consistently across all health boards, so that access to services does not depend on where people live.
- **67.** Early diagnosis of dementia is so important to ensure that people can get the support and services that they need. The potential impact of delayed diagnosis on individuals and carers is worrying, and we welcome the additional funding for the dementia action plan. However, RPBs must ensure that this money is used to bring down waiting times, and the reconvened national steering group must hold them to account for this.

Recommendation 4. The Minister for Health and Social Services should provide more information about the role, membership and work of the national steering group on dementia, and how it will ensure that regional partnership boards and dementia services are held accountable for reducing waiting times.

68. The delays children, young people and their families are experiencing in accessing assessment for neurodevelopmental conditions are truly shocking, and these issues must be addressed as a matter of urgency. It will be important that the capacity and demand review's findings are addressed without delay, including ensuring that there is sufficient capacity for ongoing treatment and support as well as assessment and diagnosis.

Recommendation 5. When she shares the findings of the neurodevelopmental services capacity and demand review with us, the Minister for Health and Social Services should also set out how and when any recommendations made by the review will be implemented and how their impact will be monitored.

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⁷⁹ Children, Young People and Education Committee, <u>The Emotional and Mental Health of Children and Young People ("Mind over Matter") – Follow-up</u> [accessed March 2022]

⁸⁰ Health and Social Care Committee, Mental health inequalities [accessed March 2022]

⁸¹ Plenary, RoP [paras 409-411], 2 March 2022

69. We also welcome the Minister's commitment⁸² to ensure that her officials consider what can be done to address the significant differences in the length of time it takes to diagnose females with neurodevelopmental conditions such as autism compared to males.⁸³ We explore issues relating to health inequalities in chapter 9, but we note here that data that is used to take decisions on health services, including data relating to waiting times, must be disaggregated on the basis of equality and diversity characteristics such as sex. Such data is key to ensuring that services meet the needs of everyone in Wales, and that no one is left behind.

Recommendation 6. The Minister for Health and Social Services should provide an update in autumn 2022 on what action has been taken to identify and address any differences in the length of time taken in Wales to diagnose females and males with neurodevelopmental conditions such as autism.

- **70.** While health services remain under pressure, it is worrying that people with chronic conditions or existing health conditions have been unable to access the routine services they need to stay healthy. In addition, health services cannot be viewed in isolation from social care or community services. For care and treatment to be properly person-centred, the full range of care and treatment they need must be taken into account.
- **71.** In our report on the Welsh Government's draft budget for 2022-23 we said:

"...unless the right balance between health and social care funding is achieved—one which properly reflects the parity of esteem that should be afforded to both sectors—the funding allocated to health services may continue to increase year on year without delivering more integrated services or improved outcomes for both social care users and patients".84

72. We also called for greater assurance from the Welsh Government that the budget would address both the immediate and longer term challenges facing social care. In its response to our report, the Welsh Government said:

"This social care allocation will enable the Welsh Government to directly influence the transformation of social care infrastructure in line with aspirations of the Social

⁸² RoP [para 235], 10 February 2022

⁸³ WT14 Fair Treatment for the Women of Wales

⁸⁴ Health and Social Care Committee, *Welsh Government draft budget 2022-23*, February 2022, p.30

Services and Well-being (Wales) Act, and 'A Healthier Wales', and is evidence of achieving a fairer and more sustainable balance of funding".85

⁸⁵ Welsh Government, Response to the Health and Social Care Committee on Draft Budget, March 2022

3. Private and independent healthcare

NHS-commissioned private healthcare

- **74.** The sheer scale of the waiting times backlog means that the NHS will be looking to private and independent hospitals to undertake as many operations as they can for the foreseeable future.⁸⁶
- **75.** The Chief Executive of NHS Wales explained that early in the pandemic the Welsh Health Specialised Services Committee had negotiated an all-Wales agreement for the use of the independent sector, but that since then health boards have made their own decisions on using private sector capacity in England or Wales. Unless the value of individual contracts exceeds a set limit, the Welsh Government is not involved.⁸⁷
- **76.** In oral evidence, the Minister said her political preference would be for people to be treated by the NHS, but that she did not feel any need to apologise for making use of the independent sector as it meant that "we were able to help thousands of people that would have otherwise been waiting for long times".⁸⁸ She added that while some NHS-commissioned private care took place at a distance from patients' homes, including in England, and inequalities could emerge in terms of access to transport, the evidence suggested that people were "ready and willing to travel to receive a faster service".⁸⁹

Individuals accessing private healthcare

77. Many people experiencing long waiting times while suffering chronic pain or worsening symptoms feel increasingly desperate, and that they have no option but to seek healthcare themselves from independent providers either in the UK or abroad. This was a common theme in our interviews and focus groups, and was reflected in the written evidence we received from individuals.⁹⁰

⁸⁶ Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

⁸⁷ RoP [para 298], 10 February 2022

⁸⁸ RoP [para 297], 10 February 2022

⁸⁹ RoP [para 304-306], 10 February 2022

⁹⁰ WT06 An individual; Senedd Citizen Engagement Team, <u>Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings</u>, January 2022

78. Helen Twidle of Age Cymru described circumstances in which people who had already waited up to three years for orthopaedic surgery were being told they might have to wait another six for NHS treatment:

"The pain levels are intolerable, for themselves, for their carers, for their families—the loss of independence, the loss of mental good health as a result of the chronic pain. It's just intolerable and it feels quite inhumane to them that they're having to wait for so long when they've already waited long enough". 91

- **79.** Unpaid carers who are themselves waiting for treatment may face "an impossible decision" between paying for private care or becoming unable to continue to provide care for their loved ones.⁹²
- **80.** Health professionals reported increasing inquiries from patients about private treatment options,⁹³ and finding themselves considering during consultations whether patients could afford private care:

"And another disturbing thing that I'm finding myself doing is trying to look somebody up and down, make a judgment about how financially affluent they are and saying, 'You know what? To be honest, you'd be better going to see somebody privately'."94

81. The decision of someone in pain, discomfort, distress, or at risk of deterioration including sight loss, to seek private treatment is clearly understandable. However, stakeholders were concerned about the emergence of a two-tier system in which people who can afford it:

"...get back to their lives free of pain, illness or with improved sight, whereas poorer older people have reduced independence and quality of life whilst waiting for treatment that they are not sure will ever happen".95

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⁹¹ RoP [para 321], 2 December 2021

⁹² RoP [para 319], 2 December 2021

⁹³ WT09 Royal College of Paediatrics and Child Health

⁹⁴ RoP [para 21], 18 November 2021

⁹⁵ WT33 Age Cymru

- **82.** We heard examples of older people living on fixed incomes using their life savings, ⁹⁶ and of people "borrowing money from friends and family, taking out personal loans, and applying for credit cards" to pay for treatment. ⁹⁷
- **83.** A participant in one of our women's health focus groups said:

"I took out a personal loan for private surgery and stage 4 endometriosis was found. I was left a bit high and dry then as I couldn't afford further treatment. We are still paying off the loan now."98

84. Similar stories were shared with Endometriosis UK in response to its COVID impact survey:

"I had to pay privately for a laparoscopy because my mental health was suffering so much as a result of daily terrible pain. I am lucky I could do this—although it has left me £4000 in debt."

"The NHS cancelled my scheduled surgery 3 times, even after my gynaecologist had emphasised how important it was that I have the surgery urgently in order to preserve my bowel. Because of this I paid over £15,000 to have two private surgeries that were essential for my health. This has made a huge impact on my finances and my life plans"99

- **85.** People unable to afford treatment from independent providers for themselves or a loved one, including parents unable to access dental care for their children, told the Board of CHCs that they felt "guilty" that they were not in a financial position to help their loved ones get treated earlier.¹⁰⁰
- **86.** We asked the Minister whether she was concerned about the emergence of a two-tier system based on ability to pay. She agreed it was concerning, and said it highlighted the need to move quickly to address the backlog.¹⁰¹

⁹⁶ WT33 Age Cymru

⁹⁷ WT14 Fair Treatment for the Women of Wales

⁹⁸ Senedd Citizen Engagement Team, *Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings*, January 2022

⁹⁹ WT20 Endometriosis UK

¹⁰⁰ WT04 Board of Community Health Councils in Wales; RoP [para 323], 2 December 2021

¹⁰¹ RoP [para 312], 10 February 2022

Our view

- **87.** We have heard considerable evidence about the desperation people feel at the length of time they are having to wait for the care and treatment they need. Parents unable to access diagnosis or treatment for their children. Unpaid carers having to decide between going into debt or not being able to continue to care for their loved ones. Older people spending their life savings to pay for treatment to avoid years of living in pain.
- **88.** We understand why people faced with these situations may feel that their only option is to seek private healthcare.
- **89.** However, we are deeply concerned about the emergence of a two-tier system in which people's ability to access healthcare is determined not by their clinical need but by their financial resources. We are especially worried about people who cannot afford to pay facing the choice between waiting for a significant number of years, or getting into debt to fund their care privately.
- **90.** The most effective solution will be to tackle the backlog and bring waiting times down. The commissioning by the NHS of private care is one way to achieve this. However, we heard some evidence to suggest that there are more private healthcare facilities available in less deprived areas in Wales.

Recommendation 7. The Minister for Health and Social Services should set out what consideration the Welsh Government has given to supporting health boards across Wales to commission private healthcare on an ongoing basis as a means of addressing the waiting times backlog, including what role the Welsh Government has in ensuring that there is effective collaboration across providers and systems, and fair sharing of resources and capacity across health boards.

4. Supporting people to 'wait well'

91. A consistent message throughout our inquiry was the risk that increased waiting times could result in clinical deterioration or increasing complexity of needs before people receive treatment. In addition to causing harm or poorer outcomes for individuals, this can increase the pressure on health services in the longer term if people need more significant interventions. Many stakeholders highlighted the need to support people who are waiting for considerable periods for diagnosis or treatment to 'wait well'.

Supported self-management, signposting and advice

- **92.** Self-management was described as "the only way the numbers [of people waiting] are being dealt with, really, and kept as low as they are", but it was also suggested that approaches developed during the pandemic needed to be evaluated as self-management may not be appropriate for everyone. Dr Christian Egeler of the Faculty of Pain Medicine told us that self-management could help some people, but warned that overreliance could risk overlooking where interventions might be needed to treat the biological and medical aspects of pain. Mary Cowern of Cymru versus Arthritis suggested that the anticipated musculoskeletal and arthritis framework would help to provide a more joined up approach to treating people with musculoskeletal conditions, including better alignment between pain management services and self-management approaches. Description
- **93.** We were told that for self-management to be effective, it needed to be supported by effective and consistent signposting, communication and the right resources to ensure that people understand how to self-manage their conditions safely and avoid deconditioning during their wait.¹⁰⁶
- **94.** However, stakeholders said that patients do not always feel that they have the right information to help them to wait well, and that they can feel "very left much to their own devices". They explained that while extensive resources are available, information is only useful if people know it is there, and how to find it. Alyson Thomas of the Board of CHCs noted, for example, that health board and local authority websites do not effectively signpost to each

¹⁰² RoP [para 9], 2 December 2021

¹⁰³ RoP [para 64], 2 December 2021

¹⁰⁴ RoP [paras 57 and 69], 2 December 2021

¹⁰⁵ RoP [paras 233-234], 2 December 2021

¹⁰⁶ RoP [para 223], 2 December 2021

¹⁰⁷ RoP [paras 250-252], 2 December 2021

other or to third sector resources.¹⁰⁸ She added that existing signposting arrangements were "patchy", and said that it was important that signposting does not rely on individual health professionals' knowledge, but rather is consistent, proactive, and takes account of the range of resources available. This includes, for example, online materials, resources provided by the NHS, local authorities and third sector organisations, and care coordinators.¹⁰⁹

95. Stakeholders said digital solutions might not be suitable for everyone, but could be useful for some people. For example, Joseph Carter of Asthma UK and the British Lung Foundation told us that the asthma and COPD apps, funded by the Welsh Government during the pandemic as part of the respiratory care delivery plan, had been effective in supporting self-monitoring by "that younger, more technologically savvy audience with asthma and COPD—milder people, rather than severe lung conditions". He noted that increased publicity for the app would be beneficial, and that continued investment was required, but suggested that the approach could be replicated for other conditions. Similarly, while online services cannot fully replace in-person support from care workers, Gemma Roberts of the British Heart Foundation told us about an online cognitive behavioural therapy programme in Scotland which had included a specific heart disease section. The service of the British Heart foundation told us about an online cognitive behavioural therapy programme in Scotland which had included a specific heart disease section.

The role of the third sector

- **96.** A clear message throughout our work has been the key role played by the third sector, alongside health boards, in supporting people who are waiting for NHS treatment and care.
- **97.** The Welsh Government, in written evidence, described signposting to third sector services as "an important part" of the approach to supporting patients while they wait. It noted that health board services and websites signpost patients towards third sector support, and that letters sent to patients waiting for treatment include further signposting to suitable charities and third-party bodies.¹¹²
- **98.** However, Barnardo's Cymru, which provides support services to families on long NHS waiting lists, pointed out "the unavoidable fact that many of our services have waiting lists of their own". Till Richard Pugh of the Wales Cancer Alliance highlighted the impact of the pandemic

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¹⁰⁸ RoP [para 378], 2 December 2021

¹⁰⁹ RoP [para 373], 2 December 2021

¹¹⁰ RoP [para 288], 2 December 2021

¹¹¹ RoP [para 251], 2 December 2021

Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

¹¹³ WT10 Barnardo's Cymru

on charities' financial and staff or volunteer resources, and therefore their ability to provide nonclinical support to complement the NHS' clinical services.¹¹⁴

99. The pandemic has also constrained the ability of third sector organisation to provide inperson services or signposting. For example, Macmillan Cancer Support information centres in hospitals have been closed as a result of pandemic-related restrictions, and unable to provide in-person signposting or advice to patients who had previously been able to walk in while attending hospital appointments. Macmillan has seen an increase in the number of people accessing online resources or contacting them by email, but this may not be sufficient to ensure that everyone receiving a cancer diagnosis gets the signposting they need.¹¹⁵

Financial advice and support

100. Different people will need different types of advice and resources. For some if their condition affects their earnings, ability to work or their outgoings, a diagnosis or a long wait could result in a significant change in their financial circumstances. They may, therefore, need advice on financial support or benefits, or support to help them stay in work while they are waiting. Helen Whyley of the Royal College of Nursing ("RCN") told us that district nurses frequently signpost patients to sources of advice on these matters. To

101. Richard Pugh of the Wales Cancer Alliance said that Wales should be "really proud" that every local authority in Wales had welfare benefit provision in place. However, he added that the majority of the provision was delivered through Macmillan Cancer Support, Maggie's and Tenovus Cancer Care, and said: "we are funding those people because the system is broken [...] patients have to apply for this money, even though they've got a cancer diagnosis". He argued that people with a cancer diagnosis should receive the financial support for which they were eligible without needing to apply.¹¹⁸

Pain management

102. Specialist pain management services can offer a wide range of treatments and support for people living with persistent pain. Such services aim to support people in developing self-help skills to control and relieve their pain. Treatments can include medication, pain-relief injections, exercise and complementary therapies. Some people waiting for treatment may be offered pain

¹¹⁴ RoP [paras 149-150], 2 December 2021

¹¹⁵ RoP [para 156], 2 December 2021

¹¹⁶ RoP [para 227], 2 December 2021

¹¹⁷ RoP [para 69], 18 November 2021

¹¹⁸ RoP [para 152], 2 December 2021

management support, but the availability of services, for example specialist nurses, community pain support systems, or physiotherapists in primary care settings, varies.¹¹⁹

103. We heard calls for pain management services to be patient-centred, taking account, for example, of whether they would prefer in-person or digital services. Calum Higgins of the CSP highlighted the ESCAPE-pain programme, which is physiotherapist-led but involves a range of other professions to help people manage their pain:

"Most health boards have implemented that, and have introduced extra resources to that because it's quite cost effective, and it does work; it's well evidenced. So, that blanket approach works for a lot of people, but within that, you do need that clarity that the patient comes first, and that you adapt to that patient to make sure that the service meets their requirements." 120

104. Dr Christian Egeler of the Faculty of Pain Medicine said significant progress had been made to provide sufficient capacity for "those patients that are actually in a position to agree and be ready to join into the self-management and pain management programme approach", but acknowledged that there was variation in the provision of pain management programmes. He added that the pressure on pain management services was "vastly increasing" and that the extent to which services had been restored following initial suspension during lockdown varied across health boards. He told us that one of the biggest problems services faced was a loss of clinic and intervention spaces due to reorganisation and infection control measures, which he said was "creating a huge bottleneck because we simply don't have the spaces to treat patients". 122

105. Other allied health professionals also raised the issue of facilities, noting that spaces have not always been reallocated as services have restarted, with an emphasis instead being placed on identifying alternative spaces in the community. While this is welcome in some instances, some community spaces such as leisure centres have been repurposed as vaccination centres, limiting the scope for allied health services to be delivered from them.¹²³

106. In written evidence, the Welsh Government highlighted its *Living with persistent pain in Wales* guidance, published in April 2019. The Welsh Government explains that health boards are

¹¹⁹ RoP [para 42], 18 November 2021

¹²⁰ RoP [para 66], 2 December 2021

¹²¹ RoP [para 55], 2 December 2021

¹²² RoP [paras 13-4], 2 December 2021

¹²³ RoP [para 18 and 21], 2 December 2021

able to use this guidance to quality assure their services. It adds that to encourage national consistency two national clinical leads will be appointed "to determine areas of improvement and to help develop future services to meet the growing demand". 124 The Deputy CMO told us that the clinical leads would work across primary and secondary care to ensure the right "protocols, policies and support packages" are in place. 125

107. We heard some concerns that health professionals may suggest people try painkillers for short-term pain relief, when painkillers are not generally considered a primary way to manage long-term pain. An individual who responded to our consultation described a doubling in her husband's pain medication while he waits for orthopaedic surgery, and outlined fears that this could result in opiate addiction. ¹²⁶

108. Professor Peter Saul of the RCGPs said "we know that it's not good to be on opiates, and that would include medication". He added:

"I have this, again probably every week—somebody on a waiting list because of, typically, musculoskeletal pain, and they're saying, 'Look, these tablets aren't working', and then I'm thinking 'Do we move them up to opiates, to stronger medication?' I'm thinking what are the long-term implications of that, given that they may be on these for a year, two years, or even longer. And then, you've got the potential harms of using stronger medications. So, it's a question I haven't got an answer for, but I acknowledge it's a serious point."¹²⁷

109. The Deputy CMO acknowledged that people waiting for treatment may experience increasing pain. He said that clinicians should support patients to "manage their situation, hopefully without recourse to medication, but, when medication is required, to opiate medication as an absolute last resort". He explained that the deployment of the psychosocial model of pain by the national clinical leads would reduce the chances of "requiring serious, dangerous medication". ¹²⁸ He added that they would be responsible for ensuring that the

Welsh Government, Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment, February 2022

¹²⁵ RoP [paras 238-239], 10 February 2022

¹²⁶ WT05 An individual

¹²⁷ RoP [para 167], 18 November 2021

RoP [paras 238-239], 10 February 2022. The psychosocial model of pain posits that pain may be affected by a range of factors, including personal, emotional, psychological and social, as well as physical.

increase in community pharmacy prescribing limits from 28 to 56 days did not increase risks in respect of opiate prescriptions.¹²⁹

Mental health support

110. The experience of waiting, and of attending appointments or seeking treatment during the pandemic, can also have an effect on mental health. People have been less able to take friends or family members to their appointments, and as a consequence may have had to hear difficult news alone. Being given a diagnosis can help to provide clarity, but as Simon Jones of Mind Cymru told us, it can also be "quite a crushing moment" as someone realises that their life may be changing. Attending appointments alone during the pandemic has also meant that patients have had to share the news with their loved ones themselves:

"So, that patient then has got to go and break the bad news to their loved one, who might be waiting in the car. That's horrendous, isn't it? You've taken it on yourself and then you've got to tell a loved one. So, the experience hasn't been the greatest for patients. And I don't think that it's a fault of the system that's what's happened here, but we've got to take account of what the knock-on effect is psychologically for that patient. We want to break bad news well, don't we? And during COVID, we haven't been able to do that."

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111. There is a clear link between long-term physical health conditions, and poor mental health. Fair Treatment for the Women of Wales ("FTWW") said that many of its members had experienced physical health symptoms being attributed to mental health problems, but that it was rare that they were referred to mental health support services. In addition, people waiting for treatment for physical health conditions may experience pain, distress or an impact on their self-perception or self-esteem. They may also be less able to take part in their usual activities. Simon Jones of Mind Cymru said that while this may not result in mental illness, it could cause distress. He told us that parity between mental and physical health should mean that "when somebody's treated for one, they're treated for both". He added, however, that discussions with organisations focused primarily on physical health conditions suggested that mental health support provision for people with physical health conditions was patchy, particularly while people were on waiting lists. It was suggested that clinicians needed to have the right training

¹²⁹ RoP [para 242], 10 February 2022

¹³⁰ RoP [paras 193], 18 November 2021

¹³¹ RoP [para 144], 2 December 2021

¹³² WT14 Fair Treatment for the Women of Wales

¹³³ RoP [para 181-3], 18 November 2021

to provide appropriate psychological support for patients who may be experiencing mental distress as a result of their physical health condition.¹³⁴

112. There are tier 0 and tier 1 services available that people can access to help with this type of distress, but as Professor Euan Hails of Adferiad Recovery told us, people can only access them if they know about them, for example through signposting or referral by "an informed GP or someone who could point them in the direction of things like SilverCloud and the like". However, as Alyson Thomas of the Board of CHCs said:

"...those who may be in the most vulnerable situations might be the least able to self-advocate and to explain how they are feeling and describe what they need. So, that ability for somebody, through carers and care co-ordination, to be signposted is essential, so that people know what is available out there". 136

113. Stakeholders also told us about different pilot projects in respect of low level mental health support provision, including the iCAN pilot in north Wales focused on addressing the interaction of mental and physical health problems at a primary care level, ¹³⁷ and a pilot in the Hywel Dda UHB area exploring how community pharmacy can help to support low-level mental health needs and identify where escalation to a GP might be required. ¹³⁸

Prehabilitation

114. Prehabilitation programmes can help people to prepare for treatment and recover more quickly from surgery. For example, podiatry services for people with diabetes can help to reduce or avoid amputations, and physiotherapy in orthopaedics and rheumatology can influence whether more invasive treatment, including surgery, is required.¹³⁹ Age Cymru suggested that prehabilitation services should be available at GP surgeries and in health centres, that they should be delivered through a range of telephone, digital and in-person methods, and that they should include information and advice on "safe exercise, healthy eating and pain management techniques".¹⁴⁰

¹³⁴ RoP [paras 191-2], 18 November 2021

¹³⁵ RoP [para 188], 18 November 2021

¹³⁶ RoP [para 338-9], 2 December 2021

¹³⁷ RoP [paras 95], 2 December 2021

¹³⁸ RoP [para 165], 18 November 2021

Welsh Government, Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment, February 2022

¹⁴⁰ WT33 Age Cymru

- **115.** Such services are in place in some health boards: Cardiff and Vale UHB highlighted the services and approaches it has in place to support people who are waiting to access planned care, including its Prehab2Rehab project, and its KeepingMeWell.com website (to which patients are signposted using QR codes on waiting list letters, as well as in other ways). However, the evidence we heard suggests that the provision of prehabilitation support for people waiting for treatment is sporadic, both across health boards and across different hospitals. He
- **116.** The RCN told us that bringing forward the timing of pre-surgery assessments could help to ensure that people receive prehabilitation support. Helen Whyley suggested that conducting assessments at the point of referral could enable consideration to be given to suitability for surgery, and also to whether social prescribing or referral to appropriate community care services could avoid a patient deteriorating, perhaps to the point where they may no longer be able to receive the treatment for which they were waiting. She said that this would enable more patient-centred care, but noted that it would need investment in multi-professional community-based teams.¹⁴³

Waiting Well support service

- **117.** The Welsh Government told us that a central part of its approach to supporting people while they are on waiting lists is the establishment of a Waiting Well support service in partnership with the British Red Cross. The service will provide "practical and emotional support, signposting and supported referral" to people who are on waiting lists, with the aim of helping them to "maintain their independence and improve their ability to better self-manage". 144
- **118.** The Chief Executive of NHS Wales told us that the service would be piloted by four health boards over the next 12 months, but that she expected all health boards to ensure they have "solid services and offers to patients who are waiting in terms of helping them to wait well". She explained that the pilot would be evaluated on an ongoing basis, including through feedback from patients and their families, to assess both its effectiveness and how it complements existing support models to avoid duplication. ¹⁴⁵

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¹⁴¹ WT21 Cardiff and Vale University Health Board

¹⁴² RoP [para 249], 2 December 2021

¹⁴³ RoP [paras 38-39 and 139], 18 November 2021

Welsh Government, Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment, February 2022

¹⁴⁵ RoP [paras 259-260], 10 February 2022

Our view

- **119.** The health service in Wales is working hard to get people seen as quickly as possible, and we thank them for that. However, the reality is that people are having to wait for significant periods for the care and treatment that they need, and this is unlikely to change soon. For many people, there is a risk that, without action, their conditions may deteriorate and their needs may become more complex. In some cases, long waits can reduce the potential effectiveness of the proposed treatment. Waiting for long periods can adversely affect people's lives, including their family life, their ability to work, and their ability to provide care for others.
- **120.** People who are waiting for diagnosis, treatment or care must be effectively and consistently supported, and have access to the right information, advice and services to manage their physical and mental health and wellbeing while they wait. The 'right' approach to achieving this is likely to vary across conditions, lengths of wait, and according to people's own personal circumstances and preferences. Care and services must be patient-centred, and make sure that people, and those supporting them, including families and carers, have choice, voice and control.
- **121.** It is clear from the evidence that crucial elements of the approach to supporting people who are waiting, and those caring for them, include:
 - Consistent, proactive and routine signposting to reliable, credible, accessible and appropriate sources of advice, information and support as part of their care and treatment pathways.
 - Recognition that, for some people, their condition or the symptoms they experience while waiting for treatment will affect their way of life considerably, including their earnings and outgoings. Particularly in the context of rising costs of living, this could be a source of considerable anxiety, as well as practical difficulties. Health professionals are not financial advisers, however, they do have an important role in signposting people to sources of advice.
 - Recognition that people may be in physical or mental pain or distress as a result of their condition and/or the experience of waiting, and that they may therefore need appropriate mental health, wellbeing or emotional support. The support that people need will vary, and people's natural emotional responses should not be overmedicalised.

- Assessment at an early stage to identify what the right approach is for the individual's own needs and circumstances. This could include elements of self-management, pain management, prehabilitiation or medication, access to community services, social prescribing, as well as consideration of whether in-person, telephone or digital delivery would be most effective.
- **122.** Both the health service and the third sector have important roles in supporting people who are waiting and those who are caring for them. The pandemic has had a significant impact on third sector organisations—a reduction in the resources available to them at the same time as demand for their services has increased. Third sector organisations are often reliant on grant funding for the provision of their services, and the pressures on them can be exacerbated by uncertainty about whether funding will be continued beyond the end of the financial year. We note that the Welsh Government, in its 2022-23 budget, has returned to multiyear financial planning. This must translate into clearer and more sustainable funding for services commissioned from third sector organisations.

Recommendation 8. The Minister for Health and Social Services should confirm whether the return to multiyear Welsh Government budgets is expected to result in longer-term funding certainty for services commissioned from third sector organisations.

123. We were concerned to hear that some services such as pain management and allied health professionals are struggling to find suitable spaces and locations from which to deliver care and treatment either in hospitals or in the community. This also reflects concerns we heard from the RCGPs about the adequacy of the primary care estate. We recognise that ongoing infection control measures and social distancing put pressure on NHS estates, and that the use of community facilities for vaccination centres may limit availability for other health services, but unless this matter is resolved people will face longer waits than necessary.

Recommendation 9. The Minister for Health and Social Services should set out what action is being taken to ensure that health boards are providing suitable venues for the delivery of services such as pain management, physiotherapy and occupational therapy both in hospitals, on the primary care estate, and in the community.

124. We are concerned about the potential overreliance on pain medication, and we welcome the Welsh Government's intention to appoint clinical leads for pain management, and for the adoption of a psychosocial model that takes into account a wide range of factors that influence pain.

Recommendation 10. The Minister for Health and Social Services should provide an update on the appointment of the national clinical leads for pain management. This should include information about their role in ensuring the appropriate use of pain medication in the management of people on waiting lists, including their contribution to managing the risks associated with the prescription of opiates.

125. It is encouraging to hear about the range of pilots and innovative approaches that health services and third sector organisations are developing to respond to the needs of those waiting for care. However, these pilots must be evaluated quickly, and, where they have been effective, they should be rolled out and mainstreamed without delay.

Recommendation 11. The Minister for Health and Social Services should provide an update in autumn 2022 on the Waiting Well support service pilot, including details of elements which are proving effective and what plans there are to roll them out to the other three health boards, and elements which have not worked as intended and have therefore been withdrawn or stopped.

5. Communication

Why communication matters

126. Effective communication was highlighted repeatedly as a key mitigation for long and uncertain waiting times. Macmillian Cancer Support said:

"People on a waiting list tend to mind less about the wait, but more about the uncertainty and lack of communication about how long they will wait and what they can do in the meantime." 146

- **127.** Others, however, cautioned that, while important, better communication alone was not a panacea, and neither could, nor should, be a substitute for ensuring that there is sufficient capacity and focus on ensuring that people receive the care that they are waiting for.¹⁴⁷
- **128.** A lack of communication, particularly if accompanied by cancellation of appointments, can contribute to deterioration of people's mental and physical health and affect their ability to self-manage their symptoms:

"...there's nothing else worse than sitting on a waiting list wondering, hoping, when that phone call, when that letter's going to come when you're in extreme pain every single day. And it is bleak, and I'm not ashamed in saying this is a really, really bleak situation for people in despair, and it just doesn't sit alongside prudent healthcare at all. We've got people suffering out there." 148

129. We also heard that in some cases it is not being made sufficiently clear to people whether they are, or are not, on a waiting list, leading in some cases to people feeling "abandoned" by health services. ¹⁴⁹ FTWW told us that many people felt the need to repeatedly follow up with health services in order to access any information, and that some had said that they would have felt "lost and abandoned" had they not had either the capacity, skills or family support to do so. ¹⁵⁰

¹⁴⁶ WT24 Macmillan Cancer Support

¹⁴⁷ RoP [para 160], 2 December 2021

¹⁴⁸ RoP [paras 216-217], 2 December 2021

¹⁴⁹ WT33 Age Cymru

¹⁵⁰ WT14 Fair Treatment for the Women of Wales

130. During our interviews people consistently said that communication problems that had existed before the pandemic had become worse as a result of COVID-19:

"The staff work very hard and it is hard to be critical during a pandemic, but the majority of my healthcare has been poor prior to the pandemic. Communication between Consultants and with patients and GP lets the system down at every turn."

"During Covid the communications have been non-existent, nothing at all – I have made 1 or 2 approaches to the surgery to see if I could make sense of it, but they are not prepared to tell me anything. If someone could give me an idea of a date, then I could look forward to it. If nothing happens in 2 years, then I am just going to give up."

"Communication doesn't have to be over-bearing. It's not asking for much, even if we were given an update once every 6 months, even once a year! It would make you feel that you haven't been forgotten about." ¹⁵¹

Listening to people who are waiting

131. In November 2020, the Board of CHCs published *Feeling forgotten? Hearing from people waiting for NHS care and treatment during the coronavirus pandemic*, which describes the impact of waiting a long time for NHS care and treatment. It explains that during the early stages of the pandemic people understood why planned care was postponed, but that as restrictions have eased people have become frustrated that they are still waiting. It suggests that one of the most distressing elements is that they do not know why they are still waiting, or when their care may start or restart. It also makes a number of recommendations to the Welsh Government and to NHS bodies, including ensuring that healthcare staff keep in regular contact with people who are waiting for care and treatment, that people who are waiting know how to get advice and support, and that more is done to reach people who may not be able to find things out by looking online.¹⁵²

¹⁵¹ Senedd Citizen Engagement Team, *Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings*, January 2022

¹⁵² Board of Community Health Councils in Wales, *Feeling forgotten? Hearing from people waiting for NHS care and treatment during the coronavirus pandemic,* November 2020

132. The Welsh NHS Confederation confirmed that health boards were working with their local community health councils to consider the report's recommendations, and that health boards were using a range of approaches to listen to patient feedback and address the issues raised. ¹⁵³

Communication approaches

133. The Deputy Chief Executive of NHS Wales told us that health services were learning from approaches to communication during the pandemic, for example blended approaches which included local, health board-specific information alongside national communication to help manage expectations. He confirmed that the planned care recovery plan due to be published in April would address communication, and that the Welsh Government intended to be.

"... honest and truthful with the public in terms of how long they may wait for some of the treatments, but do it in a way that engages them in the issue and tries to help them manage their condition whilst they wait. So, I think we can link up some of the Help Us Help You and living healthy messages that the previous questions have referred to as well in terms of how do we communicate that whole message about how you access healthcare services as we go forward as part of that message of managing long waiters". 154

134. In their written evidence, health boards described a range of ways in which they are seeking to ensure that patients are kept well-informed and supported. This includes:

- Contact with patients who have waited more than 52 weeks to ask whether they want to stay on the list, and whether there has been any change in their condition.
- The establishment of pilot single points of contact or core teams to provide support for patients on waiting lists and make things simpler for patients.
- Setting up clinical nurse specialist-led support or help groups for specific conditions.¹⁵⁵

¹⁵³ Letter from Welsh NHS Confederation, 13 January 2022

¹⁵⁴ RoP [paras 280-283], 10 February 2022

¹⁵⁵ WT12 Swansea Bay University Health Board; WT16 Aneurin Bevan University Health Board; Welsh Government,

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- **135.** Despite the efforts health boards have made, we heard from many stakeholders that communication with people who are waiting for treatment can be patchy. ¹⁵⁶ Alyson Thomas of the Board of CHCs said things had improved, but more needed to be done. ¹⁵⁷
- **136.** Health professionals told us that workforce capacity can constrain their ability to communicate proactively with patients, particularly when resources were also required to reduce waiting lists by treating patients. Dr Christian Egeler of the Faculty of Pain Medicine said that there was "just simply too much demand and too few people to actually deal with this", and added that the administrative and managerial resources required to communicate with people on waiting lists is greater for services with longer lists. Dai Davies of the RCOT agreed, saying that the scale of the issue meant that balancing communication with people on waiting lists with focusing on "the day-to-day job and the next patient" was difficult. Day 159
- **137.** The single point of contact model developed by Hywel Dda UHB was praised by several stakeholders as a model for providing advance signposting information and self-management advice, tailored information and support to meet patients' needs, "personalised contact" between the patient and the health service, and clarity as to where patients could turn if their symptoms worsened. 160
- **138.** The Minister told us that feedback from Hywel Dda UHB suggested that the pilot had been "hugely successful, but very resource intensive, in particular in terms of clinical personnel input". She was reluctant to make a firm commitment to rolling the model out elsewhere:

"So I would rather do as we've done throughout the pandemic, and that is wait until we've got everything lined up and then just be confident that what we can offer is something that is sustainable and effective. But this is the kind of thing that I would expect to see in our planned care plan that will be published, as I say, in April." 161

139. The Deputy Chief Executive of NHS Wales said that there was an intention to develop a "patient information system" on a regional or national basis. He told us that this would be "one of the early parts of the delivery plan for planned care recovery" once resources were in place,

¹⁵⁶ For example, RoP [para 216], 2 December 2021

¹⁵⁷ RoP [para 373], 2 December 2021

¹⁵⁸ RoP [paras 68 and 80], 2 December 2021

¹⁵⁹ RoP [para 77], 2 December 2021

¹⁶⁰ RoP [para 289], 2 December 2021

¹⁶¹ RoP [paras 287-9], 10 February 2022

and added that it would be both a phone and digital service to ensure it was accessible to as many people as possible.¹⁶²

- **140.** We were also told that an NHS Wales app is being developed to provide a range of information, including helping people to find out where they are on the waiting list. Alyson Thomas of the Board of CHCs acknowledged that better information would help reduce anxiety, but said that the app was still "some way away", and would not help people who are not digitally-enabled.¹⁶³
- **141.** Digital Health and Care Wales told us it had established a Digital Services for Patients and the Public Programme, and that work had begun to develop the platform and associated processes to:

"...provide digital channels for patients to easily interact with health and care services. As modules are developed this will provide patients with the information and access required of a modern health care system, empowering patients and providing far greater options to transform pathways of care". 164

Communicating accessibly

- **142.** It is vital that communication is accessible to the recipient. However, Kate Young of the Wales Carers Alliance told us that people with learning disabilities were being sent complicated letters, leaving them reliant on carers or family members to help them understand the information. She said that this could result in people missing appointments, risking harm for the individual and wasting NHS resources. ¹⁶⁵
- **143.** RNIB Cymru told us the pandemic had "shone a stark light on how inaccessible much of NHS communications is". It noted that important communications about shielding and vaccination had not always been provided in accessible formats, with implications for patient safety. It added that the Fifth Senedd Equality, Local Government and Communities Committee had recommended the appointment of a Welsh Government accessibility lead to oversee production of key public information in accessible formats, but that no appointment had been made. ¹⁶⁶

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¹⁶² RoP [para 285], 10 February 2022

¹⁶³ RoP [para 373], 2 December 2021

¹⁶⁴ Letter from Digital Health and Care Wales, 13 January 2022

¹⁶⁵ RoP [para 384], 2 December 2021

¹⁶⁶ WT01 RNIB Cymru

Waiting list validation

144. Health boards have been validating their waiting lists through a standard communication campaign to contact people who have been waiting over 52 weeks for an outpatient appointment to ensure that they still require treatment and to identify whether anything has changed in terms of their clinical need or priority. We were told that the questionnaires had also been used to identify whether patients required any additional support. 168

145. We heard that some people had found the questionnaires confusing, particularly those whose conditions are unlikely to have been resolved other than by the treatment for which they are waiting. In some cases, people were also concerned that waiting list validation was an attempt by health boards to push back against people's need for treatment. Endometriosis UK suggested that such questionnaires should be accompanied by reassurance that the individual has not been removed from the list. To

Our view

146. Communication has been a central theme throughout our inquiry. The evidence we have heard suggests that the key things people waiting for care and treatment want to know are:

- The expected timeframe for appointments, tests and treatment.
- What support services are available while they wait, including how they can be supported to safely and effectively self-manage their conditions.
- Information and advice on how to stay as fit and healthy as possible.
- Who to contact if their circumstances change.
- Where to find further information about approximate waiting times at different hospitals.

147. We recognise that proactively meeting patients' expectations and desire for information can be a substantial administrative task. However, it is inevitable that people who are waiting for delayed medical care will have concerns and questions, and health services need to ensure that their staffing and service models take into account the need for effective proactive and reactive communication with patients. This includes ensuring that health services have sufficient

¹⁶⁷ RoP [para 279], 10 February 2022

¹⁶⁸ RoP [para 81], 2 December 2021

¹⁶⁹ RoP [para 375], 2 December 2021

¹⁷⁰ WT20 Endometriosis UK

administrative and clinical capacity to communicate with patients and validate and prioritise waiting lists. Such communication is an important part of core service delivery, not an add on.

Recommendation 12. The Minister for Health and Social Services should ensure that the plan for the recovery of planned care includes clarity about how health services should be communicating with people who are waiting. This should include potential communication approaches, assurance that there is sufficient clinical and administrative resource to deliver it, and details of how communication will be evaluated and how best practice and innovation will be shared.

148. If it is to be effective, communication must be accessible. Failing to make information available in accessible formats risks patient safety, and can also result in wasted time, effort and further unnecessary delays.

Recommendation 13. The Minister for Health and Social Services should provide an update on progress made on the implementation of recommendation 37 in the *Into sharp relief: inequality and the pandemic* report published by the Fifth Senedd Equality, Local Government and Communities Committee in August 2020. The recommendation, which was accepted by the Welsh Government on 23 September 2020, called for the appointment of an accessibility lead within the Welsh Government to oversee the production of all key public health and other information in accessible formats

149. We welcome the assurance from the Minister that the aim of waiting list validation is to ensure that lists are accurate and reflect changes in patients' conditions, and that there is no intention for such exercises to result in "removing genuine patient pathways". ¹⁷¹ It is important for health boards to ensure that there is a clear picture of who is waiting, the clinical priorities, and whether additional support could be beneficial in helping people to self-manage their conditions while they are waiting. The exercises may also have provided reassurance to people who have been waiting more than 52 weeks that they have not been forgotten.

150. However, it is concerning that some patients have felt that the exercises have challenged whether they need the care and treatment for which they have been waiting. As such validation exercises are likely to need to be repeated over the coming months and years, it is important to ensure that lessons are learned in terms of the way in which the aim of the validation exercise is

¹⁷¹ Welsh Government, Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment, February 2022

explained, including the language and tone of the questionnaires and accompanying explanatory materials.

Recommendation 14. The Minister for Health and Social Services should work with health boards and community health councils to evaluate the recent standard communication campaign and waiting list validation exercise, and implement any lessons arising when planning future waiting list validation exercises. The outcome of the evaluation should be published.

6. Unpaid carers

The impact on carers

151. The waiting times backlog does not just affect those who are waiting for treatment, it also affects their families, friends and carers. Kate Young of the Wales Carers Alliance described "a growing sense of feeling of abandonment and fear" among carers about:

"...whether things will return, when they will return, if they'll return in time for me and my family's situation, before it becomes critical. [...] people being put into residential care because they weren't able to get the right assessment; people feeling that they have to adapt their homes in a way that they didn't want to because they're just waiting on an operation to become more physically able. All of those questions have been in people's minds, and there is a definite growing sense of fear and anxiety". 1772

152. We were told that some of the implications for carers of long waiting times included:

- Increased complexity and levels of care. For example, carers, including young carers, may need to administer medication, which could result in "an unpaid workforce being almost professionalised in its requirement to actually have to help and support people to manage pain and all the things that come with that". 173 In recognition of this, Community Pharmacy Wales and the Royal Pharmaceutical Society have worked with Carers Trust Wales to create materials to help pharmacists understand carers' needs and how best to support them in understanding medications for the person they are caring for. 174
- Financial hardship or concerns about financial security. Some carers have lost their jobs during the pandemic, or have had to give up work to become full-time carers if the needs of the person they are caring for become more complex, or if community or other services or treatments are unavailable. The carers support grant is available to help fund practical needs, but we were told that "people are finding themselves being pushed closer to the poverty line".¹⁷⁵

¹⁷² RoP [para 363], 2 December 2021

¹⁷³ RoP [para 331], 2 December 2021

¹⁷⁴ RoP [para 75], 18 November 2021

¹⁷⁵ RoP [paras 350, 365 and 370], 2 December 2021

- Increasing loneliness, isolation and feelings of abandonment because of a lack of services and support, or fear that their loved one would not receive treatment or care in sufficient time to improve their quality of life.¹⁷⁶
- Increased pressure on young carers who may be struggling to balance caring and managing school, college or university. Worryingly, we were told that some young carers are "questioning whether they can go back to college because the situation at home requires them to be there more often because of the situation that their family members are in".177
- Particular difficulties for older carers, who may be in co-dependent caring arrangements. Age Cymru explained that such situations can result in significant pressure on those involved, including leading to people hurting themselves while trying to provide care (and potentially being put on waiting lists themselves), or people needing to go into residential care because they are unable to access the domiciliary care they need to support them at home.¹⁷⁸
- Reduced involvement of carers and families in mental health care and treatment planning.¹⁷⁹

153. Age Cymru's survey of older carers found that half of those surveyed felt they needed support, but most did not know where to get it. Many had not received the carers assessment to which they are legally entitled, and many felt that there were no support services available:

"There's a lot of support that they need and there's an awful lot more that can be done, just in terms of extra information on how to provide the right support for the person who they're caring for—advice around medication, advice around exercise, which will help that person stay well rather than deteriorate while still waiting for treatment. So, there's an awful lot more that could be done". 180

Support for carers and families

154. Kate Young of the Wales Carers Alliance told us that the pandemic has increased pressures on carers, in many cases resulting in them feeling exhausted and isolated. This has

¹⁷⁶ RoP [paras 365-366], 2 December 2021

¹⁷⁷ RoP [para 351], 2 December 2021

¹⁷⁸ WT33 Age Cymru

¹⁷⁹ RoP [para 230], 18 November 2021

¹⁸⁰ RoP [para 357], 2 December 2021

been exacerbated by the suspension or withdrawal of projects, initiatives and services, and by the impact of annual funding arrangements which can create uncertainty as to whether services will be able to continue into the next financial year. The result, she said, is that support for unpaid carers and families is:

"...quite a complex picture, and there's some positives, but I would say the vast majority of long-term caring situations they would feel that the support isn't really there for them".¹⁸¹

- **155.** We asked the Minister about the support available for families when one person within the family receives a diagnosis, particularly when children within the family may be old enough to understand the diagnosis, but not old enough to deal psychologically with it. The Minister suggested that circumstances such as these are "where, actually, the third sector absolutely comes into its own". Barnardo's Cymru was just one of the organisations that shared examples with us of the way in which it supports the families affected by long waiting lists.
- **156.** However, we were told that the impact of a diagnosis on a person's family members or carers can "often be forgotten". Following a diagnosis, people may find themselves becoming carers for the first time, or may find that the person for whom they are caring "has changed significantly, not physically, but mentally as well, in terms of how they're emotionally coping with it." Restrictions in place during the pandemic have exacerbated the situation, as being unable to attend appointments with their loved one has resulted in families feeling less informed or involved. They may also be less able to access support or advice services that would previously have been available to them in hospital settings. Settings.
- **157.** Simon Jones of Mind Cymru emphasised the importance of considering how best family members and carers can be supported, and how their distress and trauma can be acknowledged and recognised without being unnecessarily medicalised. He suggested that this could include providing accessible information about the relevant condition, or about how they can access emotional or wellbeing support themselves.¹⁸⁷

¹⁸¹ RoP [para 345-348], 2 December 2021

¹⁸² RoP [para 249], 10 February 2022

¹⁸³ WT10 Barnardo's Cymru

¹⁸⁴ RoP [para 199], 18 November 2021

¹⁸⁵ RoP [para 250], 2 December 2021

¹⁸⁶ RoP [para 154], 2 December 2021

¹⁸⁷ RoP [para 199], 18 November 2021

Our view

158. The care and support provided by unpaid carers is essential, and we thank them for all that they do. Without their efforts, our health and social care services simply could not function. It is without doubt that the pandemic, and the resulting waiting times backlog, has increased the pressures they face, and it is vital that support is available for unpaid carers, including people who may have become carers for the first time as they support people who are waiting for diagnosis or treatment.

159. It is especially important in the context of the rising costs of living that carers, particularly those who may have had to fully or partially give up their paid work as a result of their caring responsibilities, are able to access financial support, whether through the carers support grant or other mechanisms. We note that the Welsh Government's strategy for unpaid carers delivery plan (updated in January 2022) includes the theme of promoting financial resilience, which it says is to be delivered by promoting and supporting carers in accessing a range of welfare benefits, financial support information and services.¹⁸⁸

Recommendation 15. The Minister for Health and Social Services should set out how priority theme 4 (promoting financial resilience) in the Welsh Government's unpaid carers delivery plan will be delivered. This should include details of actions that will be taken to promote and support carers in accessing a range of welfare benefits, financial support information and services, and how the impact of these actions will be assessed.

160. The involvement of carers and families in care and treatment planning is a vital part of the delivery of patient-centred care, and any reduction of their involvement during the pandemic must be reversed.

Recommendation 16. The Minister for Health and Social Services should outline her expectations for the involvement of carers and families in care and treatment planning, and how any reduction of their involvement during the pandemic will be reversed.

¹⁸⁸ Welsh Government, *Strategy for unpaid carers: delivery plan 2021*, January 2022

7. Data

Current approach

161. Currently, data about waiting times is published monthly on the StatsWales website. Public Health Wales noted that the NHS Wales Delivery Unit produces a dashboard, including modelling, broken down by specialty and health board. Digital Health and Care Wales advised that the dashboard and modelling are "available for sharing from the [Delivery Unit]". 190

162. Aneurin Bevan UHB stated in written evidence that before COVID-19 it published waiting times for each specialty, but that this ceased at the start of the pandemic. It explained that "Due to the fluctuations in waiting times and the ever increasing variances, it has proven difficult to publish accurate data, particularly when the Health Board is trying to manage the patients most at risk". ¹⁹¹ Cwm Taf Morgannwg UHB similarly said that the changing context and the nature of the demands meant that it was "not possible to accurately indicate specialty waiting times". ¹⁹²

Condition-specific data

163. Stakeholders told us that both the quality and availability of data across a range of conditions needs to be improved, for example:

- Data in respect of cardiac services in Wales was described as: "incredibly poor", meaning that there is insufficient data to assess "where we're doing well, where we're doing badly, and as much as we want to invest in services, if we don't have that accurate data, we don't know where to invest and we don't know what services need to be rolled out across Wales".¹⁹³
- Data regarding trauma and orthopaedic services is "lumped together", making it difficult to identify the balance between elective and emergency surgery, obscuring the variation in the extent to which elective services had been restored in different health boards, and making it more challenging to identify where there could be good practice that could be applied elsewhere.¹⁹⁴

¹⁸⁹ WT23 Public Health Wales

¹⁹⁰ Letter from Digital Health and Care Wales, 13 January 2022

¹⁹¹ WT16 Aneurin Bevan University Health Board

¹⁹² WT19 Cwm Taf Morgannwg University Health Board

¹⁹³ RoP [para 259], 2 December 2021

¹⁹⁴ Health and Social Care Wales, RoP [para 382], 2 December 2021

- There is no specific breakdown of waiting lists across different respiratory conditions,
 making it challenging to assess where progress may be needed.¹⁹⁵
- The Welsh Government committed in 2019 to publish a core mental health data set, including waiting times data for access to psychological therapies, but data is not yet available to enable demand and throughput in the system to be properly assessed, or to enable disaggregation on the basis of characteristics such as age or ethnicity.

 The Minister told us that data on local primary mental health services, CAMHS and mental health admissions was being published, but that the publication of the core data set had been delayed because of the pandemic.

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164. Elin Edwards of RNIB Cymru suggested that health services could learn from the eye care measure approach in order to provide a clearer picture of the nature of waiting lists. ¹⁹⁸

Potential developments

- **165.** Digital Health and Care Wales told us that it was working on a national data resource to "bring together all available health and care data facilitating advanced analytics and AI approaches at scale to risk stratify populations". ¹⁹⁹
- **166.** Audit Wales told us that it had prepared an interactive data tool as part of its work on planned care, and anticipated publishing the tool in March 2022. It added that the tool would contain information at an all-Wales and health board level about the number of people on waiting lists and how long they had waited. It would also provide information for different specialties and for patients at different points on patient pathways. The Auditor General for Wales suggested that the tool would provide "a user-friendly way of accessing waiting time data to inform dialogue, debate and scrutiny within the NHS, and more broadly".²⁰⁰
- **167.** In England, the *Delivery plan for tackling the COVID-19 backlog of elective care* includes a commitment to a new My Planned Care digital service that will "tell patients when they should expect treatment".²⁰¹

¹⁹⁵ WT13 Asthma UK and the British Lung Foundation Wales

¹⁹⁶ RoP [paras 267-268 and 271], 18 November 2021

¹⁹⁷ RoP [paras 221 and 224], 10 February 2022

¹⁹⁸ RoP [para 301], 2 December 2021

¹⁹⁹ Letter from Digital Health and Care Wales, 13 January 2022

²⁰⁰ WT08 Audit Wales

NHS England, 'NHS publishes elective recovery plan to boost capacity and give power to patients', 8 February 2022

Our view

- **168.** Data is crucial. Without robust, accurate and disaggregated data, services cannot plan properly, patients cannot get a sense of how long they might be waiting, and the Welsh Government, NHS Wales and individual health boards and hospitals cannot assess whether their plans to address the backlog are working.
- **169.** As we move out of the acute phase of the pandemic, we need to see improvements in the availability of information about anticipated waiting times within different health boards, specialties and hospitals. We understand that there are risks associated with publishing detailed information on NHS waiting times by hospital and by specialty, not least because the list of people waiting changes daily and it is very hard to give people certainty about how long they will have to wait. We recognise that the rapidly evolving context during the pandemic will have made it more challenging to publish data on an individual health board, hospital or specialty basis, or to accurately predict waiting times. However, dealing with uncertainty on top of the other discomfort, pain and distress of long waits is difficult, particularly when symptoms may be severely affecting an individual's quality of life. It is very clear that people would find it helpful to have an indication of the approximate amount of time that they might need to wait.
- **170.** Our view, therefore, is that such data should be published. To mitigate the risks that the data may become out of date or inaccurate as circumstances change—for example if planned care waiting times within a particular hospital or specialty lengthen as a result of a peak in unscheduled or emergency care needs—the data should be accompanied by the date on which it was published, and a clear explanation that anticipated waiting times should be treated as indicative and may be subject to change. This approach could help to provide the clarity people are looking for, while also managing their expectations.

Recommendation 17. The Minister for Health and Social Services should require health boards to routinely publish waiting times data disaggregated by specialty and hospital. The publication of such data should be accompanied by clear information for patients and the public to ensure that they understand that the waiting times indicated by the data may be subject to change.

171. It is disappointing that the mental health core data set has been delayed by the pandemic. As part of our inquiry into mental health inequalities we will be seeking an update on progress made by the Welsh Government in implementing the recommendations made by Fifth Senedd Committees in respect of mental health. We will expect to receive a clear update on the timescales for the publication of the mental health core data set as part of this work.

8. Collaboration and transformation

Communication and joint working

172. Stakeholders told us that health and social care services need to work together effectively. Dai Davies of the RCOT suggested that better integration of patient notes and ICT systems could facilitate more efficient care and avoid duplication when patients are referred to health services by social care services and vice versa.²⁰² We were also told that ensuring that ICT systems used in different parts of the health service were compatible could improve communication and data flows between primary and secondary care. The RCGPs said that this would improve the timeliness and quality of patient care.²⁰³

Transformation funding

173. The seven RPBs were established by the *Social Services and Wellbeing (Wales) Act 2014*, and are responsible for improving the wellbeing of the populations in their region, and for improving the delivery of health and care services. In addition to developing regional area plans, they are responsible for preparing investment plans for transformation funding. Previously such funding was provided through the integrated care fund and the transformation fund, but they will be replaced in 2022-23 by the health and social care regional integration fund and a new £50m capital fund for social care.

174. We heard throughout our inquiry about various pilots or projects being undertaken to improve care and services in different regions, health boards, hospitals and specialties. While different approaches will be appropriate for different circumstances, there was frustration that good practice is not routinely shared, and projects that are proven to be successful are not necessarily rolled out more widely or put onto a sustainable funding footing.²⁰⁴ Stakeholders told us that RPBs, as well as health boards, need to do more to facilitate learning across their regions and beyond, and to ensure that models that are shown to be effective are implemented and mainstreamed.²⁰⁵ Alyson Thomas of the Board of CHCs said:

"Too often, we see some really good pilots, then sometimes they end when the funding ends for the pilot, and sometimes they stay within parts of health boards, not even extended out across a whole health board, and certainly not extended out

²⁰² RoP [para 70], 13 January 2022

²⁰³ WT28 Royal College of GPs

²⁰⁴ RoP [para 44], 18 November 2021

²⁰⁵ RoP [para 88-89], 2 December 2021

enough to the wider NHS. Again, we are seeing, during the pandemic, much more discussions between health boards, and some shared learning between health boards, but more is needed to build that in to the psyche, I think, of the NHS in Wales, that they can learn from each other and not be constricted by their own boundaries".²⁰⁶

175. It was suggested that the Welsh Government also needs to play a more active role in ensuring that health boards work together on a regional basis. Sue Hill of the Royal College of Surgeons ("RCS") told us:

"I've spoken to health Ministers in Wales for a long time now, maybe 10 or 15 years, and I get the same answer all the time, which is: 'We set the policy and then we leave it to the health boards to enact the policy.' I'm afraid that sounds good but, in this situation, it doesn't work. You need to call the chief executives in and mandate that they do this cross-border collaboration".²⁰⁷

Our view

176. It is positive to see that there is appetite for innovation across health services, as demonstrated by the range of pilot projects taking place across Wales. However, it is disappointing that there continues to be only patchy sharing of good practice across services or geographic areas to help transform services and improve patient outcomes. We must start to see good practice travelling better.

177. We recognise that change can be difficult, especially in the context of the pandemic, and that transformation takes time. However, it cannot be sustainable that in 2022 we still have health facilities purchasing new fax machines.²⁰⁸ Progress needs to be made on digital records and information sharing—so that patients can receive seamless services from all parts of the health and social care system—and on compatibility between ICT systems used in different parts of the health and social care services.

Recommendation 18. The Minister for Health and Social Services and Digital Health and Care Wales should work with health and social care services, including primary and community services, to ensure that all health and social services have appropriate access to shared patient records.

²⁰⁶ RoP [para 378-9], 2 December 2021

²⁰⁷ RoP [para 296], 13 January 2022

²⁰⁸ RoP [para 96], 27 January 2022

Recommendation 19. The Minister for Health and Social Services and Digital Health and Care Wales should outline the approach that is being taken to ensure that ICT systems used within health and social care services are compatible in order to facilitate effective communication and information sharing.

178. As we set out in our report on the Welsh Government's draft budget for 2022-23, we strongly believe that health and social care transformation is required, as "it is not sustainable for the costs of 'business as usual' to continue to increase year on year". We called on the Welsh Government to explain how the new health and social care regional integration fund would provide the drive needed to ensure that genuine innovation and transformation is rolled out across health and social care, including the role that RPBs will play in this.

179. In its response to our report, the Welsh Government explained that RPBs' investment plans would need to demonstrate how their proposals met Welsh Government priorities. It added that the approach had been co-designed with RPBs, and included a "clear outcomes framework" which would remain under review. In addition to quarterly meetings between RPBs and the Welsh Government, and a programme of audits throughout the lifetime of the fund, a quarterly status report will be produced to "collate a set of agreed data [...] maintaining the integrity of the reporting and support a successful audit and evaluation process".²¹⁰

²⁰⁹ Health and Social Care Committee, *Welsh Government draft budget 2022-23*, February 2022, p.33

²¹⁰ Welsh Government, Response to the Health and Social Care Committee on Draft Budget, March 2022

9. Health inequalities

180. The impact of the waiting times backlog is not necessarily experienced equally by everyone in Wales. For example, older people may be disproportionately more affected as they are more likely than younger people to need planned care, and particularly more likely to need surgery or treatment for musculoskeletal conditions (services for which have been affected more than many other specialties during the pandemic).²¹¹ During our inquiry we have therefore explored evidence on the impact on different groups, and how inequalities could be addressed.

Deprivation

181. Analysis suggests that people living in more deprived areas in Wales are "more likely to require use of hospital services, especially in an emergency". Unless this is taken into account in the approach to tackling the backlog, further health inequity could result.²¹²

182. The King's Fund published research in September 2021 that showed that in England:

- There is a "clear relationship" between waiting list data and deprivation. It said that "those living in the most deprived areas are nearly twice as likely to wait more than a year for treatment compared to those living in the least deprived areas."
- On average, waiting lists had increased by more than half (55 per cent) in the most deprived areas, compared to around a third (36 per cent) in the least deprived areas, and a national average for England of 42 per cent.²¹³
- **183.** The analysis focused on England, but the researchers told us they anticipated that the patterns in Wales would be similar.²¹⁴ However, the Welsh Government said that analysis of waiting list data on the basis of the Welsh Index of Multiple Deprivation showed that waiting times had increased across all groups, but did not suggest "any significant change in patterns of treatment across the different deprivation groups during COVID-19".²¹⁵
- **184.** Nevertheless, the Chief Executive of NHS Wales told us that she was concerned about health inequalities, in particular because it was likely that there were people with potential

²¹² Letter from the Welsh NHS Confederation, 13 January 2022

²¹¹ WT33 Age Cymru

²¹³ The King's Fund, <u>Tackling the elective backlog – exploring the relationship between deprivation and waiting times</u>, 27 September 2021

²¹⁴ RoP [para 308], 13 January 2022

²¹⁵ Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

symptoms who had not yet presented to health services. She explained that as well as addressing waiting lists, the NHS was identifying how best to "work with our communities to ensure that people who do need access to care do come and present themselves". ²¹⁶ In addition, even if people from deprived areas may not be waiting longer than those in less deprived areas, the impact of waiting could be disproportionately more harmful, as people living in more deprived areas may be more likely to have existing health issues that could be exacerbated by long waits. ²¹⁷

185. There are particular issues in relation to mental health inequalities, including higher antidepressant prescription rates in poorer communities. Simon Jones of Mind Cymru called for improvements in the quality of mental health data. He said that analysis of data on the basis of deprivation and other factors would help to build a better picture of what was happening, and how it might be addressed.²¹⁸ Professor Euan Hails of Adferiad Recovery agreed, suggesting that correlating disaggregated equality and diversity data with health issues such as substance use, drug and alcohol use and obesity would improve understanding of health inequalities.²¹⁹

Impact of digital delivery

186. The increasing digitalisation of services during the pandemic has not affected all groups equally. It has helped to reach people in parts of Wales, including rural communities, where the significant distances people would otherwise have to travel or the time they would need to take away from work or caring responsibilities could represent a barrier to accessing services. However, older people, people who have lower digital skills, who do not have access to internet-enabled devices, or who cannot access private spaces in which to engage with health services may be disproportionately adversely affected by digital-only or hybrid service models. This includes, for example, people living in houses of multiple occupation or young people living with their parents, who may be less likely to have access to spaces from which they can be confident of privacy while they access digital health services. Page 121

187. For many health professionals, the shift to digital services has been a steep learning curve, and Professor Peter Saul of the RCGPs emphasised the need for ongoing training. He added that, as health professionals are becoming more experienced in digital delivery, they are more

²¹⁶ RoP [para 309], 10 February 2022

Welsh Government, Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment, February 2022

²¹⁸ RoP [para 272], 18 November 2021

²¹⁹ RoP [para 273], 18 November 2021

²²⁰ RoP [para 253 and 261], 18 November 2021

²²¹ RoP [para 264], 18 November 2021

able to identify the patients for whom digital or in-person consultations (including home visits) would be more appropriate. He confirmed that GPs' view is that "everybody who needs face to face should have one, and we're doing our best to achieve that."²²²

Capacity for self-advocacy

188. A participant in our women's health focus group told us:

"Waiting lists [before the] pandemic was huge. Now there is just no explanation – you have to constantly advocate for yourself; it's exhausting to bang your head on a brick wall".²²³

- **189.** Similarly, the Wales Cancer Alliance told us that people concerned about potential cancer symptoms felt that they had to "be persistent" in order to overcome barriers to accessing GP services.²²⁴
- **190.** We heard concerns that people who are more able to advocate for themselves may also be more able to navigate health services, and therefore more likely to access treatment or support. Stakeholders said that this risks leaving behind people whose needs might be greater, but who, for a range of potential reasons, are less able or confident to do so:

"We see it in so many things in society; the ones who push to the front of the queue are not necessarily the most needy. And my worry as a doctor is identifying the people who are not pushy but who really do need treatment expedited, because they're just sitting at home quietly suffering. But, yes, this is happening all the time."²²⁵

191. We asked Professor Peter Saul of the RCGPs whether he was confident that the Welsh Government's COVID recovery plan would be sufficient to address the backlog. He said:

²²² RoP [para 108], 18 November 2021

²²³ Senedd Citizen Engagement Team, <u>Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment: engagement findings</u>, January 2022

²²⁴ RoP [para 132], 2 December 2021

²²⁵ RoP [para 29], 18 November 2021

"I think it will deliver for some of them, but we've identified perhaps people in deprived areas who are less vociferous, who have less access, and I think there may be difficulties there. And I think the timescale is going to be longer than stated."226

Tackling health inequalities

192. The King's Fund told us that in England a national policy initiative, Core20PLUS5, is providing a framework to guide the work of local integrated care boards tasked with addressing issues in their areas. Jonathon Holmes explained:

"So, the 'Core20' would be the most deprived 20 per cent, then the 'PLUS' would be other groups exposed to health inequalities above and beyond the prevailing trend, and then the 'PLUS5' would be on the core clinical areas. So, they would be on neonatal, on cancer care, on cardiovascular, and mental health as well, I think."²²⁷

193. Danielle Jeffries, a King's Fund analyst, noted that despite the overall findings of a link between deprivation and waiting list data in England, there were some clinical commissioning groups ("CCGs") in deprived areas that were managing their waiting lists well. Further investigation suggested that the key common feature of these CCGs' approaches was effective collaboration across providers and systems to share resources and capacity.²²⁸

194. Stakeholders told us about work underway in Wales to address health inequalities, including:

- Work by the RCGPs and Welsh Government to establish a project in the next six months to "identify practices that are in the most deprived areas, with a view to networking them and to develop solutions from the ground up to help them deal better with patients who are most at need."229
- Harnessing the potential of community pharmacies as health services embedded in their communities and well-placed to understand needs and help to address the causes and consequences of health inequalities. As pharmacy delivery drivers may see housebound patients more frequently than other health services, a pilot is taking place in Hywel Dda UHB which "uses delivery drivers to check in with patients, to see

²²⁶ RoP [para 135], 18 November 2021

²²⁷ RoP [paras 313-4], 13 January 2022

²²⁸ RoP [paras 316], 13 January 2022

²²⁹ RoP [para 105], 18 November 2021

if they need additional support, and when they do, they're flagged to the Community Connectors in Pembrokeshire". It was also suggested that barriers could be reduced by enabling community pharmacy teams to refer people directly into health services, and through access to shared patient records (subject to appropriate data protection arrangements).²³⁰

Our view

195. Health inequalities is a key priority area for us, and one we intend to embed as a crosscutting theme of our work throughout the Sixth Senedd. It is reassuring that analysis by the Welsh Government and health services has found no correlation between deprivation and the length of waiting times in Wales. However, it is deeply concerning that those who are on waiting lists may experience disproportionate harm from long waits, and that there may be people in need of care or treatment who have not yet come forward.

196. It is right that the Welsh Government has prioritised tackling health inequalities, and that it recognises that "more targeted support and signposting is required across the whole system to reduce harm while waiting".²³¹

197. We note that the Royal College of Physicians, among other stakeholders, has called for a cross-government strategy to tackle the inequalities that lead to avoidable illness.²³² In our report on the Welsh Government's draft budget for 2022-23 we asked the Welsh Government to provide further detail on its strategic priorities for tackling health inequalities. In its response, the Welsh Government said that it had "worked to hard-wire action to tackle health inequalities across the breadth of the government's work programmes". It outlined a number of specific projects and programmes, and added that the revised Programme for Government provides "the overarching strategic aim to move to tackle inequality in all its forms and contains significant commitments across all areas of government activity which are designed to tackle health inequalities".²³³

Recommendation 20. The Minister for Health and Social Services should outline what actions the Welsh Government and NHS Wales are taking to deliver targeted support and signposting

²³⁰ RoP [paras 31-32 and 49-51], 18 November 2021

²³¹ Welsh Government, Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment, February 2022

²³² WT11 Royal College of Physicians

²³³ Welsh Government, Response to the Health and Social Care Committee on Draft Budget, March 2022

to people living in more deprived areas in order to reduce the health inequalities gap, and how the impact of these actions will be assessed.

198. We welcome the news that RCGPs is working with Welsh Government on a project to develop solutions to help rebalance the health inequalities that affect our most deprived communities in Wales.

Recommendation 21. The Minister for Health and Social Services should provide details of the work being undertaken with the Royal College of GPs to develop solutions to address health inequalities in Wales. This should include details of the proposed scope of the project, the anticipated timescales, how it will be resourced, and how the project will be evaluated to ensure that learning is rolled out across the health service where appropriate.

199. We also welcome the community pharmacy pilot in the Hywel Dda University Health Board area, and applaud the effort being made to ensure that all contacts that our health services have with their communities provide opportunities to support people's health and wellbeing. We agree with Community Pharmacy Wales that access to shared patient records, with suitable data protection arrangements in place, could facilitate this and help to provide more seamless and patient-centred services.

Recommendation 22. The Minister for Health and Social Services should outline what contribution the new community pharmacy contract will make to tackling health inequalities, including what scope it provides for pharmacy teams to refer patients into other health services and how it will contribute to raising awareness of the services and support community pharmacies can provide.

200. The link between deprivation and health inequalities is well-documented. However, if we are to address inequalities, it is important that we also seek to understand the other factors and determinants. Evidence shows, for example, that there are inequalities in health outcomes on the basis of sex, ethnic background, and on the basis of physical and learning disabilities.

Recommendation 23. The Minister for Health and Social Services should require all health data collected and published in Wales to be disaggregated on the basis of diversity characteristics.

10. Healthcare workforce

The impact on health professionals

201. The challenges and pressures on the workforce are significant and well-documented, as is the impact of such challenges and pressures on the waiting times backlog. The situation has been exacerbated and intensified during the pandemic, not least because of the numbers of staff unwell with COVID-19 or having to self-isolate, and the need to maintain COVID-free zones within hospitals. Staff have worked extremely hard to keep services going in very challenging circumstances, and some of those that have been redeployed are only now returning to their substantive roles.

202. Danielle Jeffries of the King's Fund summarised the issue:

"At the moment the workforce are dealing with so many different things at once—so, the usual winter pressures, now there's COVID, and now the elective backlog as well. There's just not enough staff to stretch to all of those demands."²³⁴

203. Patients who are anxious or stressed can also present greater challenges for clinical and non-clinical staff, whether through increasing calls to seek updates, or by becoming obstructive or abusive as a result of worry or frustration.²³⁵ Healthcare Inspectorate Wales told us that frustrations can also arise for staff when patients do not understand how service provision has changed as a result of COVID-19.²³⁶

204. Some health professionals reported that being unable to meet patients' needs leaves them feeling "to a degree helpless because we are asking for the advice from the secondary sector, but that's delayed because of the problems with waiting times".²³⁷ Allied health professionals told us that levels of exhaustion made it challenging to respond to cases that may have increased in complexity as a result of long waits.²³⁸ We also heard that relentless demand in secondary care was demoralising for staff, with associated risks for patient care.²³⁹

²³⁴ RoP [para 286], 13 January 2022

²³⁵ WT09 Royal College of Paediatrics and Child Health

²³⁶ WT38 Healthcare Inspectorate Wales

²³⁷ RoP [para 14], 18 November 2021

²³⁸ RoP [paras 42 and 44], 2 December 2021

²³⁹ RoP [para 348-350], 13 January 2022

205. Following the First Minister's announcement on 4 March 2022 that the majority of the remaining COVID restrictions would be lifted on 28 March, healthcare workers told the BBC that staffing levels were the biggest challenge facing health services. They said the challenges were greater because: "we have a significant proportion of the population who have been waiting a long time for treatments and whose conditions have deteriorated in this time".²⁴⁰

206. It is clear that the solution to addressing the waiting times backlog cannot simply be to ask the workforce to do more. We were told that this would risk both staff wellbeing and patient safety. The RCPsych spoke for many when it said:

"An overstretched and exhausted workforce must now be given time to rest and recuperate as they meet the challenges ahead. If staff are being pushed too hard to restore routine care in an unrealistic time frame and without suitable resources, the likelihood is that we will see a workforce squeeze due to a combination of increasingly high staff absence rates and staff reducing their hours or leaving the workforce altogether. This would make it harder for health services to get back on track and provide timely and safe care to patients who need it."²⁴¹

Longstanding issues

Recruitment and retention

207. Health professionals identified longstanding issues relating to recruitment and retention as key barriers to addressing the waiting times backlog. Staff may be experiencing burnout, approaching retirement, or lack confidence that the pressures on the health service are going to be resolved, and budget constraints may make it challenging to fill vacancies, with corresponding implications for waiting times and service quality.²⁴² There is also significant spend on agency staff, estimated by the Royal College of Physicians as potentially in the region of £200m per year, or around 2 per cent of the health and social care budget.²⁴³

208. The RCN and the RCGPs both highlighted high levels of vacancies in their professions, and said that the impact was exacerbated by the need to staff new services such as the COVID-19 vaccination programme.²⁴⁴ The RCN added that "without a sufficient workforce, waiting lists will

²⁴⁰ BBC News, Covid in Wales: Staffing and surgery backlog the post-pandemic challenge, 5 March 2022

²⁴¹ WT32 Royal College of Psychiatrists

²⁴² RoP [paras 40 and 48], 2 December 2021

²⁴³ WT11 Royal College of Physicians

²⁴⁴ RoP [para 121 and 131], 18 November 2021

only increase", noting that investment in technology would help, but only if there were sufficient staff available to use it.²⁴⁵

Education and training

209. The Royal College of Physicians stated plainly that "There are not enough staff available to bring down NHS waiting lists", highlighting in particular "a huge shortfall in doctors, nurses, allied health professionals and social care staff". It called for a doubling of medical school places in the next five years. ²⁴⁶ The need to train more health professionals in Wales was also raised by Sue Hill of the RCS, who noted that continually recruiting from abroad risked "taking doctors away from developing countries who have a greater need [...] of surgeons than we do ourselves". ²⁴⁷ The Minister acknowledged the need for ethical overseas recruitment, noting that "we're trying to take a coordinated, once-for-Wales approach in terms of ethical overseas recruitment". ²⁴⁸

210. We also heard about the need for ongoing education and training once people are in their roles, and to ensure that capacity for such training is included in workforce planning.²⁴⁹ In her written evidence, the Minister stated that the Welsh Government was investing £262m in 2022-23 to support education and training programmes for health professionals in Wales. She added that the Welsh Government would "maintain and strengthen investment in education and training of healthcare workers, delivering 12,000 more clinical staff by 2024-25".²⁵⁰

Workforce planning

211. Many stakeholders called for more effective short and long term workforce planning. The RCN described the joint Health Education and Improvement Wales ("HEIW") and Social Care Wales workforce strategy²⁵¹ as a "good start", but called for workforce planning to be stepped up, and for collaborative working to ensure that the workforce in each health board reflects the needs of their population profiles, and to ensure that primary care clusters have the skills that they need.²⁵²

²⁴⁵ WT15 Royal College of Nursing Wales

²⁴⁶ WT11 Royal College of Physicians

²⁴⁷ RoP [para 348], 13 January 2022

²⁴⁸ RoP [paras 316-7], 10 February 2022

²⁴⁹ RoP [para 64], 18 November 2021

²⁵⁰ Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

²⁵¹ Health Education and Improvement Wales and Social Care Wales, *A healthier Wales: our workforce strategy for health and social care*, October 2020

²⁵² RoP [paras 88-89], 18 November 2021

212. The Minister noted that, following the publication of the ten-year workforce strategy, HEIW and Social Care Wales are leading on the development of new national workforce plans. The first two plans will focus on nursing and mental health.²⁵³

Short term solutions

213. While fully addressing workforce pressures will require longer term action—including the implementation of the HEIW and Social Care Wales workforce strategy and investment in retention, recruitment, education and training—the Academy of Medical Royal Colleges has published a list of twelve short term actions it says would help alleviate NHS workforce pressures in the short term. Many of these were also raised by other stakeholders, including: improving facilities to support staff wellbeing, supporting social care, recognising the contribution of trainees and international colleagues, reducing administrative burdens, and improving work/life balance.²⁵⁴

Our view

- **214.** Staff have been hard-pressed throughout the pandemic, and need a period of recovery. We all owe a huge debt of gratitude for the way in which they have responded. They have faced significant and unrelenting pressures, and have dealt with the dual challenges of COVID-19 and the growing waiting list backlog.
- **215.** However, they are also a key part of the solution to the waiting times backlog; without them, waiting times will continue to grow. It is staff that provide the care and treatment that people need, and who support them while they are waiting. It is important, therefore, to ensure that we have the right workforce, with the right skills and resources, across primary, community and secondary health and care services. We are concerned, therefore, that professional bodies including the RCGPs and the RCN told us that there were insufficient staff to deliver current planned care recovery plans.
- **216.** We agree with the RCN that "a constant, stable workforce" contributes to better quality care and improved mortality rates. The workforce is a key priority area for us during the Sixth Senedd, and we discussed the workforce strategy with HEIW and Social Care Wales in November 2021. During this session we asked HEIW whether reducing the length of training placements could increase the number of people trained without compromising patient safety.

²⁵³ RoP [paras 316-7], 10 February 2022

²⁵⁴ Academy of Medical Royal Colleges, *A dozen things the NHS could do tomorrow to help the medical workforce crisis*, December 2021

²⁵⁵ RoP [para 93], 18 November 2021

The Chief Executive of HEIW told us that consideration was being given to this, including how to work with regulators and professional bodies to ensure that essential standards and criteria were not compromised and what role digital and simulation-based approaches could play.²⁵⁶

Recommendation 24. The Minister for Health and Social Services and Health Education and Improvement Wales should provide an update on what consideration has been given to reducing the length of medical training placements, including what assessment has been made of the impact on patient safety and the number of training places that can be provided.

217. We acknowledge and welcome the additional investment in healthcare professionals' education and training programmes in the coming financial years. This investment will be important in building the resilience of the workforce in the longer term. However, the impact of this investment will not be seen for a number of years, so short and medium term solutions are also required.

Recommendation 25. The Minister for Health and Social Services should set out what consideration she has given to the twelve recommendations made in December 2021 by the Academy of Medical Royal Colleges ('A dozen things the NHS could do tomorrow to help the medical workforce crisis') to alleviate the medical workforce crisis in the short term, and what actions have been taken by the Welsh Government or the NHS in Wales as a result.

74

²⁵⁶ RoP [para 176], 4 November 2021

11. Addressing the waiting times backlog

A post-pandemic reset

- **218.** Our inquiry has focused primarily on the impact of the backlog, and what is needed to support people to wait well. However, arguably, what is best for patients would be to get their diagnoses or treatment more quickly. We have therefore also considered what is being done to address the backlog, looked ahead to the publication of the Welsh Government's planned care recovery plan in April, and explored potential solutions raised by stakeholders.
- **219.** In doing so, we have maintained a focus on our vision for the Sixth Senedd: a post-pandemic reset, that delivers a health service that is working better and more effectively than before the pandemic, and which leads to people in Wales leading longer, healthier lives and having more positive experiences.²⁵⁷
- **220.** We heard similar views from those who contributed to our inquiry, including the Wales Cancer Alliance and the Wales Carers Alliance.²⁵⁸ The Board of CHCs put it clearly when it said: "People don't just want things to get back to where they were before the pandemic—waiting times were too long for too many people then."²⁵⁹

Welsh Government response

Strategies and plans

221. In March 2021 the Welsh Government published *Health and social care in Wales—COVID-19: looking forward.*²⁶⁰ This strategy document set out the Welsh Government's approach to NHS recovery in Wales. However, successive waves of the virus have hampered NHS recovery, including reductions or suspensions in planned care activity as a result of staff shortages, infection control measures, or the redeployment of staff to respond to pressures elsewhere, most notably the expansion of the COVID booster vaccination effort in response to the omicron variant.

²⁵⁷ Health and Social Care Committee, Strategy for the Sixth Senedd, December 2021

²⁵⁸ RoP [paras 160 and 388], 2 December 2021

²⁵⁹ WT04 Board of Community Health Councils in Wales

²⁶⁰ Welsh Government, *Health and social care in Wales — COVID-19: looking forward*, March 2021

- **222.** In the past year, the Welsh Government's national planned care programme has developed a new approach to planned care, based on five goals: effective referral; advice and guidance; treat accordingly; follow up prudently; and measure what is important.²⁶¹
- **223.** The Minister has committed to publish a plan for addressing the backlog in April 2022. She explained that the timing would enable the plan to take account of health boards' integrated medium term plans (due in March 2022), as well as the continuing impact of the omicron variant. She said that the plan would include clear objectives for health boards and a focus on specific specialties, but cautioned that it would need to balance bringing down overall numbers with focusing on addressing areas where there was greatest clinical need.²⁶²
- **224.** We asked the Minister what success in tackling the backlog would look like. She told us her aims were to:
 - Stop the waiting lists growing any further.
 - Stabilise and improve cancer performance.
 - Clear the backlog of people who have been waiting a long time.
 - Keep diagnostic waits to around eight weeks, and therapy waits to around 14 weeks.
 - Improve the service for urgent and emergency care.
 - Ensure that the right training and support is in place for the workforce.²⁶³

225. She added that:

"I think we're on a really difficult tightrope here because, clearly, we need to manage expectations, and we've made it clear that we don't think we're going to be able to clear the backlog to what it was pre-pandemic until the end of this Senedd term. But, at the same time, we've got to give hope to people who are suffering in pain, and that's a really difficult thing to manage".²⁶⁴

Welsh Government, Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment, February 2022

²⁶² RoP [paras 197-8], 10 February 2022

²⁶³ RoP [para 325], 10 February 2022

²⁶⁴ RoP [para 279], 10 February 2022

226. The Chief Executive of NHS Wales said the planned care recovery plan would include "specific ambitions and milestones in terms of improvement of the backlog" as well as "specific actions around those very long-waiting patients, to give them confidence that we haven't forgotten them, and our plan will ensure that they do get treated". She added that "it most definitely will set out what support patients can expect whilst they are waiting—the support that the NHS can provide—and also how they can help themselves get ready for their surgery when it is offered". See

Revenue funding

227. In 2021-22, an additional £248m was allocated to health boards to increase activity. However, because the funding was non-recurrent, health boards told us they had needed to focus on short term interventions such as insourcing,²⁶⁷ outsourcing and waiting list initiatives.²⁶⁸ Aneurin Bevan UHB said that recovery plans that required additional workforce had needed to be resourced through temporary staffing, in line with the non-recurrent nature of the funding. It added that there were risks associated with this as "fixed term posts are less attractive to potential applicants, especially with current high levels of vacancies across a range of roles within NHS and other sectors".²⁶⁹ Swansea Bay UHB similarly highlighted the limitations of non-recurrent funding, suggesting that its use should be minimised and focused on "one-off service needs" rather than ongoing initiatives such as investment in prehabilitation services.²⁷⁰

228. The 2022-23 draft budget includes an annual allocation of £170m for the next three years specifically for planned care, which would facilitate the appointment of substantive staff and the development of more sustainable solutions.

Capital funding

229. The Welsh NHS Confederation has described capital investment as key to delivering "high quality, safe health services", noting that the built environment is an important determinant of patient outcomes.²⁷¹ Professor Peter Saul of the RCGPs told us that the primary care estate currently lacks capacity to accommodate a wide range of professions and services:

²⁶⁵ RoP [para 200], 10 February 2022

²⁶⁶ RoP [para 200], 10 February 2022

²⁶⁷ Insourcing is the use of NHS premises and equipment to deliver extra clinical capacity outside of when they are normally in use.

²⁶⁸ WT12 Swansea Bay University Health Board

²⁶⁹ WT16 Aneurin Bevan University Health Board

²⁷⁰ WT12 Swansea Bay University Health Board

Welsh NHS Confederation, Response to the Finance Committee scrutiny of the Welsh Government's 2022-23 draft budget proposals, 24 November 2021

"We need something done about the estates. So, whether it's actually hosting a social prescriber who can advise patients about debt and such like, or getting specialist nurses in, or training the new nurses, new pharmacists in primary care issues, we haven't got the space to do it at the moment, and that urgently needs addressing."²⁷²

230. Responding to our questions about how to reduce reliance on NHS-commissioned private healthcare, the Minister highlighted the limited availability of capital funding to build NHS capacity.²⁷³ This echoed concerns she raised with us during our scrutiny of the Welsh Government's draft budget for 2022-23, during which she described a lack of capital as "the most challenging part of the budget".²⁷⁴

Approaches to addressing the backlog

231. We have heard a range of suggestions from stakeholders about how the backlog could be addressed. We explore these below.

Evidence from health boards

232. Health boards told us that they were already deploying a range of methods to addressing the backlog, including:

- Funding treatment from private healthcare or out of area providers.
- Waiting list validation and risk stratification.
- More efficient working, including tools such as 'Releasing time to care' and 'Getting it right first time'.
- Managing demand differently, including the provision of advice and guidance to GPs by hospital consultants to avoid referrals, patient initiated follow ups, virtual clinics, and shifting care from hospital to community settings (for example delivering surgical procedures such as the removal of basal cell carcinomas in primary care settings, or the delivery by GPs of spirometry to test patients' breathing and lung functions, echocardiography to monitor heart functions or audiology such as testing for hearing loss).

²⁷² RoP [para 71], 18 November 2021

²⁷³ RoP [para 300], 10 February 2022

²⁷⁴ RoP [para 156], 13 January 2022

- Redesigning hospital spaces to separate planned and urgent care, subject to the availability of sufficient capital funding.
- Introducing new diagnostic equipment or regional service delivery models.
- Insourcing. For example, in Swansea Bay UHB, weekend working in orthopaedics has been taking place since December 2021, and there are plans to introduce similar arrangements for gynaecology, ophthalmology, endoscopy and gastroenterology.²⁷⁵

Quality statements

- **233.** A number of stakeholders raised the Welsh Government's quality statement approach to strategic planning. Views were mixed on whether the approach was working effectively across all conditions to drive waiting list reduction, service transformation, and improved patient outcomes.
- **234.** The Wales Cancer Alliance is critical of the cancer quality statement, which it says offers only minimum standards and lacks ambition and vision. It notes that six months after the publication of the cancer quality statement, the three-year rolling implementation plan has not been published, which Andy Glyde said created a "kind of limbo where who knows what's really happening in terms of transforming cancer services right now, and all the focus is on what we're having to do around the pandemic rather than thinking about how we can save more lives by getting better at diagnosing and treating cancer". 276 He welcomed some of the innovations adopted during the pandemic to improve the way in which cancer is diagnosed and treated, but said that in other areas Wales was falling behind other parts of the UK including new procedures and pathways that could improve diagnosis and increase capacity. He argued strongly that the key missing element is a cancer strategy, saying that once the anticipated Northern Ireland cancer strategy has been published, Wales will be the only UK nation without a specific cancer strategy. He said that this made it "really difficult to see what the pathway is for improvement and innovation in cancer services long-term" and that the approach of reflecting the quality statement in health boards individual plans could result in duplication rather than a "once for Wales" approach.277
- **235.** Conversely, the British Heart Foundation is supportive of the quality statement for heart conditions, which it says has good ambitions. Significant numbers of people are waiting for cardiovascular diagnostics and treatment, and referral is increasing, placing continued upwards

²⁷⁵ WT04 Board of Community Health Councils in Wales; WT12 Swansea Bay University Health Board

²⁷⁶ RoP [para 178-180], 2 December 2021

²⁷⁷ RoP [para 165-168], 2 December 2021

pressure on waiting times. This is leading to people experiencing deterioration in their conditions as a result of delays in diagnosis or treatment, including for conditions such as angina in respect of which early intervention can prevent more serious conditions developing. The British Heart Foundation says that work is now required to address these issues—which predate the pandemic but have been exacerbated—in line with the quality statement, including investment in sustainable workforce planning to address bottlenecks in diagnostics and cardiac physiology.²⁷⁸

- **236.** The quality statement for respiratory health is due for publication in 2022. Joseph Carter of Asthma UK and the British Lung Foundation told us that he hoped that the quality statement would help to address issues relating to respiratory service recovery, but that service transformation would also require more self-management, alternative care pathways, and diagnostics being done in primary care settings. He added that one in five people in Wales are affected by lung conditions, the majority of whom require relatively little secondary care intervention. Respiratory services have been particularly affected by the pandemic, with many staff being redeployed to COVID wards, and being among the last to be returned to their substantive roles. The result has been a significant increase in secondary care waiting lists, and risks of misdiagnosis or delayed diagnosis, with serious implications for people's outcomes. Joseph Carter suggested that there had been an insufficient focus on respiratory services in initial recovery planning, in part because COVID is a respiratory virus, resulting in other services becoming the focus of recovery.²⁷⁹
- 237. We asked the Minister about the quality statement approach. She told us that quality statements set out expected standards for different conditions, but that "what we need to do now is make sure that we're driving change so that we are hitting the standards that we've set out". 280 The Deputy CMO added that the policy expectations in quality statements inform planning at "every relevant level within the NHS" including health boards integrated medium term plans and the Welsh Government's own planned care recovery plan. He acknowledged that there was "a small delay" between publication of quality statements and their reflection in detailed plans, but said that overall the approach would ensure that:

"...the plans that we do have are integral to the organisations that have to deliver them, that they're part of the governance of those organisations, rather than standing separately from those organisations and not always being completely aligned. So, this

²⁷⁸ RoP [paras 240-245 and 258-261], 2 December 2021

²⁷⁹ RoP [para 267-272 and 280-281], 2 December 2021

²⁸⁰ RoP [para 253], 10 February 2022

is a planning mechanism, it's the first step, and at the moment it probably appears that there's a gap, because we're waiting now to see the integrated medium-term plans."²⁸¹

Regional surgical hubs

- **238.** While there is variation across health boards in the pace of restoring planned care services, the Chief Executive of NHS Wales told us in February 2022 that the all-Wales day surgery rate was now at 81 per cent of pre-COVID levels.²⁸² Ongoing barriers to restoring care included pandemic-related infection control measures and the impact of delayed discharge.²⁸³
- **239.** Throughout the pandemic, the RCS has consistently called for the establishment of surgical hubs, comprising COVID-free pathways for both technical, and high-volume low-technical surgeries. Sue Hill told us that this would require additional workforce capacity. She suggested that establishing regional hubs would mitigate this, and help to offset differences in facilities for complex surgeries in each health board area.²⁸⁴
- **240.** Surgical hubs are also supported by other stakeholders, including the BOA and Cymru versus Arthritis.²⁸⁵ Some stakeholders highlighted the need to consider where aftercare would be provided, and to ensure that individual patients' needs and circumstances were taken into account. Transport and travel were raised as particular concerns,²⁸⁶ as well as the impact on people's ability to work or undertake their caring responsibilities if travelling further meant longer absences.²⁸⁷
- **241.** However, the Deputy Chief Executive of NHS Wales told us that people were willing to travel to receive care at regional centres "if it means that they get that treatment sooner or in a more effective and suitable environment". Sue Hill of the RCS agreed, saying that people need to understand that patient outcomes are better when surgery is done at high-volume centres. She added that an RCS-commissioned poll had found "about 66 per cent of adults in Wales"

²⁸¹ RoP [para 255], 10 February 2022

²⁸² RoP [para 210], 10 February 2022

²⁸³ RoP [para 218], 10 February 2022

²⁸⁴ RoP [paras 279 and 289-90], 13 January 2022

²⁸⁵ WT26 British Orthopaedic Association; RoP [para 221], 2 December 2021

²⁸⁶ WT33 Age Cymru

²⁸⁷ WT04 Board of Community Health Councils in Wales

²⁸⁸ RoP [para 322], 10 February 2022

saying that they would be prepared to travel if they thought they were going to get a safe operation in a COVID-free environment".²⁸⁹

- **242.** In written evidence, the Welsh Government stated that it had invested in two new theatres at Prince Philip Hospital in Llanelli to deliver up to 4,600 additional day case procedures per year via a dedicated 'green' pathway. It also described plans to develop regional approaches for cataracts in south east Wales to increase capacity across three health boards.²⁹⁰ Similarly, Betsi Cadwaladr UHB told us that it is looking to develop regional diagnostic and treatment centres to provide outpatient cataract services, diagnostics, including endoscopy, and inpatient orthopaedics.²⁹¹
- **243.** We asked the Minister about regional hubs. She told us that health boards' integrated medium term plans were due for submission, and her clear expectation was that they would include commitment to regional working and cooperation.²⁹² The Deputy Chief Executive of NHS Wales added that he was discussing regional approaches with health boards. He noted that there are different models, but that regional working could enable the sharing of resources, and help to address recruitment issues as:

"...regional treatment centres or regional centres for service delivery can often be seen as quite an advantageous role to take for both clinicians and nurses in terms of working in—I hate the phrase for it, but—a factory-style approach to sometimes clearing backlogs of treatment".²⁹³

Prioritising and streamlining waiting lists

244. In written evidence, the Welsh Government explained that clinical need, in particular cancer care, has taken priority throughout the pandemic in the use of planned care resources. Planned care resources are pooled, and available theatre slots are allocated based on clinical risk, with emergency and urgent care taking priority.²⁹⁴ This is in line with clinical guidelines published early in the pandemic by the RCS to inform decision-making on the basis of four

²⁸⁹ RoP [para 300-301], 13 January 2022

²⁹⁰ Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

²⁹¹ WT42 Betsi Cadwaladr University Health Board

²⁹² RoP [para 320], 10 February 2022

²⁹³ RoP [para 321], 10 February 2022

²⁹⁴ Welsh Government, <u>Evidence paper: Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment</u>, February 2022

priority levels: emergency surgery, operate within one month, operate within three months, or operate after three months.²⁹⁵

245. However, some stakeholders questioned whether sufficient efforts were being made to reassess and reprioritise lists, with the consequence that some people ended up needing acute or emergency care.²⁹⁶ Helen Whyley of the RCN said:

"We have to keep going back to that waiting list and refreshing, 'Have we got the priorities right? Do we still need those people on it? Can they go into other areas?'

That's the kind of label of prudent healthcare that I've seen and I've experienced, and I think that's most helpful to revisit that."²⁹⁷

246. Stakeholders also pointed out that people with multiple health conditions, or who may be experiencing a range of symptoms, may be on multiple waiting lists, and said that this needed to be taken into account in both the communication they receive²⁹⁸ and how health services work together to manage waiting lists and co-produce patient-centred services:

"One individual might be waiting for several different types of rehab or several different medical interventions. We'd like to see some streamlining of that. So, if you look at cardio rehab, pulmonary rehab, lots of different types of rehab, you could have one multimorbidity rehab service for a patient, rather than them waiting for several different types of rehab. That would be better for the patient, and save the NHS time and money".299

247. There is also a need to ensure that there is sufficient engagement and discussion with patients about the appropriate treatment route for them. Dai Davies of the RCOT said that, under the *Social Services and Wellbeing (Wales) Act 2014*, all health professionals should be having 'what matters' conversations with patients. But, he said that the depth in which such conversations took place could vary, and that practice did not always reflect the intended

²⁹⁵ Royal College of Surgeons of England, <u>Clinical guide to surgical prioritisation during the coronavirus pandemic</u> [accessed February 2022]

²⁹⁶ RoP [para 141], 18 November 2021

²⁹⁷ RoP [para 159], 18 November 2021

²⁹⁸ RoP [para 301], 2 December 2021

²⁹⁹ RoP [paras 107-108], 2 December 2021

detailed conversation about what matters to patients and the pros and cons of different approaches.³⁰⁰

248. The role of multidisciplinary teams in providing holistic patient-centred care was raised throughout our inquiry, including the need for robust workforce planning and education to ensure that GP clusters have the right range of health professionals and skills, including, for example, prescriber-ready nurses.³⁰¹ Professor Peter Saul of the RCGPs told us that the embedding of specialist staff, such as diabetic nurses or pain management specialists, into primary care practices was a key development. He added that GPs had a responsibility to "nurture and recognise everybody on the team", including non-clinical staff such as delivery drivers and receptionists who he said needed to be "empower[ed] to bring messages from the patients to the key individuals in their organisations".³⁰²

The role of GPs

249. For many, GPs are the front door to the NHS, and GPs are likely to be dealing with patients who are on waiting lists for elective or planned care or treatment. Improving the flow of information in to primary care could, therefore, help to support people who are waiting.

250. Digital Health and Care Wales said that it had identified the provision of e-advice for GPs to support them in the management of clinical conditions and reduce the need for referrals as a strategic area of focus.³⁰³ Similarly, Swansea Bay UHB told us that it is developing a dashboard for general practice to give GPs access to waiting times information when undertaking a consultation with a patient or responding to enquiries from patients who are on waiting lists. Better information for GPs about how many of their patients are on waiting lists, and how quickly they might be seen, would allow GPs to reassure their patients. Swansea Bay UHB added that GPs and secondary care consultants are working together to validate waiting lists by reviewing patients who are waiting for outpatient appointments to check and prioritise where they are on the list according to clinical need and whether they still want treatment.³⁰⁴

251. In some cases, the availability of support depends on the capacity of primary care services. Speaking on behalf of the RCGPs, Professor Peter Saul told us that GPs were experiencing around 125 per cent of pre-pandemic demand.³⁰⁵ Healthcare Inspectorate Wales highlighted

³⁰⁰ RoP [para 106], 2 December 2021

³⁰¹ RoP [para 62], 18 November 2021

³⁰² RoP [para 58], 18 November 2021

³⁰³ Letter from Digital Health and Care Wales, 13 January 2022

³⁰⁴ WT12 Swansea Bay University Health Board

³⁰⁵ RoP [para 19], 18 November 2021

concerns about a lack of availability of GP appointments, poor availability of access to community mental health teams, and limited appointments with dentists. It described this as "the main theme arising from the concerns raised with [it]", and said that concerns often "involved people expressing frustration at their inability to arrange appointments for the care they need and/or conditions that they want to discuss."³⁰⁶

252. There can also be issues in GPs' willingness to take on some functions. We were told that before the pandemic there had been significant investment in training and equipment to enable respiratory diagnostic tests such as spirometry to take place in primary care settings. This had enabled prescriptions for inhalers or other medication to be issued without secondary care involvement. However, spirometry was initially suspended during the pandemic over concerns about aerosol-generating procedures. While the Royal College of Physicians have since confirmed the tests could be safely conducted, we were told that some primary care practitioners still have concerns and referrals to secondary care have increased.³⁰⁷

Alternative primary and community care settings

253. While GPs have a significant role to play in addressing the waiting times backlog, the pressures on GP services and difficulties in accessing appointments are well-documented. Stakeholders suggested that shifting care to alternative primary and community care settings, and fully harnessing the skills of all health practitioners, could free up GP capacity to focus on more complex care—if people know what alternative options are available and how to access them. For example:

- Community pharmacies already deliver prescribing services, emergency contraception, smoking cessation, flu vaccination, palliative care medicines, substance misuse and the common ailments service. But, Community Pharmacy Wales noted that recent surveys suggested that fewer than 50 per cent of local people know about the common aliments service.³⁰⁸
- The pandemic has accelerated changes in the triage function provided by high street optometrists to try to reduce referrals and release secondary eye care service capacity.³⁰⁹

³⁰⁶ WT38 Healthcare Inspectorate Wales

³⁰⁷ RoP [para 269], 2 December 2021

³⁰⁸ WT07 Community Pharmacy Wales

³⁰⁹ RoP [paras 204-5], 2 December 2021

- New approaches to enable primary care involvement in medications for some respiratory conditions that would previously have required a consultation with a hospital nurse.³¹⁰
- Self-referral to first-contact trained physiotherapists or other allied health services to enable people to be seen more quickly in a multidisciplinary setting. We were told that there had been investment in such community and primary care pathways previously, but that "they're more like pilot projects, and they're based on quite unsustainable funding".311
- Self-referral to mental health services, for example Mind Cymru's online assessment tool to direct people onto appropriate pathways to help them manage anxiety, panic attacks, depression, loneliness or grief.³¹²
- Community hubs and connectors, which we were told can be particularly helpful for carers as it enables them to access services closer to home.³¹³
- **254.** Elen Jones of the Royal Pharmaceutical Society suggested that commissioning services consistently across Wales would help in providing a consistent message about what is available. She said that the 111 service was a good example of this, enabling strong and consistent messaging about available services and referral pathways.³¹⁴
- **255.** The Minister strongly supported a shift to alternative primary and community care settings, but acknowledged that: "we're going to need to educate the Welsh public in terms of a cultural shift that the expectation that you will always see your GP, that is not going to be what the future looks like "315"

Prevention

256. Several stakeholders suggested that a key part of reducing the waiting times backlog, and keeping waiting times low in future, is tackling the causes of avoidable ill health and helping people to stay healthy.³¹⁶ To achieve this, we were told there needed to be a renewed focus on

³¹⁰ RoP [paras 303], 2 December 2021

³¹¹ RoP [para 60], 2 December 2021

³¹² RoP [para 248], 18 November 2021

³¹³ RoP [para 385], 2 December 2021

³¹⁴ RoP [para 84], 18 November 2021

³¹⁵ RoP [para 269], 10 February 2022

³¹⁶ WT28 Royal College of GPs

prevention.³¹⁷ The Royal College of Physicians called for a "comprehensive, funded, crossgovernment strategy".³¹⁸

257. Many stakeholders agreed that people needed to be encouraged to take responsibility for their own health, both to reduce harms and maximise the efficient use of NHS resources.³¹⁹ An important part of this is ensuring that people have the right tools, information and support, including effective signposting to available resources to help them stay well and enable early intervention when needed.³²⁰

258. The Minister told us that prevention was one of her personal priorities, and "absolutely key to the way that we run our health services in future".³²¹

Rehabilitation and reablement

259. Stakeholders told us that rehabilitation and reablement across a range of conditions, including respiratory, cardiac and stroke, had not been given enough focus in COVID-19 recovery planning.³²² They emphasised the importance of these services, and of planning effectively for discharge from secondary care or inpatient services to ensure that people do not subsequently deteriorate and need further significant interventions. In respect of mental health, Simon Jones of Mind Cymru told us that improving care and treatment planning, and ensuring it takes broader factors into account as well as health issues, can help people to stay well after their discharge and to identify the early signs of potential deterioration.³²³

260. We asked the Minister about the importance of reablement for people who have spent time in hospital as a result of physical or mental health treatment. She agreed that people need to take responsibility for their own health, including, for example, losing weight or completing recommended physiotherapy exercises:

"So, it's really important that people start to understand that they have to contribute here, and if we don't, we're going to get into a situation where that dependency, as

³¹⁷ RoP [para 149], 18 November 2021

³¹⁸ WT11 Royal College of Physicians

³¹⁹ RoP [paras 109], 2 December 2021

³²⁰ RoP [para 247], 18 November 2021; RoP [para 225], 2 December 2021

³²¹ RoP [para 274], 10 February 2022

³²² WT13 Asthma UK and the British Lung Foundation Wales

³²³ RoP [paras 206-207], 18 November 2021

you say, is going to be harmful to them and they won't necessarily achieve the outcome that they'll be looking for."324

Digital delivery

261. A number of stakeholders noted that the development of digital interventions during the COVID pandemic offered potential benefits in tackling the backlog, and suggested that these should continue to be developed where they could improve access to services or help to reduce waiting times. However, we also heard warnings that digital approaches are not suitable for everyone or every condition:

- For mental health services, a blend of digital and in-person services may be needed, taking into account the particular needs and preferences of the person receiving care.³²⁵
- Digital prehabilitation and rehabilitation services, advice hubs, and information sources can be useful for people with cardiovascular conditions who are able to access them, but may not be accessible to those who lack digital technology or skills, and may not be everyone's preference.³²⁶
- Digital appointments with cancer key workers may be more convenient for some, but can hinder medical professionals' ability to put someone at their ease, or get a holistic sense of how a patient is, including gauging weight loss or non-verbal communication.³²⁷

Public communication and messaging

262. Stakeholders told us about the importance of clear and consistent public messaging, and the need to strike a balance between managing expectations about how long they might need to wait, and the risk of deterring people from coming forward with suspected symptoms, either because they know they will face long waits, or because they are concerned about burdening services that are already under pressure. This is important both to protect individuals from harm, and to facilitate early intervention where possible to avoid the need for more significant

³²⁴ RoP [para 272], 10 February 2022

³²⁵ RoP [para 251-252], 18 November 2021

³²⁶ RoP [para 292], 2 December 2021

³²⁷ RoP [paras 143-145], 2 December 2021

treatment being needed at a later date as a result of delayed diagnosis or worsening symptoms.³²⁸

263. Alyson Thomas of the Board of CHCs suggested that there is some confusion:

"So, some of the things that people struggle with are mixed messages about, for example, the scale of the pressures on the NHS in Wales and, 'Only use it when you need it' on the one hand, and people understand that as they can see the scale of the pressures themselves, and then, on the other hand, 'Seek help as quickly as possible when you identify that you have symptoms'. If those messages and those conversations aren't done in a holistic way, it just causes confusion and worry for people even more."³²⁹

Our view

264. Addressing the waiting times backlog is vital. We cannot continue to see planned care squeezed out by urgent or emergency care. If people do not receive the planned care and treatment that they need, there are serious risks that they will deteriorate to the point that they need urgent care, or, sadly, until their planned care is no longer viable. We recognise that it will take time to bring waiting times down and restore even the pre-pandemic position. However, we agree with stakeholders that simply restoring performance to where it was in March 2020 is not good enough. We need to see our health services continue to transform and deliver improved outcomes for patients. This includes, for example, the development of innovative approaches, and the introduction of more sustainable funding for initiatives that have proved to be effective, such as first-contact allied health service practitioners in community and primary care settings.

265. We welcome the Minister's commitment to publish a planned recovery plan in April 2022. While many of the solutions may need to be delivered at regional or local level, the Welsh Government must continue to provide national oversight and leadership, and hold health boards and RPBs to account to ensure that waiting times for care and treatment are reduced for people across Wales. We will be interested to hear the views of stakeholders on whether they have confidence that the plan will be sufficient to tackle the backlog, ensure that people are supported, and contribute to transforming our health services.

³²⁸ RoP [paras 157 and 376], 2 December 2021

³²⁹ RoP [para 391], 2 December 2021

Recommendation 26. The Minister for Health and Social Services should outline how the Welsh Government will provide national oversight and leadership for the delivery of its planned recovery plan, including how it will hold health boards to account for the detailed actions to tackle the waiting times backlog set out in their integrated medium term plans.

- **266.** We recognise that some of the solutions may not always be popular. For example, the establishment of regional hubs could be worrying for communities concerned about losing local services, or for staff whose roles could change. Delivering these solutions will therefore need effective communication and leadership, as well as the development of practical solutions such as the provision of transport or respite care to help people to attend appointments.
- **267.** A key part of the solution is prevention, and tackling the causes of ill health. This includes supporting people to take responsibility for their own health. We understand that the pandemic has affected work in this space, but a renewed focus on prevention is essential. We emphasised the importance of prevention in our report on the Welsh Government's draft budget 2022-23, and asked for further detail from the Welsh Government on its strategic priorities for prevention. In its response, the Welsh Government highlighted a number of programmes, including the reprioritisation of funding to support obesity and tobacco policy interventions, investment in Healthy Weight, Healthy Wales and the Healthy and Active Fund, and a commitment to develop an all-Wales framework for social prescribing.³³⁰
- **268.** We also firmly believe that effective rehabilitation and reablement are vital to ensure that people are able to stay healthy after they have received their treatment. We will explore these issues further in the context of our work on the impact of hospital discharge on patient flow through hospitals.
- **269.** Another part of the solution will be ensuring that people access the right services at the right time, particularly in terms of alternative primary and community care services. Achieving this will require efforts to develop people's health literacy, and tackle engrained biases and misconceptions that GPs are always the appropriate primary healthcare practitioners in every situation. We welcome the Minister's recognition of the need for a cultural shift in this regard, but we would appreciate more information about how it will be achieved.

Recommendation 27. The Minister for Health and Social Services should outline the actions the Welsh Government will take to promote awareness among people who are waiting for care

³³⁰ Welsh Government, Response to the Health and Social Care Committee on Draft Budget, March 2022

or treatment of the support that may be available to them from alternative primary and community care services.

270. In our report on the Welsh Government's draft budget 2022-23, we highlighted the contribution of capital investment, and made a number of recommendations calling for clarity on whether the Minister would be willing to consider requests from health boards to shift funding from revenue to capital, and how capital investment would be prioritised if additional capital funding became available in year. We note from the Welsh Government's response that no discussions have taken place with NHS organisations about shifting funding from revenue to capital, but that health bodies have "well-developed schemes 'on the shelf'" which will enable capital projects to be progressed at short notice should additional funding become available.³³¹

³³¹ Welsh Government, Response to the Health and Social Care Committee on Draft Budget, March 2022