Welsh Parliament
Health and Social Care Committee
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Supporting people with chronic conditions

Engagement findings

June 2024

As part of the **Health and Social Care Committee's** inquiry into *supporting people with chronic conditions*, the Citizen Engagement Team proposed a qualitative approach to engagement, comprising a series of interviews and focus groups with people across Wales with lived experience of chronic conditions. This paper communicates the findings of those interviews and focus groups.

Contents

1. Background

1. The Health and Social Care Committee are holding an inquiry into supporting people with chronic conditions. The Committee wanted to identify practical actions on how to deliver the vision of holistic, person-centred care for the growing number of people living with chronic conditions and consider what needs to change to improve people's experiences and outcomes.

2. The Committee were interested in hearing the lived experiences of people living with chronic conditions and how best to enable services to focus on the person as a whole, not their individual conditions.

Engagement

3. Between 1 December 2023 and 26 March 2024, the Citizen Engagement Team facilitated 31 individual interviews and three focus groups with a total of 56 people (45 female and 11 male) living with chronic conditions.

4. The purpose of the engagement was to provide the Committee with the views of people living with chronic conditions, on how best to implement person-centred care for people with chronic conditions, based upon their own experiences.

Participants

5. Participants were sourced via a screening survey sent to over 25 organisations and support groups relating to various chronic conditions.

6. The Citizen Engagement Team worked in collaboration with organisations and charities to identify some participants.[1]

7. All participants either live with chronic conditions or care for people with chronic conditions. Many of the participants live with multimorbidity (two or more chronic conditions).

8. Many of the participants either have worked or are currently working within the NHS in Wales, or their chosen field of work relates to the healthcare service.

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[1] See Annex 1

9. Over 20 different chronic conditions were represented in the engagement sessions.[2]

10. The ages of the participants ranged from early twenties to late seventies.

11. Participants came from all seven health boards and 14 of the Local Authority areas across Wales.

12. Thank you to everyone who contributed to the programme of engagement, especially the participants, who shared their experiences.

Methodology

13. Engagement was conducted both online and face-to-face, according to the preference of the participants.

14. The following discussion points were addressed during the programme of engagement:

a. What are the positives and/or negatives you've experienced while accessing support/treatment for chronic/long-term conditions?

b. What are the main barriers, if any, you've faced whilst accessing support/treatment for chronic conditions/multiple conditions?

c. What would have made/would make the biggest differences/improvements to your experience of accessing support/treatment? (What things/actions/policies do you think would help you and others with chronic conditions the most?)

d. What, (if anything) do you think needs to change in health and care services to better meet the needs of people with chronic conditions?

e. What practical actions do you think would help to improve person-centred care, particularly for people with multiple conditions? (so that support and treatment are designed around the person as a whole, not just individual conditions or symptoms in isolation)

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[2] See Annex 2

f. Do you feel you've been given enough support to enable effective self-management of your condition(s)? For example, mental health support. If not, what additional support is needed?

g. In your view, how can prevention and early intervention in chronic conditions be improved? Where should efforts be focused?

h. Have you come across any good practice examples of person-centred care for people with multiple conditions?

2. Executive summary

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Person-centred care The engagement findings underscore the need for person-centred care for individuals with chronic conditions, emphasizing patient involvement and strategic mindset shifts. Participants advocate for patient forums and co-production in healthcare decision-making, distinguishing between raising concerns and filing complaints with separate policies. Practical solutions proposed include dedicated phone lines for chronic condition patients, quiet A&E waiting areas, and direct medication collection from hospital pharmacies. Emphasis is placed on the necessity of face-to-face appointments and patient-initiated follow-ups, urging healthcare professionals to treat patients as individuals rather than merely symptoms. Recommendations include multidisciplinary annual reviews and a 'super team' approach for co-ordinated care.	9
Dismissed by medical and healthcare professionals Many participants report feeling dismissed by healthcare professionals, negatively impacting their physical and mental health. They recount not being listened to and questioning their judgment due to dismissive comments. Positive interactions, however, highlight the importance of empathetic communication from healthcare providers.	15
Training and refresher courses for medical and healthcare professionals Participants acknowledge excellent services but stress the need for continuous training and refresher courses for healthcare professionals. Training should focus on patient care, empathy, and understanding of chronic conditions, particularly dementia. Addressing "medical misogyny" and improving communication with neurodiverse patients and those with learning difficulties is	16

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crucial. Follow-ups to help healthcare professionals learn from missed diagnoses were suggested.	
Communication Improved communication across healthcare levels is critical. Participants describe challenges with communication between health boards, specialists, and departments, advocating for shared patient notes to streamline care. Clear communication about conditions and treatment options is essential for effective patient care.	18
'The GP barrier' Participants highlight varying quality in GP practices. Suggestions include empowering GPs to refer patients directly to specialists, recognizing the frequent healthcare needs of chronic condition patients without guilt, and ensuring consistency in care. A red flag system to identify chronic condition patients and better use of ICT, including an accessible patient notes portal, were recommended. Longer GP appointments to discuss multiple related conditions are seen as crucial for comprehensive care.	19
Diagnosis Experiences with diagnosis varied significantly. Some participants reported timely diagnoses and early intervention, while others faced delays of 10 to 25 years for conditions like endometriosis and fibromyalgia. Misdiagnoses were also an issue. The need for a holistic, person-centred approach following diagnosis is highlighted.	21
Lack of specialists There is a notable shortage of specialists for chronic conditions in Wales, impacting care quality. Participants reported seeking private treatment or travelling outside Wales due to local expertise unavailability. The suggestion of a specialist consultant role for chronic conditions was made to bridge this gap.	22
Lack of consistent quality of care, Wales-wide The quality of care across Wales is inconsistent, with rural areas particularly disadvantaged. Participants expressed concerns about inadequate provision influencing their living decisions. Travel challenges and limited public transport deter some from seeking necessary medical attention, worsening their conditions.	23
Mental health support The correlation between chronic conditions and mental health needs is significant, yet often overlooked. Participants highlighted	23

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difficulties in accessing mental health support. A holistic approach addressing psychological alongside physical needs is essential.	
Benefit of charities and support groups Charities and support groups provide crucial support and information. Participants valued the opportunity to share experiences and learn from others. Increased awareness and signposting to these groups at diagnosis could alleviate feelings of loneliness and improve well-being.	25
Support for carers Carers, particularly unpaid ones, require more recognition and support. Their presence at medical appointments should be acknowledged, and they need both practical and mental health support. Ensuring carers receive adequate support will improve care for individuals with chronic conditions and the well-being of the carers themselves.	26
Prevention and intervention Prevention strategies should include early diagnosis and intervention, improving patient outcomes and reducing NHS costs. Screening services should be expanded, and public education on healthy lifestyles enhanced. Increased resources for research and public awareness campaigns can reduce stigma and improve empathy towards those living with chronic conditions.	26

3. Recommendations

15. Participants suggested ways of improving person-centred, holistic care for people with chronic conditions.

Recommendation 1. Further use of patient forums and co-production; service users and carers need to be involved in the decision-making for better healthcare services.

Recommendation 2. Develop continuous, updated training for medical and healthcare professionals on patient communication and care.

Recommendation 3. Establish a chronic conditions information-sharing hub for GPs.

Recommendation 4. Develop an NHS online hub to enable medical and healthcare professionals to access patient notes, from all relevant healthcare services.

Recommendation 5. A multidisciplinary annual review for people with chronic conditions. The review should consider all aspects of the participant's medical, psychological and social needs.

Recommendation 6. Multidisciplinary appointments for people with chronic conditions, where possible.

Recommendation 7. Increase the number of specialist nurses for chronic conditions, especially when there are no consultants for the chronic condition(s).

Recommendation 8. Signposting to psychological support, upon diagnosis.

Recommendation 9. Establish a single point of contact, such as a co-ordinator or hub, to co-ordinate and navigate patient care for people with chronic conditions. This could be used by people with chronic conditions to consult, and seek advice and information on their chronic conditions.

Recommendation 10. NHS telephone line dedicated to people with chronic conditions, allowing immediate access to a medical professional.

Recommendation 11. Allow extended GP appointments for people with chronic conditions.

Recommendation 12. A flagging system to identify people with chronic conditions and enable them to be seen by a GP or referred as soon as possible

Recommendation 13. Offer safe spaces or quiet rooms in A&E departments for vulnerable people and people with chronic conditions.

Recommendation 14. Allowing people with chronic conditions to collect their prescribed medication from hospital pharmacies.

Recommendation 15. People with chronic conditions should be exempt from needing to apply for a blue badge.

Recommendation 16. Further research to identify people who are at risk of developing chronic conditions.

Recommendation 17. Further screening services to identify people who are at risk of developing chronic conditions.

Recommendation 18. Training courses on chronic conditions for people working in various fields, for example, retail and business.

Recommendation 19. Research and audit of support available to carers living with chronic conditions.

Recommendation 20. The Welsh Government should implement the social model of disability across the NHS in Wales.

4. Key themes

Person-centred care

16. All the participants who took part in the engagement spoke about the need for better person-centred care for people living with chronic conditions.

17. Some participants noted the need for further use of patient forums and co-production, in order to better healthcare services and provide a viable person-centred care. Service users and carers need to be involved in the decision making.

18. One participant mentioned the difference between raising a concern within the healthcare service and raising a complaint. There should be two different, separate policies. The participant would like to raise her concerns, but not necessarily make a complaint.

19. Some participants noted the need for a shift in mindset, on a strategic level.

> *"I've seen it on both sides. What needs to change and I know it sounds simplistic, and I know it isn't, is the mindset….they never take any time to just stand back…..and think, what's going to make the patient experience better. It's a fundamental shift in the mindset."*

> *"Decisions aren't being made with patients in mind. They are an absolute breach of all the duties, all the principles, all the values that*

> *are supposed to be operating on and the patients are not put at the centre….It's so easy to forget about the women in pain."*

> *"Where they [NHS] fall down is with long term conditions……..because it's a drain on resources and there's no instant win."*

20. One participant suggested the Welsh Government should implement the social model of disability across the NHS. This empowering social model would encourage co-production to achieve a more positive outlook and a service that would benefit all.

21. Other participants suggested practical solutions to improve procedures and person-centred care for people with chronic conditions. For example, rather than using the 111 telephone service, having a telephone line dedicated to people with chronic conditions, allowing them immediate access to a medical professional.

22. Another participant shared her experience of having appointments cancelled and then being placed at the bottom of the waiting list, rather than change everyone's appointment to accommodate for the cancellations. As a result, the next patient becomes the last.

23. Other practical solutions to improve person-centred care could include A&E departments having a quiet waiting room for vulnerable people and people living with chronic conditions.

24. Some participants mentioned the challenges of medications being contracted to be manufactured by external providers. The participant gave one example of a six week delay in her receiving her medications due to the sharing of inaccurate information with the external provider.

25. One participant suggested allowing people with chronic conditions to collect their prescribed medication from hospital pharmacies.

26. All participants spoke about the need for face-to-face appointments and the opportunity to talk about their chronic conditions and discuss possible options, allowing the patient (and/or carer) to be a part of the conversation, where possible. This is at the heart of person-centred care and in the long term, will lead to more sustainable and far more effective person-centred care.

> *"Sometimes, you need a face-to-face appointment, and you shouldn't have to beg for that."*

> *"Where they [NHS] fall down is with long term conditions - because it's a drain on resources and there's no instant win."*

27. One participant spoke about the pros and cons of patient initiated follow up appointments, where patients are seen as and when they need to be seen by healthcare professionals.

28. Participants noted the importance of treating people living with chronic conditions as individuals.

> "You get the impression sometimes that medics are interested in your condition and not necessarily interested in you.....I am a person, not a collection of symptoms."

> *"[Doctors] are brilliantly clinically trained in the majority of cases but when they come to a patient, they're looking at their notes, they're absorbing the clinical aspects of the individual, but they're not actually looking at the person."*

> *"The specialists just think about the impact it's having on the brain in terms of the seizures. But I think there should be more consideration of the impact on all aspects of a person's life, work, and mental health."*

29. Many participants shared their experiences of having no follow-up care, following diagnosis. Having such check-ins would greatly improve person-centred care.

30. Some participants gave examples of being told they would be referred to pain clinics, but still haven't heard anything for over twelve months. One participant mentioned that she waited four years to be referred to the pain clinic.

> *"The consultant said. 'All the things I was going suggest for you, you've already done yourself.' I said, 'Well, I've been waiting four years. I couldn't wait for you to tell me, what about this and have you thought to try this?' I have got to the stage where I thought I'm going to have to help myself."*

31. Participants suggested a multidisciplinary annual review considering all aspects of the participant's medical, psychological and social needs. This might help restore people's confidence in their own ability.

> *"We have a group of people who won't be able to meet the standards of the healthy population, but they are still a part of society and we need the flexibility of offering the possibility of education, the possibility of jobs or doing something to give value to society."*

32. One participant gave an example (pre-Covid 19) of what she described as a 'super team approach'. This involved appointments with several different disciplines and departments and felt listened and treated as a *"whole individual."*

33. Another participant suggested that adult medical care would gain a lot from taking the multi-agency approach often taken in paediatrics, noting that the role of the paediatrician in child medical services could be implemented in adult medical services for people with chronic conditions, particularly people with multimorbidity.

> *"In the transition process from children to adults almost always.....the quality of care goes down."*

34. Many participants spoke about the benefits of having specialist nurses but noted the pressures on the specialist nurses themselves, as there are so few of them.

35. Some young participants living with autoimmune conditions feel that the rheumatology departments don't cater for their age range.

36. Many participants spoke of the embarrassment of having to seek help, for example, for financial support, due to either losing their job or being unable to work, as a result of their chronic condition(s).

> *"I'm feeling uncomfortable with the fact that I've been thrust, due to my health, into a situation I never expected to be in......There needs to be a one stop shop on financial support."*

37. Social intervention is an essential aspect of person-centred care for people with chronic conditions. Patients living with chronic conditions should not need to re-apply for support of all kinds, for example, Personal Independence Plan (PIP) and the blue badge; this causes unnecessary stress.

38. There should be the same responsibility for health and social care within the NHS for people with chronic conditions, and for NHS patients, in general.

> *"It would be nice to have a joined up health and social care strategy for Wales...We need to put more respect into it."*

39. Some participants noted that many people with chronic conditions are having to stay in hospitals when they don't need to be there. This is having a substantial impact on other areas of the health service too.

40. Participants suggested re-introducing cottage hospitals in each health board. This would help to facilitate discharge from hospitals

41. Some participants noted the impact of the decline of district nurses - an invaluable point of contact when considering a more holistic approach to healthcare service.

42. Other participants suggested a return in the practice of home visits which would aid person-centred care, especially for people with chronic conditions who go 'under the radar' if they are too ill to attend hospital appointments.

43. Many participants suggested a co-ordinator or hub – a single point of contact – whereby people with chronic conditions could consult for information and advice. This would improve their confidence and experience of living with chronic condition(s) as well as relieve some of the pressures on primary care appointments. This could be an opportunity to respond to certain issues, raised by specialists, but not necessarily their area of expertise.

> *“It would be good to have someone dedicated to co-ordinate medical conversations, look at the whole picture and give the patient plenty of time."*

> *“Nobody sees or has any oversight of your journey….I’m just thinking, how are you co-ordinating care for people?”*

> “It's the patient who's required to join the dots, and to do the work to join the dots. That’s not person-centre [care].”

> *“For anyone who's got any complex health needs and particularly multiple health needs, having a central point of coordination is just logical to me.”*

44. Participants suggested that there should be far more support for people with chronic conditions, to live with the condition(s) and stay as well as possible, rather than blame them for their health issues. For example, some medications lead to weight gain, and yet they are told to try and lose weight.

45. One participant suggested the need for a similar organisation to SNAP Cymru, to support and advocate for people with chronic conditions. (SNAP Cymru is a national charity offering advice and advocacy for children and young people with additional learning needs and disabilities.)

46. Similarly, another participant suggested adopting a policy similar in principle to Allied Health Professionals (AHP) to co-ordinate and navigate patient care for people living with dementia. This policy could be adapted for other chronic conditions.

47. Participants suggested the current NHS model is *“too medically orientated”* and effective person-centred care should consider prescribing other ways of supporting people with chronic conditions, for example, attending classes at the local community centre.

48. Many participants spoke about the impact of their chronic condition(s) on their families too and that their need for support needs to be acknowledged too, as part of person-centred care.

Dismissed by medical and healthcare professionals

49. Many participants shared their experiences of not being listened to, by medical and healthcare professionals, feeling that their lived experience has or is dismissed and not being taken seriously. This has had a damaging impact on many of them.

> *"I went through seven or eight years of doctors turning me away, calling me dramatic and saying I was attention seeking. That was very damaging for my physical or mental health."*
>
> *"I do wonder whether he'd [GP] listened to me sooner, whether the condition I now have, could have been stopped or made less bad."*

50. Some participants spoke of the positive and negative impact of their medical and healthcare professionals' attitudes towards chronic conditions, on them as patients.

> *"He [doctor] said to me, 'I don't know how you've been doing this for so long'. Hearing that is amazing, when you've heard the complete opposite for so many years."*

> *"I had a doctor once tell me he didn't enjoy doing endo surgery, because the outcome is never good…it's a chronic condition and can't be cured. But, surely, the point of being a doctor is to help people and give quality of life."*

> *"…if they had taken it seriously when I first went, we possibly could have avoided me being in a situation of secondary breast cancer."*

51. Many participants shared their experiences of doubting their judgement at times, prior to diagnosis, due to some medical and healthcare professionals' comments.

> *"She [consultant] was so dismissive and made me feel like I was stupid. It was horrible….[She said]it would be a complete waste of NHS money to operate on me…..I would love to message her now and say, 'this is what was missed.'"*

52. Another participant gave an example of her GP telling her that they *"could spend a fortune testing you for things but you're not dead yet, are you?"*

Training and refresher courses for medical and healthcare professionals

53. Participants gave some examples of excellent, *"second to none"* medical and healthcare services, on all levels.

54. However, participants also noted the need for updated training and refresher courses for medical and healthcare professionals, particularly regarding patient care.

> *"I think we need to put care back into hospital treatment, which is something which is going to require retraining, because although it's happening with new recruits, we've got existing recruits that haven't had that training."*

55. Participants spoke about the need for empathy and a better understanding when medical and healthcare professionals are addressing people with chronic conditions, for example, dementia. This would improve the experience of the patient and address the lack of confidence among some medical and healthcare professionals when dealing with people with chronic conditions.

> *"There's one thing that's very difficult when you've got a diagnosis of dementia and you're already in an early stage like myself, and people assume you're at late stage and you don't understand anything......the medical aspect of dementia is a journey and it's different for everybody."*

> *"The stroke team were marvellous......The NHS is great at that. What they're poor at is when people present with things they don't understand." [Participant also lives with dementia.]*

56. Many participants mentioned the *"medical misogyny"* they face regularly and discussed the impact of attitudes towards women, among some medical and healthcare professionals.

> *"Women are the bottom of the list, but what we forget when we put women at the bottom of the list is the impact that that has elsewhere and the long-term effects that that is having on children who are growing up with things normalised for them. That shouldn't be."*

57. Some participants noted the need for specific training for medical and healthcare professionals, when communicating with people with chronic conditions, who are autistic, neurodiverse and/or have learning difficulties.

> *"He's[one individual in the participant's care] never been tested for epilepsy because the consultant didn't want to do it because he had learning difficulties.......and he told us this, he said it in front of my son."*

58. One participant suggested there should be a follow-up with medical and healthcare professionals to highlight and enable them to learn from what they have missed, at the time of consultation or diagnosis.

59. One participant gave a positive example of her GP information sharing with other GPs within the same practice.

> *“She [GP] is using it[the patient’s experience] as a tool to talk to other GPs and it’s brilliant that she has taken that learning on and keen to help more people.”*

Communication

60. Almost all participants spoke about their experiences regarding lack of communication on many different healthcare service levels.

61. To improve person-centred care, all health boards in Wales should be enabled to liaise with each other and share relevant patient notes. Some participants shared the challenges and frustration they face, living within one health board area, but having to receive treatment within one or sometimes two other health boards, yet, there is no communication between health boards.

62. One participant living with multimorbidity, receives support from more than one health board. She explained how she has resolved to keeping her own notes and shares the required information with the different departments during her appointments, due to them not having access to her full medical records.

63. The vast majority of the participants spoke about the need for better communication between different specialists and departments, especially when patients are under several consultants and/or have multiple chronic conditions.

> *“Some people are qualified to deal with certain aspects of a condition and need to communicate with others so that there is a joined-up thinking about your condition overall. That is particularly the case, I think, when the diagnosis is not an easy one.”*

64. Some participants spoke of the impact of the lack of communication between teams and departments on their chronic conditions.

> *“Slow communication between professionals added to the chronic systemic delays. I feel that if there had been quicker intervention in response to the rheumatologist’s recommendation, my finger ends might have been saved.”*

65. Participants mentioned the importance of clear communication by medical professionals, particularly when explaining conditions and options for the patient and/or carer.

> *"When the neurologist explains things they kind of expect you to know what it is.....the information that's being shared with you is not necessarily understandable."*

'The GP barrier'

66. Some participants spoke highly of their accommodating and supportive local GP practice or medical centre.

> *"When you're in with the doctor, you don't feel like they're trying to get you out of the room. I've always found that there's been time to ask the questions I want to ask."*

67. Other participants spoke about the need for a clear and well-thought-out medical appointment primary care system, based on the practical and logistical needs of the patient.

68. Many participants spoke of varying degrees of challenges they face liaising with their local GP practice or medical centre.

> *"It terrifies me just having to contact the doctor."*

69. One participant compared the response rate to her first cancer diagnosis in 2002 – two weeks – to the response rate to her second cancer diagnosis in 2016 – eight *months – "...it couldn't be more different."*

70. Some participants suggested the need to empower GPs to be able to refer patients directly to specialists. Currently they are only able to refer to secondary care, who are then able to facilitate a referral to a specialist; processes and protocols need to be reconsidered.

71. Acknowledgement of the needs of people with chronic conditions, including regular or sometimes short-notice appointments to see the local GP was discussed by many participants.

72. Many participants spoke about their ‘guilt’ of needing to access healthcare services regularly.

> *“People [with chronic conditions] can't be held accountable for the amount of NHS time they require. It is not something which is deliberate…….they're not hypochondriacs. They have genuine issues which need to be resolved quickly.”*

73. Participants spoke of their frustration regarding the lack of consistency when seeing their local GP, having to repeatedly explain their chronic condition(s) journey.

74. Many participants noted the challenges of having to telephone to book GP appointments. For example, one participant was told, whilst she was at the local medical centre, that she would have to return home to telephone and book a separate appointment to discuss her blood test results.

75. Other participants also discussed the challenges posed by telephone appointments only, for autistic and neurodivergent people, also living with chronic conditions.

76. Participants discussed the frustration of having to chase appointments and results, regularly, with nobody to advocate on their behalf.

> *“It's not good enough that in 14 years I've not had a laparoscopy and even worse, how few times I've seen a consultant and it's just not acceptable at all.”*

77. Some participants suggested ways of identifying people with chronic conditions, when they contact their local GP practice or medical centre. For example, a red flag system to raise awareness of the chronic conditions and enable them to refer the patient as soon as possible. This would also be beneficial for other situations too, for example, sometimes, for various legitimate reasons, people with chronic conditions are not able to attend medical appointments at the last minute.

78. Few participants were able to make appointments and access their medical results via the NHS app. One participant noted the benefit of e-consultations and being able to arrange appointments, blood tests etc. online.

79. However, most participants spoke of the need for further and improved use of ICT to ensure a more effective NHS service, including the use of artificial intelligence to analyse medical tests and scans.

80. Participants noted the need for an accessible portal for patient notes, available to both patient and medical professionals, to ensure better communication, lessen duplication and make sure that things aren't being missed and notes don't get lost.

81. Participants suggested people with chronic conditions should be allocated longer appointments and be allowed to discuss more than one related conditions at a time.

> *"I know they're [GPs] busy, they haven't got time……but when things are complicated, it takes time."*

Diagnosis

82. Some participants noted their quick diagnosis and early response rate to their chronic condition(s).

83. Other participants with certain chronic conditions, for example endometriosis and fibromyalgia, spoke of the delay in their diagnosis, ranging from 10 to 25 years.

84. Participants with certain chronic conditions, for example endometriosis, spoke about being misdiagnosed, usually with the *"dumping diagnosis"* of IBS.

85. Another participant spoke about the consequences of her misdiagnosis. She is now living with steroid-induced diabetes (type 2) and hypertension, as a result of being originally diagnosed with giant cell arteritis but then re-diagnosed with fibromyalgia.

86. One participant spoke about how she received her diagnosis, via a text message.

> *"The doctor texted me to say, 'Hi XXX, your blood test result shows you've got Graves' disease' with absolutely no context. That was quite scary at the time."*

87. Some participants spoke of their initial relief in getting their diagnosis and then the struggle to come to terms with living with a life-long chronic condition, with little or no support at the time. A person-centred, holistic approach would have improved their experience, particularly in the early days, following diagnosis.

Lack of specialists

88. Many participants, with a range of different chronic conditions, for example endometriosis, fibromyalgia and scleroderma, spoke about the impact of the lack of specialists for some chronic conditions in the NHS in Wales, on them.

89. Some participants explained how they were told that there was nobody for them to be referred to.

90. Some participants explained how they've chosen to seek private consultation and treatment, usually over the border, due to lack of local expertise. One participant noted she was advised to seek medical healthcare in London.

91. One participant suggested the role of a specialist consultant for chronic conditions. This role could support people with chronic conditions, particularly where there are no specialists, for example, ME and fibromyalgia and could identify the needs of both patients living with chronic conditions and the much-needed support for medical professionals to enable them to offer a more person-centred care.

> *"Had I stayed with the NHS, I probably would have lost more of my bowel than I already have."*

> *"All the new innovations and new drugs available, we're not party to."*

> *"There are so many chronic conditions and there aren't specialists here in Wales….The GP doesn't have anyone to refer to."*

Lack of consistent quality of care, Wales-wide

92. Participants shared their concern about the lack of consistent quality of care across Wales, especially in rural areas, for people with chronic conditions.

> *“Patients need to have confidence that there will be adequate joined-up provision whichever part of Wales they live in.”*

93. Some participants mentioned how this concern was a key factor in their choice of living habitat and others noted that they felt unable to consider living elsewhere in Wales, due to needing to access healthcare services regularly.

94. Participants living in rural areas in Wales noted the challenges and frustration they face travelling to medical and healthcare appointments, due to lack of public transport. This sometimes deters some people with chronic conditions from reaching out for support and/or treatment, leading to devastating consequences.

95. One participant living with epilepsy and unable to drive, noted her one-way three-hour journey on public transport, for a ten-minute appointment.

Mental health support

96. Almost all participants noted the correlation between their chronic condition(s) medical needs and psychological needs, although this is not always acknowledged by medical and healthcare professionals.

> *“From a patient perspective it feels like at times the psychological impact [of living with a chronic condition] is not understood…..I have the best of care when I'm in an acute situation, but once I'm stabilized, there's a massive drop off.”*

97. The majority of participants noted the difficulties they had faced accessing mental health support within the NHS, following diagnosis.

> *“I’m 30. This journey started when I was 13 and I've had 16 operations, multiple organ loss, and it's only now at 30, I'm offered counselling.”*

> *"I only found out psychological support was available, when I cried with the doctor....You've got to be an assertive patient to find out about this stuff, or find it out yourself."*

> *"I'm called XXXX, but I lost a part of XXXX when I was diagnosed, and I had no idea, then, how to get her back."*

98. However, some participants commented on the good quality and benefit of the support made available to them, once they had been able to access it.

99. Many participants have sought mental health support themselves and drew attention to the need for flexibility in accessing mental health support as and when needed, bearing in mind that chronic conditions are life-long conditions.

> *"I don't want to scroll through 100 screens in 50 links. I want to speak to a person and I make no excuses for feeling that way, at the time when I was really low."*
>
> *"I don't actually like asking for help, but when I do ask for help, it's because I really need it."*

100. A more holistic approach to supporting people with chronic conditions should address their psychological needs side by side with their physical needs.

> *"The impact of trauma on mental health is not necessarily resourced in a joined-up way....There needs to be a more blended approach to rehab."*

Benefit of charities and support groups

101. The vast majority of the participants who took part in the engagement, referred to the benefits of charities and support groups and spoke about the positive impact of being able to speak to and share experiences with people living with chronic conditions.

> *“Although none of these things [support group sessions] are going to cure you, trying to do something positive shifts the mindset…..It would be great if the health boards tried to do something like that as well.”*

102. Due to the lack of and/or the need for support groups, many of the participants had either set up or were involved in organising local, face-to-face or regional, online support groups for people living with similar chronic conditions.

103. Some participants noted that their support group was their best and sometimes only source for information sharing about all aspects of living with chronic condition(s) for example, how to access financial support when not able to work.

> *“I maybe could help people with things that I’ve learnt – from Access to work, from GP referrals, from adaptions you could have to your home – there’s nobody actually telling you about all these things.”*

104. Many participants spoke of the need for signposting to, and raising awareness about, charities and support groups, upon diagnosis, describing the loneliness they felt following diagnosis, and often having nobody to advocate for them. This should be a part of an improved holistic approach to supporting people with chronic conditions.

> *“When you’re not well, to have to fight…when you haven’t got that fight in you…..it’s not fair.”*

Support for carers of people with chronic conditions

105. Few of the participants who took part in the engagement were carers for people with chronic conditions, some of them living with their chronic conditions too.

106. Participants noted the need for recognition and support for carers, especially unpaid carers of people with chronic conditions. For example, the presence of carers at medical appointments should be recognised.

> *“The first thing I always have to do is explain who I am and why I’m there.”*

107. Carers of people with chronic conditions, some with chronic conditions of their own, also need practical and mental health support; this is not always recognised.

> *"Sometimes, I feel very excluded. I feel very lonely, knowing that nobody cares about me….as long as I'm here to do their bidding [individuals in the participant's care] but that's affecting my health now and I'm not getting the care for my health because of all my other responsibilities."*
>
> *"We need some way of enabling me to take care of myself and to take care of my long-term conditions in a more equitable way….My home is my workplace."*

> *"We struggle, it's really hard…..I get worn out by it."*
>
> *[advocating for the patient]*

Prevention of chronic conditions

108. Participants suggested that prevention starts with listening to the patient and that early diagnosis is key to early intervention.

> *"If you see specialists in a timely fashion, actually that can end up being both preventative, so improving the patient prognosis, but it can also end up saving money for the NHS because instead of being on that revolving door of repeated less effective interventions, you get to see someone who has a real special interest knows the medical options, knows the treatment options, can supervise more effective care early on."*

109. Acknowledging that it would not be not possible for all chronic conditions, some participants spoke about the importance of developing screening services further, at certain ages, to identify people who are at risk of developing chronic conditions.

110. Other participants spoke about the importance of educating people about healthy lifestyles, concerning the prevention of some, but not all, chronic conditions.

111. Further resources are needed for research and treatments of chronic conditions, including the impact of some chronic conditions on other chronic conditions.

> *“There needs to be a look at why people develop these chronic conditions other than dementia……it goes hand in hand….if you’ve got dementia, you’ll get something else. I’m one of them.”*

112. Many participants suggested the need to raise awareness among the general public, of the symptoms of many chronic conditions. This would also help reduce the stigma associated with many chronic conditions.

113. One participant suggested the need for awareness training courses on chronic conditions for people working in various fields, for example, retail and business. This too could reduce the stigma associated with many chronic conditions as well as develop empathy towards people living with chronic conditions.

5. Annex 1

Organisations and charities whom the Citizen Engagement Team collaborated with to identify some participants to take part in the engagement:
Alzheimer Society
Breast Cancer Now
British Heart Foundation
Epilepsy Action
Fair Treatment for the Women of Wales
MacMillan
Rare Autoimmune Rheumatic Disease Alliance

6. Annex 2

Chronic conditions represented in the engagement programme
Autoimmune diseases, including scleroderma and lupus
Bilateral Bell’s Palsy
Cancer (including breast cancer, leukaemia, melanoma, prostate cancer)
Chronic kidney disease
Chronic blood clotting disease
Coeliac disease
Dementia
Diabetes
Endometriosis
Epilepsy
Fibromyalgia
Graves’ disease
Heart conditions (for example, arrhythmogenic cardiomyopathy)
Irritable Bowel Disease (Crohn’s and Colitis)
Long Covid
Mental health conditions (short and long term)
Musculoskeletal (MSK) conditions including arthritis
Myalgic encephalomyelitis (Chronic fatigue syndrome / ME)
Respiratory diseases, including asthma
Stroke