

Supporting people with chronic conditions: stakeholder discussion

28 February 2024

Background

1. As part of our inquiry into [supporting people with chronic conditions](#), on 28 February 2024 the Health and Social Care Committee held a private informal discussion with relevant stakeholders. A list of the organisations that took part can be found in Annex 1. We are grateful to everyone who took part for sharing their views, experience and expertise with us.
2. We asked participants to consider:
 - What actions, both immediately and in the longer-term, would improve person-centred care for people with chronic conditions, and particularly for people with multiple chronic conditions?
 - How can services effectively support the mental health and wellbeing of people with chronic conditions?
 - What are the main barriers people face whilst accessing support and treatment for chronic conditions, and how can they be overcome? What actions should be taken to reduce health inequalities?
 - How can prevention and early intervention in chronic conditions be improved?
3. This note summarises issues and themes discussed during the session.



Person-centred care

- 4.** The World Health Organisation's International Classification of Functioning, Disability and Health could be used to help healthcare providers think differently about healthcare. It is a person-focused model, rather than being condition-focused. Although some other stakeholders reporting also stressed the importance of using a social model of disability.
- 5.** More recognition is needed that engaging with medical professionals can be challenging and even traumatising in some circumstances. Training, both during initial medical training and as part of CPD, should be provided to help medical professionals understand patients' experiences of accessing healthcare, unconscious bias, and understanding of intersectional barriers in healthcare. This training should be co-produced with patients with lived experience from the start.
- 6.** The system is not set up to provide long-term person-centred support. Instead there are short-term interventions before the person is returned to self-managed care, which they cannot always cope with. Waiting for these short-term interventions can be demoralising and isolating. There is a need for long-term support and care packages for people living with chronic conditions.
- 7.** People living with multiple chronic conditions can experience 'diagnostic overshadowing', where one condition is blamed for all symptoms and other causes are not adequately explored. This is true of physical and mental health, where symptoms with physical causes are blamed on mental health conditions like anxiety and depression, and similarly mental health symptoms are blamed on physical conditions. Training for medical professionals is important to address this.
- 8.** Some conditions, such as arthritis, are seen as an inevitable part of ageing and therefore are not perceived to need proactive management. A proactive approach to supporting people with long term conditions is needed.
- 9.** Health professionals often don't have a lot of time to spend with patients. One way to overcome this is better signposting to help people self-manage their conditions.
- 10.** Patients should be involved and engaged in decision making about health care provision. This is currently sometimes tokenistic, and the methodology of how and when patients should be involved can be unclear.

- 11.** Continuity of care is important, but currently not accessible for many. Some people with chronic conditions feel reluctant to approach healthcare providers because they worry about waiting times or feel misunderstood or stigmatised.
- 12.** While a focus on care closer to home is important to many, being able to see a specialist early (and being given the choice to do this) is likely to improve patient outcomes. This may also reduce the need for multiple visits to primary care.
- 13.** Care coordinators or navigators may have a role to play in helping people access and navigate the healthcare system.
- 14.** Improving access to key workers and providing individual care plans will help patients manage their condition(s). Too often, patients are aware of their key workers but are unable to access them.
- 15.** Accessing services can be challenging for those with a disability or particular access requirements, and adjustments are not being made. This is particularly the case for those patients who are housebound or bedbound. There is a lack of screening services available in people's homes, e.g. cervical screening.
- 16.** Physical and mental health are too often treated in silos. There is also a lack of parity between physical and mental health. Support for patients' mental health and wellbeing should be included in NHS Wales quality statements for chronic conditions.
- 17.** There is a lack of detail in how delivery of quality statements is progressing and not all chronic conditions are supported by a quality statement.
- 18.** Stakeholders emphasised the important role than unpaid carers play in caring for those with chronic conditions. Unpaid carers are not volunteers but are acting out of necessity and love. They are at risk of burnout and in need of support. Person-centred care needs to consider the needs of the carer too.
- 19.** There is still a lack of services for people with ME and long covid, something the Committee raised with the Health Minister in a general scrutiny session in October 2022.
- 20.** Geographical disparities are a factor in the quality of care received by patients across Wales.
- 21.** There is a disparity between the level of care provided for chronic conditions in primary and secondary care. There is a need for multi-disciplinary care in primary care.

22. Effective care and treatment plans are needed for patients addressing both their mental health and physical needs and tailoring support accordingly. Often people feel abandoned after having received their diagnosis. While physical needs are being addressed, mental health is often not mentioned.

Prevention

23. Public health campaigns to promote healthy lifestyle choices are important but can feel ableist. Not all healthy lifestyle choices are accessible to everyone, and more understanding of the root causes and wider societal determinants of health is needed. It is important that public health campaigns aren't seen to blame people living with chronic conditions as this can contribute to stigma.

24. Self-management of chronic conditions is important, and patients should be supported to self-manage. However, it is not possible for all and this needs to be understood.

25. The importance of early intervention when a condition is first diagnosed was highlighted for all those with chronic conditions, including children. Early intervention should be planned for and implemented effectively, including access to specialists at an early stage.

26. There is a postcode lottery for specialist care, and for some medications, with variation between different health boards. It is difficult to access care in another health board and this can be a barrier.

27. Communication and signposting to provide a more holistic approach to care is important, particularly for those on waiting lists. Waiting lists have a significant effect on mental health.

28. Annual health checks for those with a learning disability are important but are not currently being properly carried out by healthcare professionals with understanding of the needs of this group. Additionally, these health care checks do not include women's health issues, like menstruation and menopause.

29. Children with chronic conditions are not being sufficiently supported to access education, either through accessibility adjustments being made in schools or home tuition being provided.

- 30.** There is a lack of data about how many people are living with different chronic conditions and this makes planning services very difficult. There was discussion of a register or registers of people living with chronic conditions to enable better planning of services.
- 31.** For those conditions that disproportionately affect women, the forthcoming women's health plan should put in place additional support and planning for services to meet women's needs. It should also encourage research in under-researched areas that particularly affect women.
- 32.** The third sector has a significant role to play in supporting people living with chronic conditions. Third sector organisations can act quickly, be more agile, and respond to unmet needs that the NHS cannot address. However, the sector is experiencing huge financial pressures and funding for third sector projects can be seen as a 'nice-to-have' rather than an essential service. Short term funding for projects also causes problems with long term planning.
- 33.** Living with a chronic condition can have a significant economic impact and this needs to be understood and addressed.
- 34.** Digital infrastructure and data - there is a need to be able to share patient records across the MDT. Also the role of digital solutions, such as apps, needs to be recognised.
- 35.** Communication and awareness raising strategies need to be culturally appropriate to effectively address mental health inequalities. This is particularly important when reaching out to BAME communities.

Annex 1: Organisations that took part in the stakeholder event

Versus Arthritis

Asthma and Lung UK

Mind Cymru

Cerebral Palsy Cymru

Macmillan Cancer Support

Fair Treatment for the Women of Wales

Welsh Association of ME & CFS Support

Crohn's & Colitis UK

Rare Autoimmune Rheumatic Disease Alliance (RAIRDA)

MS Society Cymru

Kidney Care UK