

Consultation Response: Long Term Conditions Framework

18/07/25

Introduction

Given the diversity of our membership, we are unable to categorically state that we are in favour of the proposed Long Term Conditions Framework. We can see that the proposed Framework, as detailed in the [Consultation Paper](#), has the potential to simplify an overly complex and sometimes siloed approach to long term conditions. In particular, it could provide an opportunity to address existing challenges regarding access to patient data and improve workforce training around long term conditions. It could also support a more systemic approach to long-term conditions that addresses intersectional barriers and reinforces the pivotal role of the third sector as an equal partner.

However, our members have expressed concern that the proposed approach could dilute vital condition-specific policy and provision. Many important services for people with long term conditions are already underfunded, and we have heard accounts of people with long term conditions experiencing discriminatory treatment when accessing wider health services. It is vital that any new Framework improves provision for people with long term conditions, and does not dilute it.

In our response, we have answered questions 1, 3, 4, 5, 6, 7, 8, 10, 12, 14, 16, 17, and 18.

About Us

VHS exists to create a healthier, fairer Scotland served by a thriving voluntary health sector. We are a membership organisation, with our members comprising third sector organisations working across Scotland to support people's health and wellbeing, tackle inequalities, and research and advocate for better health systems and policies. We also facilitate the Scottish Community Link Worker Network, the national network for primary care community link working in Scotland.

Through our policy work, VHS seeks to ensure that the experiences, knowledge, and interests of our members and stakeholders are reflected in national decision-making about health inequalities and health creation. We regularly consult with our members to ensure that our policy voice and priorities are reflective of their views and interests. We also ensure that our members are informed about relevant policy developments through accessible communications and events, and that they are aware of opportunities to influence decision-makers individually and collectively.

We hosted a workshop for our members and stakeholders to inform this response in July 2025, which was attended by five representatives from a range of organisations.

Question Responses

1. Do you agree that Scottish Government should move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work? Why?

Unanswered

This is a complex issue, and we are unable to represent the views of our members by answering yes or no for this question.

We have heard from our members that there are many common experiences, needs, and treatments for people living with long term conditions, and that many people live with multiple long-term conditions. Whilst we do not yet know what the proposed framework would look like, there is the potential for it to support approaches which reflect the needs of people living with multiple long-term conditions, without having to navigate wholly different approaches for each condition or share their data multiple times. For this framework to be of value, it needs to promote person-centred treatment pathways and support mechanisms.

We would also expect a single long term conditions framework to address the intersectional challenges and health inequalities experienced by many people. Research into ‘missingness’, when people repeatedly miss healthcare interventions, highlights the structural barriers for many people in accessing health care, largely aligned with the social determinants of health. In a [blog for VHS](#), Professor Andrea Williamson, Professor of General Practice and Inclusion Health at the University of Glasgow, called for a ‘systemic shift’ to address missingness. A single framework for long term conditions could help to address missingness in a systemic way, helping to ensure that people with long term conditions are diagnosed at the earliest possible stage, and are able to sustain treatment.

The introduction of a Long Term Conditions Framework could also be helpful in simplifying a complicated policy landscape, making it easier for third sector partners who provide services to address multiple long term conditions to engage. However, some of our members have raised concerns around this approach. There was suggestion that the scope for the proposed framework is too broad given the number and complexity of long term conditions. There was also a worry raised that this move is a cost-saving exercise and could dilute existing policy and provision around long term conditions.

Members also expressed the need to ensure that vital condition-specific actions continue to be reflected in related policy. Most, if not all, long term conditions require condition-specific interventions and treatments which may be difficult to reflect in a single

framework. For example, in our member workshop to inform this response, a representative from Chest Heart and Stroke Scotland shared the vital importance of the door-to-needle timeframes for treating people with stroke symptoms. This position was reinforced by the Stroke Association who state that:

‘The time-sensitive treatments required for hyper acute and acute stroke and the sheer numbers of people affected, offer absolute justification for stroke-specific policy and resource.’

Similarly, a representative from Parkinson’s UK shared the complexity of Parkinson’s as a condition and the need for specialist treatments. A new Long Term Conditions Framework would need to ensure that such condition-specific interventions are also prioritised.

Finally, our members were clear that this framework could be a positive step in theory, but without clear plans for implementation, clear lines of accountability, and dedicated resource, it could end up being ‘just another framework’ that does not adequately inform treatment of long term conditions in practice. As such, we would expect to see a detailed implementation plan and dedicated resource for this framework if it were to go ahead.

3. Do you have any thoughts about how areas for condition-specific work should be selected? This means work which is very specific to a health condition or group of health conditions, rather than across conditions.

As stated in our answer to question 1, we have heard concerns from our members that a single framework could dilute government commitments related to interventions that are condition-specific. Indeed, the consultation document itself identified that of the 156 commitments identified in current related strategies, 48% of these were condition specific. As such, the Long Term Conditions Framework should ideally exist in addition to, not instead of, existing long term condition strategies and action plans, such as those for [cancer](#), [dementia](#), or [heart disease](#).

However, we recognise that part of the rationale for the framework, as stated in the consultation document is to ‘*efficiently and impactfully allocate our finite resources on long term conditions*’. With this in mind, we would urge that the aforementioned 48% of existing condition-specific commitments should be maintained within the new framework, and that new commitments should focus on recurring or overlapping themes. Rationalising and streamlining the 52% of commitments that are not condition-specific could, in theory, lead to efficiencies by removing duplication and complexity whilst also improving patient experiences.

That said, action to address recurring themes in this framework will only be effective with a clear implementation plan and sustainable dedicated resource. The five recurring themes identified in the consultation document are access to care, data, self-management and patient information, clinical information/education, and prevention and early intervention.

We have heard from our members that many of these themes are not sustainably funded currently, particularly in the third sector. There is considerable evidence that third sector primary prevention activity is being de-prioritised in funding decisions by some Health and Social Care Partnerships. Members of the Scottish Community Link Worker Network, which supports self-management, have also reported unsustainable and insecure funding. Finally, we heard in our workshop to inform this consultation that systems for recording and sharing patient data are a ‘minefield’, particularly for third sector partners.

Much of these recurring themes are identified in the recent [Health and Social Care Service Renewal Framework](#) as requiring considerable transformation and innovation. As such, a Long Term Conditions Framework which focuses on person-centred support can only be achieved with realistic and sustainable resource, and recognition that the third sector are an equal partner.

4. What would help people with a long term condition find relevant information and services more easily?

The third sector is vital in supporting people with long term conditions to find relevant information and services more easily. In our workshop to inform this response, members highlighted the particularly important role third sector partners have in supporting people pre-diagnosis to access help. Many condition-specific third sector organisations provide extensive information about the symptoms of long term conditions and lead campaigns which encourage people to seek medical advice.

The third sector are also vital in supporting people immediately post-diagnosis of a long-term condition. Many third sector organisations provide expert condition-specific information digitally or in person, helping people to understand and navigate their diagnosis. Many also provide practical information, advice and advocacy for people with long term conditions on topics including managing pain, employment rights, accessible housing, or benefit entitlement. [Age Scotland](#), a VHS member, have further highlighted the importance of non-digital options for accessing information and services given the digital skills gap experienced by many older people, and the third sector are often a key source of local or telephone support.

Third sector organisations also provide community-based support and guidance on self-management and accessing local services. For example, [Community Link Workers](#) are based in primary care settings across Scotland and support people to access local services and participate in activities that will improve their health and wellbeing, such as volunteering. They can often serve as a familiar and trusted contact for people in accessing wider support following a diagnosis.

The third sector also have an important role in supporting people with long term conditions to share their experiences, and in elevating their voices to influence decision-making. To ensure that people with long term conditions can find relevant information and services, it is

important to listen to and learn from their experiences. An example of this can be seen with [Voices of Experience \(VOX\) Scotland](#), one of our members, who are Scotland's national collective advocacy organisation for mental health. They are a membership organisation for people with lived experience of mental health difficulties and exist to represent member's views to decision-makers. They have recently informed the Scottish Government Mental Health and Wellbeing Strategy and the Mental Health Nursing Review.

Despite the clear role of the third sector in helping people with long term conditions to find information and services more easily, third sector health organisations are facing increasingly unsustainable funding. In addition, our members report difficulties accessing relevant patient data and challenges influencing decisions about health at a local and national level. To help people with long term conditions to find relevant information and services more easily, the framework should recognise the third sector as equal partners in supporting people with long term conditions, and commit to sustainable funding for third sector organisations, including the Scottish Community Link Worker Network.

5. What would help people to access care and support for long term conditions more easily?

As reported in our answer to question 4, the third sector play a vital role in helping people to access care and support for long term conditions. Many of our members provide information about treatment and support options, as well as providing independent advocacy for those who might struggle to articulate their needs and preferences, and elevating voices of lived experience to decision-makers. [EARS Independent Advocacy Service](#), one of our members, provide advocacy in Edinburgh and the Lothians to adults with physical disabilities, brain injuries, learning disabilities and autism. They assist people in articulating their preferences, provide them with information to make informed choices and ultimately help them to maintain control over their lives.

In addition, as stated previously, Community Link Workers have the potential to provide a familiar trusted contact for people with long term conditions to access care and support services in their communities.

The Royal National Institute of Blind People (RNIB), a VHS member, also reported in their response that '*adequate patient transport is essential for ensuring good health outcomes and patient dignity.*' The third sector are a key provider of community transport for people with long term conditions to access healthcare appointments and services. The [Community Transport Association in Scotland](#) has over 180 members across the country, many of which are community-led.

Again, to help people with long term conditions to access care and support, the framework should recognise the third sector as equal partners and commit to sustainable funding for third sector organisations.

6. How could the sharing of health information/data between medical professionals be improved?

The sharing of health information and data between professionals is raised frequently by our members as a particular challenge. As stated in our answer to question 1, patient data is seen by some practitioners in the third sector as a ‘minefield’, with varying patient data systems, that are often outdated, used in different health boards. In addition, third sector partners also often report challenges in accessing important patient data due to operational challenges in doing so securely, or reluctance from public sector partners to share data.

This often means that people with long term conditions, or their unpaid carers, need to share the details of their condition (or conditions) multiple times to different services. It also means that third sector organisations delivering frontline health services lack important patient information, sometimes during crises. Sarah Van Putten, CEO of Life Care Edinburgh, reflected in our workshop to inform this consultation that:

“So much relies on clients being able to give you the information for you to know about them, to provide their support, and that at times I would suggest this can place people at risk because you don't know something about them and then something goes wrong. Our clients and their unpaid carers are often quite old and frail, sometimes we end up picking up medical emergencies because we're the one that happens to go to the doorbell that's not answered and there is nothing more frustrating than the ambulance service walk through the door and they ask ‘can you tell us a medical history?’... It feels really ridiculous to know that as the workers who are in there two or three times a week, you're not able to say ‘this is this person's background medical history.’”

There is, as mentioned by Ms Van Putten above, a considerable burden placed on unpaid carers in repeatedly sharing their loved one's medical histories. Joe McCready, Policy Officer at Carers Scotland, stated in our workshop to inform this response that:

“A lot of the time it's reliant upon the unpaid carer in that situation to pass that information on and a lot of times that can be almost retraumatising [for the carer], especially if it's a different doctor and you have to go through that system again.”

Unpaid carers are seldom medical experts and are often dealing with their own trauma when caring for a loved one. However, given the current limitations in patient data, they often have to become an expert in their loved one's condition, routinely sharing medical data with new health professionals they encounter.

Members have suggested to us that it should be easier for patients and their carers to share their health information with relevant practitioners, and a digital solution where they are able to access and share this data with people supporting their health needs would be hugely beneficial. It is also vital that third sector practitioners can access relevant medical information about the people they support. The framework should explicitly recognise the

third sector as an equal partner in the provision of services for people with long term conditions and commit to identifying solutions for sharing patient data with third sector practitioners.

7. What services outside of medical care do you think are helpful in managing long term condition(s)? You may wish to comment on how these services prevent condition(s) from getting worse.

As stated in previous questions, the third sector contains a range of services outside of medical care that are helpful in managing long term conditions. Organisations like Marie Curie, Chest Heart and Stroke Scotland, and Alzheimer Scotland - all VHS members - provide helplines for people to access practical and emotional support in managing their long term condition. In addition, a range of third sector organisations will provide emotional and peer support, including befriending, to people with long term conditions, helping them to cope with their condition.

Chest Heart and Stroke Scotland's [No Life Half Lived \(NLHL\) Model](#) is an example of a third sector support service that can serve multiple long term conditions through a single pathway. Informed by clinical expertise and lived experience, the model includes a range of interventions to support people affected by chest, heart, stroke conditions, and Long Covid. Core to the pathway is the delivery of an evidence based Chronic Disease self-management programme. This 8-week programme empowers individuals to deal with the ongoing symptoms of living with a long term health condition living with different conditions and/or comorbidities with the knowledge, skills, and confidence to manage their condition(s), stay connected to their communities, and live well on their own terms.

Third sector organisations also provide independent advocacy for people who might struggle to articulate their needs and preferences. [Scottish Independent Advocacy Alliance \(SIAA\)](#), is the national intermediary organisation supporting and promoting independent advocacy and works to reinforce the role of independent advocacy in upholding people's legal rights. For example, the right to independent advocacy is enshrined in the 2003 Mental Health (Care and Treatment) (Scotland) Act.

In addition, there are a range of third sector services that promote self-management and health creation activity, such as Walking Scotland, formerly Paths for All, who facilitate [Health Walks](#) delivered by volunteer walking groups in communities across Scotland. In their response to this consultation, Walking Scotland state that:

'Walking helps prevent heart disease, diabetes and cancer. It improves our wellbeing and is linked to better sleep, improved cognitive function and an overall better quality of life. In Scotland, more than 3,400 cases of serious long-term health conditions and over 1,000 early deaths can be prevented by people walking and wheeling.'

The third sector also facilitates social prescribing activity, including the Scottish Community Link Worker network, which supports people to access a range of health creating activities and services in their local communities.

All of the above services help people in managing long term conditions and many support people to take action which can prevent their condition from getting worse.

8. What barriers, if any, do you think people face accessing these (non-medical) services?

The third sector in Scotland is made up of over [46,500 organisations](#), with over 2000 in health, over 11,000 in both social care and in culture and sport. Given this complexity, it can be difficult for people to navigate and find appropriate services. As such, third sector intermediary bodies, such as Voluntary Health Scotland, the Health and Social Care Alliance (The ALLIANCE) and local Third Sector Interfaces can have a key role in mapping and sharing details of third sector provision. The ALLIANCE host a database for finding services, groups and activities which promote health and wellbeing called [ALISS](#), which is populated by services themselves. In addition, social prescribing practitioners, including Community Link Workers, have a key role in helping people to navigate and access relevant non-medical services.

However, as stated previously, unsustainable funding of the third sector has caused many services to close or placed many at threat of closure. The most recent [SCVO Third Sector Tracker report for Spring 2025](#) found that 93% of organisations had faced challenges since Autumn 2024, and 37% of organisations reported that they are operating with a budget deficit. In addition, the [Social Justice and Social Security Committee inquiry into third sector funding principles](#) last year found that some Third Sector Infrastructure bodies have faced real-time cuts to their funding of 25-30% in the past ten years. This level of insecurity places these services, and those organisations that support service navigation, at considerable threat. To address this, it is vital that the framework acknowledges the role of third sector partners in accessing and delivering non-medical services, and commits to ensuring that they have sustainable, fair funding.

10. What would strengthen good communication and relationships between professionals who provide care and support and people with long-term condition(s)?

As stated previously throughout our response, third sector organisations who provide care and support for people with long term conditions are not always treated as equal partners, particularly in the allocation of resources, involvement in decision-making, and access to data (at both a patient and a population level).

In addition, members have highlighted that this framework could improve the provision of workforce training regarding the needs of people with long term conditions, particularly when they are accessing routine health appointments or screening services. RNIB, in their response, highlighted the need for consistent sensory impairment training for all NHS staff,

and shared that *‘lack of communication can lead to individuals feeling disempowered and vulnerable’*. We also heard the anecdotal story from one member, further explored in our answer to question 17, of a person with aphasia being refused a vaccination because they were believed to be intoxicated. Age Concern have further highlighted that many older adults experience symptoms or concerns being dismissed as *‘part of ageing’*. Greater training, as well as better patient data transparency, would avoid such situations in the future.

To strengthen good communication and relationships between professionals, we recommend that the proposed framework explicitly acknowledge that the third sector is an equal partner in supporting people with long term conditions, and commit to fair and sustainable funding for third sector partners. We would also like to see better workforce training and digital systems for information sharing between NHS workers and the third sector.

12. What new digital tools or resources do you think are needed to support people with long-term conditions?

As stated in our answer to question 6, our members have suggested to us that it should be easier for people with long term conditions to access their medical information and share this with relevant practitioners. A digital solution where people can access and share their own health data with practitioners supporting their health needs would be hugely beneficial. NHS England have made significant progress in this regard with the [NHS App](#) which allows patients to view their medical records and manage significant elements of their health journeys. A similar solution in Scotland which allows information sharing and also connects people to third sector services would be a positive development.

14. What barriers do people face making healthy decisions in preventing or slowing the progress of long-term condition(s)?

Many of the barriers people face in making healthy decisions are systemic, and a direct consequence of the social determinants of health. One of our members, [Obesity Action Scotland](#), report that in 2023/24, 66% of adults had overweight or obesity and adults from more deprived groups were more likely to have overweight and obesity than those who are less deprived (69% in SIMD quintile 1 compared with 58% in quintile 5). They state that:

‘Interventions should be focused on transforming the food environment to make healthy food options readily available and affordable for everyone, regardless of where they live.’

Similarly, [Walking Scotland](#) report that participation in regular walking or wheeling in 2023 was most common for people who are ‘very comfortable financially’ and those in ‘very good health’. In addition, when asked what factors would encourage them to walk or wheel more often, almost double the number of women than men (44% vs 23% respectively) answered with ‘feeling safer when walking at night’.

Whilst just a snapshot, these examples from our members highlight the importance of social determinants and systemic barriers in healthy decision-making. For this Framework to encourage healthy decision-making, it is vital that it takes a whole system approach which recognises and addresses the intersectional barriers that many people face. As such, this framework cannot just build on existing condition-specific strategies, but must also map and interact with other relevant strategies related to poverty, housing, built environment, community safety, equalities and many more.

16. How can the Scottish Government involve communities in preventing or slowing the progress of long term conditions?

As stated in our answer to question 4, many third sector organisations have a key role in involving people with lived experience to share their experiences of living with long term conditions with decision-makers. Similarly, the third sector often serves as a bridge between statutory services and communities, particularly given that most third sector organisations - [over 70%](#) - are community and volunteer led. As such, the third sector is a vital conduit for the Scottish Government to involve communities in preventing or slowing the progress of long term conditions.

With this in mind, we would again recommend that the proposed framework explicitly acknowledge that the third sector is an equal partner in supporting people with long term conditions and commit to fair and sustainable funding for third sector partners.

17. Are there additional important considerations for people with long term conditions? For example, people who; live in deprived areas and rural and/or island areas, have protected characteristics e.g. race, disability, who are in inclusion health groups e.g. homelessness, or who experience stigma due to perceptions of their long term condition e.g. people with dementia?

As stated in our answer to questions 1 and 14, many of the determinants of health are social in nature. Indeed, people who experience poverty, trauma, or have protected characteristics often experience barriers to accessing healthcare, or discriminatory experiences in healthcare that lead to mistrust or disengagement. In an [academic article](#) exploring the theme of missingness, Professor Andrea Williamson, Professor of General Practice and Inclusion Health, University of Glasgow, states that:

‘... people who are socially excluded, typically experience multiple overlapping risk factors for poor health (such as poverty, violence and complex trauma), experience stigma and discrimination, and are not consistently accounted for in electronic records (such as healthcare databases). These experiences frequently lead to barriers in access to healthcare and extremely poor health outcomes.’

She also concludes that:

‘Missingness in health care is a strong risk marker for a poor outcome so needs urgent attention from the healthcare community.’

In our workshop to inform this response, our members highlighted several examples of barriers in accessing healthcare. They referred to the ‘8am rush’ to get a GP appointment as a challenge, particularly for those with hearing loss, language barriers or caring responsibilities. They also highlighted homelessness and living in temporary accommodation as a considerable barrier in accessing GP services, as well as the challenges experienced by those leaving prison. If you have a long term condition that requires regular GP appointments, as well as any of the above issues, this inaccessibility could lead to poorer health outcomes.

These intersectional barriers are not limited to accessing GP appointments. One member shared an anecdotal example of an individual with aphasia as a result of stroke being refused a vaccination because they were mistakenly thought to be intoxicated. This highlights wider barriers accessing routine health care services for those with long term conditions due to a lack of understanding by healthcare professionals of long term condition symptoms and how they present. Further examples of long term conditions which might have commonly misunderstood symptoms include dementia, epilepsy or diabetes. Again, this relates to issues with how patient data is shared or communicated, and the current over-reliance on patients or their carers to repeatedly share medical histories with healthcare professionals.

Finally, members raised recent examples of discrimination in healthcare for particular groups which could create mistrust or an unwillingness to engage in health services. For example, in a [2024/25 survey report by the Young Women’s Movement](#) it was found that:

‘Young women feel that they are not taken seriously, that their health concerns are dismissed, and they have experienced discrimination and misogyny due to their multiple identities. Young women described a lack of medical understanding of issues relating to menstrual, reproductive and hormonal health, feeling like their pain and symptoms are often minimised and that they haven’t received the treatment, care and follow up that they think they deserve.’

Similarly, VHS members including Age Scotland have shared anecdotal evidence of ‘health rationing’ for older adults, where people were refused treatment that could lengthen their life or improve their quality of life due to their age. A similar theme has been highlighted during the [Scottish Covid Inquiry](#), where Sara Redmond, Chief Officer of Development for The ALLIANCE, spoke about the reports of ‘Do not resuscitate’ (DNR) orders being requested for people with long term conditions. In her evidence, Ms Redmond spoke about one example where a mother was left “questioning the support that is available for her and her son now and in the future.” Such examples of discrimination could erode trust in health services for certain groups, thus leading to poorer health outcomes.

As such, this proposed framework would need to recognise and reflect the intersectional needs of people with long term conditions. A whole system approach is required to recognise and respond to the intersectional barriers many people with long term conditions face when accessing health services. As stated in our answer to question 15, this framework cannot just build on existing condition-specific strategies but must also map and interact with other relevant strategies, specifically those related to poverty and equalities. There is also a need to reflect these intersectional barriers in wider workforce planning and training plans.

18. Given that racism and discrimination are key drivers of inequalities, what specific actions are necessary to address racism and discrimination in healthcare?

As stated in our answer to question 17, discrimination has the potential to erode trust in health services as well as contributing to poorer health outcomes for those with long term conditions. Several of our members have particular evidence related to racism in health. [Amma Birth Companions](#), for example, provide support and advocacy to women and birthing people from migrant backgrounds and other underserved groups during pregnancy, childhood and early parenthood.

In a 2024 [Birth Outcomes and Experiences Report](#), they found that in 37% of recorded cases where a birth companion supported childbirth issues of discriminatory practice were reported. These include lack of attention, delayed pain relief, inadequate communication or consent, disregard for preferences, and insensitive or disrespectful treatment. Many of the examples cited in the report stem from a lack of knowledge or cultural awareness from NHS staff. As such this framework should include commitments to health workforce equalities training, including content about being anti-racist.

Conclusion

We can see value in the proposal to introduce a unified Long Term Conditions Framework but we have reservations about the potential for it to dilute condition-specific provision. We have provided a number of recommendations that we believe would help ensure any new framework is sustainable. In our response we have made the following recommendations:

- That the proposed framework would need to recognise the vital role of the third sector as an equal partner in the provision of services to people with long term conditions, with sustainable funding, access to data and meaningful engagement in decision-making.
- That a unified Long Term Conditions Framework cannot dilute existing condition-specific provision, despite the drive to identify efficiencies.
- That a unified Long Term Conditions Framework will only be successful in practice with a clear plan for implementation, clear lines of accountability and dedicated sustainable resource.

- That a unified Long Term Conditions Framework would need to adopt a whole system approach to address missingness in health, intersectional barriers, and health inequalities experienced by many people living with long term conditions.
- That key priorities to be addressed in a unified Long Term Conditions Framework should be workforce training around long term conditions and improved systems for sharing patient data with relevant practitioners.

Further Information

If you require additional information about any of the points made in this response or if you would like to discuss them further, you can contact our Policy and Public Affairs Lead, Sarah Latto, by emailing sarah.latto@vhscotland.org.uk.