Chest Heart & Stroke Scotland's response to the Scottish Government's Long Term Conditions Framework Consultation

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?**

   Yes/No. Why do you say this?

Chest Heart & Stroke Scotland is Scotland (CHSS) is the largest health charity working to help people with chest, heart, stroke and Long-Covid conditions live life to the full.

More people than ever before are living with these conditions. Right now, one in five (1.1 million) of Scotland's population is living with a chest, heart or stroke condition, or Long Covid which has a marked impact of their lives.

Every day in Scotland...

- **30 people** will have a **stroke**
- **32 people** will have a **heart attack**
- **16 people** will be diagnosed with **heart failure**
- **16 people** will be diagnosed with **coronary heart disease**
- **41 people** will be admitted to hospital because of **chronic obstructive pulmonary disease (COPD)**

We believe there should be no life half lived in Scotland and we work to make sure that people with chest, heart and stroke conditions and Long Covid can do more than survive – they can really live. Our No Life Half Lived strategy outlines our belief that every person with our conditions should have access to quality supported self management and community recovery to ensure they can live well with the long term impacts of their condition. We deliver an approach to this that is designed by people with our conditions and puts what matters to them at the heart. We also work to develop the partnerships that will enable this to be available across Scotland.

Our vision is to help shape a Scotland where people with our conditions can live their lives well. Full lives, with the right support, at the right time, and in the right place. We aim to reach an additional 175,000 people across Scotland by 2028 to ensure that no life is half lived.

As we will discuss throughout our response, our Community Health Support Service have become a key support for those living with chest, heart, stroke and long covid conditions. People supported by CHSS rated their health and wellbeing greater than those who didn't get CHSS support . The voice of people affected by these conditions is critical to how we develop

and deliver our services at CHSS, and how we advocate with them on the care that matters to them. Their voices must be at the heart of any national policy decisions designed to improve their care and support.

Whilst we are pleased to see that the Scottish Government has carried out some consultation with lived experience groups, we are not confident that this has been done to the extent we would expect for a policy shift of this size. We also question how much input has been sought from the clinical community, with only 50% of the health and social care stakeholders we spoke to, the majority of whom were clinicians, saying they were aware of this proposal before CHSS brought it to their attention.

To combat this, we have carried out our own consultation with these groups to ensure that their voices are represented in our response alongside internal stakeholders. We carried out focus groups which reached a total of 77 people living with one or more of the long term conditions and their carers. These were held in Aberdeen (Insch), Edinburgh (Pilton), Kilmarnock, Bonnyrigg and Larbert. Participants ranged from age 50 and upwards. We also consulted with 48 health and social care stakeholders through a survey, the majority of whom were clinicians, and held two in depth discussions with leading clinicians who work in our condition areas.

Based on our experience, as Scotland's largest health charity providing support to the one in five people living with one (or more) of four individual long term conditions, and after this consultation with lived experience and clinical stakeholders, we believe a programme of cross cutting improvement work could add value to some of the pathway elements that have been identified. Our own Community Healthcare Support Service model demonstrates the value this approach can have in providing holistic and cost-effective services, contributing to whole system interventions, whilst still retaining areas of specialism. Our engagement with clinicians and people with lived experience of the four conditions we represent suggests that this community can also see how this model could help improve support for their patients in specific areas of the ecosystem.

To be successful however, such a framework and any resulting action plans would need to be supported through adequate resourcing, strong leadership and robust evaluation, with the third sector as a key strategic partner, and cannot be viewed as a way to cut essential specialist services. We hold reservations about the Scottish Government's ability to meet these conditions and, as a result, question whether it has the capacity to meaningfully deliver such a programme on a national scale. We also hold concerns about the 'limited' nature of condition specific actions and the critical impact prioritisation of certain condition over others could have on long term progress on specific conditions. This position has been informed by, and is in line with, the views of 50 individuals from the health and social care industry, the majority of whom are clinicians. Chest Heart and Stroke Scotland are cautiously supportive of this framework, however focused leadership, funding and action must follow the warm words within this framework.

People living with the long term conditions we support face a number of challenges. In our One in Five research report we found that just under one in five (19%) people who responded said

their biggest concern was managing their condition. More than a quarter (28%) said their biggest concern was staying physically active, and around a quarter (23%) were worried that they might lose their independence. One in five people (20%) with our conditions were concerned about coping with depression or feeling down and handling stress or anxiety. More than one in three (37%) people with our conditions said they experienced loneliness as a result of their condition. These are just some of the worries and challenges that individuals living with our conditions face on a daily basis.

They also experience real challenges in accessing the support services they need to live well. Our One in Five research report found that less than half (45%) had accessed NHS rehab services. 24% of people said they were not referred to rehab at all, and nearly half (47%) of respondents said there was support they needed but they couldn't access it. One in seven people (14%) said that waiting lists were a barrier to them accessing the services they need, and more than two in five (43%) of people said their condition impacted on their mental health. It is clear that action is required to improve the support offered at a national level for people living with these conditions.

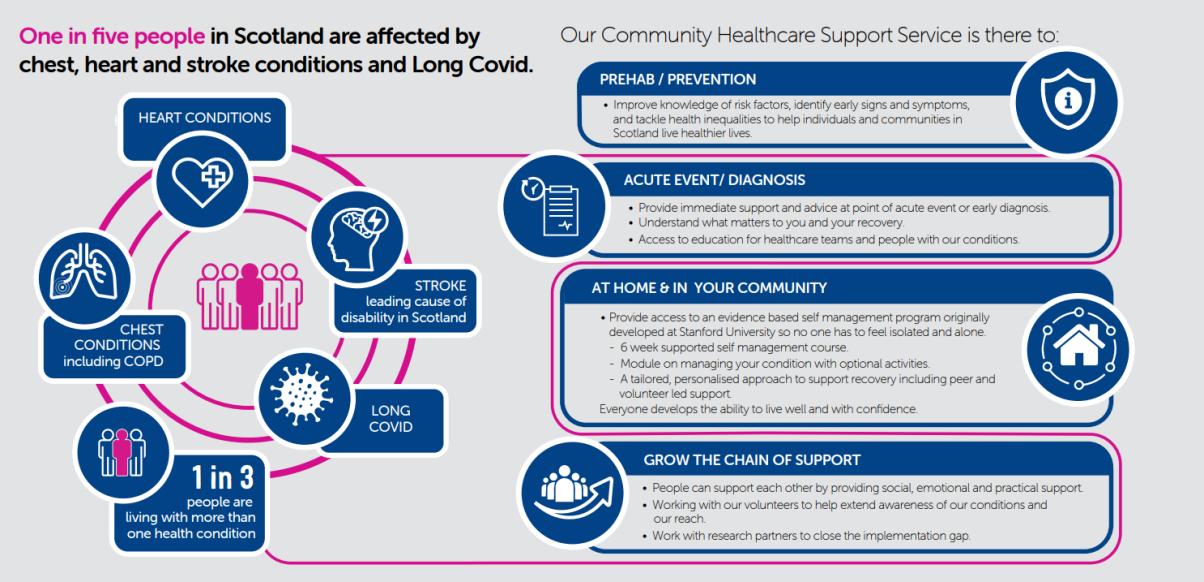
Chest Heart & Stroke Scotland's No Life Half Lived (NLHL) Model, delivered by our Community Healthcare Support Services Team, is a quality supported self management and community recovery pathway informed by clinical expertise and those with our conditions. The model includes a range of interventions to support people affected by chest, heart, stroke conditions, and Long Covid and is underpinned by the principles and ethos of supported self management. Core to the pathway is the delivery of an evidence based Chronic Disease self management programme originally developed by Stanford University. This programme empowers individuals to deal with the ongoing symptoms of living with a long term health condition 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.

This evidence-based model of cross-condition support services, supported by condition specific interventions, has proven to be successful. Our 1 in 5 report showed that people who had accessed CHSS support rated both their health and mental wellbeing higher than those who had not been able to access CHSS support. We believe that our model could be applied to other long term conditions and that our organisation can serve as an example of how this can be achieved. We would welcome the opportunity to share learning and work in partnership with the Scottish Government on this.

Our model offers support at all stages of an individual's journey with one of our conditions. Starting with support and information focused on prevention and prehab, it continues with an offering at the acute event/diagnosis stage, right through to support at home and in the community as someone learns to live with their condition. We then work to grow the chain of support through peer support, volunteering to help raise awareness and reach, and working with research partners to close the implementation gap.

It is important to note that the model recognises and supports:

- Supported self management in each key stage – we estimate that people with our conditions spend more than 95% of their time managing their condition outside of formal healthcare services
- The need for specialist skill sets, as per the needs of the individual
- Individuals can move between phases as needed
- Volunteers can contribute to all phases of the pathway
- Carers can access each phase of the model, as well as those living with our conditions.



The prehab/prevention stage of the model works to improve knowledge of risk factors, identify early signs and symptoms, and tackle health inequalities to help individuals and communities in Scotland live healthier lives. This is in part delivered through our Patient Information Forum Trusted Information Creator (PIF TICK) accredited health information, which provides a comprehensive range of resources applicable to multiple long-term conditions alongside condition specific content. This can be accessed online or in physical leaflets order at no cost to individuals or health professionals.

Our health defence hubs operate in low income, high deprivation communities and focus on bringing secondary prevention services to those communities most impacted by long term conditions, who traditionally may not uptake screening services or engage with health professionals. Their overarching aim is to empower individuals to make positive changes to their health and live healthier lives. At these hubs, we offer free health checks covering various aspects linked to long term conditions including as cholesterol checks, blood pressure monitoring, dietary reviews, and mental well-being reviews. Our teams of trained professionals are available to discuss individual health concerns and provide tailored support, including referring onto other services both within and out with the organisation. They also offer a range of free activities, such as exercise classes and groups walks, to encourage physical activity and social support. Crucially, our hubs actively work with local communities to shape services, ensure they meet local needs and gain trust within the community. Services such as these offer

a model we believe can work for other long term conditions and shows how organisations such as ours are a crucial part of the solution.

We have created a single referral pathway for clinicians, allied health professionals and individuals with any of our conditions to access support through our advice line. This single point of access ensures that individuals can receive the necessary advice, support and referrals to our range of services based on a 'What Matters To You Approach'. This ensures person centred support is delivered within a framework which works to support individuals to manage their conditions(s) in a way that can be applied regardless of the condition.

For example, our evidence based, structured six week Chronic Disease Self Management programme, originally developed at Stanford University, supports individuals to manage their condition with greater confidence and independence, regardless of which of our conditions they have. This group-formatted programme covers a wide range of topics from fatigue management to communication with healthcare professionals and has been developed for all chronic disease. From the almost 500 participants who have completed the course so far, data evaluation has informed us that 98% of participants would recommend the course, with participants saying that "it was life changing" and it helped them "make life changes to control my long term condition". It also saw a 32% improvement in patients managing fatigue, 46% improvement in managing difficult emotions and 30% improvement in managing pain and discomfort. From this success, we have started to roll this offering out to wider areas across Scotland as well as online.

Our clinical case management service is another example of support that can be tailored to different conditions. Accessed through our advice line and stroke nursing teams, we can offer 6-12 weeks of support to people with specific clinical professionals being allocated, depending on the condition(s) individuals present with. They are able to give individuals time to have in-depth discussions and receive the support they need, with the average appointment time for someone gaining support for Long Covid, for example, being 40 minutes.

Our pathway does account for the fact that some areas of support required will be condition specific, and it offers services to this effect. Our stroke nurses are an example of how we provide specialised support to individuals post-discharge from hospitals to ensure they receive support specific to their condition as they learn to live with the challenges specific to life after an acute event. This service is able to provide condition specific support in the way that works for each individual. One service user noted how this kind of support was 'invaluable to them' after a stroke and it also allowed them to be signposted to other useful services. They were able to go back to this nurse for questions further down the line as well. Another service user noted that "The CHSS Stroke Nurse provides very valuable time to discuss diagnosis and answer any questions. I had a few questions which had arisen in the few weeks since the initial shock of having a TIA. She was able to answer them all and put my mind at rest so that I can now move on." This agility and flexibility is a hallmark of third sector designed and delivered services – we can often move faster than public sector partners – this can both be a challenge and an asset. If an LTC approach is to work, the culture and systems change required within the NHS will be significant, and working with the third sector can bring expertise to that.

You can read more about our Community Health Support Service model in our 2023-28 strategy[1] and accompanying services information[2]. We would welcome the opportunity to meet to further discuss the model, and how it can inform the Long Term Conditions Framework.

Consultation with clinicians working on CHSS's conditions suggests that they also see the value in this approach to wider, long-term care. More than half of the 48 stakeholders we spoke to in health and social care said that they agreed with the proposed approach, and the potential benefits this could bring in allowing greater collaboration. The themes identified fit with the realistic medicine model and allow for greater person-centred care. However, they also raised concerns around what is required for the proposed changes to be effective. Firstly, they raised concerns around the potential deprioritisation of some conditions and the dilution of expertise and resourcing. Secondly, they expressed concern that this could lead to a lack of funding for improving single condition care, and thirdly, that this initiative would require additional funding if it is to be successful in increasing collaboration and cross condition working. We know that effective change requires investment, leadership, and strong action with explicit evaluation. Without all three areas, we risk commitments being unfulfilled.

Although the framework's design should reduce cost inefficiency in this policy area, it will still require adequate funding and investment. As noted in the Scottish Government's Population Health Framework, in the context of a rising burden of disease and an ageing population, we cannot afford to wait to invest in the future of long-term conditions and see problems continue to grow. The Respiratory Care Action Plan is just one example of an area of long term condition policy in which we have seen a marked lack of progress on due to lack of funding. We understand that resources need to be used more strategically, but we are concerned that this could be seen as a cost cutting exercise by the Scottish Government without sufficient investment to ensure impact.

We also need strong clinical expertise and leadership to head up such a change in culture in healthcare systems. Alongside their medical expertise, clinicians can offer a deep understanding of their specific strand of the health care system. Their knowledge of the dynamics and culture can be invaluable in navigating challenges, building trust, and creating buy-in for new approaches. The strong improvements we have seen in stroke care would not have been possible without credible clinical leadership being involved in the design and delivery of changes. We've also seen the challenges that can occur when clinical leadership isn't valued, as has been the case with the Respiratory Care Action Plan. The proposed cross-cutting approach will create challenges to this, but we believe it is essential that this is overcome. Expertise and leadership from across the long term conditions clinical community must be embedded into the framework and any resulting actions plans for success to be achieved.

Third sector organisations are essential to the successful delivery of this proposed shift in approach, and national service delivery organisations delivering in localities and communities across Scotland, such as Chest Heart & Stroke Scotland, have a key leadership role to play in its

[1] CHSS's No Live Half Lived Strategy 2023-28
[2] CHSS's Community Health Support Services model information

development and delivery. As demonstrated through our own service delivery in this area, the third sector is an essential partner in the design, development, delivery and evaluation of solutions to long term conditions. We have local knowledge and relationships with communities that are vital to achieving change in areas such as prevention – and a track record in successful implementation. We note, and welcome, the UK Government's new Diagnosis Connect programme[3], developed with the Richmond Group, which will ensure patients are referred directly to trusted charities and support organisations as soon as they are diagnosed. We believe that this is something that could benefit Scotland's approach and look forward to following the implementation with interest.

We are pleased to see the Scottish Government recognise the critical role the third sector plays in our health and social care system in recent publications, including the Public Sector Renewal Strategy. This needs to be reflected within this framework, with third sector organisations, especially those who specialise in multiple long-term conditions such as Chest, Heart and Stroke Scotland, being recognised – and respected - as key to the design and delivery of actions. It was disappointing that the Scottish Government did not accept our offer to use our experience as a service delivery organisation focused on long term conditions in the initial development of this framework. We hope that such organisations are explicitly seen as partners and key drivers of change in the final framework.

We also believe that a framework needs to be supported by strong and specific actions, along with an explicit evaluation and reporting model, for it to be impactful. We are pleased to see an action plan proposed to support this work and would encourage it to be bold but specific in its actions.

This has historically been a challenge for cross-cutting approaches or strategies for improvement within health policy. The Once for Scotland paper on 'Rehabilitation and recovery: a person-centred approach' is one example where we have struggled to see the impact of improvements due lack of built-in evaluation. It is also one of the reasons some long term condition policy areas have delivered results, with specific note of the Stroke Improvement Plan and Heart Disease Action Plan that have regular reporting cycles. This element only works if adequate funding and leadership is also provided.

We would also like to see an evaluation of the success of comparable strategies in other countries before progressing with this approach. We are in a fortunate position to have had other nations take this approach first, and lessons can undoubtedly be taken from their experience. We hope the Scottish Government can learn from those who have gone before us to ensure that Scotland's Long Term Conditions Framework can be as strong as possible.

We do hold some concerns about the impact of prioritising certain conditions over others for condition specific actions, particularly on acute care for conditions. Whilst we believe that a cross-cutting approach can have benefits for the prevention, data collection and monitoring, and supported self-management of multiple long-term conditions, there are many areas,

[3] The UK Government. Patients with long-term conditions to receive help from charities. July 2025

particularly in acute care, that are condition specific. Whilst this has been recognised within the consultation paper, we fear that the limited room for condition specific actions will lead to these actions being deprioritised, contributing to a lack of improvement in care and outcomes. This could inadvertently increase the burden of disease caused by long-term conditions, creating more health problems for individuals and increasing disease burden as a whole.

In our own work, for example, we can see the vital need for improvements to acute care for our different conditions which, in the proposed system, will compete for limited resources. For those who have experienced ischemic stroke, access to 24/7 thrombectomy is a priority, with those receiving the procedure three times more likely to live an independent life. For those living with COPD, we need to improve diagnosis wait times through improving access to spirometry. These improvements have very different yet pressing priorities and whilst supported self management and other actions can support people to live better, their chances of achieving this will be greatly diminished without access to the best acute care and diagnosis tools. In our consultation with clinicians, they have highlighted their concerns about deprioritising this kind of condition specific policy actions, which drive improved care and require long term clinical input. We're pleased to see the framework acknowledge this, but the limited room for this form of action causes concern. The prioritisation of certain condition-specific actions over others will leave vast ranges of the population without access to vital care they need – we hold concern and caution about this element of the proposal.

We are also concerned about how this element of the framework could impact on the ground delivery of acute care in the long run. Whilst we don't see an intention to do this in such a strategy, colleagues within our services team raised concerns that it could create an inadvertent culture which moves away from necessary specialisms. We have heard anecdotal evidence from NHS AHP's who have been asked to move their focus away from their specialism to take on more conditions, which has made it difficult for them to maintain their specialist skills which are much needed. We would like to see action taken to ensure that a new framework doesn't take away from the value of condition specific specialisms in professional fields – particularly in relation to acute care. There will also be condition specific challenges within the cross-cutting commitments which, without dedicated awareness and effort, could increase inequity across conditions. Even within our own conditions, some exceptions and adaptations are required to ensure support can be given to all who need it. For example, those who are impacted by aphasia, a broad-spectrum language disorder that impacts 1 in 3 stroke survivors, require different forms of communication and support from others. We have adapted information and developed a supported self-management programme specifically for this group as a result. Those with aphasia are just one example of the challenges unique to one condition. Any cross-cutting commitments would need to navigate these challenges to ensure all can experience improvements in a meaningful way.

Prior to the launch of this consultation, CHSS offered to work with Scottish Government to help shape proposals on long term condition care. This offer was initially accepted, and then rescinded. Involving both clinical and third sector feedback would have allowed Government to both address these concerns, and benefit from the expertise of the third sector to create a

stronger and more comprehensive approach to long term condition care. The voice of lived experience is also essential to shaping policy developments in this area. This must continue through meaningful engagement and participation as this work continues.

In summary, as a long-term conditions charity and health service provider, we see the value that taking a cross-cutting approach to improvements of long term condition policy and, with the correct systems and resources in place, we would support a move to such a model. As a leader in support service delivery for multiple long term conditions, our own models evidence how a multi-condition approach to condition management have value. At Chest Heart & Stroke Scotland we are currently in the process of further developing data sets to demonstrate this. We would welcome the opportunity to share this learning with the Scottish Government.

We do have concerns about the proposal to prioritise certain condition specific improvement actions over others and we would want reassurance, met with meaningful action, that no long term condition will be overlooked or left at a disadvantage as a result of this change. Third sector service delivery organisations must be explicitly noted as key partners in the design and delivery of such a framework, alongside clinical expertise and lived experience.

2. **Are there any improvements in prevention, care or support you have seen in a long term condition you have, or provide care and support for, that would benefit people with other long term conditions?**

As discussed in our response to the previous question, we believe that Chest Heart & Stroke Scotland's Community Healthcare Support Services pathway offers a model which could benefit those with long term conditions beyond the four we serve. The elements of this model align with the cross-cutting themes identified in the consultation, including prevention, supported self management, health information and professional engagement.

Our model offers support at all stages of an individual's journey with one of our conditions. Starting with support and information focused on prevention and prehab, it continues with an offering at the acute event or diagnosis stage, right through to support at home and in the community, before continuing to expand the chain of support. We would like to reiterate our offer to discuss our model, and the benefits we believe it can offer to wider long term condition management, further with Scottish Government colleagues.

We also believe that some of the advancements we have seen at a national policy level within specific conditions could be applied, with benefit, to other long term conditions. The concept of the stroke care bundle is an example of this. Since its introduction in 2013, it has improved the baseline provision of these elements of stroke care. This has reduced mortality rates and improved functional outcomes and, whilst many health boards are still aspiring to reach these stretch targets, the model has created a culture which drives progress and improvement toward greater equity in access to care through a clear and measurable standard. The way the bundle framed the essential elements of critical care, and the supporting monitoring through the Scottish Stroke Care Audit, helped to create a culture change in stroke treatment, applying an urgency we see in other traumatic events, such as cardiac arrest. We are aware of, and support, conversations to develop a national care bundle for COPD care.

The idea of 'bundling' key aspects of care to create a trackable standard of care could be applied to other conditions with benefit. For example, Diabetes UK note in their 'Diabetes health checks (annual review)' resources that people 'are less likely to have their urine check for kidney disease, eye check and foot check than the other diabetes health checks [such as blood pressure check and HbA1c Test]' in their annual health check. Lessons could be taken from the stroke care bundle, and supporting data, to create a new standard that benefits clinicians and patients alike.

The data-driven element of this work has been essential to making progress. The Scottish Stroke Care Audit has allowed real-time feedback to hospitals, benchmarking across health boards and targeted interventions where performance lags. For example, data showed that only 33% of stroke patients in NHS Highlands received the full bundle in 2022[4]. This allowed them to make targeted interventions which led to an increase to 45% in 2023. Data is essential to enabling progress, and other long term conditions, including respiratory conditions, would benefit from a similar audits.

Clinical leadership has also been key to realising improvements to stroke bundle delivery, amongst other improvements to stroke care. Local stroke leads and Managed Clinical Networks have enabled tangible change by adapting national goals to local contexts. Funding for clinician-led projects to improve cardiovascular disease has also seen good updates and success, with clinicians being able to drive change locally and tangibly. Empowering and embedding this leadership in solutions is something other conditions could benefit from.

The Cardiovascular Disease (CVD) Risk Factors programme is another improvement which other conditions could benefit from. We have welcomed this work with a focus on prevention and would be interested to see it applied to other long term conditions where risk factors can be identified in individuals. The risk factors for CVD are not exclusive to CVD. In particular, the CVD DES is a great example of an improvement that is working well. In line with the Population Health Framework's prevention focused system principle, we hope to see work on long term condition prevention expand in partnership with third sector service delivery partners, and see where such programmes could be expanded to wider long term conditions.

Improvements on both stroke and heart health have in part been possible due to the resourcing allocated within Scottish Government to drive it. As we have seen within respiratory policy, which receives one part-time civil servant's time, it is hard to drive change without the capacity within policy-making structures to facilitate the work and funding to match this. However, even where an approach has been successful, it has features of inconsistency of implementation across health boards and outcomes for patients. This has to be kept in mind for a future model.

Mass public education and awareness campaigns have enabled improvement that other conditions could utilise. While these are usually condition specific, there is an opportunity to explore how cross-condition risk factors (i.e. hypertension) can be addressed. Furthermore, this is also an area where the third sector can lead with new campaigns, reaching more people and

[4] Public Health Scotland. Scottish stroke improvement programme annual report. 2024

engaging them in preventative health behaviours. The F.A.S.T public awareness campaign, which aims to raise awareness of stroke symptoms, is a key example of how the third sector can effectively support delivery here. In October 2024, Chest Heart & Stroke Scotland relaunched a F.A.S.T stroke awareness campaign in place of the Scottish Government's previous campaigns, in partnership with the Scottish Ambulance Service and supported by Lane Agency. Research suggested that awareness of F.A.S.T amongst Scottish adults aged 18+ increased from 62% pre-campaign launch to 68% post-campaign launch.

It is important to note that many of the improvements we have seen in our relevant policy areas are condition specific. As noted in the consultation paper, improvements to door- to-needle time for stroke patients and improved survival rate for out of hospital cardiac arrests have required specific action. Specialist care, and improvements specific to specialism, much continue to be a priority. Clinicians have raised this concern with Chest Heart & Stroke Scotland during consultation.

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.**

   Please give reasons for your answer.

As previously mentioned, we have concerns about the selection of condition-specific actions as we believe that this will lead to deprioritisation of vital improvements.

We also do not agree that this question should be answered through a written consultation question which allows no room for dialogue. Instead of transactional questioning, we feel this would be best addressed through a meaningful conversation with key partners around evidence-based methods of prioritisation. This would need to follow co-production principles and be held in a safe and respectful environment.

This question also fails to recognise the diversity of both the organisations and their governance arrangements that will respond to this consultation. With charities being regulated under OSCR to act towards their stated charitable purpose, organisations are duty bound to advocate towards the mission they were set up to deliver. Charities are usually, particularly in health, set up to plug gaps in current health systems by citizens willing to donate their time, money and expertise. Without further conversation, we risk conditions which have great advocacy levels (either due to size, volume or mission of organisations representing their interests) becoming defacto priorities. Clinicians have also shared with us their concerns that conditions could be selected by lobbying rather than evidence. We are concerned for our partners within the third sector and beyond who may stand alone in their support of or advocacy for a specific condition. Systems must enable voices to be heard and the diversity and inequity of current health systems acknowledged.

It is also unclear what methodology has been used – and been used consistently – in deciding clinical priorities to date. Without this information, we risk losing vital experience required to build a strong foundation in a new system or risk having no comparison for measurement.

From an external perspective, it appears that the majority of improvements cited seem to have been made following direct pressure from civil society. The examples given within the consultation paper the six dimensions of healthcare quality can be traced back to campaigning action by third sector organisations and/or proactive clinical leaders with a specialist skills set or interest. They have also been pivotal delivery partners across many of these actions. The creation of a national learning toolkit and knowledge hub for Chronic Pain was achieved, in significant part, by campaigning work led by the Cross Party Group on Chronic Pain. Epilepsy Scotland led the campaign to establish the Scottish Epilepsy Register, which enabled 100% of women with epilepsy in NHS Greater Glasgow and Clyde to be offered specialist appointment.

The third sector, including our organisation and the British Heart Foundation, have been key to the successful delivery of the Out of Hospital Cardiac Arrest Strategy. Chest Heart & Stroke Scotland also proposed the idea for, and delivered, long covid information to be provided in different languages to reduce isolation and loneliness.

Not only have organisations brought these issues to the Scottish Government's attention, but they've often had to fight to keep issues on the agenda. Increased access to thrombectomy services has only been achieved through repeated campaigning by Chest Heart & Stroke Scotland – both to restate the procedure and then protect it from yet further cuts. The establishment of a national diabetes technology roll out programme to provide hybrid closed loop systems to any child or young person who wishes to use it may be clinician led, but it has been kept alive through patient voice in Diabetes Scotland campaigns such as 'Pump up the Volume' and 'Diabetes Tech Can't Wait'.

These are just some of the ways in which the third sector and clinical specialists have been integral to improving condition specific care. The development of criteria for how condition specific work should be selected should be a top priority for any new approach to Long Term conditions and should be developed in partnership with people living with long term conditions, with clinicians, with NHS and social care leaders, and the third sector partners who provide significant in community support, insight and expertise.

We would like to highlight some key considerations that we believe are vital to further conversations and considerations on this topic:

- **Population impact**: prioritisation criteria must consider the level of impact across the organisation that an action on a specific condition can have. If resources must be prioritised, then this system will enable the framework to reach the most people. This should not be solely focused on cause of death rates, but widen out to incorporate factors such as cause of disability and impact on healthy life expectancy, as well as impact on society as a whole.

For example, cardiovascular disease and stroke are two of the biggest killers in Scotland, followed closely by respiratory disorders, with COPD killing three times more people in Scotland than breast cancer each year[5]. Taking action on these conditions is essential to ensuring the most people benefit from condition specific policy work.

- **Equality impact:** as we discuss in our answer to question 18, all proposed actions within the framework should include equality impact assessment to ensure that actions do not disadvantage any protected characteristics or demographic . We suggest that prioritisation tools go further than this and ensure that conditions that have a disproportionate impact on marginalised communities and protected groups are given fair, and perhaps ring fenced, consideration for condition specific action. For example, someone from the most deprived area of Glasgow is 8 times more likely to be hospitalised for COPD than someone in the least deprived area of the city. Whilst kidney disease ranks 10th in terms of prevalence in Scotland's disease studies, it is more common and progresses faster in Black and South Asian communities[6]. We need a way of identifying and accounting for this to ensure the needs of different communities in specific actions are accounted for.

- **Structural challenges and lack of representation**: We also need to account for conditions which are less understood, less well known, or lack clinical representation to ensure they aren't left behind in this work. For example, an estimated 2500 people in Scotland live with Interstitial Lung Disease(ILD), an umbrella condition covering a number of respiratory diseases. Idiopathic pulmonary fibrosis(IPF), one of the conditions listed in the respiratory care action plan, is an ILD. However, due to lack of awareness, capacity and specialist expertise, progress on improving care for people with ILD has been slow. This is important because a diagnosis of IPF brings with it the knowledge that the person living with the condition has 3-5 years to live – and so appropriate care needs to be delivered in a timely manner.
  A survey with Scottish Health Boards in 2023 revealed that two thirds of respondents felt their service did not have capacity to meet the current demand[7]. Within this, specialist clinics and clinicians were only available in 7 health boards which is delaying diagnosis and acute treatment. With a condition that currently has a 3-5 year life expectancy after diagnosis, a targeted intervention to improve this could make a dramatic impact for those impacted.

[5] National Record of Scotland. Vital Events Reference Tables 2023: Table 6.04: Deaths, by sex, age and cause, Scotland, 2023
[6] Stafford M, Steventon A, Thorlby R, Fisher R, Turton C, Deeny S. Briefing: Understanding the health care needs of people with multiple health conditions . 2018
[7] Interstitial Lung Disease Interdisciplinary Network, Interstitial Lung Disease Service Evaluation: A snapshot of specialist interstitial lung disease (ILD) services in the United Kingdom and recommendations for improvement. 2023

We invite the Scottish Government to be open to innovative ideas and suggestions such as the progress work on a prioritisation model with the partners we have discussed. For example, different strands of condition specific work could be considered to allow for action on conditions that have greatest population impact to be prioritised, whilst still allowing room for vital action on other conditions that are less known or impact marginalised communities to be taken.

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

Better integration of third sector health information and services within the NHS would help people find information and services more easily, with referrals from trusted medical professionals essential to increasing access.

In Scotland, there are over 2000 voluntary health organisations that already provide a wide range of services and support to help people manage and mitigate long term health conditions. Chest Heart & Stroke Scotland alone provides a wide range of information on specific conditions and wider management of long term conditions via leaflets, our website, and advice line. These sit alongside a wide range of services such as clinical case management, supported self-management, supported access to movement and exercise, and peer support groups.

However, the challenge lies in how best to make people aware of services outside of the traditional NHS offering. With so much misinformation online, as well as the volume of information available, accreditation marks on information and referrals from trusted health professionals are essential to enabling people to engage with health information and services.

Now more than ever, accreditation marks such as the Patient Information Forum Trusted Information Creator (PIF TICK) are vital to ensuring people can be confident in discerning which health information to follow. All of Chest Heart & Stroke Scotland's health information is PIF TICK accredited which ensures individuals can trust the guidance we issue. There is a need for more awareness of PIF TICK to help people understand the value of the accreditation mark when seeking out information.

Alongside this assurance, health professionals have a role to play in directing people to trusted information. People living with our conditions noted that they feel more confident in receiving information and referrals to services directly from their medical teams rather than relying on their own research. Referrals from GPs, Community Link Workers and wider primary care professionals in particular are vital.

From our own experience, we know that referring patients directly to services, rather than signposting, is the most effective way to ensure people can access the services and support we need. In health boards where Chest Heart & Stroke Scotland have service level agreements to provide follow up care, we find that a much higher number of people with our conditions are able to access our services. Removing barriers to referrals will ensure people have access to vital information and services.

The creation of a single point system to enable health care professionals to be aware of what services and information available within the third sector, and supporting systems to create simple referral pathways onto services, could remove barriers to people engaging with the many avenues that already exist.

An example of where this has worked well is our pilot COPD referral pathway. Launched in November 2024, the Mid-Lothian Community Rehabilitation Team (CRT) trialled directly referring COPD patients to CHSS for ongoing support. Referrals come through our online portal, and every individual referred receives a call within three working days. During this call, they're given an overview of the services available, helping them make an informed decision on the support they need. Work also needs to be done to ensure that primary care professionals see the third sector as key delivery partners and part of the solution to long term condition information and support. They hold public trust and if they are not aware or do not see the value of services with clinical expertise on long term conditions out with of the NHS offering, individuals could miss out on key elements of additional support. Our services and information offer a wider, whole person approach which can complement clinical guidance and services. There are other clinical areas where trust and awareness in this audiences have been achieved, such as third sector hospice provision. Work to improve trust for long term condition organisations would ensure that individuals can fully benefit from existing services is essential.

We note the UK Government's new Diagnosis Connect programme, which aims to ensure patients are referred directly to trusted charities and support organisations as soon as they are diagnosed. Such a model could offer a solution to this challenge and we will be monitoring the implementation of this with interest.

As we will address in later questions, there is also a range of factors which should be kept in mind including the challenges presented by inequalities, language and cultural barriers, accessibility issues and digital exclusion.

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

We know that people see their GPs and professionals associated with their GPs practices as their single point of contact for accessing care and support for long term conditions. This emerged as a key theme for some of the focus groups with service users for this consultation. On the one hand, we know that improved access to appointments and primary care in general is a key issue needing to be addressed through wider NHS reform. The challenges associated with accessing this causes real distress to individuals living with our conditions, and it was one of the top priorities for improvement they highlighted during focus groups for this consultation.

However, we also need to move towards a wider view of primary and community care that includes the third sector, pharmacy and other community players. As noted in our answer to question 4, referrals from GPs and other trusted clinical staff to resources and services beyond the NHS will support this transition. Some of the individuals living with conditions shared that

they just want to speak to someone knowledgeable, indicating this doesn't have to always be traditional primary care but can be other trusted partners.

Support specifically focused on long term condition management is essential to improving access, and the third sector play a vital role in delivery. Chest Heart & Stroke Scotland's supported self management programme has been developed with specialist clinical skills to ensure that people can manage their condition and find additional support in an informed way. Our supported self management approach also supports personalisation, not just based on condition, but that specific individual's needs. This model, which could be applied to other long term conditions, demonstrates an avenue for increasing access to care and support without increasing pressure on the NHS.

Reform to data sharing systems would enable greater access to such services offered by third sector and community partners. Please refer to question 6 for more information on this.

Social prescribing has a key role to play to ensure individuals can access the full range of services available to them to make preventative lifestyle changes and gain support to manage a long term condition. Community link workers have a key role to play in ensuring an individual's needs are identified and connected to support, such as CHSS services. Our own services also have a role to play in social prescribing, with our advice line, clinical case management service and health defence teams able to refer individuals onto other internal and external services. Communications to the public around what is available through other channels needs to be explore as well. A review of pathways for long term conditions and where, when and how information is being offered would allow for a better understanding of where opportunities are being missed. Chest Heart & Stroke Scotland have identified an opportunity to improve awareness of services through our own referral pathways and stroke packs, issued before someone is discharged from hospital, to ensure people get direct information to services available to them. Lessons could be taken from this model and applied to wider long term conditions.

Rural communities experience wider challenges to accessing services, with geographical distance, transport challenges and digital connectivity creating barriers to engaging with services. Compared to urban localities, they are less likely to have local service offering and will have to travel to access services. Travelling may not be possible or practical for some individuals due to the nature of their condition and resulting disability, availability of transport or lack of time available to make journeys. Digital solutions offer an opportunity to improve equity in access to services across Scotland's regions, if supported by inclusive practices and digital connectivity improvement work. We offer a number of our services via online channels (e.g. online supported self management courses and physical activity offerings) which can benefit these communities.

This needs to take place alongside continued investment in wider primary and secondary care services, alongside workforce planning. For example, people living with our conditions find that access to rehabilitation services, such as physiotherapy, continues to be an ongoing challenge due to waiting lists times. A survey by the Chartered Society of Physiotherapy found that a

staggering 98% of physiotherapists say they are concerned that current staffing levels are inadequate to meet patients' needs[8]. Workforce planning and investment in specialist services which people may require to live well with their condition must continue to be a priority. In many ways, this is about catching up with long term disinvestment. This is the first step, as with speech and language therapists and other allied healthcare professionals, on the journey to supported self management, which can be delivered by a range of professional and volunteer support. This is also the referral step – without an appropriate assessment individuals are not referred to the relevant next service.

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

The most effective way to improve the sharing of health data is through better integration and standardisation of data systems, both between individual NHS Health Boards, and between health boards and third sector services. We believe a simplified, nationwide approach to data sharing with the third sector would be much more efficient than current approaches, allowing a whole system approach to sharing of health data. This would allow us to support more people across multiple health boards by being able to receive and share appropriate levels of service user data, offering the best holistic support possible and reducing the burden on statutory services. It should be remembered that the data is not 'the NHS's' - the data is owned by citizens, and they should have full access to their health data and information.

Scottish Government and partners have singularly failed to deliver a national health record or seamless patient information between services and localities. The CHI number, first introduced in the 1970's in primary care, has seen a new system delivered in 2023 including, for the first time, exploring roll out to community and social care – a step that seems obvious and not before time. CHSS has lobbied for a better governance system to enable third sector delivery partners to more seamlessly access CHI and health and social care data systems to aid smoother referral processes for the individual and collated data to analyse impact and identify areas for improvement – progress on this is extremely slow. The Kings Fund has published a plethora of documents, including one specifically on long term conditions, and how the specialised nature of NHS structures and the barriers of poor data integration.

Those living with our conditions share the challenges current systems have created for them in receiving the right follow up care. One participant shared how her GP was not even aware she had a stroke when she booked an appointment to discuss side effects of medications. The participant noted it "lowered my confidence in the system and in the GP." The Royal College of General Practitioners has repeatedly highlighted the challenges current data systems create on their ability to provide care. They have said that 'IT systems must be developed which enable

[8] The Chartered Society of Physiotherapists, Discharge to sink or swim: the human cost of Scotland's physiotherapy shortage. 2024

information to be shared which is relevant to a person's care, to reduce duplication, repetition and the risk of gaps and lack of access to relevant data[9]'.

In our own experience as a health service provider, challenges in both receiving and sharing service user data with NHS services can become a major block to being able to holistically support an individual. Individuals tell us they find that different professionals in their NHS teams often don't have information from one and other.

Referrals outwith NHS services are challenging, requiring significant effort either from the point of the clinician or from the service provider (particularly through complex data sharing agreements). As a service provider, we find there is insufficient integration to allow us to send information back to a service users' GP, or other parts of their clinical team. As an organisation, we navigate different systems across 14 health boards, 32 local authorities and 30 integrated joint boards which we estimate costs our charity £250k a year in resources and staff time. This money could instead fund staff time to answer 2500 calls to our advice line or provided 12,500 hours of vital one-to-one support at home which would enable us to support an additional 1000 people after a hospital stay. This inefficiency not only negatively impacts public service provision but also on third sector service delivery organisations' wider ability to support individuals.

Work to integrate systems so that information could be easily accessed by all involved in supporting someone's care would be most effective solution to this. Improvements could be also made through better training and awareness of current data sharing agreements, so that NHS staff are aware of where people can be referred for further support. We have found that even when data sharing agreements are in place, staff involved in an individual's case is not aware of this. For example, sometimes our stroke nurses will receive a referral but not receive all the information they require due to a lack of awareness that we have an agreement in place. Greater integration, ideally through the development of a nationwide approach to data sharing with the third sector, would be more efficient and support a whole system approach.

Any improvements to data systems must be accompanied by upskilling of staff to ensure uptake as well as consideration to the time given to enable effective data sharing on a day-to-day basis. This culture shift might take time but with correct systems, training and leadership we believe it can be achieved.

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.

Non medical services are essential for long term condition management, and can mitigate the physical impact of health conditions, improve mental health and wellbeing, and reduce isolation. The third sector is a leader in providing support to help people manage their health,

[9] Royal College of General Practitioners, RCGP Scotland's relationship with IT, eHealth and digital. 2023

including both specialist clinical services and peer support groups. Scotland has over 2000 voluntary health organisations that already provide a wide range of services and support to prevent people developing serious health conditions and help them manage and mitigate long term health conditions.

Chest Heart & Stroke Scotland is a national delivery organisation and has a wide range of services outside traditional medical care which is proven to help individuals manage long term conditions. This includes:

- **Supported Self Management Skills -** Our evidence based, structured six week supported self management course, originally developed at Stanford University, supports individuals to manage their condition with greater confidence and independence, regardless of which of our conditions they have. This group-formatted program covers a wide range of topics from fatigue management to communication with healthcare professionals which could be adapted to serve wider range of long term conditions. From the almost 500 participants who have completed the course so far, data evaluation has informed us that 98% of participants would recommend the course, with participants saying that "It was life changing" and it helped them "make life changes to control my long term condition". It also saw a 32% improvement in patients managing fatigue, 46% improvement in managing difficult emotions and 30% improvement in managing pain and discomfort.
- **Peer Groups –** we partner with over 120 peer groups, which give people with our conditions access to social support. Peer groups are essential in helping people build new relationships, learning new skills to manage their condition, and building their confidence. The value of peer support was raised repeatedly by people with lived experience in relation to managing their conditions effectively.
- **Physical Activity** – We offer a range of activities to help people stay active, including walking groups, walking football and boccia. Physical activity helps people maintain their fitness, reduce their risk of a major health event, and builds wellbeing.
- **Health Defence -** Our Health Defence Hubs, which offer health screening, advice and support, and physical activity programs, are an example of how we can increase prevention, early diagnosis and manage progression. By focusing on geographical areas with high levels of deprivation, we've been able to bring targeted support to those most at risk of developing one of the conditions and who will therefore gain the most benefit. Our hub teams work with these communities to design services, building trust and engagement as a result.
- **Access to specialist advice -** Our advice line is a valuable resource which allows individuals and loved ones to gain information on and support to manage a long-term condition. From one off-calls through to 8-12 clinical case management, this service offers a service that can provide holistic support to individuals to learn to live with their condition that might not be available to them from primary care providers. For example, an individual with long-covid has an appointment time averaging 40 minutes with one of our clinical team on the advice line as opposed to 10 minutes with their GP. Our

multidisciplinary team allows us to carer for the range of conditions we support in a seamless way and also enables referrals to other services we offer. They also offer support beyond the medical elements of our condition, with specialties extending to rights, cost of living and benefits which are key elements to someone's holistic health.

The services we offer, and the pathways to accessing them, offer a model which we believe can be replicated to serve the prevention and management of other long-term conditions. We reiterate our offer to discuss this in greater detail with Scottish Government colleagues.

Throughout all of our services, there is an offering of emotional and mental support which individuals often require when managing a long term condition. Whether it be through our clinical case management, supported self management programme or kindness calls, individuals are seen as whole individuals and are supported in this area of their health as well. Services such as ours which support metal wellbeing and reduce isolation and loneliness are key to ensuring people are fully supported when living with a long term condition.

Social prescribing is essential to enabling people to access services such as ours. Community link workers have a key role to play in enabling referrals and encouraging people to engage in services that could benefit their long term condition management. Our own services are able to offer social prescribing services as well with, for example, our health defence teams able to direct individuals towards other programmes such as our physical activity offering or wider services beyond CHSS.

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

   Please give reasons for your answer.

Ultimately, the largest barrier people have in facing these non-medical services is a lack of awareness and support to access them.

As we have discussed in our answers to previous questions, people living with long term conditions see medical professionals as their initial trusted source for information on their health and where they can receive support. Referrals from health and social care partners to other evidence and clinically based services designed to support people to live well with long term conditions, such as Chest Heart & Stroke Scotland's, are essential to improving access.

The lack of awareness of, or value placed on, third sector and community services are a barrier to referrals happening on a consistent basis. We are aware that such service providers are not always seen as valuable by some professionals. We were pleased to see a recognition of the importance of the third sector's role in health and social care within Public Sector Reform Strategy. It is essential that their role is embedded into strategic policy work on long term conditions to help ensure we create this culture change across systems.

There are also challenges in ensuring that health and social care professionals are aware of where they can refer people onto. Community link workers have a valuable role to play in the solution to this. National service provision organisations such as Chest Heart & Stroke Scotland

that can support multiple conditions become a key answer to this as professionals can be assured that we can offer support to individuals regardless of their location. Our advice line, which acts as the front door to our services, is available to anyone in Scotland. We are able to triage people to support appropriate to their specific condition and locality and signpost to other organisations if it is more appropriate.

Where awareness and willingness to refer to these services exist, the current challenges around data sharing, making referrals and ability to support are barriers. We need to see greater integration of systems and solutions, such as a single referral system for third sector services, developed to ensure everyone can access services. Our own referral system aims to make it as simple as possible for professionals and individuals to refer in, but we cannot overcome these challenges fully without structural changes.

Alongside improvements to awareness and referrals, there are a number of structural challenges which require a whole systems level approach to creating equity in access:

- **Geographical equity in service provisions:** there isn't equity in the provision of non-medical services across the country. Whilst solutions should be designed with individual community needs in mind, we do see examples of individuals in certain communities who will be able to access support that others cannot. National service delivery organisations such as Chest Heart & Stroke Scotland can be instrumental in creating national approaches with local delivery. Our Community Health Support Service can be applied across the country to create uniformity in offering.
- **Transport challenges:** individuals, particularly those in rural communities, may not be able to access the transport they need to get to non-medical services. Online offerings, such as our online physical activity and peer support groups can help circumvent these challenges but wider improvements to transport access are also required.
- **Financial barriers:** even where services are available and known of, those who face poverty and deprivation face additional barriers to participating.

Rural communities experience wider challenges to accessing services, with geographical distance, transport challenges and digital connectivity creating barriers to engaging with services. Compared to urban localities, they are less likely to have a local service offering and will have to travel to access services. Travelling may not be possible or practical for some individuals due to the nature of their condition and resulting disability, availability of transport or lack of time available to make journeys.

One way this could be overcome is through stronger integration, as seen in the newly announced UK Government's new Diagnosis Connect programme. Developed with the Richmond Group, the scheme will work to ensure patients are referred directly to trusted charities and support organisations as soon as they are diagnosed. We look forward to monitoring its implementation and what lessons can be applied to the Scottish context.

9. **What should we know about the challenges of managing one or more long term conditions?**

In Scotland, it is estimated one in five people live with a chest, heart, stroke conditions or Long Covid. In Scotland, around 154,000 people in are living with the impact of a stroke, 217,000 are living with coronary heart disease, 555,000 are living with asthma or COPD, and since 2020 it is estimated that 180,000 people have developed long covid[10].

The challenges of managing one or more long term conditions are well known and rehearsed. Below we provide a summary of these, but the real challenge is taking action to address those issues and create real change. We hope the Scottish Government can make real change based on these issues so that the 1 in 5 people living with our conditions, and beyond, see action rather than words.

Managing one or more of these conditions is an incredibly challenging experience for individuals on a physical and emotional level. It involves significant changes to their lives and not only navigating, and fighting to gain access to different services and specialists, but learning to live life with adapted abilities, changes in capacity to work and shifts in family dynamics. People with our conditions tell us that one of the most difficult transitions is from acute event/diagnosis to coming to terms with a changed life – and what happens next. Not enough time and resource is focused and invested in this.

The Kings Fund has produced research which further highlights the current challenges clinical co-ordination of care for people with multiple long-term conditions[11]. They note that 'current models of care based on isolated care plans and siloed service pathways lead to poorer experiences and outcomes for people and inefficiencies for service providers' and that improving the coordination of care will require changes to how both clinicians and supporting systems operate. We would encourage the Scottish Government to read their findings and recommendations.

Managing a long term condition takes up a significant amount of an individual's time, and we estimate that 95% of management happens in homes and communities, outside of formal health and social care settings. In our 1 in 5 report, nearly eight in ten (78%) people who responded felt that they had a key role to play in managing their condition, with support from health professionals. Fewer than one in ten (9%) felt that their healthcare provider was ultimately driving management of their condition.

There are some common challenges individuals face regardless of which of our conditions they have. In practical terms, these include:

- difficulties in managing fatigue
- pacing their energy
- problem solving
- managing medication
- healthy eating
- coping with difficult emotions

[10] Public Health Scotland, General Practice - disease prevalence visualisation. July 2025
[11] The King's Fund Improving Clinical Coordination Of Multiple Long-Term Conditions. May 2025.

- learning how to effectively communicate with healthcare professionals.

Our evidence based, supported self management programme is designed to help individuals build skills and support in all of these areas and more.

There are also more common structural challenges which people living with our conditions face, the most prominent being their ability to access the services they need on an ongoing basis. In our 1 in 5 report, nearly half (47%) of people we spoke to said there was support they needed but weren't able to access, and more than half (65%) experienced some kind of difficulty in accessing services. One participant in our focus groups showed emotion while explaining his experience of having no support after leaving hospital. He showed a lot of compassion for the medical professionals but said his entire experience has been *"soul destroying"*.

People with our conditions often find that their follow up care is minimal, and many said they weren't sign posted or referred on to wider support services such as peer groups. This is supported by findings in our 1 in 5 report, which found that only half (45%) of people with our conditions had accessed NHS rehab, and a quarter (24%) of people said they were not referred to rehab at all. A small number of people in our focus groups had been offered support via their local authority or primary care providers. One woman recalled being phoned and offered a range of services, including adaptations to her home, and another shared how a stroke nurse supported her with next steps, including applying for her blue badge, but this level of support was reported by the minority of patients. Others felt they have been sent home without support and weren't sure where to turn to. Chest Heart & Stroke Scotland's Community Healthcare Support Service model offers an answer to this, but the earlier challenges we have identified around access to support prevent people from benefitting from these services.

Even when people are referred onto the services they need, long waiting lists prevent people from being able to live well with their condition. One of our focus group participants shared that they have been promised physiotherapy following their event but are still on the waiting list years later. They do not expect to receive this care anytime soon and are therefore living with pain and discomfort. Our pathway can offer crucial support to help people waiting well, and taking a shared care support at this point in an individual's journey could transform this experience. We know from evaluation that people who had accessed CHSS support rated both their health and mental wellbeing higher than those who had not been able to access CHSS support. All elements of our model, from clinical case management to our supported self management programme can offer valuable support to people at this earlier stage whilst they wait for further treatment or support, rather than at the end once an individual is discharged. Cancer pathways are an example of where this is currently working well.

People living with one or more of our conditions also find it has a significant impact on their mental wellbeing. In our 1 in 5 report, more than two in five (43%) people living with our conditions say that it impacts their mental health, with four in nine (44%) people said their conditions caused them anxiety and stress. Loneliness leads into these challenges, more than

one in three (37%) people with our conditions said they experienced loneliness as a result of their condition.

In our focus groups for this consultation, some individuals with lived experience of a long term condition felt there was little offer to them in the way of support for mental health and wellbeing after their acute event or diagnosis. One participant explained that due to the lack of support offer "*we switch off"* and explained her struggles with her mental health as a result.

Chest Heart & Stroke Scotland's services work to help people living with our conditions overcome these challenges. Our advice line is there for people to reach out to share their concerns and anxiety. Our Community Health Support Service, including our supported self management programme, helps individuals to feel less alone and supports them to build resilience. Our community programmes, including health walks, exercise classes, associated peer groups and Kindness Calls, allow people to connect, build community and feel less alone as they handle their condition on an ongoing basis. In one for our focus groups, participants noted how invaluable peer support was, saying "*it doesn't fix everything, but it is always here"*. They noted that peer support groups reduce isolation and are there only chance to properly get out and socialise during the week.

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

Long term condition management should be a partnership between the person living with a long term condition, and professionals and others who support them. When people living with long term conditions are asked to be solely responsible for their health, or alternatively do not feel listened to, this can lead to poor relationships between them and clinicians. For example, we are aware that a common issue for people living with Long Covid is to be offered no medical treatment and signposted to information with no further support. Difficulties can also arise when people's experiences and needs are not listened to, and where referrals or advice given are inappropriate – i.e. when care is not patient centred or does not reflect their needs as a whole person.

We understand the pressures that the NHS is under and do not expect them to be able to do this alone. Third sector service providers, such as Chest Heart & Stroke Scotland, play a key role in supporting statutory services by providing a holistic approach to supporting people with long term conditions. For example, if a medical professional was to refer an individual with Long Covid to our services, our team would contact them within three days and offer support at a level that persons needs. This could include an offer of case management, where a person with Long Covid can be supported to use different strategies and access additional help. The average length of one of these phone appointments is 40 minutes, much greater than the average time of a GP appointment (10 minutes).

To provide effective, meaningful care relationships, care must be person centred and holistic to their needs. Listening to what's important to an individual and providing tailored support can help build trust and increase their confidence in managing their health. Improved and up to date awareness of what additional services and resources are available on a local and national level are essential to ensuring that they are used by those who need them. One focus group participant living with our conditions noted how he was signposted to a website for support but when he searched for it, it was no longer active. Others did not receive any signposting or referrals from their health care teams after diagnosis or acute incident. Community Link Workers are key to ensuring individuals get ger access to the most up to date support offering. Improved referral systems to community and third sector organisation, as well as a shift in attitudes to valuing the key role they play, are also key in this.

There also needs to better work force training of how different long term conditions present across medical services so individuals, their challenges, and their capacity is better understood and respected. People living with aphasia have shared how they find medical professionals they interact with for care related to other conditions or health concerns do not understand the impact aphasia has on them. This can lead to assumptions, stigma and discrimination.

Improvements to health and social care administration systems also have a key role to play in improving communication between professionals and those living with conditions. The Kings Fund report on the impact of NHS administration on patient care notes that 'For people who live with long-term conditions…their experience of admin can play a critical role in their overall experience of care.[12]' Their research found that patients, carers and staff all found that current administration processes do not consistently meet the needs of those who use them, and can 'place a heavy practical burden on patients and carers, restrict their access to care, negatively affect their wellbeing, and have knock-on consequences for staff.' High quality administration processes that are co-designed have the ability to transform patient experience. We invite the Scottish Government to explore the Kings Fund research further and consider what reform needs to take place for our systems to be fit for purpose.

11. What digital tools or resources provide support to people with long-term conditions?

Chest Heart & Heart Stroke Scotland currently have a range of digitally available resources which are designed to help people to understand and manage their condition, as well as improve areas of their health. These resources are well placed to help support people to manage their long term conditions and can be easily downloaded and accessed via Chest Heart & Stroke Scotland's website. Our e-learning model could be utilised for other conditions to reach more professionals and individuals to improve education and access to care.

Our website hosts a wide range of health information on chest, heart, stoke and long covid conditions, including information specific to aphasia and communication difficulties, and

[12] The King's Fund, Admin Matters: The Impact Of NHS Administration On Patient Care. 2021

information more generally applicable to the prevention and management of a long term condition (e.g. diet, exercise, salt intake, stopping smoking etc). We are unique in our ability to offer PIF TICK accredited health information on multiple conditions and wider management of long term conditions as a trusted health information provider that individuals can access online, and health care professionals can refer patients to.

For each of our conditions, we have webpages that cover information about specific conditions, how to live well with that condition, and how to look after your health more generally. We also offer our full range of health information leaflets that can be read digitally and downloaded from our website by anyone free of charge. These resources cover similar topics, as well as a large range of information applicable to living well with a long term condition and various ways to generally improve your health and wellbeing. Many of our resources are available in community languages including publications available in Arabic, Chinese, Czech, Hindi, Japanese, Polish, Punjabi, Romanian, Ukrainian and Urdu. All of our resources are also available to order in physical form, for free for individuals, communities and health care professionals.

We also provide a portfolio of over 80 free e-learning resources which can be used by both individuals with long term conditions and health care professionals to learn more about the conditions we represent. These resources provide evidence-based learning and CPD credits for health and social care staff. They enable them to become more knowledgeable and skilful in the challenging areas of chest, heart and stroke care. They are free to access and are housed on Chest Heart & Stroke Scotland's own domains. In 2024, we reached 17,000 health care professionals in Scotland with our online resources to help improve their ability to care for people with our conditions. Our e-learning model could be utilised for other conditions to reach more professionals and individuals to improve education and access to care.

Some individuals face challenges with attending support services in person due to the impact of their condition. To account for this, we offer online versions of our key Community Healthcare Support Services where possible. We are in the process of piloting an online version of our Supported Self Management programme to ensure that people can access this evidence-based programme in the most convenient way for them. This follows the same format as our in-person course but has been adapted to be delivered over a group video call. To date it has received the same high level of evaluation from participants with further evaluation and learning to take place to ensure it fully meets the needs of individuals with our conditions. Several of our partnered peer groups also operate over video call to ensure that individuals can establish mutual support with those living with long term conditions in a way that suits their need.

As we explain in our answer to question 12, digital resources are vital but must be supported by physical resources as well to ensure that everyone gets the support they require. Physical copies of health information and in-person services are, and will continue, to be required. One way we utilise physical information to ensure maximum impact is through our Stroke Packs. These are disseminated by NHS Stroke teams to patients as they are being discharged to ensure they have all the information they would need on their condition, how to manage it, and where to access further support from Chest Heart & Stroke Scotland. This model has been well

received by healthcare professionals working within stroke services and we plan to expand this model to other conditions in the near future.

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

Chest Heart & Stroke Scotland see that there is a need for a digital resource that can allow people living with long term conditions to take control of their health and access support in one single location. To this end, we are currently in the process of developing a digital supported self management portal which will offer this to the 1 in 5 people in Scotland living with one of our conditions. This online offering will amplify and increase the reach of our existing services, allowing people to access the Community Health Support Services offering into one digital location. We are currently in the process of co-designing what this tool would include but we envisage it will have a service recommendation, self-referral route, appointment management and digital offerings of our face-to-face services. The design will work to integrate with wider healthcare systems, such as enabling faster, more direct referrals from hospitals and GPs. We would welcome the opportunity to speak to colleagues within the Scottish Government about this new offering to see how it could be integrated into wider work on long term conditions.

Digital resources have a key role to play in widening the reach of support to individuals living with long term conditions, but they must be as well as, not instead of, in person and analogue support. Our research with those living with our conditions to inform our own digital tool found that how people like to access support is very individual and also varies depending on context. Digital tools, resources and services have a valuable role to play in improving support for long term conditions and we welcome the Scottish Government's current work to both reduce digital inequality and provide new digital solutions (e.g. the Digital Front Door app). However, given that many long term conditions disproportionately impact digitally disenfranchised groups (e.g communities facing deprivation and older generations), we cannot be reliant on them to provide the full answer to this challenge .

Any digital tools must also account for the wide range of accessibility needs that someone with a long term condition may have. For example, people with aphasia can struggle to process digital information and may require adaptations such as a specific layout or simpler text. Whilst this presents a challenge, as no one person's experience of aphasia is the same as another, we will prioritise creating an aphasia friendly version of our digital offering.

There is a growing challenge in getting individuals to trust information provided online. Participants in our focus groups noted that being referred by a trusted medical professional is their preferred way of finding the most trusted information. Again, professional support for any new digital tools, easy referral pathways and integrated information sharing is essential to getting public buy in to any new digital tools. We have ensured these elements are kept at the heart of our own digital development.

13. How do you think long-term conditions can be detected earlier more easily?

Please give reasons for your answer.

As noted in the Health and Social Care Service Renewal Framework, a shift towards Preventative and Proactive Care is key in detecting conditions more easily. We're pleased to see this recognised within that framework and believe this needs to be embedded into improvement work for Long Term Conditions across the board to ensure people can gain support to take control of any new or developing conditions as early as possible.

The Health and Social Care Service Renewal Framework notes some good examples of where this has progressed with changes to dentistry and the role of community pharmacy. But as has been reflected in that framework, whole systems change needs to occur to ensure that all communities can benefit from screening action. There are challenges to achieving this, with uptake in socioeconomically deprived communities, who have a higher prevalence of long-term conditions, being lower. With the Scottish Equity in Screening Strategy work to tackle this coming to an end in 2026, we hope this strategy can learn from this work and apply it to its strategy. Programmes such as the Cardiovascular Disease Enhanced Service also show promising steps towards earlier detection.

There is also evidence to suggest that there can be a reluctance within primary care to diagnose or detect some long-term conditions. This could be due to concern of a lack of pathway or resources that can offer an individual as next steps, or due to an individual's internal bias or lack of education about a condition's legitimacy. This is an issue that individuals with long covid have long reported, with a 2022 study showing a common theme of individuals being scared of being 'invalidated' by their doctor due to previous experience[13].

Women also face significant barriers to receiving the correct care and diagnosis due to inherent sexism and biases built into our society and medical systems. The Scottish Government's own research into Women's experiences of discrimination and the impact on health found that women often had legitimate health concerns dismissed or blamed on stress or hormones. Research shows how women living with the long term conditions we support do not receive the same care as men. For example, stroke survivors who are women are less likely to be prescribed medication aimed at reducing the risk of future strokes[14] or heart disease[15]. Our system and medical solutions have been designed around the needs of men, and women suffer as a result. The Scottish Women's Health Plan has a key role to play removing these barriers. Chest Heart & Stroke Scotland have not only contributed to the development of this plan, but we have created our own internal women's health plan to ensure women receive equal care within our services and beyond.

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[13] Adams, N.N. et al, 2022, The GP can't help me, there's no point bothering them: exploring the complex healthcare journeys of NHS workers in Scotland suffering from long COVID: a longitudinal study. BSA MedSoc 2022.

[14] Sterling, K.A. et al, 2024. Acute care, secondary prevention, and outcomes after ischaemic and haemorrhagic stroke in men and women: A Data-Linkage Study. Cerebrovascular Disease (2024) Jul 17:1-8

[15] Pana, T.A. et al, 2024. Sex differences in myocardial infarction care and outcomes: a longitudinal Scottish National Data-Linkage Study. European Journal of Preventive Cardiology Nov 27, zwae333,

The third sector can and must play a key role in overcoming these challenges with Chest, Heart & Stroke Scotland demonstrating this through our Health Defence Hubs. These hubs, currently based in Maryhill and Dundee, focus on bringing primary and secondary prevention services to those communities most impacted by long term conditions and who traditionally may not uptake screening services or engage with health professionals. Their overarching aim is to empower individuals to make positive changes to their health and live healthier lives. At these hubs, we offer free health checks covering various aspects linked to long term conditions such as cholesterol, blood pressure, mood, and mental well-being. Our teams of trained professionals is available to discuss individual health concerns and provide tailored support, including referring onto other services both within and out with the organisation. We also offer a range of free physical activity services such as exercise classes and groups walks, to encourage physical activity and social support. Crucially, our hubs actively work with local communities to shape services, ensure they meet local need and gain trust within the community. Within our strategy, we are also considering how these services can be adapted to serve specific groups needs, such as women. Services such as these offer a model we believe can work for other long term conditions and shows how organisations such as ours are a crucial part of the solution.

Our wider Community Health Support Service model also offers a solution to primary care clinicians' concerns around support they can offer to an individual after diagnosis. GPs and other primary care professionals can refer onto our free Community Health Support Services offer a comprehensive range of information and support to help individuals come to terms with one of our conditions and learn to manage a new conditions or risk factor. For example, we have contacted practices who are participating in the current Cardiovascular Disease Enhanced Service to increase detection to highlight how we can support. This has been met warmly by this community and work to support follow up action is already underway in Tayside and Grampian.

As mentioned in previous answers, it is vital that work is done to both simplify the referral system and increase professional knowledge of and trust in third sector services. We offer a wrap around solution to ensure individuals are supported that will ease professional pressure around next steps when making a diagnosis, this framework needs to work to embed this into the wider eco-system.

Further investment in specialist diagnostic services and tools, as well as improved professional education is also essential, as these factors continue to block diagnosis in some long term conditions. For example, a quarter of respondents to an Asthma+Lung UK study reported waiting more than five years for a diagnosis. There are a number of factors to this, including health inequalities and missingness, but lack of professional awareness of symptoms and access to specialist tools such as spirometry remains a challenge[16]. Specialism and condition specific solutions are part of the answer to this.

[16] Asthma + Lung UK, Delayed diagnosis and unequal care: The reality for people with chronic obstructive pulmonary disease (COPD) in the UK in 2022. Nov 2022.

14. **What barriers do people face making healthy decisions in preventing or slowing the progress of long-term condition(s)?** Please give reasons for your answer.

To reference the Scottish Government's Population Health Framework, 'Research shows that ... social, economic and environmental factors are the primary drivers of health and together have a greater effect on health than individual behaviours and health services.' It notes that the key building blocks of good health include 'a focus on the earlier years.... Good education, fair work and income, healthy places, social networks and appropriate public services, and inequality of access to these elements are the ultimate barriers to having good health. The barriers to making these 'healthy decisions' are complex, entrenched and impacted by our whole socio-economic system. They include:

- Economic inequality
- Housing
- Commercial determinants of health
- Access to education
- Environmental factors (e.g. pollution, climate change)
- Gender, age, race, disability
- Location and access to community resource
- Access to transport

This list is non-exhaustive.

We require whole-system changes to overcome these. We welcome the Population Health Framework and other related frameworks published by the Scottish Government as a step towards changing those systems. A Long Term Conditions Framework should learn from the development of these frameworks and link into their vision. Without these systemic changes to our society, we will not see meaningful improvements to the burden of disease in Scotland. It is unfair, and unrealistic, to expect society to make better food choices whilst McDonald's continues to spend an estimated £7-8 million per annum on adverts within Scotland.

There are some specific barriers to making healthier decisions we see in people living with our conditions, which are perhaps not recognised in these frameworks, we'd like to highlight.

- **Lack of ongoing support to make changes** – an individual may struggle to make changes that would help them prevent or slow the progress of a long term condition due to a lack of ongoing support. Behaviour science studies show that change can best occur through ongoing support over weeks or months, using tools such as goal setting, action planning and problem solving[17]. Many people may not have family support, confidence or knowledge to make the changes required. As individuals living with a long term condition spends around 95% of their time outwith formal health and social care settings , a different form of ongoing support is required to enable this.

[17] Susan, M et al. 2018. Evaluating the effectiveness of behavior change techniques in health-related behavior: a scoping review of methods used, *Translational Behavioral Medicine*, Volume 8, Issue 2, April 2018, Pages 212–224, https://doi.org/10.1093/tbm/ibx019

Chest Heart and Stroke Scotland's Community Health Support Service model is able to overcome through a range of support to help people improve their health. Our evidence based, accredited Supported Self Management program is designed to empower individuals to manage their condition with greater confidence and independence, and includes content such as problem solving and goal setting, medication management and healthy eating, which help prevent future acute events occurring. Individuals can then continue on to one of our affiliated peer support groups to continue their journey.

- **Timing of support** – individuals who have had an acute event may need to make lifestyle changes, but they may not be able to engage with this in the immediate aftermath of the event. People need ongoing access to information and support about how they can improve their risk factors, at the time they feel they can engage. Chest Heart and Stroke Scotland's Community Health Support Services model enables individuals to access different kinds of support at their own pace.
- **Knowledge of information and support available** – as previously mentioned, people can be unsure of what additional support is currently available to them to help make changes to their lives to improve their health. The third sector is a key provider for community health support but we still face challenges in raising awareness of services with those who would benefit. Improving referrals from primary care, including through community link workers, could help overcome this barrier. Working together to get the right information into the right individual's hands is essential. Our stroke packs, which are now issued to patients upon discharge from stroke wards, are an example of how information about healthy life changes, and the support available to make them, can easily be communicated to the correct audiences.
- **Misinformation in media** – with the rise of misinformation across traditional and social media, individuals can be more confused than ever about what changes they should be making. Participants in our focus groups noted that knowing where to access trusted information was vital to them. Our own health information is PIF TICK accredited to ensure peace of mind for those accessing it.
- **Disability benefit security** – a recent study by Scottish Disability Sport found that 40% of people with a disability in Scotland are worried about losing their benefits if they are seen to be more physically active[18]. This lack of financial security could create a barrier to those already living with a long term condition or disability from taking action to engage in preventative action such as physical activity.

To effectively overcome these barriers, drivers of change should be focused on need rather than numbers. The majority of Scotland's burden of disease and general ill health is still focused on communities facing the most deprivation. Solutions need to be developed with these communities in a way that meets their needs and goals, rather than simply working towards national targets. Integrated Joint Boards will have a key role to play in this, but it will also require focus from our whole system and service delivery organisations such as Chest Heart & Stroke Scotland can share valuable lessons on how this can be achieved.

[18] Queen Margaret University & Scottish Disability Sport. National Survey Results 2025. 2025.

15. **Is there anything currently working well within your community to prevent or slow progression of long term conditions?** Please give reasons for your answer.

As noted in our answer to the previous questions, Chest Heart & Stroke Scotland's Community Health Support Services are working well to both prevent and slow the progress of long term conditions in communities across Scotland.

Our Health Defence Hubs, which offer health screening, advice and support, alongside our Physical Activity Services, are an example of how we can increase prevention, early diagnosis and manage progression. By focusing on geographical areas with high levels of deprivation, we've been able to bring targeted support to those most at risk of developing one of the conditions and who will therefore gain the most benefit. Our hubs take a Community Development approach to design services, making sure they service the needs of the community and build trust. These services have an open door policy to allow anyone to benefit and share their ideas. For example, our Dundee Health Defence Hub team has worked with the local Gypsy Traveller community to build trust and help them access services. We've also been able to offer services to wider communities, such as pop-up health check clinics and walking for health groups which have enabled greater connection and community. Our physical activity services also includes a flexible digital offer which allows us to reach more rural and less well served areas of Scotland. We are continuing to expand this model to other areas of Scotland, through new services and planned digital expansion work, and believe that it could be amplified to help prevent and manage other long term conditions.

Our supported self management programme is, to our knowledge, the only accredited, evidence-based model within Scotland. Delivered over six weeks, it works to empower individuals to manage their condition with greater confidence and independence. Our group-formatted program covers a wide range of topics from fatigue management to communication with healthcare professionals, which could be adapted to serve wider range of long term conditions. Delivered both online and in-person to support accessibility, 98% of participants in our pilot said they would recommend this course. We also found participants had a 32% improvement in patients managing fatigue, 41% improvement in other health issues and 26% improvement in their need for medication. As one of the only national service delivery organisations working in the supported self management space, we would welcome the opportunity to work with the Scottish Government to see how this could be amplified to support the wider condition management.

Our affiliated peer groups also have a vital role to play in enabling individuals to manage their conditions, slowing their progress and living their lives to the full. Participants in our focus groups highlighted how vital support groups had been for them in being able to learn to live with a long term condition. One group agreed that their peer group gave them "somewhere to go, people to talk to and people to laugh with" which they felt was valuable in learning to live with the reality of their new condition. Another participant noted how their group provides 'a day out of the house', the chance to talk to others and lets carers have a break. This community is vital not only to learning to live with a condition but also to improving an individuals mental wellbeing

and sense of connectedness. Our affiliation model of offering support to peer groups, whilst allowing the groups to retain control is one which could be applied to wider conditions.

Another key development in the prevention and health equity space over the past year, which CHSS has welcomed, is the partnership work between Public Health Scotland and the University College London's Institute of Health Equity (IHE) to deliver a two-year programme called Collaboration for Health Equity in Scotland (CHES).

Working with Professor Sir Michael Marmot, the director of the Institute, this collaboration aims to strengthen and accelerate the action underway to:

- improve Scotland's health
- increase wellbeing
- reduce health inequities

As the leading global health institute, the IHE has worked to improve health and reduce inequities. The partnership between PHS and IHE is key to delivering meaningful public service reform and providing new insights into the most effective ways to progress with health equity in Scotland through Marmot's eight principles. CHES is working in three areas in partnership with local authorities and NHS Boards across Aberdeen City, North Ayrshire and South Lanarkshire to develop and implement strategies to enhance health equity

CHSS believes this kind of partnership working with collaboration and learning at its core is part of the solution to prevention and tackling health inequity.

16. **How can the Scottish Government involve communities in preventing or slowing the progress of long term conditions?** Please give reasons for your answer. l

Communities have a key role to play in not only the design and implementation of national initiatives for the prevention and management of long term conditions, but in wider moves to create a whole system approach to health and social care. Communities are agents of change in their own right and without their insights and buy in, we risk creating solutions which do not serve those who need them.

With this in mind, it is vital that people with lived experience and the wider community are involved at all stages of development of a long term conditions framework. In particular, we highlight the need for timeliness, inclusion, transparency and accessibly, to align with the principles of participation in policymaking.

We do note the Scottish Government's work to include the voices of lived experience, wider communities and the third sector. We are not convinced that this has been adequate for the scale of change this proposal presents would like to see transparent processes which are designed around the principles of participation. We also do not believe that the consultation survey is accessible to individuals with lived experience. In our own work to consult people living with our conditions we found that questions required significant rewording or explanation. We also ask what action the Scottish Government has made to ensure their consultation is accessible to those with additional needs. For example, an individual living with a long term

condition like aphasia would not be able to respond to these questions in their current format. With many people living with long term conditions experiencing disability or additional support needs it is disappointing to see that even the basic requirement of an easy read version or other action to ensure participation has not been created.

We believe it is crucial that communities involved in long term condition management are meaningfully involved throughout, particularly in areas of higher deprivation and risk. National policy makers can benefit from the experience and expertise that communities and groups have in preventing and managing long term conditions. For example, the 120+ peer support groups that partner with Chest Heart and Stroke Scotland have a wealth of experience to share about the transformative role peer support has in enabling people to better self-manage their long term condition.

Organisations like Chest Heart and Stroke Scotland have trusted relationships with our communities, and we can support effective engagement. Trusted organisations can support meaningful participation in a way that works for their communities. For example, we have experience in enabling individuals with different accessibility needs, including aphasia, to meaningfully participate in the design and delivery of our services. We would caution against consultation or engagement solely via a single intermediary on any occasion – service delivery organisations experience in facilitating meaningful participation such as CHSS, have a key role to play.

The principles of participation provide for a multi-faceted approach in favour of linear consultation and single method engagement. Organisations that support people with long term conditions, including Chest Heart & Stroke Scotland, have developed various participation and engagement models and strategies to involve their communities. At Chest Heart and Stroke Scotland, our Participation and Involvement Framework aims to ensure that everyone affected by our conditions can participate and contribute in a meaningful way. However, this takes time and resource, and we feel this has not been taken into account during this consultation process. We would welcome an opportunity to explore how we can support the Scottish Government with this in future and in delivering the framework.

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?**

Age is one area where this presents a challenge, with the rates of long-term conditions rising for older populations alongside a decline in digital literacy rates. The 2023 Scottish Health survey showed that limiting long-term conditions among adults increased with age, from 24% among

those aged 16-24 to 59% among those aged 75 and over[19]. In 2023, almost all (99 per cent) adults aged 16-34 reported using the internet compared to 77 per cent of those aged 60+. Sixty-nine per cent of disabled adults aged 60+ reported using the internet, compared with 83 per cent of non-disabled adults aged 60+. This correlates with the focus groups CHSS ran for this consultation, where some participants, all aged 55 and over, noted that they didn't use the internet or had to get a family member to look things up for them.

People with our conditions noted they lacked confidence in their own research and would prefer to be given physical leaflets from trusted medical professionals. With those managing long term health conditions more likely to be older and less likely to be online, solutions need to account for this and have alternative options in addition to digital resources. Resources like peer support groups and community health teams are also vital in getting information to this community.

People also report experience of direct discrimination linked to their age. Age Scotland has reported that older people frequently feel like they are being dismissed or not receiving the same quality of care and support as younger people as symptoms/concerns are simply passed off as inevitable part of ageing. There needs to be the same level of proactive support and services to help older people live as well as possible with long term conditions, regardless of what age they receive a diagnosis.

Those living in **areas of deprivation** face a similar challenge. One third (34%) of adults living in Scotland's most deprived communities report a limiting long-term health condition or illness[20] and only 84% of their households reported having internet access[21]. This is in comparison to least deprived communities, where 16% of adults report a long-term condition and 96% of households have internet access. Whilst we appreciate the Scottish Government's continued effort to reduce digital inequalities, these communities will require support and resources beyond digital information and service to ensure equality in access. In-person services such as health defence hubs, peer groups, and supported self-management courses delivered within the community are key to overcoming this.

This group faces wider challenges in accessing support, with financial burden meaning less free time and resources to dedicate to health challenges. This can pose a significant challenge in the prevention space, but one that can be overcome by working with local communities and investing in community-specific projects which gain the trust of individuals, such as CHSS's Health Defence Hubs.

A challenge facing both of the aforementioned groups, as well as those in **rural areas**, is transportation and access to physical services. Our focus groups of older people from a range of areas highlighted the challenge of accessing transport to services. This could be due to rural location or due to their own **disabilities** as a result of a long term condition. Whilst digital services can support recovery, participants in focus groups highlight how valuable face to face, in person support was to them in processing and managing a long term condition. Continued

[19] Scottish Government. *Scottish Health Survey 2023: Volume 1 – Main Report*. 2024
[20] Scottish Government. Scottish Health Survey 2022: supplementary tables 2023
[21] The Scottish Government. Scottish Household Survey 2022: Key Findings. 2024.

work to improve provision of bus services and inclusive options such as 'neighbourhood coach' services is essential to equity of care.

Location more generally continues to be a factor in equity of care, with many individuals noting they still feel their access to care is a postcode lottery. Long Covid support is a key example of this, with those living with the condition frequently noting inconsistencies in access to support across the country[22].

Consideration should also be given to those with **different communication needs** to ensure they also receive access to the same level of information and support as the wider population. Aphasia[23] is one example of a condition which would create a barrier to an individual receiving information in the same way as someone else. People living with aphasia need to receive information that has been adapted to meet their needs, and each individual may have a different need. This not only impacts the support they receive post-stroke but also for any other long term condition they want to prevent or manage. At CHSS, we have adapted our information and support for this purpose, with aphasia friendly resources and a supported self management course specifically for people living with aphasia[24]. One size cannot fit all, different solutions must be offered.

Gender should also be considered, with women's experience of prevention of and treatment for long-term conditions being different to men's. For example, stroke survivors who are women are less likely to be prescribed medication aimed at reducing the risk of future strokes[25] or heart disease[26]. This needs to be reflected in the framework and we recommend that this work aligns with work on the Women's Health Plan.

18. **Given that racism and discrimination are key drivers of inequalities, what specific actions are necessary to address racism and discrimination in healthcare?** Please give reasons for your answer.

As noted, racism and discrimination are key drivers in inequalities in Scotland, and this extends both the prevalence of long term conditions and the experience of health care. This is something we see within the conditions we support people with:

[22] Health and Social Care Alliance Scotland. *Accessing Long Covid services in Scotland: To be believed, listened to, and supported.* 2024

[23] Aphasia is a communication disorder caused by damage to the language centres in the left side of the brain. Aphasia is most common after a stroke (it affects 1 in 3 stroke survivors), but can occur with other neurological conditions or head injuries.

[24] This course in the pilot stages. It takes steps to make information easier to digest by, for example, delivering the course over 12 weeks rather than 6.

[25] Sterling, K.A. et al, 2024. Acute care, secondary prevention, and outcomes after ischaemic and haemorrhagic stroke in men and women: A Data-Linkage Study. Cerebrovascular Disease (2024) Jul 17:1-8 https://doi.org/10.1159/000540371

[26] Pana, T.A. et al, 2024. Sex differences in myocardial infarction care and outcomes: a longitudinal Scottish National Data-Linkage Study. European Journal of Preventive Cardiology Nov 27, zwae333, https://doi.org/10.1093/eurjpc/zwae333

- Black patients are **more likely** to be admitted to hospital for respiratory causes, and both Black and South Asian patients are less likely to receive certain inhaled medications or referrals to pulmonary rehabilitation[27].
- People of Pakistani origin in Scotland are **50% more likely** to be admitted to hospital for asthma than White Scottish people[28].
- Pakistani men in Scotland are **45% more likely** and Pakistani women **80% more likely** to suffer a heart attack than White Scottish[29].
- African Caribbean groups in the UK are **40–50% more likely** to have high blood pressure than White groups; South Asians are **20–30% more likely**[30]**.**
- South Asian and Black groups in Scotland are **25–35% more likely** to experience stroke or TIA than White Scottish[31]
- Data on ethnic differences in long COVID prevalence and severity in Scotland is limited, but UK-wide evidence suggests higher rates in minority groups[32].

Meaningful consultation with organisations focused on ending racism and discrimination, and the communities they support, are vital to identifying further specific actions that can be taken. The Scottish Government should proactively carry out consultation in partnership with community organisations with appropriate funding to enable participation.

Equality Impact Assessments continue to be a vital tool to identify areas of racism and discrimination in Scotland's healthcare system. Their effectiveness is dependent on consistent implementation and willingness to act on the findings. These should be carried out on any mass strand of action around long term conditions that are proposed.

19. Is there anything else you would like to raise that was not covered elsewhere in the consultation paper?

To reiterate:

As Scotland's largest health charity providing support to the one in five people living with one (or more) of four individual long term conditions, we believe a programme of cross cutting improvement work could add value to some of the pathway elements that have been identified. Our own community support service model demonstrates the value this approach can have in providing holistic and cost-effective services, contributing to whole system interventions, whilst

[27] Martin, A et al, 2012. Effect of ethnicity on the prevalence, severity, and management of COPD in general practice. British Journal of General Practice 2012. https://doi.org/10.3399/bjgp12X625120
[28] Sheikh, A. *et al.* Ethnic variations in asthma hospital admission, readmission and death: a retrospective, national cohort study of 4.62 million people in Scotland. *BMC Med* **14**, 3 (2016). https://doi.org/10.1186/s12916-015-0546-6
[29] Bansal N, Fischbacher CM, Bhopal RS*, et al* Myocardial infarction incidence and survival by ethnic group: Scottish Health and Ethnicity Linkage retrospective cohort study. *BMJ Open* 2013;**3:**e003415. doi: 10.1136/bmjopen-2013-003415
[30] Khan JM, Beevers DG. 2005. Management of hypertension in ethnic minorities. *Heart* 2005;**91:**1105-1109. https://heart.bmj.com/content/91/8/1105
[31] The Scottish Public Health Observatory, Ethnic minorities: disease incidence. June 2023
[32] NHS Scotland, NHS Scotland Service Evaluation of Long-COVID Services – Long COVID. Dec 2024

still retaining areas of specialism. Our engagement with clinicians, and people with lived experience of the four conditions we represent, suggests that this community can also see how this model could help improve support for their patients in specific areas of the ecosystem.

To be successful, such a framework and any resulting action plans would need to be supported through adequate resourcing, strong leadership and robust evaluation, **with the third sector as a key strategic partner**, and cannot be viewed as a way to cut essential specialist services. We hold reservations about the Scottish Government's ability to meet these conditions and, as a result, question whether it has the capacity to meaningfully deliver such a programme a national scale. We also hold concerns about the 'limited' nature of condition specific actions and the critical impact prioritisation for these actions could have on long term progress on specific conditions.

We are disappointed that the Scottish Government did not accept our offer to use our experience and knowledge as service delivery organisation focused on long term conditions in the initial development of this framework. We hope that service delivery organisations, such as Chest Heart & Stroke Scotland, are explicitly recognised as the partners and drivers of change that we know they are in any framework that results from this work.

Chest Heart & Stroke Scotland are cautiously supportive of this framework - funding and action must follow the warm words within this framework.

For any questions related to this response, please contact:

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