

Long Term Conditions – Framework Social Work Scotland response to Scottish Government consultation

July 2025

Introduction

Social Work Scotland is the professional body for social work leaders, working closely with our partners to shape policy and practice, and improve the quality and experience of social services. We welcome the opportunity to provide a response to the Long-Term Conditions Framework Consultation.

Background

More than one-third of people in Scotland live with at least one long-term health condition, often facing challenges that go beyond physical symptoms, affecting their mental wellbeing, financial security, and ability to work. At the same time, 46% of school-aged children have additional support needs. While this includes groups such as looked-after children and young carers, a significant number are living with disabilities or long-term conditions.

To effectively support these individuals, a more integrated, person-centred and childcentred approach is essential, one that considers broader contributing factors such as poverty, the accessibility of cheap fast food, reliance on food banks, societal pressures, and the role of education.

Historically, health policies have focused on individual conditions, leading to important progress in areas like heart disease and chronic pain. However, the increasing prevalence of multi-morbidity highlights the need for a more holistic and coordinated approach.

In response, the Scottish Government has outlined a new vision for health and social care, one that empowers people to live longer, healthier, and more fulfilling lives. This vision emphasises prevention, fairness in access, high-quality services, and better overall population health. As part of this transformation, the government has consulted on a cross-cutting policy framework for long-term conditions. The proposed framework aims to meet shared needs across different conditions while continuing to support condition-specific care where necessary. Importantly, it seeks

input from both the public and professionals to ensure future policies are inclusive, sustainable, and informed by lived experience.

Summary

Social Work Scotland has prepared this response to the Scottish Government's consultation on the long-term conditions framework. Social Work Scotland welcomes the Scottish Government's move toward a more integrated, person-centred approach to managing long-term conditions. The organisation supports a shift away from condition-specific policies toward a balanced framework that combines cross-cutting improvement work with targeted interventions and community/contextual provision where necessary. This approach is seen as essential in addressing the growing prevalence of multi-morbidities and ensuring equitable care and wellbeing.

A central theme throughout Social Work Scotland's response is the importance of early intervention, prevention, and community-based support. The organisation highlights the critical role of social work, and the social care which follows, in enabling people to live well with long-term conditions and calls for greater investment in these services, particularly considering current workforce shortages, funding constraints, and geographic inequalities.

Social Work Scotland emphasises the value of Local Area Coordination, peer support, and voluntary sector initiatives in building resilient communities and reducing reliance on statutory services. However, it also raises concerns about the erosion of community infrastructure and the increasing reliance on under-resourced third sector organisations, funded by local authorities with restricted budgets.

The response stresses the need for:

- Improved integration of health and social work data, and data related to service provision, ensuring that both medical and social information are accessible to all relevant professionals.
- For children, close multi-agency working between education, health and social work, in line with the principles of GIRFEC.
- Accessible and inclusive digital tools, co-designed with people with lived experience, and supported by digital inclusion initiatives.
- Clear, accessible information and signposting, both online and in community settings.
- Recognition of the social determinants of health, including poverty, housing, and caring responsibilities, which can act as barriers to wellbeing, healthy living, and timely access to care.

Social Work Scotland also calls for a realistic understanding of equity, particularly in rural and deprived areas, and urges the Scottish Government to ensure that funding and service provision reflect local needs. The organisation supports antidiscriminatory training and practice across all sectors and encourages inclusive approaches that consider the needs of people with protected characteristics and those in marginalised groups.

In conclusion, Social Work Scotland supports the direction of the proposed framework but urges the Scottish Government to ensure that social work and social care are fully included as part of what is required to ensure the wellbeing of our citizens, are adequately resourced, and recognised as essential components of longterm condition management.

This document presents the 19 consultation questions alongside a summary of the responses gathered from our members, who represent the leadership and management of social work services across Scotland.

Questions

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

Social Work Scotland and our members are broadly supportive of the proposal to transition from a condition-specific policy approach to one that strikes a balance between cross-cutting improvement initiatives for long-term conditions and targeted, condition-specific interventions. Given the increasing prevalence of multi-morbidities, we believe it is essential that services are designed to be person-centred and equitable wherever possible.

While the proposed framework demonstrates a strong medical orientation, which we recognise as important, particularly in relation to early diagnosis, information sharing, clinician education, and self-management support, we would emphasise that a truly person-centred approach must go beyond clinical engagement. It should involve working collaboratively with individuals to enable them to exercise agency and control over their own care and treatment. This is enshrined in the legislative context of GIRFEC¹ and the policy context of GIRFE², and underpinned by our human rights agenda.

We strongly advocate for the early involvement of social work professionals, supported by appropriate resourcing. Early social work and social care engagement can mobilise support from individuals' personal networks and resources, contributing to more holistic and sustainable care. This approach not only enhances outcomes for individuals but also alleviates pressure on the health system, social work, and the care system, and delivers long-term cost savings.

Additionally, we would like to raise concerns regarding the use of the term "burden" within the framework. This language risks reinforcing negative perceptions and could lead individuals with long-term conditions to internalise harmful labels. We recommend the use of more empowering and respectful terminology.

In conclusion, while we support the overarching aims of the framework, we urge the inclusion of more detailed consideration of the role of social work in delivering integrated, person-centred care.

¹ <u>https://www.gov.scot/policies/girfec/</u>

² <u>https://www.gov.scot/publications/getting-it-right-for-everyone-girfe/</u>

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?

Social Work Scotland is the professional leadership body for social work in Scotland. While we do not deliver services directly, we support the leaders and managers of social work services across the country, including all 32 Chief Social Work Officers (CSWOs). Our members operate in diverse contexts, each facing unique challenges shaped by variations in geography, workforce capacity, resource availability, and socio-economic conditions.

Through our engagement with members, we have observed that where meaningful improvements in prevention, care, and support have been achieved, these are often linked to the work of Local Area Coordinators (LACs). LACs play a vital role in supporting individuals and communities by offering advice, facilitating access to appropriate services, and helping people to navigate complex systems of care. Importantly, they also foster community connections by linking individuals with shared experiences, enabling mutual support and reducing isolation.

This model of support aligns closely with the principles of early intervention and person-centred care. By empowering individuals and strengthening informal networks, LACs contribute to more resilient communities and reduce reliance on statutory services. We believe that further investment in and expansion of such roles could significantly enhance outcomes across Scotland, particularly in areas facing acute socio-economic or geographic challenges.

Our members also highlight that having a named contact to provide continuity of care is advantageous as this person can advocate and support the care pathway for people with more than one health condition. Models of community health work in Brazil were raised as examples of good practice in terms of preventative and proactive holistic, person-centred approaches which may be useful to learn from. We encourage the framework to recognise and build upon the value of these community-based approaches, and to ensure that social work, and social care, leadership is embedded in the design and delivery of integrated care systems.

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.

Social Work Scotland and our members strongly advocate for meaningful and sustained dialogue between all stakeholders involved in the design and delivery of care and support. This includes health professionals, social workers, social care staff, carers' organisations, and, crucially, individuals with lived experience of long-

term conditions. We believe that such inclusive engagement is the most effective way to identify priorities for condition-specific work and to ensure that services are responsive to the diverse needs of individuals and communities.

It is essential that this dialogue is conducted in a way that reflects genuine partnership. No single agency or profession should assume a dominant role; instead, all contributions must be recognised as equally valid and valuable. This collaborative ethos is fundamental to achieving integrated, person-centred care.

In addition, we encourage open and transparent conversations about the financing of condition-specific and cross-cutting interventions. Too often, funding streams are siloed along professional or sectoral lines, typically divided into "medical" and "social" categories, which can create barriers to holistic and coordinated support. Addressing this tension requires a shift in how resources are allocated and governed, with a focus on shared outcomes rather than organisational boundaries. It would be useful to see a financial framework to support this integrated approach.

We recommend that the framework explicitly supports co-production and joint decision-making, underpinned by integrated funding models that enable flexible, needs-led responses.

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

Social Work Scotland supports the principle that access to information, advice, and support should be straightforward, inclusive, and embedded within communities. One effective approach is to ensure that there are visible, trusted individuals within local communities, such as Local Area Coordinators, community link workers, or other outreach staff, who can provide signposting to relevant services, resources, and sources of support. These individuals play a key role in bridging the gap between people and the systems that serve them, particularly for those who may be less confident navigating formal structures.

In addition to the human element, we believe that better use should be made of existing community infrastructure to disseminate information. Community and health centres, GP practices, libraries, public buildings, and other local hubs, including schools and places of worship, can all serve as accessible points for sharing up-todate, relevant information about available services and supports. These venues are often well-used and trusted by local populations, making them ideal for reaching a broad audience.

Given the increasing reliance on digital tools, it is also essential that online information is clear, accessible, and well-signposted. Many individuals turn to search

engines as a first step in seeking help, and it is therefore critical that dedicated web pages containing localised information are easy to find and navigate. We recommend that such pages be hosted on both NHS and Local Authority websites, as these are the most commonly accessed and trusted platforms. These pages should be regularly updated and co-produced with service users to ensure they reflect real needs and lived experiences, and accessible to all.

Improving both physical and digital access to information will help ensure that individuals and families can make informed decisions, access support earlier, and feel more empowered in managing their health and wellbeing.

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

To improve access to care and support for individuals living with long-term conditions, Social Work Scotland offers the following observations.

Firstly, we believe that the presence of knowledgeable and approachable staff within health and community-based facilities, such as outpatient clinics, schools and early years provision, day centres for older people, and other local hubs, can play a crucial role in connecting individuals to the support they need. These staff members, whether health professionals, teachers, social care workers, or community link workers, should be equipped to engage with individuals, provide accurate and timely information, and signpost them to appropriate services and resources, supporting a "no wrong door" approach to access. Their visibility and accessibility within familiar settings can help reduce barriers to engagement, particularly for those who may be unsure of where to begin seeking help.

Secondly, we emphasise that access to care and support is dependent on two interrelated factors: the availability of services, and the visibility of those services to the public. It is not sufficient to create facilities and programmes if people are unaware of them or unsure how to access them. Therefore, investment must be made not only in the development and delivery of services, but also in the communication infrastructure that ensures individuals and families are informed about what is available, how to access it, and what to expect.

This includes both in-person and digital approaches to information-sharing, tailored to meet the needs of diverse populations. A coordinated, multi-channel strategy, combining community-based outreach with clear, accessible online resources, will be essential to ensuring equitable access to care and support across Scotland. We would also draw attention to prison-based populations where there may well be adults who have long term conditions. Consideration needs to be given as to how the framework meets the needs of those in prison and how they access diagnosis,

treatment and preventative measures. The physical environment in a prison can make it difficult for certain conditions (for example, wheelchair users), though we recognise that some of the newer prisons are more accessible. Getting bespoke, person-centred care, can be challenging in large institutions.

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

Social Work Scotland acknowledges the Scottish Government's ongoing efforts to improve information sharing within health and social care, particularly through the development of the national Data Strategy and the enhanced use of the Community Health Index (CHI) system³. These initiatives represent important progress in enabling more effective communication and coordination among medical professionals.

However, our members have identified a significant challenge that remains unresolved: the integration of medical and non-medical information within multidisciplinary teams. While systems such as CHI facilitate the sharing of clinical data among healthcare professionals, there is a persistent gap in how relevant social care information is incorporated and accessed. This disconnect can hinder the delivery of truly person-centred care, especially when timely access to both medical and social information is critical for informed decision-making. We appreciate that any sharing of information is governed by data protection legislation except where there is immediate risk of harm, and that therefore there will always be limitations to sharing between agencies.

To address this, further investment is required to ensure that all areas of Scotland, regardless of geography or resource levels, have the infrastructure, training, and governance frameworks necessary to support secure, appropriate, and efficient information sharing across professional boundaries. This includes ensuring interoperability between health and social care systems and developing shared protocols that respect confidentiality while enabling collaborative practice.

Moreover, we would stress the importance of clinical professionals engaging fully with the information available to them. It is essential that all relevant notes and records are reviewed to ensure that treatment plans are safe, appropriate, and take into account the full range of a person's health conditions and the wider context of their lives, especially for children.

³ <u>https://www.gov.scot/publications/data-strategy-health-social-care-2024-update-progress-priorities/pages/7/</u>

In conclusion, while progress has been made in improving data sharing within the health sector, a more integrated and inclusive approach is needed, one that fully incorporates social care perspectives and ensures that all professionals involved in a person's care have access to the right information, at the right time.

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.

Social Work Scotland would like to highlight the significant and often underrecognised role that community-based resources play in supporting individuals with long-term conditions. Rather than listing specific services, we wish to emphasise the broader ecosystem of support that exists beyond the medical model, an ecosystem that has historically included local authorities, charities, and third sector organisations working in partnership to provide accessible, person-centred support. These community-based services have offered individuals greater choice and flexibility in how they manage their conditions, often enabling earlier intervention, reducing isolation, and promoting independence. However, in recent years, there has been an increasing reliance on the third sector to deliver these supports. This shift has occurred in the context of short-term funding cycles, workforce recruitment and retention challenges, and limited capacity for long-term planning. As a result, the sustainability and consistency of these vital services are under threat.

Where provision has worked well, it has often centred around a trusted, accessible community hub, such as a day centre, local resource centre, or voluntary organisation, where individuals with long-term conditions and their carers (or parents, with regards some children) can access information, advice, and peer support. These spaces foster a sense of belonging and empowerment, and evidence shows that peer support groups can significantly enhance self-esteem, self-efficacy, and overall wellbeing.

In addition, staff working in day centres and community settings often develop strong, trusting relationships with individuals, enabling them to provide tailored support that reflects the person's preferences and needs. Similarly, Personal Assistants (PAs) employed through Self Directed Support offer highly individualised care, grounded in a deep understanding of the person's daily life and condition. These relationships are central to enabling people to live well with long-term conditions.

Voluntary and third sector organisations also play a critical role in providing accessible, non-stigmatising support. They offer a wide range of services, from information and advocacy to practical assistance and emotional support, that complement formal health and social care provision.

In summary, services outside of medical care are not ancillary; they are essential. They help prevent deterioration, reduce pressure on statutory services, and enable people to live with dignity, autonomy, and connection. To maximise their impact, these services must be sustainably funded, strategically integrated, and recognised as core components of long-term condition management.

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

Social Work Scotland wishes to highlight several systemic challenges currently affecting access to social work and social care services, all of which have a direct impact on the support available to individuals living with long-term conditions.

While the integration of health and social care was intended to create more seamless, person-centred services, in practice, there has been a disproportionate emphasis on the health component with varied models of integration being implemented across Scotland. This has often come at the expense of social work and social care, whose contributions are equally vital in supporting people to live well with long-term conditions. Social Work Scotland strongly advocates for renewed investment in social work and social care, recognising that these services are essential for enabling early intervention, prevention, and the development of community-based supports.

Social work services across Scotland are facing acute workforce challenges. High vacancy rates, combined with recruitment freezes in some areas, have led to increased workloads for existing staff and reduced capacity to deliver preventative and early intervention work. As a result, services are increasingly focused on crisis response, with limited ability to engage in the kind of relationship-based, strengths-focused work that is most effective in the early stages of managing a long-term condition. This represents a missed opportunity to build resilience, connect individuals to peer and community supports, and reduce future demand on acute services.

Access to care and support also varies significantly between urban and rural areas. In remote and rural communities, limited transport options, workforce shortages, and the small scale of local populations can make it difficult to deliver services locally. Individuals may be required to travel long distances to access support, which is not always feasible, particularly for those with mobility issues or limited financial means. While digital technologies offer potential solutions, their effectiveness is dependent on reliable infrastructure, which remains inconsistent across Scotland. We welcome the Scottish Government's ongoing work to improve digital inclusion, but further investment is needed to ensure equitable access. A substantial proportion of care is provided informally by family members and unpaid carers. While we acknowledge the efforts being made to improve support for carers, significant gaps remain. Many carers struggle to access respite or short breaks, training, or financial support. Older carers may face additional barriers, such as limited digital literacy or physical health challenges. The emotional and practical toll of caring can lead to isolation, loss of confidence, and burnout, particularly when carers feel unsupported or unable to navigate complex systems.

Barriers frequently reported by carers include difficulty accessing timely responses from services, complex and inaccessible forms, low literacy or digital skills, long waiting lists, and financial constraints such as travel costs or the inability to purchase necessary items. A lack of transport or the inability to drive can further isolate carers, while the fear of losing independence or being labelled as vulnerable may discourage individuals from seeking help. Previous negative experiences, such as being "let down" by services, can also erode trust and reduce the likelihood of future engagement.

Finally, Social Work Scotland emphasises the need to improve the profile, pay, and career development opportunities for the social care workforce. Personal Assistants (PAs), employed through Self Directed Support, and other frontline care staff often provide highly personalised, relationship-based support that is essential for managing long-term conditions. However, recruitment and retention remain significant challenges. A national effort is needed to raise the status of care work, ensure fair pay, and provide meaningful training and progression pathways.

To improve outcomes for people with long-term conditions, Scotland must invest in a sustainable, community-based model of care that values social work and social care equally alongside health services. This includes addressing workforce challenges, ensuring equitable access across geographies, supporting unpaid carers, and removing barriers that prevent people from accessing the help they need.

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

Managing one or more long-term conditions presents a complex and often overwhelming set of challenges for individuals and their carers. These challenges are not limited to the clinical aspects of care but extend deeply into emotional, physical, and financial wellbeing.

A significant issue is the emotional toll that long-term conditions can take. Individuals often experience ongoing stress, anxiety, and fear, particularly in relation to the progression of their condition, the uncertainty of their future, and the impact on their independence. Carers, too, are affected by this emotional strain, frequently

experiencing burnout, isolation, and a sense of helplessness. The mental health impact on both parties can be profound and enduring, and it is essential that this is recognised and addressed as part of a holistic care approach.

There is also a physical burden associated with managing long-term conditions. For individuals, this may include pain, fatigue, and reduced mobility, all of which can limit daily activities and quality of life. For carers, the physical demands of providing support, such as lifting, assisting with personal care, or managing medication, can be exhausting, particularly when sustained over long periods without adequate respite or support.

Financial pressures are another major concern. The costs associated with managing long-term conditions, such as travel to appointments, specialist equipment, home adaptations, or reduced income due to inability to work, can place significant strain on households. Carers may also face financial hardship if they reduce their working hours or leave employment to provide care.

In addition, individuals and carers often report frustration with navigating services. Long waiting times, difficulty getting through to the right person or service, and a lack of continuity in care can all contribute to a sense of being unsupported. Repeatedly having to explain one's situation to different professionals, or being passed between services without resolution, can be demoralising and exhausting. These experiences can lead to disengagement from services altogether, particularly when people feel they are not being listened to or taken seriously.

Practical barriers such as low digital literacy, difficulty completing forms, poor reading and writing skills, and lack of access to transport can further compound these challenges. For some, the fear of losing independence or being perceived as vulnerable may prevent them from seeking help in the first place.

In summary, managing long-term conditions is not solely a medical issue, it is a deeply personal, social, and economic experience. Any strategy aimed at improving outcomes must take into account the full spectrum of challenges faced by individuals and carers, and ensure that services are accessible, responsive, and designed with empathy and understanding.

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

Effective communication between professionals across sectors is essential for delivering coordinated, person-centred care, particularly for individuals living with long-term conditions. Social Work Scotland believes that several key mechanisms

could significantly strengthen communication and collaboration across health, social work, social care, and third sector services.

One important approach is the introduction of a dedicated link role, a professional or team responsible for facilitating communication and coordination between the public sector (including health and social care services) and the third and independent sectors. This role could act as a consistent point of contact, helping to bridge organisational boundaries, reduce duplication, and ensure that relevant information is shared in a timely and appropriate manner. Such a role would be particularly valuable in supporting transitions between services and ensuring continuity of care. In addition, the development of a shared register of individuals with long-term conditions, maintained with appropriate consent and data governance, could support more proactive and coordinated care planning. Regular, multi-agency reviews, perhaps through a panel or case management approach, would allow professionals from different disciplines to monitor progress, identify emerging needs, and agree on appropriate interventions. This would help ensure that individuals receive the right support at the right time, and that no one falls through the gaps.

Local Area Coordination (LAC) is another model that has proven effective in strengthening communication between individuals, professionals, and community resources. LACs work alongside people to identify their goals, connect them with local supports, and build relationships with services. Their community-based, person-centred approach helps ensure that professional communication is grounded in the lived experience of the individual and their family.

To support these approaches, it is also essential to invest in shared digital systems, interoperable record-keeping, and joint training opportunities that bring professionals together across sectors. Building mutual understanding and trust is key to effective communication, and this can be fostered through regular, structured opportunities for collaboration.

In summary, strengthening communication between professionals requires both structural and cultural change. Dedicated coordination roles, shared information systems, and community-based models like Local Area Coordination can all contribute to more integrated, responsive, and person-centred care.

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

A wide range of digital tools are currently used to support individuals living with longterm conditions, helping them manage their health and care needs, maintain safety, and stay connected to both professional and personal support networks. These technologies play a vital role in promoting independence, enabling early intervention, and enhancing overall wellbeing.

Telecare systems are among the most widely used digital supports. Devices such as pendant alarms, fall detectors, motion sensors, and environmental monitors (e.g. smoke or flood alerts) provide reassurance and rapid access to emergency assistance, particularly for individuals living alone or with limited mobility. These systems can significantly reduce risk and support people to remain safely in their own homes.

Remote health monitoring tools, including blood pressure monitors, glucose meters, pulse oximeters, and digital weight scales, allow individuals to track key health indicators from home. Many of these devices can transmit data directly to clinicians or carers, enabling early detection of potential issues and reducing the need for hospital visits or emergency interventions.

Tablet and iPad-based communication tools (such as video calling platforms like Attend Anywhere, Zoom, and WhatsApp) play a vital role in helping individuals stay connected with healthcare professionals, carers, family members, and peer support networks. These technologies are especially valuable in reducing social isolation and supporting emotional wellbeing, particularly for those who are housebound or living in remote or rural areas.

In addition to healthcare, digital platforms also offer important opportunities in education. For children who are temporarily unable to attend mainstream school (due to illness, long-term conditions, or other barriers) remote learning tools can provide continuity in education. This includes not only access to virtual classrooms and learning resources, but also tailored support within school settings to help children engage with their education while receiving necessary medical treatment. Smart home technologies also offer practical support. Digital door entry systems, voice-activated assistants (e.g. Alexa, Google Home), and smart plugs or lighting systems can help individuals manage daily routines more easily and safely. These adaptations promote autonomy and reduce reliance on others for basic tasks.

Health apps and websites provide accessible tools for tracking symptoms, setting medication reminders, maintaining mood journals, and accessing condition-specific information. Many NHS-endorsed apps offer structured self-management support for conditions such as diabetes, asthma, and chronic pain, empowering individuals to take an active role in their care.

Access to digital health records and online services, such as those available through NHS Scotland platforms (e.g. NHS Inform, GP portals), allows individuals to view test

results, manage appointments, and request prescriptions. This can streamline communication with healthcare providers and improve continuity of care.

Additionally, eLearning and self-help resources, including online courses, instructional videos, and peer forums hosted by third sector organisations, offer valuable education and emotional support. These resources help individuals build confidence in managing their condition and connect with others facing similar challenges.

However, while digital tools offer significant benefits, accessibility remains a key concern. Digital poverty, low confidence with technology, and inconsistent connectivity, particularly in rural and island communities, can limit the effectiveness of these solutions. Older adults and carers may face additional barriers, such as limited digital literacy or lack of access to devices. Therefore, digital interventions must always be accompanied by face-to-face alternatives and tailored support to build digital skills and ensure equitable access.

Digital tools have the potential to transform how long-term conditions are managed, but their success depends on inclusive design, reliable infrastructure, and ongoing support for users. A blended approach that combines technology with human connection will be essential to meeting the diverse needs of Scotland's population.

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

Social Work Scotland recognises the growing potential of digital tools to enhance the management of long-term conditions. However, for these tools to be effective, they must be digitally inclusive, person-centred, and designed to complement human relationships and face-to-face support. It is essential that new digital solutions are co-designed with people who have lived experience of long-term conditions to ensure they are usable, relevant, and accessible to all.

One key area for development is the creation of integrated digital care records that are accessible to both the individual and the full multidisciplinary team. These records should support coordination across health, social care, and third sector providers, and include space for individuals to record their own goals, preferences, and concerns. This would promote shared decision-making and ensure that care is tailored to the person's unique circumstances in line with GIRFEC and GIRFE.

A national app or online hub could serve as a centralised platform for verified information, self-management resources, peer support networks, and local service directories. To ensure accessibility, such a tool should include features like text-to-

speech, large print, and multiple language options, and be designed for ease of use by individuals with low digital confidence.

Expanding the use of remote monitoring technologies, such as blood pressure monitors, glucose sensors, and movement trackers, would allow individuals to manage their conditions from home (where this is appropriate, and safe), with the option to share data securely with relevant professionals. These tools should include alert systems and check-in functions to support early intervention and reduce the need for emergency care.

Digital personal planning tools could also be developed to help individuals, parents, and carers build and update anticipatory care plans, link with other care, and flag changes in their circumstances quickly. These tools would support proactive care planning and ensure that support is responsive to evolving needs.

To improve access to professional support, user-friendly video and chat platforms should be designed to work effectively on mobile devices and slower internet connections, recognising the realities of digital poverty and rural connectivity challenges. These platforms should be secure, intuitive, and capable of supporting meaningful interactions between individuals and professionals.

Finally, digital inclusion support services, such as community-based digital navigators or 'tech buddy' schemes, are essential to ensure that no one is left behind. These services can build people's confidence in using technology, provide hands-on assistance, and help overcome barriers related to digital literacy and access.

While digital tools offer significant opportunities, it is vital that non-digital alternatives remain available. Digital solutions should enhance, not replace, the personal relationships and face-to-face support that are often central to effective care and wellbeing.

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

From a non-medical standpoint, early detection of long-term conditions can be significantly improved through a combination of proactive public engagement, accessible screening opportunities, and increased awareness of risk factors and early warning signs.

Firstly, regular health screening should be made more accessible and convenient for individuals across all communities. This includes offering flexible appointment times, localised screening venues, and simplified booking processes. Proactive outreach,

particularly to underserved or at-risk populations, can help ensure that screening is not only available but actively encouraged.

There should also be a greater emphasis on family history and known risk factors. Individuals with a family history of certain conditions should be offered early and ongoing monitoring, even before symptoms appear. This preventative approach can help identify emerging issues at an earlier stage, allowing for timely intervention and support.

In addition, public awareness campaigns play a crucial role in improving early detection. Increasing understanding of the signs and symptoms of common long-term conditions, through schools, workplaces, community centres, and digital platforms, can empower individuals to seek help sooner. These campaigns should be inclusive, culturally sensitive, and tailored to different literacy levels to ensure they reach a broad audience.

Finally, it is important to actively encourage participation in screening and early assessment programmes. This includes addressing barriers such as fear, stigma, or lack of understanding, and ensuring that individuals feel supported and informed throughout the process.

Early detection of long-term conditions can be strengthened by making screening more accessible, promoting awareness of risk factors and symptoms, and fostering a culture of prevention and early action. These efforts must be supported by clear communication, community engagement, and a commitment to equity in access.

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

Social Work Scotland recognises that the best people to answer this question are the individuals themselves, or their parents/carers. As an organisation we would observe that while individuals may be motivated to make healthy lifestyle choices, a range of structural and personal barriers can make this difficult or, in some cases, unattainable.

Financial constraints are a significant barrier. The cost of healthy food, particularly fresh produce, can be prohibitive for individuals and families on low incomes. Similarly, the expense associated with gym memberships, fitness classes, or other leisure activities often places them out of reach for those who would benefit most. Without affordable alternatives, opportunities to engage in physical activity and maintain a balanced diet are limited.

Accessibility issues further compound these challenges. People with poor mobility, long-term health conditions, or disabilities may find it difficult to travel to leisure facilities or community activities. In rural or poorly connected areas, limited public transport options can make it even harder to access services that promote health and wellbeing.

There is a clear need for enhanced education and support around healthy living. Many individuals would benefit from practical, accessible guidance on preparing nutritious meals on a budget, interpreting food labels, and making informed lifestyle choices. Without this foundational knowledge, adopting healthier habits can feel daunting or out of reach.

Government action could play a pivotal role in addressing these challenges, particularly through regulation of the fast-food industry. This might include setting stricter standards for nutritional content, including salt and sugar levels, as well as reviewing the density and availability of fast-food outlets within communities. Additionally, the school curriculum could be strengthened to include more comprehensive food and nutrition education. Innovative community-based initiatives, such as introducing 'adopted grannies' or local mentors, could also help families learn how to cook simple, fresh meals affordably. Such efforts would help dispel the misconception that healthy eating is inherently expensive and instead promote the idea that nutritious food can be both accessible and economical.

Social isolation can also be a barrier. People are more likely to engage in healthy behaviours when they feel supported and connected. Opportunities to join group activities, attend classes, or participate in peer support networks can make a significant difference, particularly when individuals are encouraged to attend with others or are supported to build confidence in new environments.

Poor housing conditions can directly impact health and limit the ability to make healthy choices. For example, damp or poorly ventilated homes can exacerbate respiratory conditions such as asthma or COPD, while overcrowding or lack of kitchen facilities can make it difficult to prepare healthy meals.

Finally, carers and those with significant caring responsibilities often experience exhaustion and burnout, leaving little time or energy to prioritise their own health. Without adequate respite or support, carers may struggle to maintain their own wellbeing, despite being at increased risk of stress-related health issues.

Making healthy decisions is not solely a matter of personal choice, it is shaped by a complex interplay of financial, social, environmental, and systemic factors. Addressing these barriers requires a coordinated, cross-sector approach that ensures healthy options are affordable, accessible, and supported by education, infrastructure, and community connection.

15. Is there anything currently working well within your community to prevent or slow progression of long-term conditions?

Within many communities, a number of local initiatives and informal supports are playing a valuable role in helping to prevent or slow the progression of long-term conditions. These include community transport schemes and volunteer-led services that enable individuals, particularly those with mobility challenges or limited access to public transport, to attend social groups, wellbeing activities, and health-related appointments. These services are vital in reducing isolation and supporting continued engagement in community life.

Volunteer support, including befriending and transport assistance, helps individuals maintain social connections and access essential services. This kind of informal, community-based support can have a significant impact on mental and emotional wellbeing, which in turn contributes to better physical health outcomes.

Support groups, whether condition-specific or more general, also provide a valuable space for peer connection, shared learning, and emotional support. These groups empower individuals to manage their conditions more confidently and reduce the sense of isolation that often accompanies long-term illness.

Additionally, some GP practices and community health settings offer pastoral care or chaplaincy services, which many individuals find beneficial. These services provide emotional and spiritual support, helping people to cope with the psychological and existential challenges that can arise when living with a long-term condition.

Together, these community-based initiatives demonstrate the importance of holistic, person-centred approaches that go beyond clinical care. They highlight the value of social connection, emotional support, and accessible local services in promoting wellbeing and preventing deterioration.

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

Social Work Scotland encourages the Scottish Government to place greater emphasis on the development of compassionate communities, building on the positive direction seen in the national dementia strategy⁴. We believe that while rights-based and service-led approaches are essential, an over-reliance on formal

⁴ <u>https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/</u>

systems can unintentionally disempower communities by shifting focus away from local capacity, relationships, and informal support networks.

The erosion of community infrastructure, such as local halls, community schools, libraries, and meeting spaces, has significantly reduced opportunities for people to come together, share knowledge, and support one another. Peer support groups, which are known to be highly effective in promoting self-management and emotional wellbeing, often struggle to find accessible and affordable venues. This lack of space contributes to social isolation and limits the potential for community-led innovation. To address this, we recommend investment in the enhancement and protection of community spaces, ensuring that local groups have the physical infrastructure needed to meet, collaborate, and grow. When communities are given the space and support to organise, they often develop creative and sustainable solutions tailored to local needs.

We also advocate for the expansion of Local Area Coordination (LAC) services. LACs play a vital role in connecting individuals with one another, facilitating peer support, and linking people to local resources. Their person-centred, asset-based approach helps build community resilience and reduces reliance on formal services. In addition, we recommend sustained funding for initiatives across health, social care, and the third sector that support people with long-term conditions. These initiatives should focus on providing accessible advice, practical support, and early intervention, while maintaining strong links with health professionals to ensure continuity of care.

Involving communities meaningfully requires more than consultation, it requires coproduction, shared decision-making, and long-term investment in the social infrastructure that enables people to support one another. By fostering compassionate, well-connected communities, the Scottish Government can help slow the progression of long-term conditions and improve quality of life for individuals and carers alike.

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?

If the framework is to be genuinely person-centred, it must recognise that individual needs vary significantly and cannot be addressed through a one-size-fits-all approach. Person-centred care requires flexibility, responsiveness, and a commitment to understanding the unique circumstances of each individual. However,

as highlighted in our earlier response regarding barriers, there are significant challenges related to staffing and resourcing, particularly in remote and rural areas, that must be acknowledged and addressed.

The framework's commitment to "equitable" provision must be underpinned by a realistic understanding of what equity entails in practice. Equity does not mean identical provision across all areas but rather ensuring that everyone has access to the support they need, regardless of geography or circumstance. Achieving this will require targeted investment across all local authorities, with particular attention to areas where workforce shortages, infrastructure limitations, and geographic isolation currently hinder service delivery.

In addition, any projects or initiatives developed under the framework should include a clear focus on identifying and supporting individuals with protected characteristics, in line with the Equality Act 2010. These individuals may face additional barriers to accessing care and support, and their needs must be proactively considered. Where appropriate, individuals with complex or multiple needs could be included in tools such as the Dynamic Support Register or monitored through other mechanisms that ensure timely and coordinated responses.

Ultimately, for the framework to succeed in delivering person-centred, equitable care, it must be supported by adequate funding, inclusive design, and a commitment to addressing structural inequalities across Scotland's diverse communities.

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

As Social Work Scotland represents the leaders and managers of social work services, we do not seek to prescribe specific actions for healthcare. However, drawing on good practice within the social work profession, we recommend that all staff receive training on the Equality Act 2010 and anti-discriminatory practice. Where poor practice is identified, it should be addressed through supportive and corrective measures wherever possible.

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

We are aware that many charities rely on a specific condition to generate funds so we suggest there must be engagement with the sector if there is a move from condition specific to long term conditions. Neil Gibson Adult Social Work Policy and Practice Lead Social Work Scotland