Long Term Conditions Framework: Consultation Analysis

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Scottish Government
Riaghaltas na h-Alba

Contents

Executive summary

Introduction

This executive summary presents the high-level findings from the independent analysis of responses received to the Scottish Government consultation on the Long Term Conditions Framework. It does not report on the consultation analysis question by question – rather it looks to draw out key and recurring themes.

A total of 371 validated responses have been included in the final analysis. The majority (60%) of responses were received from individuals (for example, people with long term conditions, people who work in the health and social care sector), and the remainder of responses (40%) were from a wide range of public, third and private sector organisations.

As part of the consultation process, six focus groups were held with seldom heard groups to reach those who may not traditionally respond to public consultations to ensure the consultation captured a diverse range of views. Key messages from the focus groups aligned with those from the public consultation.

Setting the analysis in context

Responses to questions asked within the consultation paper were often framed by respondents (particularly service providers and third sector organisations and individual respondents) in the context of the challenges currently facing the health and social care sector in Scotland. The challenges mentioned in these responses included:

- workforce recruitment and retention challenges
- funding and capacity pressures
- waiting lists and the impact on access to treatment, care, and support
- public trust in the health and social care system

Further, responses to consultation questions were often framed in terms of the valuable role of the third sector in providing support to people with long term conditions. Points frequently raised in responses included:

- the historic under-recognised value and contribution of third sector services outside of medical care in helping people to manage long term conditions
- the role of the third sector in bridging gaps in public sector provision
- sustainable and longer-term funding for the third sector – equal partners in care delivery for people living with long-term conditions
- workforce recruitment and retention challenges

Moving 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

The vast majority of respondents (80%) who answered the consultation question agreed that the 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. These respondents:

- identified several benefits to adopting a cross-cutting approach – for example: whole-system, person-centred and integrated models of care; improved coordination of care; increased efficiency of healthcare delivery; and reduced siloed working practices and improved pathways
- emphasised that highly specific condition-specific improvement work should continue to be undertaken alongside cross-cutting work

The remainder of respondents (20%) who answered this question disagreed with the Scottish Government proposal. These respondents identified a risk of losing momentum, focus and progress on condition-specific work as well as unintended consequences.

How condition-specific work could be selected

The importance of condition-specific work was emphasised by respondents throughout their responses to the consultation questions. Personalised and tailored care and support was viewed as critically important to improve the early diagnosis, treatment, care, and management of long term conditions – and that this could help to improve outcomes and enhance quality of life for people.

In thinking about how areas for condition-specific work could be selected (that is, work which is very specific to a health condition or group of health conditions, rather than across conditions), respondents identified considerations including:

- the prevalence and impact of long term conditions
- selection should be guided by evidence and data
- the importance of tackling health inequalities and addressing unmet needs

Equitable access

Equitable access to information, care, treatment, and support services was considered vital regardless of condition, location, or background. Respondents said this could help: initiate early intervention from the point of diagnosis onwards; people make informed decisions about their health, treatment, care, and support; and empower people with long term conditions take ownership of their own health and care.

Prevention and early intervention

A recurring theme in consultation responses was prevention and early intervention activity in its many different forms – support was expressed for this to be embedded in the Long Term Conditions Framework. An increased focus on prevention and early intervention was seen as critical to help address issues before they escalate, support better physical and mental health and wellbeing, and reduce pressure on health services.

Whole-system, person-centred and integrated models of care

Respondents expressed support throughout the consultation for whole-system, person-centred and integrated models of care. They emphasised that many people experience multiple symptoms or conditions which are often interlinked. They added that a whole-system approach could help services respond more effectively to the real world complexity of people's lives, especially where multimorbidity and inequality are key factors. The important role of multi-disciplinary teams in the delivery of integrated care and support to people with long term conditions – and continuity of care – were also emphasised. Respondents felt that continuing efforts were required to:

- improve communication and joined-up working between health care professionals
- improve communication between healthcare professionals and people with long term conditions

Digital infrastructure improvements were viewed by respondents as part of the solution. For example, taking forward work aligned to the 'digital front door' – a health and social care app that will enable people in Scotland to interact more effectively with health and social care services. As well as addressing wider challenges around fragmented IT systems which could hinder the effective communication between service providers. Ensuring that all healthcare professionals involved in a person's care could access relevant information was considered vitally important – as was ensuring people with long term conditions could see their own health information and records.

Respondents mentioned the importance of digital tools and resources (in their many different forms) complementing not replacing other delivery methods. They advocated for a balance between physical and online information and services for people with long term conditions and for people who care for them – and for accessible information and services to be available in a range of formats and settings.

Tackling inequalities and barriers to accessing information, care and support

Respondents highlighted the multi-faceted nature of the barriers faced by people with long term conditions accessing information, treatment, care, and support services.

They also stressed the importance of holistic support that addressed the broader determinants of health – for example, welfare rights and financial advice services, employment advice, housing advice services. Respondents emphasised that barriers could be particularly pronounced for: those living in rural and island communities; those living in disadvantaged areas; disadvantaged or marginalised groups; people from lower socio-economic backgrounds; and people with protected characteristics. Across various consultation questions a common set of barriers emerged from responses, including:

- a lack of knowledge and awareness of services and how to access them
- personal, psychological, and attitudinal barriers
- physical and geographic barriers
- financial barriers
- digital accessibility, connectivity, literacy, and confidence barriers
- language, cultural and communications barriers
- organisational barriers

Respondents also emphasised the importance of:

- co-developing information and services with input from people with lived experience, grassroots organisations, and healthcare professionals
- adopting an inclusive communications approach
- improving health literacy
- psychologically informed information and services
- culturally appropriate information and care

The importance of access to non-medical services

Services outside of medical care were considered particularly helpful for people in managing long term conditions. Here, consultation respondents highlighted the valuable contribution of third sector and community-based support that provides trusted information and advice, emotional and practical support, advocacy, peer networks, tailored support for specific conditions, and general support that complements clinical care. Wider points raised by respondents included that non-medical services should be available close to home, and there was recognition of the important care and support provided to people with long term conditions by local authorities, unpaid carers, family members, and friends.

Workforce development

Workforce development and training for healthcare professionals (at all levels) was considered important to: help healthcare professionals better understand individual conditions; improve communication and interaction with people with long term conditions; and improve proactive signposting and referral to medical and community-support.

1. Introduction

This report

This report presents the independent analysis of responses received to the Scottish Government consultation on the Long Term Conditions Framework. The analysis was undertaken by EKOS Ltd on behalf of the Scottish Government.

Section 1 sets out:

- background to the consultation
- what the consultation sought views on
- next steps
- structure of this consultation analysis report

Background to the consultation

Until now, the Scottish Government's policy approach to long term conditions has focused primarily on individual conditions and there are a number of strategies and policies in place to improve care and support for a range of long term conditions and condition groups. These do not join up actions or prioritise according to burden of disease or impact. Whilst much has been achieved, in terms of clinical guidelines, patient and clinician information and education and service delivery, resources are not allocated as impactfully as they could be. Conditions that are major contributors to the burden of disease, but which happen not to have a strategy, receive less resource than conditions which have a framework or action plan.

Continuing to add to the list of conditions with dedicated strategies and/or action plans is not a viable way forward due to finite resources and places an additional burden on NHS boards and other delivery partners. The Scottish Government recognises that it needs to more efficiently and impactfully allocate finite resources on long term conditions.

Some condition-specific Scottish Government policies are approaching the end of their planned duration. This has provided an opportunity for the Scottish Government to review its current approach to policy for the care and support of people with long term conditions to ensure it evolves and responds to the changing context, builds on progress achieved to date, and considers if and how policy support for other long term conditions can also be provided. The review also supports the vision for reform by exploring how the Scottish Government and its partners can improve the approach to healthcare quality, care, support, and inequalities in long term conditions. As the Scottish Government reassesses how best to focus policy work for long term conditions, it is recognised there will be a need to prioritise areas for improvement, and that improvement priorities may sometimes cut across all conditions, and other times be more condition-specific.

What the consultation sought views on

The Scottish Government consultation has sought views on the development of a national Long Term Conditions Framework – a unified policy approach – to improve the prevention, identification, management, and experience of living with long term conditions in Scotland. For this consultation 'long term conditions' means any physical illness or mental illness expected to last a year or more.

The role of the consultation is intended to help the Scottish Government identify improvement priorities for long term conditions at a national level. It is also intended to support the delivery of the NHS reform and renewal work which is underway to make people's experience of the NHS in Scotland better than it is today, and to ensure the national framework is prepared in a way that meaningfully reflects the needs of those living with long term conditions and the organisations that support them.

To inform topics and questions for this consultation, the Scottish Government spoke to a small number of people with lived experience across a range of long term conditions, to understand what is and isn't working well with their care and support. The same questions were asked of a number of third sector organisations, as well as clinicians via the Scottish Government's Professional Advisory Group, again to help inform consultation topics and questions.

The consultation asked a range of questions around what is working well in long term conditions, what could be better, and how the Scottish Government could prioritise work. The consultation has sought to gather the views of a wide range of individuals and organisations on what matters when it comes to prevention, care, support, and equalities in long term conditions.

Next steps

The consultation analysis report will form part of the evidence base that will be used by the Scottish Government to help develop and finalise the Long Term Conditions Framework which will set out principles, priorities, and themes to then guide action across health and social care. Insights from work delivered through the existing condition-specific Scottish Government policies will also help to inform an integrated approach. It is expected that the finalised Long Term Conditions Framework will be published by the Scottish Government before the end of December 2025, with the first in a series of action plans published by March 2026.

Structure of this consultation analysis report

The remainder of this report is structured in line with the 19 questions asked within the consultation paper. It also provides an overview of the consultation methodology, responses, analysis, and limitations. A summary of feedback captured at the focus group sessions has also been provided.

2. Consultation methodology and analysis

Introduction

Section 2 provides details on the consultation methodology and analysis, and comprises sub-sections on:

- the public consultation
- focus groups
- analysis
- consultation challenges and limitations

Please refer to **Appendix A** for more information on data management and cleaning and analysis.

Public consultation

A total of 371 validated responses have been included in the final analysis. The Respondent Information Form (RIF) captured information about individual and organisation respondents. **Table 2.1** shows that: the majority of responses (60%) were from individuals; and two-fifths of responses (40%) were from organisations.

A review of the consultation responses from individual respondents shows that this included a good mix of responses from:

- **people with long term condition(s)** or who have a family member with a long term condition(s)
- **people who work in or who previously worked** in the health and social care sector

Table 2.1: Consultation respondents by respondent type

Respondent type	Number	Percentage
Individuals	224	60%
Organisations	147	40%

Base = 371

EKOS, in discussion and agreement with the Scottish Government Long Term Conditions Strategy Unit, categorised organisation respondents under four broad categories, and **Table 2.2**, below, shows the number of each type of organisation respondent. It is recognised that there are instances in which third sector organisations fulfil a dual function of both representing member/stakeholder views and directly providing support/healthcare services. A 'best-fit' approach has been adopted to categorisation.

A diverse range of organisations responded to the consultation – more than two-fifths (42%) of responses were from third sector organisations. A review of organisation responses showed that many engaged with their members and/or with people with long term conditions to help inform their consultation response.

Table 2.2: Organisation respondent by sub-category

Organisation respondent	Number	Percentage
Third sector	62	42%
Representative organisation/group for health and social care staff	33	22%
Service provider	31	21%
Other	21	14%

Base = 147

Organisation sub-categories have been defined as follows:

- **third sector** – covering organisations such as charities, community groups, social enterprises, and voluntary sector organisations that offer support and services for specific conditions and/or to specific population groups
- **representative organisation/group for health and social care staff** – defined as organisations/groups representing a specific group of health or social care staff, for example membership bodies and professional associations
- **service provider** – encompassing organisations that provide health and social care services, including but not limited to NHS boards and Health and Social Partnerships (HSCPs)
- **other** – organisations which could not be easily categorised into one of the above categories, such as academia and private sector organisations

These categories have been used to highlight common and differing views of organisation respondents (where appropriate) in the remainder of this consultation analysis report.

Focus groups

The Scottish Government organised and delivered six engagement events to supplement the main public consultation. The events with seldom heard groups were undertaken to reach those who may not traditionally respond to public consultations to ensure the consultation captured a diverse range of views. The engagement events held included:

- New Scots Women's Group (Stirling) event which was held on 20 June 2025 and involved women from refugee backgrounds (Sudanese and Afghan participants)

- Sikorski Polish Club (Glasgow) engagement event was held on 22 June 2025 and involved members of the Older People's Group
- an online engagement event at The Scottish Assembly was held on 27 June 2025 and involved around 30 adults with a learning disability from all over Scotland, alongside carers and staff from The Scottish Assembly
- three in-person events with the Chinese and Gypsy/Traveller communities (July 2025) and a written submission from the Arabic-speaking community

A summary overview of the main themes that emerged from the focus groups can be found in **Appendix B**. Themes chimed with the main public consultation.

Analysis

There were limited closed-ended questions asked in the consultation. For open-ended questions, the analysis aims to convey both the strength and frequency of the themes raised. The qualitative analysis identifies the key themes across responses to each question. This means that:

- most sections in the report contain numbered themes (for example, Theme 1, Theme 2, Theme 3) – these have been set out in order of relative importance with Theme 1 noted by the greatest number of respondents
- themes/points raised have been quantified in some way to articulate the strength of opinion – for example, we use the terms 'a small number' (10% or less of respondents), 'some' (11% to 25% of respondents), 'many' (26% to 50% of respondents), 'the majority' (51% to 74% of respondents), and 'the vast majority' (75% or more of respondents)

This consultation analysis report includes quotes from respondents who gave permission for their response to be made public to add richness to the analysis. This does not indicate that these comments will be acted upon or given greater weight than others.

Consultation challenges and limitations

Similar to other public consultations, the main limitation of the consultation process is that respondents are self-selecting, and the responses may not be representative of the population as a whole. That being said, it is clear from a review of the responses that they have been submitted by people who manage long term conditions, as well as family members, clinicians, and organisations that support them.

3. Question 1

Do you agree that the 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?

Introduction

Section 3 provides an overview of:

- the response to the closed-question (Question 1)
- the views of respondents who agreed with the proposal
- the views of respondents who disagreed with the proposal
- the view of respondents who were unsure

Closed-question response

The vast majority of respondents (80%) who answered Question 1 agreed that the 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, **Table 3.1**. The remainder of respondents (20%) who answered this question disagreed with this proposal.

Table 3.1: Do you agree that the 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?

Respondent type	Yes		No	
	Number	Percentage	Number	Percentage
Individuals	174	81%	41	19%
Organisations	91	77%	27	23%
Total	**265**	**80%**	**68**	**20%**

Base = 333 (38 individuals and organisations did not answer this closed question)

A small number of respondents, almost exclusively organisations, did not answer the closed-ended question. A review of the qualitative feedback indicates that most of these respondents considered the proposal a ‘complex’ issue and that it was not possible for them to provide a simple ‘Yes’ or ‘No’ response.

Some said that they would have welcomed a 'not sure' or 'don't know' category[1]. Further, some organisations had consulted with people with lived experience of long term conditions and/or with staff, members, or stakeholders to inform their consultation submission, and views on the Scottish Government proposal were mixed.

Table 3.2 provides a further breakdown of responses to Question 1 by organisation sub-category. A sizable proportion (38%) of third sector organisations disagreed with the Scottish Government proposal.

Table 3.2: Do you agree that the 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? – by organisation sub-category

Organisation respondent type	Yes		No	
	Number	Percentage	Number	Percentage
Representative organisation/group for health and social care staff	21	88%	3	13%
Service provider	26	87%	4	13%
Third sector	29	62%	18	38%
Other	15	88%	2	12%
Total	**91**	**77%**	**27**	**23%**

Base = 118 (29 organisations did not answer this closed question)

Respondents who agreed with the proposal

As noted above, 80% of respondents who answered Question 1 agreed that the 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.

Most respondents who expressed support intimated in their response that this either 'made sense', or was 'a welcome and necessary shift', 'desirable', 'a long-overdue step', or 'a positive move to address inequities in service provision.'

The main themes that emerged from these responses were:

- **theme 1**: several benefits to adopting a cross-cutting approach
- **theme 2**: highly specific condition-specific improvement work should continue to be undertaken alongside cross-cutting work
- **theme 3**: other issues and challenges raised

[1] If 'not answered' is included in the responses this would change **Table 3.1** to 72% (Yes), 18% (No), and 10% (not answered).

Theme 1: Several benefits to adopting a cross-cutting approach

Respondents who agreed with the Scottish Government proposal identified benefits of moving away from the current condition-specific policy approach, including:

- whole-system, person-centred, holistic, and integrated models of care
- equitable and sustainable access to care, treatment, and support
- an increased focus on prevention and early intervention
- a unified approach could be easier to communicate

Whole-system, person-centred, holistic, and integrated models of care

These respondents expressed support for a policy approach that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work, and said this was sensible as:

- changing demographics (ageing population) meant that most people would experience the older or latter stages of life with multiple long term conditions
- many people experience multiple long term health conditions that are overlapping, linked or intersect across their life – a policy approach that focused on multi-morbidity rather than a condition-specific approach better reflected the reality for many people living with long term conditions
- many aspects of living with a long term condition were considered shared across different conditions – for example, symptoms like fatigue and pain, the development or progression of mental health conditions, the value of accessing peer support and supported self-management, and challenges in accessing statutory services and timely diagnoses
- it could help services respond more effectively to the real world complexity of people's lives, especially where multimorbidity and inequality are key factors to help people with long term conditions live healthier lives and improve patient care and outcomes
- it provided an opportunity to design services in a more integrated, person-centred way that made best use of available expertise across the system (for example, supported self-management, prevention and early intervention). This could help by: reducing duplication of effort, appointments, and reviews; reducing unnecessary referral journeys; ensuring interventions covered all of their needs; and maximising resource efficiency.

Equitable and sustainable access to care, treatment, and support, especially for marginalised and underserved groups

These respondents said a cross-cutting approach could ensure people have equal access to the care, treatment and support they need 'regardless of the specific long term condition' they have.

Points raised included a perception among these respondents that: some long term conditions are currently 'neglected and others prioritised'; there could often be a 'focus on certain conditions'; access to care, treatment, and support could be a 'lottery' for some people with long term conditions depending on where they lived; or that some conditions were not covered by existing strategies and 'under-resourced'; and that the proposed approach could help to 'close the gap.'

Prioritise early intervention and prevention

Respondents said that cross-cutting work could allow for 'upstream, preventative interventions' which would help address the common risk factors across multiple long term conditions, such as physical inactivity and poor diet.

A unified approach could be easier to communicate to the general public and healthcare staff.

Respondent quotes to illustrate points raised under theme 1 are provided below.

> "People would benefit from having someone at the centre point of care, to listen to their issues. This person, who would have experience of many medical conditions (for example, a GP who would be provided with longer appointment times to listen fully to the person with multiple conditions) would ensure they were referred to the right specialty for that issue and be able to keep in touch with them throughout their care. This would allow continuity of care and familiarity. The person at the centre of care should also be aware of all services outside the NHS that could help with that condition." Individual respondent

> "There is significant benefit from having a non-condition specific approach in the management of resources especially in remote and rural areas. For those with long term conditions having support within a group where people have different conditions can be very supportive rather than seeing those with the same diagnosis. It also allows more of a focus on what the individual can do rather than what stage they are at with their condition." Individual respondent

Theme 2: Highly specific condition-specific improvement work should continue to be undertaken alongside cross-cutting work

Many of the respondents supportive of the proposal also indicated that the new policy approach would need to strike an appropriate balance between enhancing cross-cutting improvement work alongside condition-specific work where required, rather than 'focussing exclusively on one or the other.'

These respondents emphasised that a balanced approach would be critically important as condition-specific work remained essential to maintain the momentum of condition-specific policy work. It was also noted that a policy shift must be implemented with flexibility and sensitivity to the unique needs of individual conditions.

Respondents intimated the policy change should not result in less funding or resources for condition-specific work, and 'cannot be viewed as a way to cut essential specialist services', or that the primary objective for the new policy approach should not be 'cost saving'. Further, they emphasised that care was needed to ensure there were 'no unintended consequences' of moving away from the current condition-specific policy approach. These responses highlighted potential risk factors including:

- a 'generic model' could dilute the focus on disease-specific needs and outcomes
- loss of investment, existing specialist services and approaches, and focus/ attention on specific conditions
- pitting different organisations and conditions against one another for attention under a single Long Term Conditions Framework
- the existing 'uneven landscape' of support for different conditions may build inequality into the new framework from the start
- if care for long term conditions were to be streamlined, this could necessitate greater administrative or delivery burden on decision-makers or frontline services, or come at the expense of supporting preventative approaches

Further, organisation respondents called for greater clarity on:

- how existing condition-specific strategies and related actions and services would be taken forward in the future?
- what would happen with existing strategies that have not come to the end of their current delivery cycle?
- the role that current clinical oversight groups would have in guiding the implementation of the framework?
- what would be included under the umbrella of long term conditions in a new framework?
- how future condition-specific work would be integrated into a new framework?
- how would the framework address the intersectional challenges and health inequalities experienced by many people with long term conditions?
- how strategic planning would take place on action plans delivered as part of the framework?
- how measures would be prioritised and funded within the framework?

Some respondents highlighted: the 'continued value of targeted strategies for specific conditions where personalisation is important'; that 'there remains a very important role for condition-specific focused policies to continue'; that it would be important 'to acknowledge the unique characteristics of specific conditions and recognise that condition-specific work remains vital to quality care'; 'that efforts to improve treatment, care, and wellbeing should always be done through the lens of a condition and age-specific approach.'

Respondent quotes to illustrate points raised under theme 2 are provided below.

> "We would recommend that cardiovascular disease maintains a separate, condition specific policy approach to continue to build upon the progress in the Heart Disease Action Plan 2021. We feel this would maintain and consolidate a focus on cardiovascular disease in Scotland at a time when this is particularly important, while facilitating cross-cutting and collaborative working to improve the lives of all living with long term conditions." National Heart Disease Task Force

> "It is crucial that this change in approach does not reduce or undermine access to specialist care, where appropriate…a move towards a cross-cutting approach should not mean that these specialist skills are lost in favour of a more generalist approach." Royal College of Nursing Scotland (RCN Scotland)

Theme 3: Other issues and challenges raised

Other issues or challenges raised by respondents who agreed with the proposal to move towards a balance of cross-cutting improvement work for long term conditions alongside condition-specific work are outlined below. Each point was raised by a very small number of respondents. Points raised included, for example:

- the scope of the proposed framework appears to be 'overly focused on physical health conditions', failing to recognise the prevalence of long term mental health conditions in Scotland
- concerns were raised that there could have been a more significant consultation process given the scale of the policy shift
- terminology used (for example, 'burden') risks reinforcing negative perceptions and could lead individuals with long term conditions to internalise harmful labels – using 'empowering and respectful' terminology was suggested

Respondents who disagreed with the proposal

As noted above, 20% of respondents who answered Question 1 disagreed with the Scottish Government proposal. The main themes included:

- **theme 1**: there could be a risk of losing momentum, focus and progress on condition-specific work as well as unintended consequences
- **theme 2**: other reasons or concerns raised

Theme 1: There could be a risk of losing momentum, focus and progress on condition-specific work as well as unintended consequences

Most respondents who disagreed with the proposal felt the proposed shift in policy emphasis could risk losing momentum, focus and progress on condition-specific work and result in unintended consequences.

These respondents raised similar points as covered in theme 2 above (where respondents agreed with the proposal), and wider feedback included that:

- it would be important to recognise the experiences and needs of people with long term conditions were not the same and that specialist care was needed for the best possible outcomes
- condition-specific strategies were not considered a barrier to integrated care – they suggested this ensured specialist knowledge, tailored care pathways, national audits, multidisciplinary standards, and targeted investment were in place to meet the needs of people with complex health conditions

A respondent quote to illustrate points raised under theme 1 is provided below.

> "I recognise that condition-specific work will still continue however through creating a work programme that encompasses all long term conditions, this holds the risk of losing patient-centred care, and not meeting the health, support and social care needs of the population." Individual respondent

Theme 2: Other reasons or concerns raised

A small number of respondents who disagreed with the proposal expressed similar concerns to those raised in theme 2 and theme 3 above (by respondents who agreed with the proposal). This included calls for greater clarity in aspects of the Scottish Government proposal (for example, around the selection and definition of long term conditions) and the risk of inequalities in support for different conditions being built into the new framework from the start.

A respondent quote to illustrate points raised under theme 2 is provided below.

> "It is not clear what conditions may or may not be included or excluded in this policy work and what the rationale for this is. Until this is clear, it is difficult not to conclude that grouping a number of conditions together is either a cost-cutting exercise, in which case we are incredibly concerned about the detrimental effects for people with Cerebral Palsy or else is it a lack of understanding of the detail and the nature of different conditions and lack of capacity to engage with the nuances and issues raised by such conditions." Cerebral Palsy Scotland

Respondents with mixed views on the proposal

A small number of respondents intimated they either responded 'No' to Question 1 or did not answer the closed question. These respondents typically said it was not a straight 'Yes' or 'No' response, and responses set out the **pros and/or cons of the proposal**, as reflected in the sub-sections above.

4. Question 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?

Introduction

The vast majority (91%) of respondents answered Question 2. This section provides information on:

- how respondents answered this question
- what was considered to have worked well and/or what could be improved in prevention, care, or support for people with long term conditions
- the views of respondents who said there has been limited improvement in prevention, care, and support for people with long term conditions

How respondents answered this question

Respondents answered this question in different ways. For example, some respondents:

- set out **what they considered currently worked well** in terms of prevention, care or support for people with long term conditions. These respondents have drawn on: the respondent's personal or professional experience of long term conditions and existing models of prevention, care, and support; existing review, research, and evaluation evidence; progress made in condition-specific strategies and action plans; and/or on developments from other sectors (or for particular long term conditions) which they felt could be replicated
- described the different ways in which they considered prevention, care, or support for people with long term conditions could be **further improved** or what this should look like to achieve marked improvements in the future
- identified **underpinning principles** for the provision of prevention, care, or support, including: whole-person, whole-system approaches; early intervention and prevention; equitable access; continuity of care; the valuable role of community resources and support; and meaningful engagement and involvement of people with lived experience, their families, and carers
- described **barriers** to the delivery of improvements in prevention, care, or support, including: the historic under-funding of some long term conditions and services; sustainable funding challenges more generally, including for the third sector; reduced budgets, including for preventative support services; reduced investment in research; de-prioritisation of training; downgrading of specialist support; and staff retention challenges, including the loss of specialist knowledge and skills

What worked well and/or what could be improved

The vast majority (85%) of respondents who answered the question set out examples of where improvement work relating to prevention, care, or support for people with long term conditions worked well and/or how it could be further improved. Themes which emerged from these responses included:

- **theme 1:** prevention and early intervention
- **theme 2:** access to personalised and specialist care and support
- **theme 3:** supported self-management
- **theme 4:** communication and collaboration
- **theme 5:** involvement of, and support for, carers

Theme 1: Prevention and early intervention

Organisation respondents highlighted their long history of delivering preventative interventions to the public and more specifically to people with long term conditions. They emphasised the importance of primary and secondary prevention in: preventing and detecting ill health or some long term health conditions; improving early diagnosis; delaying deterioration; and reducing pressure on NHS and social care services. They suggested a greater emphasis on early intervention and prevention was required for the proposed framework and the healthcare system in general.

Prevention and early intervention activities and approaches described in responses included:

- public health campaigns and interventions to improve awareness and early detection
- tailored information and education about healthy and active lifestyles and behaviours, such as healthy eating, hydration, regular exercise, smoking cessation, staying in recovery, good sleep, and good mental health
- information and education on individual long term conditions – respondents said this could help with symptoms identification, pain and risk management as well as reduce stigma (for example, information leaflets, condition-specific workbooks, structured education programmes, group-based information and education sessions)
- raising awareness and educating healthcare professionals on long term conditions and preventive measures – particularly in primary care where, for example, general practice (GP) is often a person's first point of contact
- accessible community-based services and staff (for example, Community Link Workers, wellbeing practitioners) and proactive outreach – for people generally, but more specifically as a way to: help reach people at risk of, or with poor health, who may otherwise be disengaged from public sector health services; facilitate referral/access to appropriate services; and help people to navigate complex systems of care

- routine health check-ups and integrated screening and support (for example, those that use ‘traffic light systems’ were mentioned) help to: identify early health risks; enable earlier intervention; support anticipatory care planning; signpost people to appropriate support such as the third sector, self-help resources, psychosocial groups; and slow progression in some cases
- clinical reviews, routine annual reviews, routine medication reviews, proactive symptom management separate to monitoring reviews – opportunities to consider all the long term conditions a person has in one appointment
- holistic and whole-system approach/working that take account of an individual’s broader needs, and recognise the importance of income security, housing stability, and community connection in health outcomes – this could support a better understanding of, and address the root causes and wider determinants of, poor health and inequalities

A respondent quote to illustrate the points raised is presented below.

> “Other potential clinical areas for Community Pharmacy teams to support detection and prevention of long term health conditions include an effective national weight loss service and cardiovascular disease screening. Our network of 1,244 pharmacies are easily accessible and are a key touchpoint for both people who already receive NHS care and those who are disengaged from services – we firmly believe that this accessibility and reach could be harnessed to great impact with respect to detection and prevention of illness.” Community Pharmacy Scotland

There was also acknowledgement that prevention was not always possible for all long term conditions, and feedback was also framed around changing population demographics and the importance of access to specialist care and support.

Theme 2: Access to personalised and specialist care and support

Both individual and organisation respondents said that access to personalised and specialist care and support for people with long term conditions was essential to help ensure effective outcomes. Critical factors identified within these responses included:

- **person-centred or whole-person approaches**, including personalised care and treatment plans, trauma-informed approaches, recovery focused and outcomes and strengths based approaches as well as needs assessment to understand preferences, values and address barriers to access (for example, choice of appointment type)
- **timely access to medical/clinical services** (for example, effective treatments and medications, including psychological support, medicines optimisation) **and non-medical/non-clinical services** (for example, therapeutic services and support, practical and emotional support such as benefits advice, workplace support) – this could provide support for people with long term conditions to live independently for longer

- **timely access to relevant health care professionals** (for example specialist nurses), including access to highly specialist condition-specific knowledge, understanding, expertise, skills, and care – supported by workforce development
- **shared care planning and decision-making**, such as involving people in decisions about their care and increased access to health records, care plans and test results – this could give people more autonomy and control of their care and empower people to prepare emotionally, physically, and logistically for treatment
- **consistency and continuity of care**, including a named single point of contact, integrated and co-located care and support, and ensuring care navigation was optimised across different settings and providers
- **embracing digital and advanced technologies**, digital wellbeing platforms, Artificial Intelligence (AI) driven tools (for example, chatbots, wearables) and making better use of diagnostic tools, data and analytics to: support digital triage; ensure earlier detection; support home-based care and management; improve confidence, self-monitoring and self-management; allow clinician remote monitoring and save clinical time; enhance engagement; avoid exacerbation of the condition; and reduce unnecessary hospital visits and admissions
- **lived experience** was considered central to co-designing and delivering inclusive services and systems to drive service improvement

A respondent quote to illustrate points raised under theme 2 is presented below.

> "Specialised care and support work best where individuals have named points of contact; where there are joined up care pathways between the NHS, community and local authority." MND Scotland

Theme 3: Supported self-management

Individual and organisation respondents highlighted the importance of supported self-management in its many forms, as well as the highly transferable nature of this support across different long term conditions.

Peer educators, peer support networks, and community-led support were specifically mentioned in responses, with feedback that this support was a 'highly valued' mechanism to: connect people with long term conditions with others who have a similar condition; strengthen informal networks; share experiences; help people feel listened to; enable mutual support; and reduce isolation.

A respondent quote to illustrate points raised is presented below.

> "People with lived experience refer to their participation in community-led activity as 'my medication' and credit it with facilitating a lengthier independent, autonomous life. We should learn more about how this happens, gather evidence, and share across long term conditions." Meeting Centres Scotland

Individual and organisation respondents identified other effective approaches to **self-management or self-care** as vitally important – for example, educational support and information, personalised action plans, self-management plans, coaching, digital resources, group sessions, drop-in sessions, the provision of practical tools, tips and strategies for self-management, expanding access to self-monitoring equipment and structured self-monitoring plans, and regular check-ins. Points raised included that this type of support could help people with long term conditions to:

- have increased knowledge, skills, and confidence to manage their symptoms and condition, leading to improved engagement with their treatment, reduce hospital admissions, and have a better quality of life
- be empowered to manage their health – to better understand, monitor, and manage their conditions – and live as well as possible with the condition and support good mental health and wellbeing
- build resilience, manage their health proactively, and adjust to the challenges of their long term condition

A respondent quote to illustrate points raised is presented below.

> "Dietitians contribute to public health initiatives, such as integrated self-management programmes (including digital resources and group sessions) which have proven effective in diabetes and weight management. Approaches which emphasise patient education, digital support, and regular asynchronous check-ins, could benefit people with other long term conditions by empowering them to manage their health proactively." British Dietetic Association (BDA)

Feedback on self-management was at times framed within the context of the importance of access to specialist care and support, or self-management as a way for services to save money, as reflected in following respondent quote below.

> "Self-management cannot replace specialist healthcare. Treatment is needed first. We want care and treatment, testing and diagnostics first, not 'support'." Long Covid Scotland

Theme 4: Communication and collaboration

Respondents highlighted the important benefits that could be derived from: improved and consistent communication; closer collaboration and enhanced coordination between the third sector and statutory services; and greater multidisciplinary integration.

Points raised centred on: reducing siloed working to enhance care; improving ease of referral; joining up care pathways; embedding multidisciplinary models of care and cross sector working; adopting co-produced care models involving voluntary sector organisations to help lead to more trusted, accessible care; having more joint events; and providing increased opportunities to share ideas and resources.

A respondent quote to illustrate points raised under theme 4 is presented below.

> "We have also seen the benefit of closer collaboration between optometrists and secondary care. In some areas, optometrists are part of shared care models for glaucoma or urgent anterior eye conditions. These models show that community-based professionals can manage stable cases effectively with the right training and support. This not only benefits patients by reducing hospital appointments but also eases pressure on secondary care." Optometry Scotland

Theme 5: Involvement of, and support for, carers

A small number of organisation respondents referred to the involvement of, and support for, carers in their response. Important factors in the provision of carer involvement support were identified as:

- involvement in the co-design and improvement of services
- greater recognition of the role of caregivers
- unpaid carer support
- training (for example, moving and handling and other practical skills)
- ensuring carers have access to the information, advice and support they need to support the person with a long term condition they care for – for example, maximising the use of the carers' passport scheme for unpaid carers
- family-centred clinical teams
- increasing access for unpaid carers (and people with long term conditions and practitioners) to use computer/assistive technology at home

Respondents who said there has been limited improvement in prevention, care, and support for people with long term conditions

Some respondents (all individuals, specifically people or a family member with a long term condition) explicitly said their personal experience was that they have seen limited or no improvement in prevention, care, and support for people with long term conditions. Points raised included:

- some long term conditions were felt to be less well understood or recognised (and resourced) than other conditions
- the time taken to receive a diagnosis and long waiting lists to access care, treatment, and support – and for some the need to access private healthcare
- difficulties in accessing GP appointments
- the short-term nature of some support services
- a poor experience of transitional planning support
- funding issues and constraints

Respondent quotes to illustrate points raised by these respondents are provided below.

> “There is absolutely no long term care/support. Any intervention has been short term because of the number of patients waiting for care.” Individual respondent

> “Had to seek private health care to find treatments for my long Covid. Meaning I have had patchy treatments and no NHS support.” Individual respondent

5. Question 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.

Introduction

The vast majority (84%) of respondents answered Question 3. This section provides information on how respondents answered this question, and then describes the themes that emerged from the analysis, including:

- **theme 1**: how condition-specific work could be selected
- **theme 2**: conditions that could be prioritised
- **theme 3**: other points raised

How respondents answered this question

Some respondents outlined potential methods and metrics for how condition-specific work could be selected or prioritised in their response. Others advocated on behalf of a specific health condition or group of long term conditions to be explicitly considered by the Scottish Government for condition-specific work as part of the Long Term Conditions Framework.

Theme 1: How condition-specific work could be selected

Over half (56%) of respondents outlined their thoughts about how areas for condition-specific work could be selected or prioritised. Please note that most of these respondents identified multiple factors or considerations which were not considered mutually exclusive. Related points raised under theme 1 have been grouped as follows:

- the prevalence of long term conditions
- the impact of interventions
- selection of condition-specific work should be guided by evidence and data
- tackling health inequalities and addressing unmet needs
- a person-centred approach

The prevalence of long term conditions

The most common factor identified by both individual and organisation respondents was that condition-specific work could be selected based on the prevalence of the condition amongst the general population. This view was largely predicated on the fact that long term conditions with the highest prevalence have the largest population level impacts, and the largest number of people possible could benefit from condition-specific work.

Further, some of these respondents also recognised the importance of a focus on rarer conditions which could have a large impact on people.

Respondent quotes which illustrate points raised are presented below.

> "Conditions should be selected based on need and population density as we know that long term conditions are the main drivers for GP appointments and hospital stays (in 2009 long term conditions amounted to 70% of appointments and bed stays) together with an increased cost on health and social care." National Rheumatoid Arthritis Society (UK)

> "It is difficult to give a single answer. Obviously while resources are limited, the focus should be on those conditions that affect the majority of the population and on the types of approaches that have the greatest impact (for example, prevention). But it is also important to consider rarer conditions that could have a lifelong impact." The Innovative Healthcare Delivery Programme (IHDP) Patient and lived experience reference group

The impact of interventions

Organisation and individual respondents suggested that the Scottish Government could consider the impact that any particular condition-specific work would have when selecting or prioritising areas. These respondents felt it would be important to target limited resources at areas which have the biggest burden on health and quality of life and where there were cost-effective and impactful interventions. Further, it was suggested that interventions which helped reduce the financial burden on the NHS in the longer-term, such as preventative medicine, could be prioritised to help use/allocate resources more effectively.

A small number of respondents felt that consideration could be given to the economic impact of condition-specific interventions, such as those which enabled people who were economically inactive to re-enter the workforce and sustain employment.

A respondent quote which further illustrates points raised is presented below.

> "Other key areas should be a focus on high "economic/cost" burden such as highest hospital admissions, greatest drug costs, highest GP/outpatient and other multidisciplinary team appointments. A focus should also be where there are gaps or unmet needs in long term conditions." The Royal Pharmaceutical Society

Selection of condition-specific work must be guided by evidence and data

Some respondents, primarily organisations, expressed support for selecting condition-specific work guided by robust evidence and data.

Whilst they also advocated for prioritisation based on factors outlined elsewhere in this section, they considered it vitally important that the selection process was transparent, evidence-based, and data and health intelligence driven in order to determine priorities, allocate resources more effectively and improve population health outcomes.

Tackling health inequalities and addressing unmet needs

Some respondents, primarily organisations, said that the Scottish Government could consider how best to tackle health inequalities and address unmet need when selecting areas for condition-specific work. Specific examples of population groups that experience health inequalities included:

- people living in socio-economically disadvantaged areas – for example, the link between deprivation and poor health was made as well as increased prevalence of developing one or more long term conditions
- minority ethnic communities are more likely to suffer poorer health outcomes, be affected disproportionately by socio-economic inequality, discrimination and other structural drivers of racism
- other population groups that share certain protected characteristics
- people living in rural and island areas – for example, geographic barriers to accessing services, care, and support

A person-centred approach

Some respondents, largely individual and third sector respondents, said that a person-centred approach should underpin how areas for condition-specific work were prioritised and selected. Among other things, these respondents emphasised the importance of ensuring the meaningful participation of people with lived experience of long term conditions or a 'human rights budgeting approach'.

Theme 2: Conditions that could be prioritised

Around one-quarter (26%) of respondents identified a specific health condition or group of health conditions which could be considered when selecting areas for condition-specific work. Conditions mentioned in responses included:

- mental health
- long COVID and fatigue syndromes
- kidney disease
- other specific conditions

Mental health

Some respondents, primarily individuals, identified mental health as an area that could be prioritised for condition-specific work and/or a cross-cutting theme within the framework.

These respondents felt the current standard of mental health services in Scotland was not sufficient to meet growth in poor mental health among the Scottish population, including people with long term conditions.

These responses mentioned issues relating to the quality of mental health care services as well as long waiting lists and called for greater prioritisation and additional resources for mental health. Some also said that people managing one or more long term conditions were more likely to develop or suffer from poor mental health.

They advocated for increased availability of, and access to, mental health support services for people with long term conditions as it plays an important role in helping people to be more proactive in their engagement with their treatment, care, and support, as well as helps people to make important lifestyle changes. They emphasised the interaction between mental and physical health which they said called for a more integrated approach.

A respondent quote which illustrates these points is presented below.

> "In my role as a Principal Health Psychologist…I have seen clear and consistent evidence that psychological interventions, behaviour change strategies and self-management approaches led by Health Psychologists can make a real and lasting difference to people living with long term conditions. These approaches are highly transferable. While tailored to individual needs, the underlying principles apply across a wide range of conditions." Individual respondent

Long COVID and fatigue syndromes

Some respondents (almost all individuals and third sector organisations) suggested that long COVID and fatigue syndromes such as ME and Chronic Fatigue Syndrome could be prioritised for condition-specific work. The main points raised were that these conditions were considered poorly understood and resourced, despite their high prevalence among the general population and the long term effects of these conditions on a person's overall health and wellbeing.

A respondent quote which illustrates points raised is presented below.

> "The Scottish Government must be willing to acknowledge and prioritise disabling conditions like long Covid, ME/CFS, PoTS, and FND. These conditions are under-recognised, under-reported, poorly resourced, and often dismissed. While they share overlapping features – such as dysautonomia, post-exertional symptom exacerbation, and neurological symptoms – each also has distinct clinical presentations and needs. Policy must be precise enough to reflect both the overlap and the differences." Individual respondent

Kidney disease

Some respondents, mainly kidney disease related third sector organisations, highlighted the need for condition-specific work on kidney disease. Similar to the feedback on long COVID and fatigue syndromes, these respondents said that kidney disease has insufficient priority despite its high prevalence among the general population and its major impact on people living with this long term condition.

Other specific conditions mentioned in responses

A small number of respondents (largely individuals and third sector organisations) advocated for other specific conditions to be considered for condition-specific work. These responses included a mix of:

- those that called for a greater focus/prioritisation of a specific condition
- conditions that currently have a condition-specific strategy or action plan

This includes conditions such as: respiratory conditions, Crohn's disease and colitis, dementia, diabetes, stroke, chronic Lyme disease, and HIV.

Theme 3: Other points raised

Other issues raised by respondents to Question 3 included:

- avoiding competition between conditions with concerns that selecting areas for condition-specific work could result in pitting different organisations and conditions against one another for attention under a single framework
- condition-specific work should be selected in a collaborative basis including wide ranging consultation and engagement with healthcare practitioners, the third sector, and people with lived experience of long term conditions, amongst others
- condition-specific work should be retained to avoid losing focus, momentum, and progress on specific long term conditions
- unintended consequences of moving to a unified approach could be that it may be harmful to people with long term conditions if treatment, care, and support becomes more generalised rather than based on individual needs, and it could also reduce access to specialist care and skills

A respondent quote which illustrates these points is presented below.

> "Informed selection of the condition-specific work must be achieved through full, open and equal consultation with all healthcare staff involved in the prevention, diagnosis and management of each condition, and input from patients managing their own conditions." Royal College of Podiatry

6. Question 4

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

Introduction

The vast majority (92%) of respondents answered Question 4. The analysis identified four themes comprising:

- **theme 1:** accessible information and services available in a range of formats and settings
- **theme 2:** a national or centralised one-stop shop – digital front door
- **theme 3:** proactive and coordinated signposting and referral pathways, including a single point of access/contact
- **theme 4:** education and training for healthcare professionals

Theme 1: Accessible information and services available in a range of formats and settings

Under theme 1, two sub-themes emerged, including:

- using a variety of formats and settings
- condition and non-condition specific information

Using a variety of formats and settings

Many individual and organisation respondents said that accessible information and services available in a range of formats and settings could help people with long term conditions find information and services more easily. They said that this was key to the 'effective management of long term conditions.' These responses acknowledged that people with long term conditions accessed and used information from a range of in-person and online sources – statutory health and third sector advocacy organisations websites, and from healthcare professionals such as GPs, specialist clinicians, community nurses, link workers, allied health professionals, pharmacists, optometrists, and word of mouth were all mentioned.

Respondents emphasised the importance of:

- using different channels and formats:
    - physical – information and advice leaflets, posters and booklets, self-management workbooks, emails, and letters.
    - online – public and third sector websites (for example, NHS Inform, NHS websites), social media channels, mobile apps, visual guides and videos, patient forums, other digital tools and resources

    - TV, radio, and newspapers – national public health messaging, campaigns, and discussions, and articles
- understanding diverse needs – including those with visual, auditory, cognitive and physical impairments, and systems which made alternative formats readily available, such as British Sign Language (BSL), Easy Read, Braille, Large Print, audio and other formats, in different languages, access to interpreters, culturally appropriate support, and age-appropriate communications
- a balance between online and physical information – recognising that digital services were not accessible to everyone, and that some population groups lacked digital skills and literacy or had data sharing concerns
- different places and settings – for example, community and health centres, GP practices, care homes, libraries, pharmacies, public buildings, social spaces and hubs (including schools/colleges, leisure centres and sports clubs, and places of worship), workplaces, and other public places and settings (for example, in supermarkets, on business and trains)
- proactive outreach – especially for people who were isolated, marginalised, or that have complex conditions
- supported self-management – information and resources, peer support

Condition and non-condition specific information

Many respondents highlighted the importance of condition-specific information and services (including for less common or misunderstood conditions) and tailored information and services for different population groups. Others also mentioned the importance of non-condition specific information and support (for example, benefits, workplace support).

Theme 2: National or centralised one-stop shop – digital front door

Many respondents expressed support for a national or centralised one-stop shop approach to help people with long term conditions and healthcare professionals find information and services more easily. Suggestions included support for:

- **a one-stop-shop** or similar, including 'joined-up digital hub' or 'online portal for all long term conditions' – this could provide a consistent, high quality message and reduce duplication of effort across heath board areas
- **improving and enhancing NHS Inform** – this was considered a 'well-established' and 'valued source' of trusted information with feedback that the Long Term Conditions Framework could support the expansion of its content and functionality
- the creation of **condition-specific hubs**
- digital front door – some organisation respondents expressed support for the work underway in Scotland to develop a 'digital front door' – a health and social care app that will enable people in Scotland to interact more effectively with health and social care services

Respondent quotes which illustrate these points are presented below.

> "Single, trusted points of access: having a dedicated, well-publicised hub, such as a website, helpline, or community centre, would allow people to access high-quality, up-to-date information about their condition, local services, and support options in one place." Royal College of Nursing Scotland (RCN Scotland)

> "Condition-specific hubs like the SPEN website, in collaboration with third sector organisations, provide trusted, accurate, and relevant information. Overall, centralised but condition-specific platforms are more effective than generic portals." Scottish Paediatric Epilepsy Network (SPEN)

> "A digital hub, such as the proposed 'Digital Front Door,' could be an effective long-term solution if it includes personalised filtering by condition, location, and need. Integration with GP records and inclusion of third-sector and community-based support would enhance its utility and accessibility." Public Health Scotland

Theme 3: Proactive and coordinated signposting and referral pathways, including a single point of access/contact

Many respondents said that a more proactive and coordinated approach to signposting and clear referral pathways (including self-referral) could help people with long term conditions find information and services more easily.

To ensure easy access to information and services, these responses suggested a strengthened 'person-centred approach' (for example, a named 'single point of contact' such as a 'dedicated care coordinator', 'Link Worker', or 'Social Prescribing role'). Within these responses, there was broad reference to:

- an identified need for people with long term conditions to better understand what services were available, how to access them, and what to expect
- people with long term conditions often feeling they leave an appointment with little or no information about what to do next after receiving a diagnosis
- the complex and fragmented landscape – the importance of supporting and guiding people with long term conditions to navigate this
- helping people with long term conditions make informed decisions at every stage of their care and during critical transition points such as initiating treatment, experiencing relapse, or as the condition progresses
- the importance of connecting people with long term conditions to clinical and non-clinical services, including community activities, groups, and services to address the practical, social, and emotional needs affecting their health and wellbeing – and closer collaboration and enhanced coordination between statutory services and the third sector
- the importance of trusted relationships and continuity of care – in helping people with long term conditions find information and services more easily – and, importantly acting on that information

- improved access to information and services could reduce delays in people accessing services and improve efficiencies in the system

A respondent quote which further illustrates the points raised is presented below.

> "A co-ordinator allocated to the individual or a referral to a specialist centre. Individuals and carers don't know what they don't know. There are all too often websites that are not maintained and contact numbers that have an answer machine that take weeks if not months to respond." Individual respondent

Theme 4: Education and training for healthcare professionals

Some individual and organisation respondents (including third sector organisations) recognised the important role that primary care providers, including GPs and other community-based health professionals, play in helping people with long term conditions find relevant information and services more easily.

They said that awareness building, education, and training for healthcare professionals in primary and secondary care was essential to help them provide effective support, such as signposting.

A respondent quote which helps to illustrate this point is presented below.

> "It's not just the public who need this information – GPs and primary care teams do too. Too often, patients are told there's 'nothing available' when the truth is that services exist but are unknown to the professionals they rely on. A Scotland-wide, mapped directory of services, updated regularly and made available to all referrers, could make a significant difference." Individual respondent

7. Question 5

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

Introduction

The vast majority (90%) of respondents answered Question 5. The analysis identified three themes, including:

- **theme 1**: recurring themes from earlier questions
- **theme 2**: addressing inequalities and barriers to accessing care and support
- **theme 3**: addressing challenges facing the health and social care sector

Theme 1: Recurring themes

The vast majority of respondents reiterated points raised at Question 4 and/or points raised at earlier questions. In summary, respondents highlighted things that could help people access care and support for long term conditions more easily. These included:

- **awareness raising and education** – activities to increase understanding of: their rights; available care and support; accessing care and support; and how to manage their condition(s) as effectively as possible
- people with long term conditions must be able to **find the information they need easily**, and healthcare professionals must be able to provide accurate and timely information and signpost to appropriate care pathways/resources
- **accessible information and services available in a range of formats and settings** – including digital and in-person support
- **a joined-up, integrated and whole-system approach to care and support across all sectors** – to improve coordination and continuity of care and opportunities for personalised needs assessment, care planning and support
- **accessible and inclusive routes for engagement, improved referral pathways** (including self-referral options) into care and support, and to ensure effective transition between services
- **development of central holistic care hubs/one-stop-shop access points/single point of access/contact model** ('no wrong door approach'), including a simplified and proactive approach to referral pathways and signposting, streamlined communication between healthcare professionals and people with long term conditions, and improved data sharing
- greater use of **integrated technology and digital innovation**
- an increased focus on **prevention and early intervention** – for example, making health condition screening more accessible to the public

Respondent quotes which help to illustrate theme 1 are presented below.

"There are multiple front doors to services and many access routes which can result in people ending up on different pathways, receiving different services with different outcomes or experiences. We need to provide clear and accessible information, simplify referrals, increase self-referrals, and improve links across systems." Edinburgh Health and Social Care Partnership

"Paediatric and adult healthcare teams must work together to ensure the transfer of care is joined-up. A Young Epilepsy survey found significant disparities in how many joint appointments young people with epilepsy received as part of the transition process." Young Epilepsy

Theme 2: Addressing inequalities and barriers to accessing care and support

Many individual and organisation respondents highlighted the range of barriers people with long term conditions (and unpaid carers) faced in accessing care and support. These responses called for action to address issues such as: digital exclusion and low health literacy; geographic barriers; cultural and communication barriers; finance barriers (for example, cost of travelling to appointments, cost of healthy eating); stigma; dismissive experiences; and limited local availability of care and support.

Consistent and equitable access to care and support for people with long term conditions regardless of the person's condition, location or background was emphasised as critical – as well as continued work to tackle the barriers people with long term conditions faced in accessing care and support.

These respondents also called for: greater flexibility in the timing and location of care and support; minimising gatekeeping delays; increasing awareness of, and access to, advocates; embracing technology to improve access to care and support; ensuring people with long term conditions did not have to repeatedly present in different medical settings before being referred onto a pathway; minimising the number of appointments, assessments and tests people with long term conditions needed to attend when they have multiple professionals/ service providers involved in their care; and enhancing trauma-informed practice.

Respondent quotes that illustrate theme 2 are presented below.

"You cannot access a GP easily – the phone call at 8am is really stressful and you get told there are no appointments left and you repeat this for several days in a row." Individual respondent

"New Scots repeatedly stress the need for improved English language training, alongside the reliable provision of interpretation and translation services in both health and social care. The group suggested creating better welcome packs and local information guides in different languages, which would explain their rights and how to access healthcare." Scottish Refugee Council

Theme 3: Addressing challenges facing the health and social care sector

Some respondents highlighted the challenges faced by the health and social care sector in Scotland and suggested these would need to be addressed to help people access care and support for long term conditions more easily and improve the availability and quality of health and social care support. These challenges included:

- workforce challenges – staff attraction and retention, staff shortages, pay and conditions, investment in workforce development and training
- funding and capacity pressures
- waiting lists and the impact on access to care and support
- trust in the health and social care system and the impact this has on ensuring people come forward for care and support earlier

Respondent quotes that illustrate theme 3 are presented below.

> “You can’t build effective healthcare services without secure, long-term funding. You can’t hire staff, plan services, or deliver real care when funding is short-term, inadequate, and based on guesswork.” Individual respondent

> “Expanding and strengthening services through adequate staffing and funding is essential to ensure that people living with MS can access the care and support they need in a timely and consistent manner. Significant barriers to access – largely driven by insufficient workforce capacity and resources – are adversely affecting quality of life, effective management of the condition, and overall health outcomes. A pressing challenge is the lengthy waiting times for neurology appointments across several health boards in Scotland.” MS Society Scotland

8. Question 6

How could the sharing of health information and data between medical professionals be improved?

Introduction

The vast majority (85%) of respondents answered Question 6. The analysis identified three themes, including:

- **theme 1**: digital infrastructure improvements
- **theme 2**: considerations when making digital infrastructure improvements
- **theme 3**: adopting a person-centred and multi-disciplinary approach

Theme 1: Digital infrastructure improvements

The vast majority of respondents expressed the need for digital infrastructure improvements to facilitate and enable improved sharing of information and data between medical professionals. Most touched on IT and digital infrastructure improvements in some shape or form in their response. Theme 1 covers:

- current barriers to the sharing of health information and data between medical professionals
- why improvements in the sharing of health information and data between medical professionals would be helpful
- what needs to change
- people with long term conditions should be able to access their own information and data

Current barriers to the sharing of health information and data between medical professionals

Most respondents noted the different barriers that existed to the sharing of health information and data between medical professionals. Points raised largely centred on fragmented systems and siloed working within and between organisations, as well as to outdated IT systems. In summary, these responses highlighted:

- that current systems do not communicate effectively – especially between primary and secondary care, and as noted above, respondents also said that this could lead to duplication of effort
- incompatible record systems across services – respondents said that this barrier could lead to delays, errors, and frustration for people with long term conditions, their families and for healthcare professionals
- fragmented systems meant that individuals often have to repeatedly explain their situation and retell distressing stories to different medical professionals

- the use of outdated IT systems – respondents said that this issue was inefficient for service providers and harmed patient care

A respondent quote that helps to illustrate these points are presented below.

> "Current electronic records are chaotic, despite integration, NHS staff still use different records systems than social work colleagues (even within the same "integrated" team." Individual respondent

Why improvements in the sharing of health information and data between medical professionals would be helpful

Many respondents highlighted the range of ways in which improvements in the sharing of health information and data between medical professionals would be helpful. Common points raised included:

- that people with long term conditions often required input from multiple specialists and services – sharing information would improve coordination across services and communication between medical professionals
- to facilitate faster and more accurate diagnoses and referrals to specialists and to support better clinical decision-making
- to ensure delivery of safe, coordinated, and person-centred care for people with long term conditions – for example, respondents said that improved information and data sharing could maintain continuous, personalised care pathways, reduce the risk of medication errors or duplicated efforts, and ensure that no critical information was missed during transitions
- to empower people with long term conditions – improved information and data sharing could support greater self-management as well as help to build trusted relationships

What needs to change to facilitate improvements in information/data sharing

Many respondents provided suggestions for what needs to change to enable easier sharing of information and data between medical professionals. Some responses were framed in line with responses to Question 4, namely support for a 'digital front door' approach or a 'once for Scotland' digital approach. Other recurring themes included improvements/expansion to the NHS Inform and Right Decisions platforms as mechanisms to support improved information sharing.

Many respondents called for investment to establish a secure single, national, fully interoperable digital system/electronic patient record accessible across all levels of care – primary, secondary, tertiary, and community.

People with long term conditions should be able to access their own information and data

Some respondents emphasised the equal importance of people with long term conditions being able to access their own information and data to improve transparency and to (re)build trust with healthcare services.

Theme 2: Considerations when making digital infrastructure improvements

Many respondents highlighted wider considerations around digital processes, procedures, and protocols, as well as to culture and resources. The main points included:

- ensuring robust data security – including data sharing agreements, protocols, and consent
- putting in place effective processes and protocols to help ensure effective and improved communications and information sharing between medical professionals
- the involvement of medical professionals in the design and testing of any new systems – as well as consideration of workforce development and training requirements
- embedding feedback on patient experience – to help measure whether there have been improvements in the way that information and data is shared
- ensuring consistency in information and data that is routinely collected and reported on

Theme 3: Adopting a person-centred and multi-disciplinary approach

A small number of respondents, primarily individuals, also said that adopting a more multi-disciplinary or whole-person approach to the provision of treatment, care, and support for people with long term conditions could facilitate improved information and data sharing between medical professionals. Such an approach was considered particularly helpful for people with co-morbidities. Related points raised included:

- the importance of condition-specific education
- continuing professional development sessions for healthcare professionals to aid and support a person-centred approach

9. Question 7

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

Introduction

The vast majority (92%) of respondents answered Question 7. The analysis identified three themes, including:

- **theme 1**: services outside of medical care identified as helpful in managing long term conditions
- **theme 2**: the important role and benefit of services outside of medical care
- **theme 3**: other issues raised

Theme 1: Services outside of medical care identified as helpful in managing long term conditions

The vast majority of individual and organisation respondents identified a wide range of services outside of medical care that are helpful in managing long term conditions. This aligns to theme 2 in this section which highlights the importance of providing holistic support to people with long term conditions that addresses the broader determinants of health (for example, welfare rights and financial advice services, employment advice, housing advice services).

These respondents frequently mentioned the important and valuable role of the workforce who provide services outside of medical care to people with long term conditions – for example, charities and third sector organisations, local authorities, specialist nurses/advanced nurse practitioners and allied health professionals (such as physiotherapists, occupational therapists, speech and language therapists, pharmacists and dietitians), community link workers and care coordinators.

Some organisations, including third sector organisations, advocated for the services outside of medical care that their own organisation provides. Individuals (people with lived experience of long term conditions) often mentioned the services they accessed and considered helpful and/or would like to have improved access to.

A consistent set of services outside of medical care were mentioned as helpful in these responses, including:

- social prescribing support and pathways – connecting people to activities, groups, and services in their community to meet the practical, social, and emotional needs that affect their health and wellbeing
- nutrition, physical activity, and behavioural and lifestyle services
- mental health, psychological, and psychosocial support

- self-management and education support
- peer mentoring and lived experience support
- social care and practical support for home care
- vocational rehabilitation – for example, physiotherapy and occupational therapy to support people manage daily activities, to get into work, and to prevent them from falling out of work due to health reasons
- other services mentioned included: speech and language therapy; employment, training, and volunteering opportunities; alternative therapies; and support for unpaid carers (for example, respite care, financial support)

Theme 2: The important role and benefit of non-medical care and support services

Many respondents (primarily organisations) mentioned the important role and benefit of non-medical care and support services including:

- **integrated and holistic approaches** that: connect medical and non-medical care across NHS and independent health and social care sectors; highlight the broader ecosystem of support beyond the medical model (including third sector, community based services, local authorities, unpaid carers, family members); and tackle health inequalities and address the broader determinants of health to help people with long term conditions make meaningful lifestyle changes to improve their overall quality of life
- **benefits of services outside of medical care** including to: support earlier intervention; improve management and education of symptoms and long term conditions; promote physical and mental health and wellbeing; foster social connections, provide emotional support, and to share experiences; reduce loneliness and social isolation through befriending and peer support; and reduce unplanned and emergency care and reduce hospital admissions

Respondents reiterated the **challenges faced by organisations that provide non-medical care and services** including: the historic under-recognised value/contribution of the third sector/ services outside of medical care in helping people to manage long term conditions; the role of the third sector in bridging gaps in public sector provision; funding challenges faced by these organisations and the need for sustainable longer-term funding; and workforce recruitment and retention challenges.

Respondent quotes that illustrate these points are presented below.

> “Medical care alone cannot address the structural, emotional, and practical barriers many people face in managing long term conditions. Non-medical services are often the critical enablers that allow people with long-term conditions to manage their health effectively, maintain independence, and avoid crisis escalation.” Vantive

"While many people with long term conditions access social care services, care is predominantly provided by unpaid carers. Therefore any framework will need to recognise this and include actions to support the unpaid care workforce." National Carer Organisations

"Social prescribing plays a vital role in the recovery model for individuals experiencing mental ill-health by promoting a holistic approach to wellbeing. Community Link Practitioners in General Practice are instrumental in connecting patients to these resources." South Ayrshire Health and Social Care Partnership

Theme 3: Other issues raised

Some individual and organisation respondents identified other issues or considerations related to services outside of medical care for people with long term conditions. Most were recurring points raised at previous questions, and included:

- there would need to be a cultural change within health and care services to facilitate more people with long term conditions being supported to access services outside of medical care to help them manage their long term conditions – increased collaboration between the NHS and third sector
- there could be an increased focus on early detection, prevention, and early intervention services within the Long Term Conditions Framework
- there should be consistent and equitable access to services outside of medical care regardless of background, condition, or location
- barriers to accessing services outside of medical care need to be addressed – for example, cost and transport barriers
- services outside of medical care should be available close to home – and be available in a range of formats and settings
- improvements in the marketing, awareness raising and signposting of services outside of medical care among people with long term conditions
- further awareness raising and education on long term conditions within different settings, such as schools and workplaces, to strengthen prevention and support and to destigmatise the condition(s)
- stronger legislation, regulation and enforcement on harm causing environments, products and practices

10. Question 8

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

Introduction

The vast majority (88%) of respondents answered Question 8 and typically identified the multi-faceted nature of the barriers faced by people with long term conditions accessing non-medical services. They also emphasised that barriers could be particularly pronounced for: those living in rural and island communities; those living in disadvantaged areas; disadvantaged or marginalised groups; people from lower socio-economic backgrounds; and people with protected characteristics.

Respondents identified a common set of barriers covering seven themes, including:

- **theme 1**: organisational barriers
- **theme 2**: lack of knowledge/awareness of services and how to access them
- **theme 3**: personal, psychological, and attitudinal barriers
- **theme 4**: physical and geographic barriers
- **theme 5**: financial barriers
- **theme 6**: digital accessibility, connectivity, literacy, and confidence barriers
- **theme 7**: language, cultural and communications barriers

Theme 1: Organisational barriers

The majority of respondents identified organisational barriers that people faced when accessing non-medical services. These barriers can be summarised as:

- inequality of access across different health board areas – including variation in the range of services available and service capacity ('postcode lottery')
- eligibility criteria thresholds and services that required professional referral – respondents said this may delay support or exclude those who would benefit but do not meet arbitrary thresholds
- fragmentation of service delivery and siloed working between services
- a reliance on healthcare professionals to signpost and/or refer people with long term conditions to appropriate services outside of medical care – a lack of awareness and understanding among healthcare professionals of individual conditions and likely progression could lead to poor clinical signposting and integration
- sector challenges – long waiting lists, reducing budgets, a lack of long-term sustainable funding, workforce challenges, a lack of recognition or value placed on third sector services

- bureaucratic obstacles such as: navigating the system to access publicly funded or grant funded non-medical services; time constraints on clinicians; and a lack of flexibility to facilitate person-centred and holistic approaches
- a medical rather than social model of health

Theme 2: A lack of knowledge and awareness of services and how to access them

Many respondents said that people with long term conditions lacked awareness, knowledge and understanding of: the range of services outside of medical care available locally; the potential benefits of non-medical services; the quality of these services; and how to access them.

Further, there were said to be several factors at play, including:

- the extent to which high-quality and up-to-date information was available in a range of formats and settings – and a lack of inclusive communications
- misinformation and conflicting information and advice
- ineffective signposting and referral pathways
- the person's poor health may constrain their ability to search for and find information on services outside of medical care that could help them

Theme 3: Personal, psychological, and attitudinal barriers

Many respondents identified the range of personal, psychological, and attitudinal barriers that people faced when accessing non-medical services, including: feeling not valued or listened to; poor physical and/or mental health; perceived importance or relevance; reluctance to engage with non-clinical services (for example, mistrust of unfamiliar agencies or have concerns around confidentiality); lack of motivation, confidence, or self-esteem; social isolation; emotional readiness, fear and anxiety; shame and stigma; and time constraints (for example, time off work or caring responsibilities).

Theme 4: Physical and geographic barriers

Some respondents identified the range of physical and geographic barriers that people faced when accessing non-medical services, including:

- physical accessibility issues – relating to the accessibility or otherwise of buildings, including the availability of accessible facilities
- geographic location – for example, distance to services (particularly for those in rural or island communities), poor public transport links, lack of access to a car, transport costs
- environmental factors – for example, poor weather conditions which could affect the ability to travel

Theme 5: Financial barriers

Some respondents mentioned the range of financial barriers that people with long term conditions faced when accessing non-medical services. The feedback was often framed in the context of the cost-of-living crisis, the impact of long term conditions on the ability to work, and the pressure on household income.

Financial barriers identified included: transport costs to and from appointments; the cost of accessing non-medical services (for example, gym memberships); the cost of accessing support longer-term and/or private sector provision; the cost associated with digital access; and confusion about funding and whether sessions would be covered by insurance or public health services.

Theme 6: Digital accessibility, connectivity, literacy, and confidence barriers

Some respondents (mainly organisations) highlighted barriers related to digital accessibility, connectivity, literacy, and confidence barriers, including for particular groups of people with long term conditions. The main points raised in these responses were:

- digital poverty and exclusion – factors such as a lack of access to devices, inadequate internet connectivity, and insufficient digital skills
- fear of cyber-attacks or data breaches
- a lack of integrated digital pathways linking hospital-at-home services, primary care, specialist teams, and community support – meaning patients often still required multiple points of contact rather than seamless coordination
- insufficient patient awareness and education about the availability and benefits of technologies (for example, remote monitoring or hospital-at-home options), meaning uptake remained lower than it could be

Theme 7: Language, cultural and communications barriers

A small number of respondents (primarily organisations) mentioned language, cultural and communications barriers in their responses. They also specifically mentioned minority ethnic communities and people with learning difficulties or neurodivergent conditions. The main points raised in these responses included:

- language barriers and insufficient translation of materials, which could limit understanding and engagement with services
- cultural misunderstandings – the need for culturally sensitive options, such as multilingual materials, dietary needs, inclusive settings, women-only groups
- a lack of funding for, and access to, interpretation services
- cultural stigma – for example, expectations to ‘cope’ without external support

11. Question 9

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

Introduction

The vast majority (87%) of respondents answered Question 9, and the analysis covers two broad areas, including:

- the challenges for people managing long term conditions
- the challenges for healthcare providers who support people managing long term conditions and the healthcare system

Organisations highlighted the context of an increasing number of people presenting with, or living with multiple long term conditions, and the complexities and challenges that arises from this – from diagnosis and symptom management, as well as from a treatment, care, and support perspective.

The challenges for people managing long term conditions

Themes which emerged from consultation responses included:

- **theme 1:** emotional and mental health challenges
- **theme 2:** accessing and managing complex treatment, care, and support
- **theme 3:** financial burden for people with long term conditions

Theme 1: Emotional and mental health challenges

Many respondents, particularly individuals and third sector organisations, reported that people managing one or more long term conditions were at greater risk of poor mental health and wellbeing (for example, depression, anxiety, stress), especially those with multiple conditions. Specific conditions such as diabetes, heart conditions and multiple sclerosis were noted as carrying increased risks.

Respondents described the ‘emotional toll’ of symptom management, flare-ups and long waits and delays in accessing NHS treatment, care and specialist support. These issues often worsened the mental health and wellbeing of people managing one or more long term conditions.

Individual respondents highlighted the unpredictability of their conditions, the fatigue and burnout of attending multiple appointments and repeating their medical history to different practitioners which often resulted in a lengthy recovery time for them personally. They emphasised the importance of accessing the right support at the right time to help them manage their condition and health better.

Further, respondents said that people managing one or more long term conditions could often be socially isolated or have feelings of loneliness – for example, these responses mentioned issues relating to pain, reduced mobility, limited social participation, inability or lack of willingness to leave home and impact on employment.

Respondents also highlighted the interaction between mental and physical health in managing one or more long term conditions as a particular challenge, emphasising the need for accessing timely support for both their mental and physical health.

A respondent quote which illustrates points raised is presented below.

> "It's exhausting. It's like a full-time job, but one where you have no power, no resources, no training, and no supportive colleagues. It's like telling the same story again and again and again to people who it turns out aren't the right folk to help you, so you end up being passed like a parcel to someone else. And starting all over again." Individual respondent

Theme 2: Accessing and managing complex treatment, care, and support

Many individual and organisation respondents highlighted the challenges people managing one or more long term conditions faced when accessing treatment, care, and support. They also said there were particular challenges for certain groups of people with long term conditions (for example, people who lived on their own, or in rural or island areas). Challenges included:

- **barriers to accessing care and support** – this spanned: socio-economic challenges; advocacy needs; the location of services; the time taken to travel to and from appointments; and the availability of services
- **navigating the healthcare system** – respondents mentioned a lack of awareness among people managing one or more long term conditions of the clinical and non-clinical services available that could help with the management of their conditions, and/or on how to access them, particularly for certain groups such as disabled people
- **lack of specialist care support** – respondents reported long waiting lists that meant they turned to private healthcare to access the specialist support they needed but recognised that this was not feasible or possible for everyone
- **support and services could be too siloed and specific to one condition** – respondents highlighted that this results in challenges such as people with long term conditions having to deal with different clinicians and specialists, the need to access different services or attend different appointments for each condition, and the extent to which everyone involved in the person's care worked together and shared information about their health, treatment, and care

- **keeping track of, and managing, multiple medications** (polypharmacy) including taking medication which contradicts one another, risks of incorrect drug usage and taking medication at the wrong times
- **receiving conflicting or contradictory information and advice** – often as a result of various health professionals being involved in their care. Respondents added this was largely driven by fragmented communication and care and a lack of information sharing, and that contradictory information was confusing for the person with long term conditions

A respondent quote which illustrates the points raised is presented below.

> "People may be juggling complex medication routines, conflicting advice from different services or appointments that are hard to coordinate, as well as inconsistent approaches. This can lead to confusion, frustration, and burnout. Health literacy also plays a role. If someone does not fully understand their treatment plan or what is expected of them, they are less likely to follow it." British Psychological Society

Theme 3: Financial burden for people with long term conditions

Some respondents, particularly individuals, mentioned managing one or more long term conditions has caused financial worry, strain, and hardship for them personally (and for their families).

There was reference that people with long term conditions have higher living costs than those without such conditions. These responses mentioned the increased costs for people managing one or more long term conditions associated with:

- travelling to and from multiple medical appointments and for treatment
- the purchase of assistive equipment and devices and mobility aids
- the cost of making adjustments in the home
- making changes to dietary requirements
- increased energy bills

Some individual respondents reported a negative impact on their employment. They intimated financial hardship and strain caused by having to take unpaid leave, changes to their shift patterns, reducing their working hours or giving up work altogether as result of managing long term conditions. These individuals often mentioned a worsening in their long term conditions or that they had fluctuating symptoms which they found difficult to manage. Some individuals felt their employer could have done more to make reasonable adjustments in the workplace or to provide additional in-work support.

Other individual respondents mentioned the role of family members that supported their care, with some saying that family members had to change their working hours or give up work to help them in their caring role.

Taking on this unpaid carer role was said to have added further financial strain and hardship for the person with long term conditions, their carer, and the wider family unit.

A small number of individual respondents also reported difficulties accessing the right benefits and financial support or completing paperwork.

The challenges for healthcare providers and the healthcare system

Themes which emerged from consultation responses included:

- **theme 1:** fragmented care and support
- **theme 2:** information and data sharing challenges

Theme 1: Fragmented care and support

A majority of individual and organisation respondents said that the provision of healthcare and specialist support could be fragmented, and siloed working was a common feature.

They added that this created challenges for people managing one or more long term conditions, especially where they have various healthcare professionals involved in their care, as well as challenges for service providers in ensuring the provision of effective person-centred care and support for people with comorbidity.

As noted earlier in this section, respondents said fragmented care and support resulted in a range of challenges around, for example:

- ensuring effective communication between service providers, and between service providers and people managing one or more long term conditions
- minimising the number of appointments, assessments and tests people with long term conditions needed to attend when they have multiple professionals/ service providers involved in their care
- treatment complexity
- ensuring the provision of person-centred or whole-person support
- ensuring the provision of coordinated care and support

Respondent quotes which illustrate the points raised are presented below.

> “Services operate in unhelpful silos. There is rarely a truly effective multi-disciplinary approach resulting in delayed diagnosis of correlating conditions or extra disease manifestations which aren't picked up and are undertreated causing suffering, debilitation, crisis management and invasive and expensive interventions later on.” Individual respondent

> “Managing these challenges requires a holistic, person-centred approach – one that integrates clinical care with emotional, social, and peer-based support.” Resuscitation Council UK

Theme 2: Information and data sharing challenges

Some individual and organisation respondents highlighted that the lack of information and data sharing, including between primary and secondary care, could create challenges for people managing one or more long term conditions and for those that supported them. These responses mentioned:

- that people with long term conditions often had to repeat their medical history across services, using up limited appointment time, while wanting providers to have an accurate, up-to-date understanding of all their conditions to provide tailored care
- the lack of an integrated or holistic view of the person's health, conditions, and treatment plans

A respondent quote which illustrates the points raised is presented below.

> "The absence of integrated data systems between primary and secondary care can result in duplicated assessments, such as repeated blood tests or consultations. Individuals may be invited to similar checks by different healthcare professionals, which not only wastes resources but also contributes to unnecessary physical interventions and emotional strain." Shetland Health and Social Care

12. Question 10

What would strengthen good communication and relationships between professionals who provide care and support and people with long term conditions?

Introduction

The vast majority (87%) of respondents answered Question 10, and the analysis identified three themes:

- **theme 1**: person-centred and shared care planning and support
- **theme 2**: digital infrastructure improvements
- **theme 3**: improved knowledge and understanding of long term conditions among professionals who provide care and support to people with long term conditions

Theme 1: Person-centred and shared care planning and support

Most respondents identified a greater use of person-centred/whole-person approaches and shared care planning and support as a way to strengthen communication and relationships between professionals who provide care and support and people with long term conditions. The main points included that:

- most respondents highlighted the **important role of multi-disciplinary teams** in the delivery of integrated care and support to people with long term conditions, especially those with co-morbidities and complex needs
- many respondents felt that **communications and relationships between healthcare professionals and people with long term conditions were stymied by silo working and could be improved** – there were calls for better coordination, more joined-up care and support pathways and greater opportunities to share insights and perspectives to support a person-centred approach
- some respondents (mainly organisations) said **that people with long term conditions should be proactively involved in decisions about their treatment, care, and support** – this could also give greater autonomy and control of their care and improve their experience/engagement
- some respondents (mainly individuals) highlighted **the need for more regular, effective and inclusive communications** between healthcare professionals, organisations who provide care and support, and people with long term conditions – this could build trusted relationships, ensure sufficient time for information sharing; increase awareness and understanding among professionals of others' roles; and encourage greater collaborative and joined-up working between professionals (for example, regular sharing of updates and learning between professionals)

Theme 2: Digital infrastructure improvements

Many respondents said digital infrastructure improvements could help to strengthen good communication and relationships between professionals who provide care and support and people with long term conditions. The main points included that:

- **improved and integrated IT/digital systems and tools (for example, an electronic shared patient record) could facilitate sharing of information and data** between professionals who provide care and support to people with long term conditions - many respondents were critical of current NHS IT systems describing them as fragmented and outdated, which made communication and the sharing of information and data more challenging
- **people with long term conditions should have easier access to their own health information** to support person-centred care and empower individuals to take an active role in managing their health (for example, this could ideally be in one place with the ability to add personal notes or updates)

Theme 3: Improved knowledge and understanding of long term conditions among professionals who provide care and support to people with long term conditions

Many respondents felt that professionals who provide care and support to people with long term conditions could have a better knowledge and understanding of different long term conditions as well as of the lived experiences of people with long term conditions – this could strengthen communications and relationships between professionals and people with long term conditions. Many of these respondents believed that professionals/clinicians did not always fully understand their specific condition or the challenges they faced in daily life. Several factors were said to be at play, for example:

- there was limited time to properly discuss health issues and their condition(s) at health appointments
- some said people with long term conditions were not always believed or dismissed

There was also recognition it was not possible or realistic for professionals to have a detailed knowledge and understanding of all conditions.

These respondents made various suggestions for improvement, including:

- more time with clinicians at healthcare appointments, particularly with GPs
- workforce development and training for healthcare professionals to better understand long term conditions
- other training for healthcare professionals – for example, on interacting with people with long term conditions (listening techniques, empathy and relationship building)

13. Question 11

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

Introduction

The vast majority (83%) of respondents answered Question 11. This section covers how consultation respondents answered this question and then identifies three broad headings, including:

- **theme 1** - there are a large and growing number of digital tools and resources available
- **theme 2** - digital tools and resources benefit people with long term conditions in a range of ways
- **theme 3** - digital tools and resources should not be the only way people living with long term conditions can access support

How consultation respondents answered this question

Some respondents identified the range of existing digital tools and resources that provide support to people with long term conditions. Further, some respondents highlighted issues that may arise from the use of digital tools and resources, such as digital poverty, exclusion, and accessibility challenges.

Others identified digital tools and resources which are not currently available in Scotland, but which could support people with long term conditions. These responses focused on: good practice examples from elsewhere (such as the new NHS app in England and the Isle of Man); as well as other suggestions for digital tools and resources which could support people with long term conditions. These points have been described at Question 12 and have not been covered in this section.

Theme 1 - There are a large and growing number of digital tools and resources available

The vast majority of respondents highlighted the many and varied digital tools and resources that people with long term conditions use. These respondents noted that the availability of digital tools and resources has been increasing, especially since the pandemic. Here, respondents emphasised that digital tools and resources played an important and valuable role in supporting individuals with long term conditions, but that they did not suit everyone.

The main points included that many respondents:

- provided examples of **condition-specific digital tools and resources** such as: trusted NHS and third sector websites, platforms and apps (for example, My Diabetes My Way, long COVID handbook, and My FND); online peer support groups and forums; online self-management tools, resources and tips; and health monitoring tools that could be used at home (for example, glucose monitors for people with diabetes) – these tools were considered useful for more personalised and tailored support
- highlighted **other general digital tools and resources** such as NHS Inform, Right Decisions and Waiting Well; self-management tools and trackers (for example, Sleepio and symptom trackers); online consultations, booking systems, virtual appointments, and telephone consultation services; home health monitoring tools; and smart home technologies to simplify daily routines (for example, smart plugs and video doorbells)
- identified **challenges with digital tools and resources** including: the extent to which all digital sources were credible, trustworthy, and up-to-date; the potential for conflicting information and advice; a lack of integration between digital tools and resources and personal health records/data; and the wide variety of digital tools and resources available could lead some individuals to feel overwhelmed and unsure of the best option for them

Respondent quotes to illustrate these points are provided below.

> "Online peer support forums and survivor networks such as Sudden Cardiac Arrest UK which offer community, reduce isolation, and empower individuals to share experiences and coping strategies – a key element of holistic recovery." Resuscitation Council UK

> "The digital landscape for long-term conditions support lacks coherence and standardisation across Scotland. While some excellent tools exist, they operate in silos without integration into broader care pathways… Integration between third-party tools and NHS systems remains poor, limiting their clinical utility." Individual respondent

Theme 2 - Digital tools and resources benefit people with long term conditions in a range of ways

The majority of respondents said trusted digital tools and resources were 'critical' and 'vital' for supporting people with long term conditions and identified the many and varied ways that digital tools and resources could benefit people with long term conditions. Common points raised included that digital tools and resources:

- allowed people who may struggle with their physical health and mobility have access to online consultations, and digital support
- could be convenient for people with long term conditions that live in rural and island areas – for example, those who may otherwise have to travel long distances or face transport costs to access medical and non-medical services

- such as online peer support provided opportunities for people with similar conditions to come together to share experiences, get mutual support, and reduce feelings of isolation
- could support symptom management by providing a way for individuals to track their symptoms, mood, identify potential triggers, manage their conditions, and reduce the number of GP or hospital appointments
- such as digital patient portals gave individuals access to their personal health records, allowing them to see lab results, manage appointments, book appointments, manage medications and contact clinical teams – reducing the administrative burden and supporting greater self-management
- such as remote monitoring technologies (for example, wearable health monitors) provided real-time tracking of an individual's condition, symptoms, and/or medication – allowing for supported home-based care and proactive clinical interventions
- encourage independent living by simplifying daily routines (for example, through the use of smart home technologies) and allowing people to live independently for as long as possible

Theme 3 - Digital tools and resources should not be the only way people living with long term conditions can access support

Many respondents said digital tools and resources should not be the only way people living with long term conditions can access support. The main points raised were that:

- barriers to accessing digital tools and resources included digital literacy (ability to use digital technologies independently), digital accessibility (digital tools may not be designed in an inclusive way), and digital poverty (range of costs associated with accessing digital tools and resources)
- barriers could be disproportionately experienced by older people (who may lack the technical skills and confidence), people who live in rural and island areas (due to connectivity challenges), and people with disabilities or certain long term conditions (who may rely on accessibility technologies such as screen readers, closed captioning and hearing-aid compatible devices)
- some respondents reiterated that digital tools and resources need to complement not replace other forms of support to ensure existing health inequalities were not exacerbated

14. Question 12

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

Introduction

The vast majority (78%) of respondents answered Question 12. Prior to setting out the themes identified from the responses to this question, some respondents reiterated points previously raised, such as:

- digital tools and resources need to complement not replace other forms of support – and ongoing efforts would be required to address digital poverty, exclusion, and accessibility challenges
- some people with long term conditions may lack awareness of existing digital tools and resources – more needed to be done to raise awareness of what is currently available and improve signposting to trusted sources of information and support
- the development of new digital tools and resources should be co-designed with individuals with lived experience of long term conditions (and organisations who support them) to ensure they were inclusive and accessible
- digital resources may become outdated, provide conflicting advice and information, and may not all be credible and trustworthy sources

The analysis then identified three themes, including:

- **theme 1:** there is a requirement for more integrated healthcare information, systems, and resources
- **theme 2:** additional digital tools and resources could be developed
- **theme 3:** existing digital tools and resources could be adapted or further improved and developed

Theme 1: There is a requirement for more integrated healthcare information, systems and resources

Many individual and organisation respondents expressed support for improvements in the integration of existing healthcare information, systems, and resources as a way to:

- support person-centred care and support
- ensure the coordination of care and support for people with long term conditions
- encourage better communication and collaboration between healthcare professionals (less siloed working)

- support access to real-time information and data – to share information and data more easily between healthcare professionals and to support earlier diagnosis, timely decision-making and referrals
- empower people with lived experience of managing long term conditions – increased access to their own information and data would give individuals more control over their health

These respondents typically suggested it could be beneficial to have an integrated app or IT system (for example, a website or online portal) that healthcare professionals and people with long term conditions could access. They said this could help people with long term conditions interact more effectively with health and social care services. For example, responses mentioned that a development such as this could include:

- access to medical records and notes from primary and secondary care providers, including test and lab results
- appointment booking and management services
- prescription ordering and management services
- symptom and condition trackers for identifying symptoms and triggers
- access to condition-specific advice and support, for example weblinks to relevant support services, including to the third sector
- access to online video appointments and telephone consultations

Many of these respondents referred to the NHS app in England and the Isle of Man, which acts as a hub for healthcare management, information and support – and suggested something similar could be considered for Scotland. Here, there was also reference to the Digital Front Door app which is currently in development in Scotland – with feedback that this app would ultimately create a 'hub' to help people interact more effectively with health and social care services.

The following respondent quote reflects the points raised under theme 1.

> "There is a clear need for a unified digital platform that integrates medical records, self-monitoring data, appointment scheduling, health education, coaching, and access to peer support: all in one place. Such a platform should be designed to support both patients and carers, and include personalised risk factor tracking, goal-setting, and tools to empower people in managing their own health." Public Health Scotland

Theme 2: Additional digital tools and resources could be developed

Some respondents felt that additional tools and resources could be developed to support people with long term conditions.

These respondents reiterated the types of digital tools and resources that help people with long term conditions access information, care and support, including:

- condition-specific digital tools
- self-management resources (for example, trackers and monitoring)
- online information and advice
- online peer support
- online appointment services (including booking and management systems)

These respondents highlighted a need for additional condition-specific tools and resources to support people with long term conditions to plug gaps in provision. They felt condition-specific digital tools and resources enabled more personalised and tailored support when compared to more general information and support.

Theme 3: Existing digital tools and resources could be adapted or further improved and developed

Some respondents felt existing digital tools and resources could be further improved, expanded and/or developed where they have been proven to work well. They suggested this could increase the accessibility, applicability, and usability of existing digital tools and resources as well as ensure online information and support was updated. Respondents were supportive of this approach as aspects of long term condition management were similar across conditions.

> “Tools like myDiabetes and myCOPD have shown promise in supporting self-management for specific conditions. Expanding such resources to cover conditions like long Covid and ASD could provide tailored support, combining evidence-based guidance with user-friendly interfaces.” Individual respondent

> “Examples of effective digital health interventions which can be built upon include NHS Near Me and remote monitoring for conditions like COPD and heart failure. These improve access, early intervention and empower patients especially in rural areas but require the digital infrastructure to be in place for both patient and healthcare professionals to access.” Royal College of Nursing Scotland (RCN Scotland)

15. Question 13

How do you think long term conditions can be detected earlier or more easily?

Introduction

The vast majority (85%) of respondents answered Question 13. The analysis identified four themes, including:

- **theme 1**: screening and regular check-ups
- **theme 2**: education and awareness raising activities
- **theme 3**: workforce development for healthcare professionals
- **theme 4**: greater availability of GP appointments

Theme 1: Screening and regular check-ups

Most respondents identified the importance of screening and regular check-ups as a way to help long term conditions be detected earlier or more easily. These respondents emphasised the importance of early detection and diagnosis in achieving positive population health outcomes, including for people with long term conditions and that screening and regular check-ups were the most effective way to do this.

Some respondents felt the provision of screening services in local community settings (for example, pharmacies, supermarkets, leisure centres, and in workplaces) could be useful to increase uptake of these services as this may reach people who may not otherwise engage in traditional healthcare settings. Some suggested that screening services could be 'opportunistic' and undertaken when people were there for other reasons (for example, at pharmacies, podiatrists, or during home visits).

Some respondents felt that a targeted approach to screening was equally important as a way to help long term conditions be detected earlier or more easily. For example, responses frequently mentioned the targeting of: younger age groups; people living in deprived areas; population groups who experience health inequalities; and at risk groups or other vulnerable groups who already have long term conditions (for example, people with diabetes, people living with chronic pain, people with mental health issues).

A small number of respondents felt that care should be taken to ensure screening programmes were evidenced- based and proportionate. They said that screening was not always cost effective and it could sometimes lead to overdiagnosis.

A respondent quote to illustrate theme 1 is presented below.

> "Early detection may require active screening. Many long term conditions can be detected early before symptoms appear. Resource into disease screening must

strike a risk/benefit balance, but early detection of diabetes, hypertension, cancer, COPD and CKD for example are conditions where early detection can result in better outcomes. There are a number of pilots where community pharmacies have been involved in early detection such as point of care testing for diabetes in NHS Tayside." The Royal Pharmaceutical Society

Theme 2: Education and awareness raising activities

Many individual and organisation respondents identified awareness raising activities as a key method to help long term conditions be detected earlier or more easily. These respondents said it was vitally important the public were made aware of risk factors, warning signs and symptoms – and that this may encourage earlier engagement with healthcare providers.

Prevention and early intervention activity (and health literacy) was emphasised given the role of lifestyle factors (such as diet, physical activity, alcohol consumption, smoking) in influencing health and wellbeing. Encouraging healthier behaviours and lifestyles was considered vitally important in this regard – among the general population as a whole and for at risk groups.

Theme 3: Workforce development for healthcare professionals

Many respondents identified the need for additional and ongoing workforce development and training for healthcare professionals, including GPs and frontline healthcare professionals, to help improve the early detection of long term conditions.

These respondents emphasised the need for healthcare professionals to have an up-to-date and good working knowledge and understanding to enable them to recognise the early signs associated with long term conditions. This could improve early detection, reduce misdiagnosis, and improve long term outcomes for people.

A respondent quote which illustrates theme 3 is presented below.

"We regularly hear from older people that if someone is living with one long term condition, for example dementia, if they go to their GP with new concerns, they are often quickly dismissed as being due to dementia, when they may be entirely unrelated. Therefore, improving GPs and other primary care professionals' awareness of less common symptoms and co-morbidities between long term conditions, would help to detect conditions earlier and easier." Age Scotland

Theme 4: Greater availability of GP appointments

Many respondents reported that a key barrier to the early detection of long term conditions was that many people found it difficult to access GP appointments and/or that GP appointments were too short.

The main feedback was that people often struggled to get a GP appointment which then made it difficult for them to discuss their symptoms and to receive an early diagnosis and appropriate signposting.

Some respondents reported that when they did have a GP appointment, appointments were short in duration. They said this meant people did not have long enough with their GP to discuss their symptoms in any great detail (particularly if they were managing multiple long term conditions) and that GPs were often time constrained which meant that long term conditions were not always detected early, or progression of a condition may be missed. A small number of respondents said some people may delay going to see their GP because they know GPs face a range of challenges, including increased demand for appointments.

A respondent quote which illustrates theme 4 is presented below.

> “GP practices are experiencing lengthy waiting times, which may discourage people from attending who perceive themselves to only have a minor issue, even if it might be something they only considered checking due to an awareness raising campaign. If people cannot access timely services in the right place, opportunities to prevent the onset or progression of a condition may be missed. That person’s minor issue may be an early indication of a more serious condition.” Health and Social Care Alliance Scotland

16. Question 14

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

Introduction

The vast majority (87%) of respondents answered Question 14, and the analysis identified four themes:

- **theme 1:** socio-economic barriers
- **theme 2:** insufficient knowledge and health literacy
- **theme 3:** personal, psychological, and attitudinal barriers
- **theme 4:** structural and systemic barriers

Respondents said that barriers were multi-faceted, shaped by a wide range of personal, social, and environmental factors, and intersectional. Further, many barriers identified at Question 14 have been described earlier at Question 8 and have only been covered in summary form in this section.

Theme 1: Socio-economic barriers

The majority of individual and organisation respondents said that socio-economic factors made it difficult for people to make healthy decisions in preventing or slowing the progress of long term conditions. Here, respondents mentioned:

- **financial challenges** – many respondents noted that poverty limited people's ability to make healthy decisions, which has been exacerbated by the cost-of-living crisis. Also, the nature of their long term conditions can result in additional financial costs and challenges (for example, travel and transport costs, rising household bills, and reduced household income if working reduced hours)
- **geographical barriers** – some respondents said that people living in deprived urban and rural areas may experience accessibility challenges – for example, poor public transport or have to travel long distances to access supermarkets or shops that sold fresh food and produce, distance to access greenspace, gyms and sports centres, and non-medical services
- **protected characteristics and health inequalities** – a small number of respondents noted the intersectionality of barriers were shaped by a range of social factors, including ethnicity, gender, disability
- **digital barriers** – a small number of respondents highlighted that digital poverty, exclusion, and accessibility challenges made it difficult for people to make healthy decisions

Theme 2: Insufficient knowledge and health literacy

The majority of respondents said that insufficient knowledge and health literacy were key barriers that made it difficult for people to make healthy decisions to prevent or slow the progress of long term conditions. For example, they said some people may lack knowledge, skills and understanding on nutrition, appropriate physical activity, or how to manage their own health and condition. Wider issues around capacity to access, understand, and apply relevant information were also mentioned.

Theme 3: Personal, psychological and attitudinal barriers

Many respondents said there were a range of personal, psychological and attitudinal barriers for people in making healthy decisions to help prevent or slow the progress of long term conditions. These responses mentioned:

- **mental health and wellbeing** – some respondents said that a person's mental health and wellbeing could be a barrier to making healthy decisions with reference to feelings of stress, anxiety, and fear – and the impact of these issues on a person's confidence and motivation to make healthy lifestyle choices or to engage with support services
- **stigma and attitudes (including self-stigma)** – some respondents cited experiences of being ignored or dismissed when accessing healthcare and support services, and that it may also affect people's willingness and ability to make healthy decisions or engage in treatment and care

Theme 4: Structural and systemic barriers

Some respondents identified wider structural and systemic barriers were also important considerations. The main points raised in responses centred on:

- **limited access to healthcare and support** – there may be limited support available to individuals within their local community
- **long waiting times** – individuals may be placed on long waiting lists for appointments, referrals to specialists, and treatment – which could result in a worsening of their condition if support is not accessed in a timely manner
- **short consultation times** – appointment times could be not long enough for individuals to provide information on their condition and receive adequate information and support from healthcare professionals

17. Question 15

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

The vast majority (79%) of respondents answered Question 15. This section provides an overview of:

- the views of respondents who identified examples of things that worked well within their community to prevent or slow progression of long term conditions
- the views of respondents who said they could not think of anything that currently worked well within their community to prevent or slow progression of long term conditions

Examples of things that worked well within communities to prevent or slow progression of long term conditions

The vast majority of respondents highlighted several aspects which they considered to work well within their community to prevent or slow progression of long term conditions. The main themes that emerged from these responses were:

- **theme 1**: prevention and early intervention
- **theme 2**: community based support
- **theme 3**: integrated and coordinated care

Theme 1: Prevention and early intervention approaches

Many individual and organisation respondents said that approaches aimed at prevention and early intervention currently worked well within their community. They often noted such approaches and support ensured a focus on stopping problems before they started and supported early detection of issues that enabled early intervention to halt or slow progression of long term conditions.

Points raised under theme 1 can be grouped as follows:

- **lifestyle and behavioural change programmes** – some respondents, particularly service providers, highlighted interventions aimed at encouraging physical activity, health eating and nutrition, falls prevention and physiotherapy. These programmes were considered effective as they: reduced risk factors associated with long term conditions; encouraged and promoted healthy lifestyle; reduced demand and pressure on primary care services; and could be more cost-effective if intervention happens early. These respondents highlighted the important role of a wide range of service providers in signposting and referring people to lifestyle and behavioural change activities and programmes

- **supported self-management** – some respondents identified the importance of educational support and information, personalised action plans, self-management plans, coaching, digital resources, group sessions, drop-in sessions, the provision of practical tools, self-monitoring equipment and structured self-monitoring plans, and regular check-ins. Self-referrals were highlighted as important mechanisms to access care and support in a timely manner and to support early detection
- **public health campaigns** – some respondents said it was vital that people with long term conditions (or at risk of developing long term conditions) were provided with clear, accessible information to support and empower them to make informed decisions about their care, lifestyle choices and behaviours. Public health campaigns (including those supported by legislation) mentioned as good examples were smoking cessation and ultra processed food
- **detection, screening and regular reviews –** a small number of respondents highlighted examples such as national eye screening programmes for optometry, physiotherapy, cardiovascular health, diabetes. A key example noted was the Psychology Adding Value Epilepsy Screening (PAVES) programme which is targeted at children and young people with epilepsy who experience mental health issues providing mental health screening and, if required, access to a tailored early intervention pathway. Respondents also referred to the important role of community pharmacies in terms of their accessibility in local communities and skilled and experienced staff
- **evidence-based prescribing of clinically proven drugs or treatments** – a small number of respondents identified pharmacological interventions and innovations with proven efficacy as important preventative measures. Examples included: SGLT2 inhibitors which are primarily used to treat diabetes, heart failure and chronic kidney disease; and the growing use of weight loss medication from both private and public health providers to slow or prevent many long term conditions by maintaining healthy weight to increase mobility

Respondent quotes to illustrate points raised are provided below.

> “The CHS Self-management Skills programme has been hugely beneficial to my daughter, she thoroughly enjoys her time at the group, and it has increased her confidence. It's usually quite difficult to get her to take part in activities especially with new people. It is especially hard to get her out the house on time. However, with SMS she is up and ready to leave early and never wants to miss a session.” RCPCH Scotland and Children's Health Scotland

> “The option to re-refer back into services has been helpful and avoids waits for GP referral back into specialist services. Re-referral means that symptoms can be treated promptly and often stops progression to more severe or limiting symptoms.” The Innovative Healthcare Delivery Programme (IHDP) Patient and lived experience reference group

Theme 2: Community based support

Many individual and organisation respondents highlighted the valuable role of third sector organisations and community based support as examples of good practice within their community to prevent or slow progression of long term conditions. Points raised under theme 2 have been grouped as follows:

- accessibility of community based support
- social aspect of community based support

Accessibility of community based support

Some respondents emphasised the importance of the accessibility of local community hubs, day centres, leisure centres and libraries and how they could be used to deliver information sessions, drop-in support and advice, lifestyle and health improvement programmes and signposting for people with long term conditions. Such facilities were close to home and familiar.

Respondents identified targeted outreach delivered through community based support as a key strength. For example, Community Appointment Days, where a range of allied health professionals provided triage and connected people to relevant services, were considered highly effective and valued by people with long term conditions and health professionals alike.

Similarly, responses noted the creation of Health Defence Hubs in areas of high deprivation allowed interventions to be tailored to the needs of local communities. They added that this approach helped remove barriers to accessing care and support services. Another example of good practice in the third sector included volunteer-led community transport, befriending and buddying schemes – respondents said these helped to remove barriers to accessing healthcare appointments as well as social activities – and were important lifelines for people with long term conditions.

Social aspect of community based support

Some respondents mentioned the social value and benefit of community based support. They said that support networks and peer groups were crucial for providing a shared sense of community for people with long term conditions which could often be isolating. Key people identified in responses included Community Link Workers and similar roles that helped build relationships and connect people with the right local support provided by the third sector and community organisations. They identified the important role of social prescribing approaches (for example, physical activity, social or hobby groups) to help people access non-medical interventions that could help prevent or slow progression of long term conditions and reduce pressure and demand on primary care.

Respondents stated that community based support also increased the visibility of long term conditions and the services available – it helped to widen access and ensure more people received timely support.

Responses noted this support could help address issues such as mobility, isolation and wellbeing by linking people to support networks (for example, social prescribing of Men's Sheds) – and could help to improve quality of life.

Another social benefit identified was that access to community based support increased the confidence of people with long term conditions, and could encourage them to access other support, and stay engaged with their own care – all of which contributed to better management of long term conditions.

Respondent quotes to illustrate theme 2 are provided below.

> "Our hubs take a Community Development approach to design services, making sure they service the needs of the community and build trust. For example, our Dundee Health Defence Hub team has worked with the local Gypsy Traveller community to build trust and help them access services." Chest Heart and Stroke Scotland

> "Community Link Workers are a success story locally and support people in the community to live their lives to the fullest and reduce demand on primary care and other health and social care services." Clackmannanshire and Stirling Health and Social Care Partnership

Theme 3: Integrated and coordinated care

Some respondents, mostly representative organisations/groups for health and social care staff, highlighted examples where multidisciplinary teams provided integrated and coordinated care and support to people with long term conditions and said this worked well in practice. These respondents said the prevention and slowing of long term conditions was best supported when care was integrated and coordinated across different parts of the healthcare system. They added that this was often enabled and facilitated (and accelerated) by clear referral pathways, joined-up service delivery, and the co-location of different services.

Key strengths of this approach were considered to include: timely access to care and support; holistic and person-centred support; and strong relationships and communication between people and service providers (consistency and continuity of care). Organisations (mostly service providers) noted that integrated rather than fragmented care helped to raise awareness and understanding of long term conditions (and how individual conditions may progress) amongst healthcare professionals.

While integrated and coordinated care was highlighted as an example of good practice, a small number of respondents highlighted that the level and efficiency of collaboration and joint working varied across Scotland. They stated more could be done to ensure a more integrated and coordinated approach to care and support regardless of where a person lived, and that such an approach would require to be supported by workforce education, development and training.

Respondents who could not identify any examples of what is working well within their community

Some respondents (mainly individuals) stated they could not identify anything that worked well within their community to prevent or slow progression of long term conditions. The main points that emerged from these responses were:

- a lack of available care and support for certain long term conditions – for example, long COVID was mentioned in responses
- that a continuing pressure on budgets has reduced funding and resources for activities that prevent or slow the progression of long term conditions

18. Question 16

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

The vast majority (80%) of respondents answered Question 16, and the main themes that emerged from these responses were:

- **theme 1**: increased investment for prevention and early intervention
- **theme 2**: co-design, co-production, and capacity building

Theme 1: Increased investment for prevention and early intervention

Many individual and organisation respondents identified increased investment for prevention and early intervention as a mechanism to involve communities in preventing or slowing the progress of long term conditions. The main points included that many respondents:

- called for **increased investment in community resources and infrastructure** to provide financial and other support to organisations working in this space to do more, as well as to harness the knowledge, experience and expertise that existed in communities. Funding challenges faced by third sector organisations were reiterated which has implications for organisations' ability to increase the involvement of communities in preventing and slowing the progression of people with long term conditions. Respondents also highlighted recent closures of community facilities and the need for sustainable investment to protect local infrastructure to help ensure consistency and continuity of service provision
- highlighted the importance of tailored and inclusive **awareness and education programmes** to involve communities. This included public health campaigns to promote healthier lifestyle choices and behaviours, support a prevention and early intervention approach, communicate relevant legislation to the general public and raise awareness of the risk factors associated with long term conditions. Awareness and education were considered crucial across all stages of life – starting from a nursery and school setting to embed healthy and preventative behaviours from an early age
- called for greater investment in **workforce development of community-based health professionals**, for example community link workers, to allow expansion of their existing and valued services, such as social prescribing, to involve communities and reduce pressure and demand on primary care

A respondent quote to illustrate theme 1 is provided below.

> "The erosion of community infrastructure (local halls, libraries, and meeting spaces), has significantly reduced opportunities for people to come together, share knowledge, and support one another. Peer support groups often struggle to find accessible and affordable venues. This lack of space contributes to social isolation and limits the potential for community-led innovation." Scottish Association of Social Work

Theme 2: Co-design, co-production and capacity building

Many respondents, particularly organisations, emphasised the importance of the co-design and co-production of services as well as capacity building support to involve communities in preventing and slowing the progression of long term conditions. Points raised under theme 2 can be grouped as follows:

- co-design, co-production and participation
- community empowerment and capacity building

Co-design, co-production and participation

Many respondents emphasised the importance of adopting co-design and co-production of services as a key mechanism to involve communities in preventing and slowing the progression of long term conditions. These respondents highlighted the importance of meaningfully integrating the views, knowledge and expertise of people with lived experience of long term conditions (and organisations that support them) at all stages of service planning, design, delivery, monitoring and reporting. Building in monitoring and feedback loops from the outset was considered critical to ensure services remained responsive and accountable to people with long term conditions. They said there should be a 'genuine' commitment to collaboration where communities were treated as equal partners.

Some respondents pointed to existing mechanisms used by the Scottish Government to involve communities in the design and delivery of health and social care services, such as citizen, peer and group advocacy (for example, citizen panels), public social partnership models, and community-led health and social care models. Mixed views were provided on the effectiveness of these – some valued these models and considered them impactful for community involvement while others described them as 'inadequate' or 'tokenistic'.

Respondents considered it important that diverse participation underpinned any co-design and co-production processes – to ensure that involvement extended beyond community leaders to reflect a diverse mix of people within marginalised and underrepresented groups (including intersectionality).

There were calls for the Scottish Government to further invest in the social infrastructure to enable this to happen. Suggestions included:

- the provision of incentives and remuneration for community involvement

- engaging and building strong relationships with community leaders to build trust and deliver effective outreach, particularly in communities and with population groups that may not engage with traditional healthcare services
- greater flexibility to improve access for communities to be involved – for example, community involvement or services in non-traditional settings and flexible meeting times

Respondents identified the range of benefits that could be derived from adopting a co-design and co-production approach to community involvement, including that:

- this would be consistent with a human rights based approach to participation
- services would be designed to meet the needs of people with long term conditions
- it could (re)build trust and stronger relationships between communities and the Scottish Government

A respondent quote to further illustrate the points raised above is provided below.

> "There is a need for more participation of children and young people to be more effectively facilitated across health policy in Scotland – a citizen panel approach is unlikely to fulfil this." Children and Young People's Commissioner Scotland

Community empowerment and capacity building

Many respondents, particularly organisations, identified a need for greater capacity building support to help empower/involve communities in preventing and slowing the progression of long term conditions. These respondents highlighted the important role of the wide range of organisations and partnerships that regularly undertook this type of activity – they were viewed as key enablers of community involvement which could be further built on and developed.

These respondents also highlighted the role of local community organisations and partnerships in providing safe and welcoming physical spaces (such as community centres) and resources for community involvement – this was seen as a simple and effective way to facilitate and build capacity within peer support networks, self-help groups and community led support – and which would be supported to become self-sustaining over time.

Peer support networks were considered particularly useful mechanisms for community involvement, including for reaching and engaging underserved communities and groups. There were again calls for sustainable investment to help these networks to grow and expand their reach and to enable organisations to train more peer educators with lived experience of long term conditions.

19. Question 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?

Introduction

The vast majority (80%) of respondents answered Question 17. While a small number of respondents indicated in their responses that everyone should be treated equally, the majority of respondents who answered this question identified several additional important considerations for people with long term conditions. The main themes that emerged from these responses were:

- **theme 1**: tackling health inequalities
- **theme 2**: accessibility, availability, and capacity of services

Theme 1: Tackling health inequalities

Respondents said that tackling deep-rooted health inequalities was an important additional consideration for people with long term conditions. Points raised under theme 1 can be grouped as follows:

- identification, evidence and impacts of health inequalities
- what is required to address health inequalities

Identification, evidence and impacts of health inequalities

Respondents identified a range of factors that contributed to health inequalities for people with long term conditions and agreed with the examples provided in the question (for example, people who live in deprived areas, in rural and island communities). Some respondents pointed the Scottish Government to existing research or other evidence in support of this viewpoint.

Many respondents highlighted that people living in **rural and island areas** required additional consideration as they faced particular challenges due to transport difficulties, housing pressures, a growing ageing population and workforce shortages. Respondents felt that access to general and specialist services could be a “postcode lottery” and that this could lead to delays in diagnosis, treatment, and care, as well as wider issues such as increased social isolation.

Many respondents, particularly representative organisations/groups for health and social care staff, highlighted **socioeconomic deprivation** as a key driver of health inequalities. They said that people who live in deprived areas were more likely to have a range of health conditions and poorer health outcomes (for example, lower life expectancy) than those who live in less deprived areas.

They emphasised that a range of social and economic factors have an impact on people's health (for example, education, income, employment) and should be considered.

Many respondents, particularly representative organisations/groups for health and social care staff, highlighted that people with **protected characteristics** were more likely to experience health inequalities. Respondents mentioned people with protected characteristics were more likely to experience certain conditions (for example, higher prevalence in some groups) and they were also more likely to experience discrimination, unconscious bias or exclusion within the health and social care system.

Many respondents, particularly service providers, highlighted that some groups and conditions experience **stigma** and this should be an additional consideration for long term conditions. Specific conditions mentioned in responses included for example, fibromyalgia, long COVID and ME, HIV, cerebal palsy, dementia, obesity. These respondents said stigma acts as a barrier to an individual's willingness to engage with service providers, reinforcing isolation and exacerbating poorer health outcomes and health inequalities. It was noted that a poor experience with healthcare professionals could reinforce this and could lead to a mistrust in services.

Some respondents, mostly individual respondents and service providers, identified people in **inclusion health groups** (for example, homelessness) as an important additional consideration. Respondents said that these groups faced additional barriers to accessing treatment, care and support due to not having a permanent address – and that more action was needed to reach and support these individuals.

What is required to address health inequalities

Many respondents provided suggestions for what was required to tackle health inequalities. The points raised have been reflected throughout this consultation analysis report, and in summary included:

- whole-system, person-centred, holistic, and integrated models of care
- equitable, accessible and inclusive information and services
- trauma-informed approaches and practice
- ongoing workforce development and training for healthcare professionals
- greater co-design and co-production of services, involving people with lived experience of managing long term conditions
- employability and workplace-based support for people with long term conditions

Respondent quotes to illustrate the points raised are provided below.

"Groups such as people experiencing homelessness require holistic, trauma-informed, and flexible care due to the instability of their living circumstances... National standards and strategies must acknowledge these overlapping challenges and ensure that tailored, equitable support is built into service design and funding models across geography and population groups." Public Health Scotland

"Consideration of the intersectionality of mental health alongside other factors which act as barriers to good health is absolutely essential in this framework. For example, different forms of discrimination – such as racism, sexism, ageism, ableism, etc. interact and compound the experiences of those with long term mental health conditions." Royal College of Psychiatrists in Scotland (RCPsychiS)

Theme 2: Accessibility, availability and capacity of services

Many respondents, particularly individuals, reported the accessibility, availability and capacity of services was an important additional consideration for people with long term conditions. These responses were often framed in the context of a growing ageing population, and that more people were living with/would live with long term conditions. This would likely place an increasing demand for health and social care services and create workforce challenges for the health and social care sector. They also reemphasised the importance of information and services being available and accessible in a range of format and settings.

20. Question 18

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

The majority (73%) of respondents answered Question 18, and the main themes that emerged from responses were:

- **theme 1**: education and training
- **theme 2**: equitable access to treatment, care and support
- **theme 3**: governance and accountability mechanisms
- **theme 4**: community engagement and co-production
- **theme 5**: increasing workforce diversity
- **theme 6**: structural issues

Analysis of responses to this question confirmed that a multi-faceted approach would continue to be required to address racism and discrimination in healthcare.

Theme 1: Education and training

The majority of respondents, particularly individuals and service providers, identified education and training as vitally important to tackle racism and discrimination in healthcare. There was strong agreement that relevant workforce development and training should be mandatory, ongoing and embedded at all levels of the healthcare system – from senior leadership teams to frontline staff.

Some respondents felt current approaches to anti-racism and anti-discrimination training for healthcare professionals were not good enough and provision was also variable. There were calls for improvements in training (such as cultural competence training) that equipped healthcare professionals with the knowledge and understanding of the issues around culture and health, and how this might influence health care outcomes. In addition, this could develop a better understanding of the way to deliver health care and respond to the needs of Scotland's diverse population.

Related points on education and training included:

- the importance of targeted public health campaigns to reduce stigma and to challenge discriminatory attitudes and behaviours
- that people with long term conditions and healthcare professionals both experienced racism and discrimination in healthcare – and that action was needed on several fronts

Respondent quotes that illustrate points raised in theme 1 are provided below.

"Diversity education is appalling. In a lot of cases. The tropes and stereotypes in these existing courses serve to reinforce negative perceptions and drive unconscious bias." Individual respondent

"There is a need for more education on health conditions and how these may present differently in ethnic minority physiologies from recognition of skin conditions on different colours of skin, to menopause symptoms being earlier in South Asian women, and risk factors of cardiovascular conditions and type 2 diabetes also presenting in lower BMIs in Asian older people." Age Scotland

Theme 2: Equitable access to treatment, care and support

Many respondents highlighted specific actions to support equitable access to treatment, care and support. These respondents said certain population groups (for example, people with protected characteristics) were at greater risk of racism and discrimination in healthcare – and this could result in differences in terms of their access to healthcare, treatment, care and support, as well as health outcomes.

These respondents called for: person-centred/whole-person approaches; culturally appropriate care, information and education materials, including greater access to interpreting and translation services; and greater flexibility in service delivery (for example, community-based provision, flexible appointments).

A respondent quote that illustrates points raised under theme 2 is provided below.

"Refugees and people seeking asylum repeatedly stress the importance of culturally sensitive health provision that acknowledges their specific health histories and current needs, including the provision of more interpreters and training for healthcare providers to better understand and respect cultural differences in health practices." Scottish Refugee Council

Theme 3: Governance and accountability mechanisms

Many respondents identified robust governance and accountability mechanisms as key to addressing racism and discrimination in healthcare. This included calls for:

- **more robust governance, leadership and accountability mechanisms** (for example, whistleblowing) to address racism and discrimination in healthcare. These respondents emphasised the critical role of strong leadership in: setting the tone (for example, not dismissing instances of racism or discrimination as isolated incidents); shaping governance and accountability practices, including greater alignment with existing anti-racism and discrimination commitments (such as NHS principles and values); ensuring greater transparency; and building trust with the general public
- **embedding equalities and equalities outcome monitoring** in policies and strategies for improvements in the collection of appropriate data (metrics) and insights to better understand and tackle health inequalities and racism and discrimination in healthcare.

Some felt that the availability of data was limited at a Scotland and local level, and that improvements were needed to ensure improvements in service delivery were evidence-based and consistently implemented (for example, Equality Impact Assessments)

Theme 4: Community engagement and co-production

Many respondents, particularly representative organisations/groups for health and social care staff, said that the genuine involvement and engagement of people with lived experience of managing long term conditions was key to:

- developing a better understanding of the barriers to accessing healthcare
- understanding different perspectives on racism and discrimination in healthcare
- informing all stages of healthcare including service planning, design, delivery, and improvement
- building trust
- ensuring culturally appropriate care

A respondent quote that illustrates theme 4 is provided below.

> "In Lothian, the Minority Ethnic Health Inclusion Service ensures minority ethnic groups can voice their views, have equality of access to services and support, delivers health promotion programmes and facilitates health screening with minority ethnic groups… Partner organisations work with black and minority ethnic unpaid carers in Edinburgh and the Lothians to reduce health inequalities, using local knowledge about diverse population needs to improve outcomes." Edinburgh Health and Social Care Partnership

Theme 5: Increasing workforce diversity

Some respondents said more could be done to continue to improve workforce diversity in healthcare which could help to reduce health inequalities and improve health outcomes. Inclusive recruitment and retention policies were highlighted as a way to help ensure the healthcare workforce better reflected diverse population demographics, as was continued investment in continuous professional development.

Theme 6: Wider structural issues

A small number of respondents said that racism and discrimination in healthcare could not be understood or addressed in isolation. They called for consideration of racism and discrimination through the lens of wider structural issues (for example, poverty, deprivation, and housing) as well as adopting an intersectional approach.

21. Question 19

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

Over half (55%) of respondents answered Question 19, and the main themes that emerged from responses were:

- **theme 1**: recurring themes from earlier questions
- **theme 2**: concerns with the consultation process

Theme 1: Recurring themes

Many respondents in their response to Question 19 reiterated points they raised at earlier questions. These included:

- calls for greater clarity on implementation, particularly around how condition-specific work would be selected, workforce and resource implications, and governance and accountability structures
- a Long Term Conditions Framework could help to facilitate whole-system, person-centred, holistic, and integrated models of care approaches
- a unified framework could risk losing momentum, focus and progress on condition-specific work – or be perceived as a cost-cutting exercise
- the importance of recognising third sector and community based support as an equal partner
- the importance of prevention and early intervention approaches

Theme 2: Concerns with consultation process

A small number of individuals and third sector organisations raised some concerns with the consultation process. These included:

- the consultation document was considered to be ‘inaccessible’ with reference to its length, complexity, and denseness, particularly for some individuals with fatigue or brain fog
- a perception that the decision to implement the Long Term Conditions framework has already been made by the Scottish Government and/or that some organisations and groups may not have been adequately consulted – this was raised by a small number of third sector organisations
- a lack of confidence in meaningful impact or action as outcomes of the consultation process – a small number of individuals cited their experience from undertaking previous consultation exercises
- limited or a lack of reference to certain conditions, target groups, or approaches in the consultation paper - for example, human-rights based approach, children and young people, and long COVID were mentioned

Appendix A: Responses and analysis

A total of 384 responses were received to the consultation.

The data review and cleaning process identified 12 individual and organisation respondents who had each submitted duplicate responses. To avoid over-representing these individuals and organisations in the analysis:

- either one response for each individual and organisation was removed where the duplicate responses were identical
- or where responses were similar duplicate responses were combined into a composite submission for each individual or organisation

Further, one blank response was removed as this did not contain any responses to the consultation questions.

A total of 13 responses were therefore removed.

This means that a total of 371 validated responses have been included in the final analysis.

No campaign responses were identified. There were a very small number of responses with partial similar wording. This likely reflects organisations promoting the consultation within their community and through their networks, sharing their suggested responses and key messages, and/or posing questions to help others consider and respond to the consultation.

All responses to the public consultation were moderated by Scottish Government officials in the Long Term Conditions Strategy Unit to ensure they were genuine responses to the consultation and specific information was redacted to ensure responses could not identify any individuals. This process included screening for offensive or discriminatory language which might require redaction prior to publication, or if there was a response which was completely irrelevant to the consultation. No responses have been excluded from the consultation analysis for either of these reasons.

EKOS then exported consultation responses from Citizen Space into Microsoft Excel for data management and cleaning. Where responses were submitted in another format, Scottish Government officials moderated these prior to uploading the documents to Citizen Space.

In Excel, EKOS conducted an initial readthrough and review of responses to each question – this gave a nuanced understanding of the different perspectives presented in the responses. Following this initial readthrough and review, EKOS formulated various themes and coded each response into one or more themes.

The analysis gave equal weight to all responses, regardless of whether they were submitted by individuals or organisations. The analysis has sought to identify the most common themes and issues. It does not report on every single or specific point raised.

The consultation paper structure allowed respondents to answer questions independently, in recognition that respondents may answer some questions without expressing views on others. There was some repetition of views expressed across the question set. Judgement was applied to determine the most appropriate placement for each theme within the report.

Appendix B: Focus groups summary

This appendix provides an overview of the main themes that emerged from a review of the six focus group event notes.

The focus groups did not entirely follow the layout of the consultation document – rather they asked key questions relevant to the groups attending each focus group. These questions predominantly focused on barriers to accessing information, care and support, and how people with long term conditions could be supported to access information and support more easily.

There were strong recurring themes spanning the focus group events, including:

- language and communication barriers
- digital exclusion
- access to healthcare
- the importance of non-medical support
- housing and local area
- mental health and wellbeing
- the role of advocacy and third-sector organisations

Language and communication barriers

Focus group attendees reported significant difficulties in accessing information, healthcare and support services due to limited English proficiency and poor literacy levels in some cases. They noted that these impacted various aspects of their lives including:

- understanding their condition
- self-management
- treatment and medication

Attendees stated that there could be a lack of translated information and materials available to them relevant to their long term condition(s) and on how to access support. NHS resources were cited as ‘inaccessible’ without additional help and support. Moreover, interpreter services were highlighted in some cases as being of ‘poor’ quality, lacking professionalism or cultural sensitivity.

Many attendees said they relied on family members, friends, or third-sector organisations to provide translations and advocate on their behalf. This included reading information and materials, booking and interpreting healthcare appointments, and help to access support. Relying on others for translation was noted as a point of stress and/or embarrassment for those with long term conditions, as often this could involve disclosing personal or sensitive information.

Digital exclusion

Digital exclusion was raised as a key concern across the focus group events. Attendees noted there were a range of barriers to accessing health information, care and support due to digital exclusion issues. This included:

- digital poverty and a lack of access to digital devices (for example, smartphones, tablets, and laptops)
- limited digital literacy – which made it difficult to navigate online systems, book appointments or respond to emails/messages
- a lack of, or poorly translated, digital resources

Attendees noted that they preferred face-to-face communications and printed materials (for example, letters) to provide information, appointment times, and in terms of accessing support.

Stigma and accessing healthcare

Some attendees noted concerns relating to stigma and feeling dismissed by healthcare professionals at times. Attendees suggested they felt 'ignored' or 'not listened to' due to their background.

Similarly, attendees raised a point that they experienced long waiting times and inconsistent care for their long term condition. Some said they had used accident and emergency services as a last resort due to for example, poor access to primary care support or a lack of specialist support.

Non-medical support

Attendees noted that non-medical support was valuable for supporting their long term condition, citing resources such as peer support, respite care, gym memberships and advocacy support. Attendees said they often experienced inconsistent support, delays or lacked access to this type of support due to cost factors. Some noted that funding cuts threatened to reduce the non-medical support available to them even further.

Housing and local area

Some attendees expressed dissatisfaction with their housing conditions and the local area in which they lived – they felt these issues impacted on their overall health and wellbeing. Some noted they lived in inadequate housing which was exacerbating their long term condition and had resulted in other health issues. Issues raised included:

- accessibility issues (for example, wheelchair accessibility, lack of outdoor access)
- poor housing conditions (for example, damp, mould)

Additionally, some attendees cited issues with their neighbourhood and local area. This included feelings of stigma and discrimination from neighbours, along with poor housing allocation from local authorities.

Mental health and wellbeing

Attendees reported struggling with their mental health and wellbeing. Specifically, they noted that this was compounded by stress and other barriers, including language and access issues, long waiting lists to access support, and stigma and exclusion. Mental health diagnoses, such as anxiety, depression and stress were prevalent among groups such as carers and refugees. Attendees noted that peer support and access to culturally affirming spaces were invaluable in supporting and improving mental health conditions.

Advocacy and third sector organisations

Attendees praised third sector and advocacy organisations for providing support tailored to individuals' needs. These organisations – including Minority Ethnic Carers of People Project (MECOPP) – were highlighted as providing support which is 'culturally and linguistically' appropriate.

Attendees highlighted the importance of providing 'culturally competent' services to ensure an individual's cultural background was respected and that services responded appropriately to diverse needs and preferences. Whilst advocacy and culturally competent services were noted as 'essential', attendees felt these services could be lacking in availability and that efforts could focus on increasing availability of, and equitable access to, culturally competent services.

Appendix C: Consent to further contact

Table C.1: Do you consent to the Scottish Government contacting you again in relation to this consultation exercise? – future contact/internal sharing

Response	Number	Percentage
Yes	327	88%
No	44	12%

Base = 371

Appendix D: Satisfaction with the consultation

Table D.1: How satisfied were you with this consultation?

Response	Number	Percentage
Satisfied	172	57%
Neither satisfied nor dissatisfied	75	25%
Dissatisfied	53	18%

Base = 300

Table D.2: How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?

Response	Number	Percentage
Satisfied	208	69%
Neither satisfied nor dissatisfied	68	23%
Dissatisfied	21	7%

Base = 297

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