

Gathering Views Report on Palliative Care

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Section 1: Executive summary

- 1.1 The Scottish Government is developing a new Palliative Care Strategy for Scotland, to be published in 2024. Healthcare Improvement Scotland was commissioned to undertake a Gathering Views exercise in January 2024 to support the ongoing development and implementation of the strategy by gathering views from people in Scotland with experiences of Palliative Care or caring for someone who has received Palliative Care. Conclusions from this exercise will be used to inform the new Palliative Care strategy.
- 1.2 A total of 42 people across Scotland took part in this exercise over an 8-week period. Views were sought from 6-10 people across Scotland in each of the five groups:
 1. People living in rural and island communities with health problems that mean they would be eligible for Palliative Care as patients or family members/carers
 2. Older people (with multiple health problems, long-term conditions and/or general frailty)
 3. Parents, children, and young people
 4. Carers (may include some bereaved carers)
 5. People and families with experiences of receiving specialist Palliative Care (e.g. a hospice day unit group).
- 1.3 Interviews were carried out via group discussions or via one-to-one interviews either by phone, video or in person using links through local contacts, NHS services and third sector organisations. The interviews gathered views from all five groups and included a mix of experiences from urban, rural and island communities.
- 1.4 The work involved gathering views from individuals who had experience of Palliative Care or experiences of caring for someone who has received Palliative Care by asking questions about the care and support they had experienced through health and social care services and local support groups. Based on findings from this Gathering Views exercise, this report sets out a range of themes that matter most to the people we spoke to regarding Palliative Care.
- 1.5 This report is a summary of findings from interviews and group discussions conducted by Healthcare Improvement Scotland (HIS) with individuals who have experiences with Palliative Care or caring for someone who has received Palliative Care. The document covers various aspects of Palliative Care, including what it means to participants, areas for improvement, suggestions for how Palliative Care providers could improve their services, and the importance of communication, information, and support in Palliative Care. Participants discussed the need for early discussions in their treatment, person-centred care, coordination of services and access to emotional and peer support.

- 1.6 Suggestions for improvements included better information provision, coordination and access to specialist care, especially in rural areas. The report also highlights the participants' views on staff involvement in Palliative Care and the importance of holistic support for patients and families.
- 1.7 Findings and conclusions are presented in full in this report.

Section 2: Background

- 2.1 Healthcare Improvement Scotland enables the people of Scotland to experience the best quality of health and social care. Healthcare Improvement Scotland is committed to supporting the engagement of people and communities in the development and design of health and social care services.
- 2.2 In January 2024, the Scottish Government commissioned Healthcare Improvement Scotland to undertake a Gathering Views exercise. The feedback from this exercise will be used to complement Scottish Government's own research in support of the development of a new Palliative Care strategy in 2024.

2.3 A new Palliative Care strategy for Scotland - Aims

The strategy will have two high level aims:

- 1. Everyone in Scotland receives well-coordinated, timely and high-quality Palliative Care, care around death and bereavement support based on their needs and preferences, including support for families and carers.
- 2. Scotland is a place where people and communities can come together to support each other, take action and talk openly about planning ahead, serious illness, dying, death and bereavement.

Section 3: Approach

- 3.1 Healthcare Improvement Scotland has developed an approach called Gathering Views¹. This aims to gather lived experience views on specific subject areas to inform the development of health and care policy and services.
- 3.2 Gathering Views exercises are not undertaken as formal research, nor as formal public consultation. The engagement is intended to supplement work undertaken by Scottish Government or other commissioners, consider new or different ideas, and based on the findings.
- 3.3 The Scottish Government produced a national EqlA (Equality Impact Assessment) and Fairer Scotland Duty Summary Draft Framework for Palliative Care, to assess potential impacts for people from each of the protected characteristics, socio-economic factors and rural and island settings. The EqlA will be published alongside the new Palliative Care strategy on their website, [Palliative and end of life care strategy: aims, principles and priorities - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/palliative-and-end-of-life-care-strategy/summary-draft-framework/pages/2/#:~:q=palliative%20care%20strategy&as_s=1).
- 3.4 While some lived experience engagement activities had already been delivered at national level, there was a need to hear from the five key groups identified. Due to the sensitive topic of this exercise, it was decided that a qualitative approach using individual interviews and discussion groups would be the most meaningful method of engagement. We were keen to engage with people who represented several areas and had potentially not had their voices heard. We spoke with all the people identified throughout the eight-week engagement period.
- 3.5 The question set ([Appendix 1](#)) was developed to help us to gather people's views, insights and experiences of Palliative Care or caring for someone who has received Palliative Care. A total of twelve questions were presented.
- 3.6 An information sheet was provided for the participants as well as a consent form to take part in the work, and all participants provided written or verbal consent in advance of the interview or group discussion ([Appendix 2](#)).
- 3.7 Equality monitoring questions, in the form of an online survey were shared with the participants, either before or during discussion ([Appendix 3](#)), which they could also complete via email or paper copy, achieving a 71% (N=30) response rate.
- 3.8 Recruitment methods were agreed based on the scope and aims of this work. Throughout January and February 2024, over an eight-week period, we engaged with

¹ On behalf of the Scottish Government and Healthcare Improvement Scotland, views are gathered from members of the public across a variety of health-related topics.

42 people via 32 one-to-one individual interviews and two group discussions (each with seven people and three people) with experience of Palliative Care or caring for someone who has received Palliative Care, collecting extensive and in-depth responses. The Gathering Views exercise obtained feedback through discussions with individuals and focus groups via phone, video call and face to face.

3.9 Following a qualitative approach and aligning with the objectives of this work, the aim was to collect rich and meaningful feedback from the targeted groupings identified by the Scottish Government. Carrying out 32 interviews and two group discussions provided both insight into the national picture around Palliative Care and people's experiences of it and allowed sub-group analysis to highlight examples or challenges that people from the specific groupings face, for example carers or people living in rural or island communities.

3.10 The questions covered the following areas:

- participants' understanding of Palliative Care
- the benefits of Palliative Care
- participants' understanding of the differences between general and specialist Palliative Care
- awareness raising and promotion of Palliative Care
- providers of Palliative Care and good ways of doing it
- timing of general Palliative Care and specialist Palliative Care
- equitable Access to Palliative Care
- improvements to Palliative Care, and
- what matters most to participants about Palliative Care.

3.11 The themes that emerged from the questions can be found in the feedback section of this report, as well as improvements and conclusions that were identified during the analysis process. Where appropriate, anonymised quotes from people who participated were used to illustrate what was discussed. Quotes are not associated by any identifiable characteristics, such as location, but are attributed to a specific grouping, for example; older people or individuals from rural and island communities, when appropriate.

3.12 The analysis process focused on a qualitative approach and took place in two stages. At the first stage, all participant responses were themed and categorised, identifying several key and overarching themes discussed in this report.

3.13 At a second stage, analysis was conducted aiming to highlight specific themes, barriers or support needed by particular sub-groups of the participant sample and around key demographics. Specifically, we targeted people with the following demographic, which were asked prior to the interviews or discussion groups taking place:

- older people - 2 participants
- rural and island communities - 14 participants (including a group of 7)
- specialist Palliative Care - 8 participants
- carers - 10 participants, and
- parents and children - 14 participants (including a group of 3).

3.14 Please note that participants have been placed in multiple groupings, as they may belong to more than one of the above groups. For example, a participant may have been a carer, over the age of 66 years old and living in a rural or island community. Their views contributed to all three groupings when the analysis was fully completed. In the case of the group interviews, all feedback collected was analysed as one overall response; therefore, distinguishing the responses of individual participants in the group interviews, and what other groups they may belong to was not possible. To note, equalities monitoring information was not considered, as it was collected separately, anonymously and for monitoring rather than analysis purposes.

3.15 The interviews were informative for both participants and interviewers given the complexity of the subject. Participants provided comprehensive feedback, and to ensure clarity and understanding, an information briefing ([Appendix 2](#)) was shared with all participants before the interviews took place.

3.2. Limitations and influencing factors

3.21 It is important to highlight certain limitations and influencing factors around this work, to provide context and inform the reader's understanding and interpretation of the findings outlined in the next sections.

3.22 We used a qualitative approach for this Gathering Views exercise. This was adopted as an appropriate and pragmatic approach to obtain an in-depth insight into participants' experiences, views and perceptions by asking focused open questions that encouraged participants to share their stories and views. The resulting limitations and influencing factors are further explained within this section.

3.23 These findings are based on interviews and group discussions with people who have experiences of Palliative Care or have cared for someone receiving Palliative Care. During these interviews, participants were asked to recall details and relied on memory to answer the interview questions. According to the qualitative methodological approach employed for this piece of work, the findings reflect the participants' "truths" at the time and their narratives at the time of interview, tightly linked with the individual participants' contexts.

3.24 These findings are intended to offer insight and direction for improvement and further exploration. However, caution should be exercised if these findings were to be generalised.

Section 4: Feedback

Having interviewed 42 participants, a significant amount of feedback was received through this Gathering Views exercise. The quotes that appear throughout the report are from people who took part.

This section provides context to this work by providing a summary of the analysis from each of the targeted groupings. It then outlines key findings from all the questions that were asked throughout this Gathering Views exercise.

4.1. Summary from specific groups

Participants emphasised the importance of clear and accessible information about Palliative Care. They recommended various methods for disseminating information, such as TV, radio, social media, GP surgeries and hospitals. It was highlighted that information should be tailored to different age groups, cultures and locations across the country. Participants stressed the need for compassionate delivery of information, considering individual beliefs, circumstances and faiths.

Participants also discussed the need for early intervention and person-centred care in Palliative Care, stressing the importance of timely access to the right support tailored to individual needs. They highlighted challenges in accessing support in rural areas and the need for consistent care across regions.

In terms of staff involvement, participants suggested including non-healthcare roles in Palliative Care and adopting a holistic approach that encompasses social care and mental health support. They emphasised the importance of effective communication and coordination among care providers to ensure a person-centred approach.

Suggestions for improving Palliative Care included supporting person-centredness, enhancing communication, providing early and meaningful conversations, and ensuring continuity in care. Participants also stressed the importance of having dedicated professionals to offer information, improving information availability and clarity, and providing support for families even after a patient has died. Participants also highlighted the need for holistic care, coordination of services and training for healthcare professionals. A few individuals expressed challenges in accessing support in rural areas and inconsistencies in care between regions.

Overall, participants valued the compassionate care provided by healthcare professionals in Palliative Care, the relationships built and the support received. They highlighted the need for coordinated, accessible, and person-centred Palliative Care services that cater to individual needs and preferences, ensuring dignity and respect throughout the care journey.

4.1.1. Rural and Island Communities

Participants' discussions revolved around the challenges and gaps in Palliative Care in rural and island areas. Participants highlighted the lack of local hospices, misconceptions about

Palliative Care services, and the struggle with accessing dedicated Palliative Care support beyond hospitals. Issues like difficulties in rural transport, delays due to weather conditions, and the absence of specialist care in rural settings were discussed.

Some participants emphasised the need for consistency in support across different areas to avoid a “postcode lottery” scenario that leads to stress for patients and carers. They also highlighted the unsuitability of hospital at home care for all patients and the challenges in adapting urban-based care models in rural settings.

The need for more funding for rural and island models of care, local access to Palliative Care specialists, and continuity of care in general practice was discussed. Some participants stressed the importance of having specialist treatment available locally to avoid the burden of travel, especially for patients with specific medical needs and conditions that make travel difficult. The need for effective representation of rural and island views and experiences and ways to provide feedback and have input into the development and continuous improvement of services was also highlighted.

Discussions also touched on the timing of offering general and specialist Palliative Care services, with challenges highlighted in rural areas where there is a lack of awareness and pathways.

4.1.2. Parents and Children

The discussions around Palliative Care for children with complex needs and life-limiting conditions highlight the importance of offering support and care in a sensitive and compassionate manner. There is a wide range of opinions on when and how to introduce the concept of Palliative Care to families, with some preferring honesty while others prefer a gradual process as a more compassionate approach. Peer support plays a significant role in helping families navigate the challenges of Palliative Care, providing practical advice and emotional comfort. It is crucial to have paediatric Palliative Care nurses who can establish a close link with families and offer support consistently.

The need for emotional support, therapy, peer support and counselling for parents and families was emphasised in the discussions. Transitioning between children and adult Palliative Care services needs to be smooth and continuous, avoiding abrupt changes in care. Some parents who find out about their child's life-limiting condition during pregnancy faced challenges in receiving appropriate support, indicating a need for specialist support provided during this critical period.

Raising awareness and promoting a better understanding of Palliative Care early in a child's illness is crucial. Various strategies such as media campaigns, school initiatives and engaging social media platforms were suggested to reach different audiences effectively. The timing of introducing Palliative Care varies for each child, emphasising the need for individualised approaches that consider the unique circumstances of each family.

Specialist Palliative Care is deemed essential for children with complex needs due to the severity of their conditions. This can involve making memories before the end of life and

requires specific expertise and equipment. The benefits of Palliative Care are highlighted, including the support provided by organisations like Children's Hospices Across Scotland (CHAS) and the importance of Community Children Nurses (CCN) in delivering care.

4.1.3. Carers

The feedback provided by carers did not differ too much from the overall key findings section, below. Overall, key themes from carers feedback included the need for effective communication, early initiation of Palliative Care, equitable access to services, compassionate support and care, ongoing education and training, and a holistic approach that prioritises the patient's wellbeing and preferences throughout their Palliative Care journey.

4.1.4. Specialist Care

The discussions surrounding Palliative Care from those receiving specialist Palliative Care again was similar to the overall findings. Participants emphasised the importance of prompt access to Palliative Care, suggesting that it should be offered at the time of diagnosis or as soon as the patient knows they have a terminal condition. However, it was noted that broaching the topic of Palliative Care too early can be distressing for individuals not ready to confront end of life issues. The benefits of Palliative Care were emphasised, including support for patients and their families, relief from stress and the provision of holistic care that addresses emotional, mental and financial needs.

Areas for improvement in Palliative Care were also discussed, such as the need for more regulation through unannounced visits and better promotion of information. Participants advocated for a more person-centred approach, emphasising the importance of respecting patient and family wishes, fostering close relationships with care teams, and ensuring that care is provided in the right way for everyone. Suggestions were made for increased funding, better staff training and enhanced coordination among different care providers to deliver comprehensive Palliative Care services.

4.1.5. Older People

Key themes from older participants included the importance of communication, care and support, information provision and timing in the delivery of Palliative Care.

Communication was an important aspect, with participants highlighting instances of miscommunication between healthcare professionals, leading to distress and inadequate care. There is a strong emphasis on the need for clear communication about Palliative Care, its role and the differences between general and specialist Palliative Care.

The feedback also emphasises the significance of providing timely and accurate information to patients and carers. Concerns about confusion about funding, upfront costs and lack of awareness about available support services were highlighted. Participants called for more patient and carer information on the Palliative Care process to enable informed decision-making and alleviate stress. Specifically, feedback highlighted the need for improved support and care coordination, particularly in cases where both spouses have medical conditions.

4.2. Key findings

This section presents key findings from each question, including where similarities or differences emerged when doing sub-group analysis.

4.2.1. What Palliative Care means to participants

When asked what Palliative Care means to participants, many participants said that Palliative Care is about end of life, having a life-threatening or life-limiting condition, and they saw being told one is going into Palliative Care meaning that they are dying.

“When we know there is no recovery, I think that’s what Palliative Care is.”

However, many said that Palliative Care is not end of life care, that there can be an overlap but that Palliative Care is essentially when someone has a condition that is incurable or not expected to improve, and that this can last from weeks to years, and a few participants said there’s no time limit to this. This was the case across all groups we spoke with, including parents.

“Society gets Palliative (care), and end of life care mixed up.”

This suggests there is no clear understanding of what Palliative Care is and when it starts for people, and participants’ experiences confirm this, with some receiving Palliative Care support much earlier in their journey than others.

“Everyone has a different perception of what it (Palliative Care) is.”

Another participant said,

“I don’t know if I’m on Palliative Care or not at the moment. If I am, no one has told me.”

Participants also noted misconceptions around Palliative Care being more relevant to certain conditions and saying that there is more support from the third sector due to this e.g. for cancer, and they highlighted that public understanding around this needs to be improved. Through participating in these interviews and reading the accompanying information, some participants understood that they are supporting family members through Palliative Care as carers but did not realise this beforehand.

Some explained that starting Palliative Care can be positive as, while it can mean there is no hope towards a cure, it means everyone is focused on quality of life and is on the same page, helping the medical team, the patient and their family to focus their efforts on the patient’s wellbeing and comfort. When discussing Palliative Care, participants explained it is holistic and involves a range of aspects, for example pain management and enabling patients to do activities they wish to, supported by a range of staff and focusing on respecting the patient’s wishes and needs. Some discussed Palliative Care as being better than general care.

4.2.2. The benefits of Palliative Care

When asked about the benefits of Palliative Care, many participants discussed the importance of knowing that the person requiring or receiving Palliative Care was being cared for and that their needs were being met. This was support both in relation to the person receiving Palliative Care and their family, with the family knowing they had someone to turn to and a support network.

“It (Palliative Care) provides support at a very emotional, stressful and scary time in your life.”

Participants explained that Palliative Care supports the patient through providing medication and symptom management, while also keeping family members informed and involved in discussions around the patient’s care and what to expect. This helps to reduce the stress and emotional worry of family and friends for their loved one.

“The Doctor got down on his knees and spoke face to face with my husband and that meant a lot to me and to him.”

4.2.3. Palliative Care timing and scope

When participants were asked their thoughts about the fact that Palliative Care is not just for people who are dying, many felt that individualised Palliative Care should be offered early on in their patients journey or from diagnosis, not just at the end of life stage, and for as long as required. Some said this would help the participant remain well for longer, while also helping the patient and their family plan and make informed decisions. Similarly, participants noted the importance of building trusting relationships with patients and their families early on.

In terms of timing around general Palliative Care specifically, many participants felt that it should be offered as early as possible and from the time of diagnosis, and it should be person-centred and holistic as every situation is different.

“Each person should be treated as an individual; it depends on the patient as you can’t treat them all the same.”

Some participants said that general Palliative Care should be offered once medical professionals within the health and care system have decided on the diagnosis. Another participant highlighted that the offer of general Palliative Care needed to be an ongoing conversation and it should run alongside treatment.

In terms of timing around specialist Palliative Care, participants said similarly that early intervention is important at this stage and that it should be offered as soon as the patient’s health has started to decline. This would support early building of relationships and help the patient and their family navigate options of care and transition, adopting a person-centred approach and effective communication, potentially before the patient deteriorates. Other participants said that access to the right care at the right time is important, as this will differ for each individual.

“Everything is done by timetables, which is not good. It doesn’t take into account the individual.”

Some participants also discussed that support is also needed once a family member has died, saying,

“as soon as someone passes on the discussion stops.”

However, most participants were unaware that Palliative Care could be provided early on. One participant was unsure of what term was used when a patient has a serious illness which is not terminal. Many participants also believed that staff are also unclear of the meaning of Palliative Care and that they can find it difficult to recognise and discuss when Palliative Care is needed.

Some participants noted that people’s preferences around Palliative Care may differ, and it is important to tailor the type of care offered, as well as when it is offered and how it is discussed, to the individual and to respect their preferences.

Some participants said they would like a single point of contact throughout Palliative Care, such as a Palliative Care nurse. Some participants also commented that further support, such as financial and emotional support, are also important as well.

Many participants discussed positive experiences, highlighting the importance of being treated as an individual, with dignity, respect and humour, as well as of offering holistic therapies, such as art therapy or specialist equipment being fitted at home.

Several participants discussed negative experiences, such as being unaware of available support leading to suffering, having to investigate everything themselves, or having anxiety due to their role as a carer supporting a family member with their Palliative Care needs.

Access to information was an issue mentioned by some participants, mentioning that information about Palliative Care and support was not available in their experience and they had to undertake their own research. Another participant commented that hard copy leaflets are no longer available following the pandemic, with another two participants noting that it would be beneficial to have more physical information on the next stages of treatment, what the care will be like and what is available. Some participants noted that there can be issues accessing information online, particularly for older people and that it can be difficult to know what to look for online if there isn’t an awareness of what’s available (e.g. Facebook support groups) and that there should be more promotion of end of life websites.

Some participants felt that the main carer/family member for the patient should receive an initial explanation and be kept informed throughout. Another comment from a participant focused around feeling more informed due to their Palliative Care experience before the point of crisis and how they would now find it less scary if a hospice stay were required.

One participant in a rural and island setting said that there can be limited choice of alternative clinicians, and another felt that the care on offer was down to *“postcode lottery,”* with no Palliative Care available in their area.

4.2.4. Specialist Palliative Care

When asked about their understanding of the difference between general Palliative Care and specialist Palliative Care (descriptions of both are outlined in [Appendix 2](#)), many of the participants were able to differentiate between general and specialist care in their, or their families, experience. They noted that when going from general to specialist Palliative Care, the location of care and the providers of care changed; general Palliative Care was often provided at home by family members or carers with support from their GP or community nurse, and specialist Palliative Care was often provided by more specialised staff and in a more medical setting such as a hospital, hospice or in some cases at home, but using specialist equipment and condition-specific consultants and nurses. A participant said,

“A specialist to me is someone who excels in what they do.”

On the other hand, some participants said that there needs to be more public understanding of the differences between general Palliative Care and specialist Palliative Care.

“I think sometimes some parents need to realise that their child is within the Palliative Care.”

A number of participants were unaware of this distinction and the definitions of the two forms of Palliative Care, with one participant explaining that they thought,

“Palliative Care was Palliative Care.”

The participants also highlighted that at the time Palliative Care is needed, the language used in these definitions needs to support clear communication to families and carers, as it can be easily confused in amongst other information. A participant said,

“I think people need to be told about these differences, that’s if people are able to understand that is.”

When discussing specialist Palliative Care with a parent, they highlighted its importance, saying that,

“given the gravity of a child dying, I think it needs specialist Palliative Care because it is too much of a risk to rely on general care and people who may not fully understand. It would be almost unjust and not right to not give it its specialist place.”

4.2.5. Raising awareness and promoting better understanding of Palliative Care early on

When participants were asked how they think health and social care services could raise awareness and promote a better understanding of Palliative Care early on in someone’s illness many participants discussed the importance of information around Palliative Care. Most

participants felt that this information should be readily available to family and patients at the point of diagnosis and as early on as possible, with several participants discussing their challenges around obtaining information, leading to a delay in accessing appropriate support and lack of involvement for some.

There were different views on who should be responsible for raising awareness of Palliative Care, for example whether this should be with the clinicians or there should be guidelines on when Palliative Care conversations should begin. Participants said that this information should be simple and practical, presented in a positive way on diagnosis or as early as possible. Information should recognise sensitivities and a range of aspects, for example there should be information relevant to a range of conditions, there should be information appropriate to all cultures, as well as different locations across the country.

"It is important to receive information in a caring and compassionate way. A specialist trained Macmillan nurse would deliver information in a caring and compassionate and in a much gentler way which may not always be the case with a GP."

Another participant said,

"depending on your faith, for example, if you come from a different faith group, they deal with death in a very different way so what might be appropriate to be said to me, might not be appropriate to be said to someone with a different belief or faith. It needs to be delivered in an appropriate way."

Information should signpost to relevant resources, such as third sector or a key contact. Some participants mentioned that signposting may be challenging in rural areas due to awareness of what may be available.

Participants discussed the need to have information in different formats, e.g. leaflets, posters and online, and suggestions of where this information should be available included:

- TV and Radio, newspapers and flyers, to target a specific range of ages
- In GP surgeries and hospital clinic areas
- General promotion via social media and specific promotion via social media for young people e.g. social media videos
- Adverts about death and a Palliative Care support system
- Promoted in hospitals through frontline staff, filtering down to GPs
- Upbeat, attractive literature
- Talks with community groups and lunch clubs
- Information for retirees
- Information to be added to school curriculum
- Accessible literature to be available everywhere, not only via social media.

Beyond public understanding, participants also discussed staff understanding of Palliative Care, saying they felt that frontline staff often had different levels of knowledge and that all staff involved in the Palliative Care journey, in both health and social care, should be better informed or receive good quality, visual based training with simple, practical language. Some participants felt there was a need to simplify communication and eliminate jargon, particularly when in hospital.

4.2.6. Staff involvement in Palliative Care

When asked about who should provide Palliative Care, many mentioned GPs, nurses, hospital staff and specialist clinicians but many wanted this to be extended to include non-healthcare roles as well. Many participants stated that ‘anyone’ involved in providing support in the Palliative Care context should be included, emphasising the importance of a holistic approach, and possibly including social care, mental health support, voluntary organisations and private healthcare. Some participants highlighted that support may differ depending on the patients’ needs so it is important to have further specific roles involved, such as physiotherapists and occupational therapists.

When discussing the involvement of a range of staff roles, participants highlighted the importance of information-sharing and communication, to ensure a coordinated and joined-up approach, with clarity around roles and continuity of care.

4.2.7. Providing Palliative Care during other treatment and care

When asked about the best way to provide other treatment and care alongside Palliative, participants discussed the need to involve Palliative Care providers from all sectors in the communication process. This was seen as the key to good Palliative Care delivery, with the patient and their family and carers having a voice and being listened to. Some participants emphasised the need for a person-centred approach.

Several participants said that having a professional lead or coordinator ensuring effective communication is essential for the Palliative Care team to work well together. Views varied on who should be responsible for coordinating Palliative Care teams. Some felt a lead professional (such as a GP) might be better equipped for this role, though some identified reasons why GPs are not suited for this role, for example due to other responsibilities and difficulty in contacting them at short notice.

Of the roles mentioned in the above context and beyond, occupational therapy and physiotherapy featured prominently. One participant highlighted how their occupational therapist *“managed 70% of their care”* for them. Where physiotherapy and occupational therapists are included in the answers this most often relates to them providing the right physical aids to patients, for example, hospital equipment (beds, commodes), wheelchairs, walking aids and ramps.

4.2.8. Ensuring that Palliative Care is provided in the right way for everyone

When asked how to ensure that Palliative Care is provided in the right way for everyone, no matter what their health condition or background, many participants discussed the importance of communication and having information available, with one participant stating they *“Shouldn’t have to fight for things.”* When speaking to parents, participants said they need to be *“listened to, respected more and honesty”* with professionals being *“open and upfront when dealing with parents.”* Recognising that people’s needs and preferences are different highlighted the importance of early discussions with patients and including family to share information about support and how to access it, and what they can do should a crisis arise. Participants also discussed the need for more specialised training for nursing staff so they can provide specialist support. Participants thought that this often does not happen due to lack of funding.

Other aspects discussed were challenges in accessing support when it’s not available locally, lack of continuity in support between boards for example, with a participant saying that support should be consistent,

“from down the Borders right up to Orkney” and *“little things make a massive difference to families and in the grand scheme of things these sorts of things wouldn’t cost much.”*

4.2.9. The value of Palliative Care

When participants were asked to discuss what they value most about Palliative Care based on their experiences, the majority were very appreciative of the care they or their family members have received. Many participants felt that healthcare professionals at all levels were kind, caring and helped both patients and family members enormously with end of life care, removing the burden of care from the family. Knowing that the right people were doing the job was important to some, as well as developing relationships, valuing the dignity and attention paid by staff, knowing that people cared. Some mentioned it was important to be able to access services according to their preferences, e.g. face to face. Some participants mentioned accessing different support services, for example a day service and holistic therapies, and the support they received from carers when they were struggling, one mentioning carers attending their parents’ funerals. One patient found having a therapy dog on the wards to be particularly therapeutic.

Many participants explained they valued the relationships fostered and the staff’s non-judgemental, understanding approach, emphasising the need for cheerful and pleasant staff whilst offering a personal touch and building a rapport with patients and families alike, with *“all the small things adding up,”* such as being offered a cup of tea. A participant said,

“She loved the nurses and they seemed to adore her.”

The value of communication was also discussed, for example timely and effective communication between staff, and clear, thorough communication throughout with patients, including signposting to further help and support e.g. advocacy, third sector.

Participants also discussed the value of an environment where people feel safe, comfortable and can trust everyone. Some participants said that a relaxed, non-clinical environment, that is accessible can make it comfortable for all involved, though there were different views on whether hospitals or hospices, for example, could best support such an environment. Several participants also discussed care at home, for example having access to pain relief or specialist equipment at home, giving peace of mind to family. It was acknowledged that this may depend on the patient's needs, for example one participant discussed being placed in a care home with older residents as difficult.

4.2.10 Areas for improvement in Palliative Care

When asked for suggestions on how Palliative Care providers could improve or do something differently to improve the service for everyone, one area for improvement was around supporting improved person-centredness and communication. Participants noted the importance of more early and meaningful conversations with patients and their families, potentially in purpose-built rooms for difficult discussions of this nature.

"I think if it was explained in a bit more detail that would have taken away some of the shock and stress of seeing our family member like that and not being able to communicate with them."

A few participants said they would like continuity in staff to form relationships and understanding and improve communication between staff. Two participants suggested having a ***"named person"*** for support and co-ordination.

"Having a 'go-to' person or co-ordinator for care."

In terms of the information itself, a few participants felt that there could be an improvement on information provided, with it being readily available to all and up to date, with better explanations around what is going to happen and what people might experience at all stages. This should also include information on financial implications and costs, and signpost to other forms of support.

Suggestions from participants to improve information and coordination included:

- Having a dedicated professional to speak to the patient and family offering information around options for care and support.
- Ensuring all information is communicated between all involved in an honest, realistic, time-appropriate and sensitive manner.
- Discussing and being informed about next steps before crisis point is reached.
- Discussing final wishes with a clinician and informing the family.

Improvements in terms of support were also discussed by participants, such as bereavement support, early discussions about power of attorney and guardianship, peer support and befrienders to combat loneliness. Participants discussed lack of support and resources and

coordination between services around care at home, as well as the need for more staff training, for example on how to have difficult conversations and empathise with patients.

“Please bear in mind that ‘Hospital at Home’ is not suitable for everyone, especially when it involves family members lacking formal medical training.”

Another participant said,

“More awareness of paediatric Palliative Care, even among NHS staff not everyone is aware of what it means. They should also know who to refer to.”

The need to have a standardised pathway comprising of consistent, accessible and local Palliative Care services across Scotland for everyone was also mentioned, especially for those from rural and island communities.

“Scottish Government always create models based on cities for care, but they do not work in rural settings – there needs to be two models of care. Remote and rural model needs more money – as this involves more travel, money, time.”

Another participant said,

“Having access locally to Palliative Care specialists, for example a specialist doctor for managing pain, would be good.”

Some parents also discussed the need for improvement around the transition between child and adult Palliative Care, one saying,

“it becomes a much bigger beast... it doesn’t get any easier, if anything it gets harder but when you move from paediatrics to adult (services) you fall off a cliff face.”

4.2.11. Areas for improvement for children and young people, and families to access Palliative Care early on

When asked for suggestions on how to support families to access Palliative Care earlier in their child’s life, views differed as participants had different experiences of Palliative Care, some positive and some not so. Some discussed positive relationships with clinicians and receiving appropriate support, while others said they received no support and felt they had been dismissed. Another participant was not aware that their child was receiving specialist Palliative Care. Some highlighted that a more person-centred approach is needed, being aware of everyone’s individual and personal views, as information on dying could be offered too early for some. Participants also discussed the importance of staff having a non-judgemental, empathic and compassionate approach towards all.

Suggestions for improvement included:

- Ensuring Palliative Care is offered at the point of diagnosis, including signposting to local support.

- Patients and family having the ability to self-refer to Palliative Care and to know how to find out what support is available.
- Having access to emotional support and peer support for family.
- Having a much more holistic approach, ensuring that families are listened to.
- Improved communication between staff.
- Support for families to understand general and specialist Palliative Care and their distinction, as well as things like what a hospice is.
- Having one person take the lead and coordinate care across teams, which should also be the main decision-maker.

“If there was funding for someone to take the lead and co-ordinate all the people involved in providing care and social support, then that would be amazing.”

Section 5: Conclusions

This section of the report brings together the main conclusions drawn from the findings of this Gathering Views exercise. The findings are not ranked in order, they are numbered for ease of reference.

5.1 The benefits of Palliative Care and what it means to participants

Participants emphasised that this type of care ensures the needs of the patient are met and provides a support network for both the patient and their family. They also noted that Palliative Care aids in medication and symptom management, and keeps the family informed about the patient's condition. This involvement helps alleviate the stress and emotional worry of their family and friends, knowing their loved one is well cared for.

Participants had diverse interpretations of Palliative Care. Some viewed it as end of life care or for life-threatening conditions, while others saw it as care for incurable conditions without a specific time limit. There was general agreement on the ambiguity about when to start Palliative Care, and experiences varied among participants. Misunderstandings, such as Palliative Care being more applicable to conditions like cancer, were observed and the need for better public understanding was emphasised. Some participants realised they were providing Palliative Care as care givers without prior knowledge.

The shift to Palliative Care was seen positively by some, focusing on the patient's quality of life and comfort despite the lack of a cure. Palliative Care was described as comprehensive, covering aspects like pain management and facilitating patient activities, supported by various staff and respecting the patient's desires and needs. Some participants deemed Palliative Care to be better than general care.

5.2 Palliative Care timing and scope

Participants advocated for early introduction of Palliative Care, ideally from the time of diagnosis, to help patients stay well longer, aid in planning and facilitate informed decision-making. They emphasised the importance of establishing trusting relationships with patients and their families early on, and tailoring care to the individual's preferences. They also highlighted the need for ongoing support, even after a patient's death. However, many participants were unaware that Palliative Care could be provided early on and felt that medical staff often struggle to recognise when it's needed and discuss it appropriately.

The preference for a single point of contact, such as a Palliative Care nurse, was expressed. Participants also discussed the need for additional support, including financial and emotional assistance. While some shared positive experiences, others reported negative ones, such as a lack of awareness of available support, having to

conduct their own research, and anxiety due to their role as a carer. Issues with accessing information about Palliative Care, particularly online, were noted and more promotion of end of life websites was suggested. Limited choices of clinicians and a “postcode lottery” affecting the availability of Palliative Care were mentioned, particularly by participants in rural and island settings.

5.3 Specialist Palliative Care

Participants discussed the differences between general and specialist Palliative Care. General care, often provided at home by family or carers with GP or community nurse support, is contrasted with specialist care, which involves specialised staff and equipment in a medical setting or at home. Some participants expressed a need for greater public understanding of these differences, as many people are unaware of this distinction. They stressed the importance of clear communication when Palliative Care is needed, as the language used can be confusing. The significance of specialist Palliative Care was particularly prevalent in discussions with parents.

5.4 Raising awareness and promoting better understanding of Palliative Care early on

Participants discussed the importance of early and accessible information about Palliative Care for patients and their families. They identified challenges in obtaining this information, leading to delays in accessing necessary support. Opinions varied on who should raise Palliative Care awareness, with suggestions ranging from clinicians to guidelines for initiating conversations. The consensus was that the information should be simple, practical, positive and provided as early as possible. It should cater to different sensitivities, conditions, cultures, and locations and guide individuals to relevant resources.

However, participants acknowledged the difficulty of signposting in rural areas due to limited service awareness. Various formats and platforms were suggested for information dissemination, including leaflets, posters, online platforms, TV, radio, newspapers, GP surgeries, hospital clinics, social media, community groups and school curriculums. In addition to public understanding, the need for frontline health and social care staff to have a thorough understanding of Palliative Care was stressed. Participants suggested visual based training with simple, practical language and the elimination of jargon to simplify communication.

5.5 Staff involvement and providing Palliative Care during other treatment and care

Participants discussed that the provision of care should not be limited to healthcare professionals like GPs, nurses and specialist clinicians. They advocated for a holistic approach, involving non-healthcare roles, potentially including social care, mental health support, voluntary organisations and the private sector. They emphasised that the support provided should be tailored to the patients’ needs, possibly involving specific roles like physiotherapists and occupational therapists. Participants also stressed the importance of information-sharing and good communication among all

involved, to ensure a coordinated approach, clear understanding of roles and continuity of care.

Participants discussed best practices for delivering Palliative Care, highlighting the importance of involving Palliative Care providers from all sectors in the communication process, the need for the patient and their family to have a voice and be listened to, emphasising a person-centred approach.

The necessity of having a professional lead or coordinator to ensure effective communication within the Palliative Care team was highlighted as were differing views on who should coordinate Palliative Care teams, with some suggesting a GP, but others pointing out potential issues with this, such as other responsibilities and availability. The significant roles of occupational therapy and physiotherapy in Palliative Care were discussed, with therapists often providing essential physical aids to patients.

5.6 The value of Palliative Care and ensuring it is provided in the right way for everyone

Participants highlighted the importance of fostering relationships, the importance of a non-judgemental approach of staff, and the value of small gestures. Effective and timely communication between staff and patients was seen as crucial. The environment was also a key topic, with participants preferring a safe, comfortable and trustworthy space although opinions varied on whether hospitals or hospices could best provide such an environment. The possibility of care at home, including access to pain relief or specialist equipment, was discussed, acknowledging that patient needs may dictate the best setting.

Discussion took place around the provision of Palliative Care and the challenges faced, including the importance of communication and availability of information for everyone, regardless of their health condition or background. The need for patients to be listened to, respected, and dealt with honestly by professionals along with the importance of early discussions with patients and their families to share information about support, how to access it and what to do in a crisis.

Participants noted a need for specialised training for nursing staff to provide specialist support, which is often hindered by lack of funding. Challenges in accessing support when it's not available locally and lack of continuity in support between boards was also highlighted along with the need for consistent support across regions throughout Scotland.

5.7 Areas for improvement in Palliative Care

Several key areas for improvement were identified by participants:

1. **Person-centeredness and communication:** Participants emphasised the need for early, meaningful conversations with patients and their families, having a named

person for support and coordination, and continuity in staff to improve relationships and communication.

2. **Information provision:** Participants felt that information should be readily available, up-to-date and include clarity on what Palliative Care is, with clear explanations of what to expect at all stages. This should also cover financial implications, costs and other forms of support.
3. **Improvements to support and training:** Suggestions included bereavement support, early discussions about power of attorney and guardianship, peer support and befrienders to combat loneliness. There was also a call for more staff training, particularly on how to have difficult conversations and show empathy.
4. **Standardised pathway:** Participants highlighted the need for a standardised pathway of consistent, accessible and local Palliative Care services across Scotland, especially for those from rural and island communities.
5. **Transition between child and adult Palliative Care:** Some parents discussed the need for improvements in the transition between child and adult Palliative Care.

Section 6: Next steps and acknowledgements

- 6.1 This report has been shared with the Scottish Government. The findings will be used to help inform the development and implementation of a new Palliative Care strategy for Scotland in 2024.
- 6.2 Healthcare Improvement Scotland will liaise with the Scottish Government to provide feedback to participants about how the views expressed in this report have been used.
- 6.3 Healthcare Improvement Scotland will liaise with relevant stakeholders to collect information around the impact of these findings and recommendations 6, 12 and 18 months after this report's publication. A summary of this information on impact will be posted on our website.
- 6.4 We will use the learning and experience of this exercise including the equality monitoring information within our work to inform future methods of Gathering Views.
- 6.5 We thank everyone who took part and shared their experiences, thoughts, insights, comments and suggestions. We are incredibly grateful to the organisations who supported us to link with groups and individuals and for the time they gave us throughout the engagement phase. A special thank you goes to Children's Hospices Across Scotland (CHAS), Carers Scotland, The Prince & Princess of Wales Hospice, Children with Exceptional Healthcare Needs (CEN) and Paediatric End of Life Care Network (PELiCaN).

Section 7: Appendices

Appendix 1 – The questions used in the Gathering Views

Gathering Views – Palliative Care Questions

1. What does Palliative Care mean to you?

(Prompt - how would you describe it to friends and family?)

2. What would you say are the benefits of Palliative Care?

(Prompt - how can Palliative Care help people, their families and friends?)

3. People can receive Palliative Care early on in their illness when their health is getting worse with several health problems or a serious illness. It's not just for people who are dying. What are your thoughts on this?

4. Can you explain what your understanding is of the difference between general Palliative Care and specialist Palliative Care?

(Refer to Palliative and end of life care – an overview)

5. How do you think the health and social care services could raise awareness and promote a better understanding of Palliative Care early on in someone's illness?

6. Who should offer Palliative Care? GP, nurses, specialist doctor, hospital staff, other?

7. Palliative Care can be provided by many different professionals (mentioned above), at the same time as other treatment and care. Any suggestions on good ways of doing this?

8. In terms of timing, when would it be best to offer people general Palliative Care?

9. When would it be best to offer people specialist Palliative Care?

(Prompt - how and when should this be offered to people whose health is getting worse?)

10. How can we make sure Palliative Care is offered and provided in the right way for everyone, no matter what their health condition or background?

11. Based on your experiences as a patient or family or carer, what do / would you value most about Palliative Care (at all stages of illness and including general Palliative Care and specialist Palliative Care)?

12. What could Palliative Care providers improve on or do differently to improve Palliative Care (general and specialist) for everyone?

Appendix 2 – Materials circulated to participants before the Gathering Views discussions

Participant Information Sheet Gathering Views – Palliative Care

Background

Scottish Government are looking for feedback through a gathering views exercise to complement their own research in support of the development of a new Palliative Care strategy in 2024. The strategy will have two high level aims;

1. Everyone in Scotland receives well-coordinated, timely and high-quality Palliative Care, care around death and bereavement support based on their needs and preferences, including support for families and carers.
2. Scotland is a place where people and communities can come together to support each other, take action and talk openly about planning ahead, serious illness, dying, death and bereavement.

Gathering Views

[Healthcare Improvement Scotland](#) (HIS) has been asked to conduct a [Gathering Views](#) exercise to gather feedback to help inform the development of the strategy and wish to speak to a range of people in terms of age, gender, ethnicity and where people live. Your views are as important to us as everyone else's, so we want to speak with you.

The conversation

You will be invited to participate in a group or individual discussion with an engagement officer from Healthcare Improvement Scotland. The conversation can be face to face, over the telephone or through an online platform such as Zoom or MS Teams. We will ask you some questions that will be helpful to Scottish Government in developing the strategy. We will share the planned questions with you beforehand so that you have time to digest the questions and consider your responses.

During the conversation, we will be taking notes. Your responses will be analysed and captured in a report, which will be shared with the Scottish Government. Quotes may be used to illustrate the main things that we've talked about. Quotes used will not contain the individual's name or job title, however, they may be associated with a particular group. Text may be edited to enable use in a variety of formats.

Do I need to take part?

Taking part is completely voluntary but we hope you will take the time to do so. This is a way of working with members of the public to help inform decisions about how care is provided – it really will make a difference to how we aim to deliver health and social care services in Scotland.

Even if you decide to take part, you can change your mind at any time without giving a reason. When talking about your experiences or when thinking about the interview afterwards, please tell us if you do not want us to include certain information.

Equality Monitoring

Equality monitoring information will be captured, including data relating to sex, sexual orientation, disability, age, religion and ethnic group. Providing this information is extremely helpful to ensure we gather feedback from people from a range of backgrounds but is entirely optional.

Data Protection

Healthcare Improvement Scotland comply with the Data Protection Act 2018 and GDPR 2018 when handling your personal information.

Any personal information about you will be treated as private and confidential and any identifying information you provide will be made anonymous in any published reports. Your information will only be used in this Gathering Views exercise and the resulting report. Your details will not be used for general marketing activities, nor shared with anyone outside Healthcare Improvement Scotland unless we have your permission or are required to do so by law.

All personal information, written notes and related information, including this consent form, will be stored safely and in compliance with the Data Protection Act 2018. If you wish to see a copy of the notes taken during the discussion, please submit a sharing request to his.informationgovernance@nhs.scot. Please note that these notes will not be shared with you as a matter of course.

This discussion may be held over an online platform. Although we do not plan to gather personal information from participants, if you register to take part you must be aware that some companies transfer data to servers based in the USA and that any personal information you choose to share will be transferred to a country that does not provide the same data protection safeguards as the UK and EU.

For our full privacy policy, please go to www.hisengage.scot/privacy.

For more information about how we process your personal data, or if you have a concern, contact our Data Protection Officer at his.informationgovernance@nhs.scot. Alternatively, you have the right to complain to the ICO <https://ico.org.uk/concerns/>.

Get in touch

If you have any questions, please contact Kevin Ward, Area Teams Manager (Community Engagement – South East Region), Healthcare Improvement Scotland by telephone on 07812 379885 or by email kevin.ward1@nhs.scot.

Palliative and end of life care – an overview

Palliative Care is provided by health and social care professionals to people of all ages living and dying with any advanced or progressive health condition. Palliative Care focuses on quality of life for the

person, their family and others who are close to them at every stage of their illness journey from diagnosis through death and bereavement.

Palliative Care prevents and relieves suffering through the early identification, correct assessment and holistic management of pain, other symptoms and wider aspects of care, including mental health, social and spiritual problems.

Underpinning this approach is person-centred care, based on what matters most to the person as well as their families and carers. Palliative Care adds value by focusing on the individual and their situation, and helping people clarify their priorities for treatment and care. This applies equally whether the person is an adult or a child or young person.

General Palliative Care is provided by clinicians and other staff across health and social care (including GP's) for the people they look after with Palliative Care needs, alongside giving other treatments and care. It includes care around death for those who are dying at home, in care homes or in hospitals.

Specialist Palliative Care is provided by specially trained, multi-professional Palliative Care teams for people living in the community and in care homes, and patients in hospitals and in hospices. Specialist Palliative Care has a particular role in providing support, advice and education to the rest of the health and care system.

Participant Consent Form

Gathering Views – Palliative Care

By ticking the options below you are giving your consent to take part in a Gathering Views discussion on Palliative Care between 8th January and 29th February 2024.

- 1 I have read and understood the information sheet. ☐
- 2 I have been able to ask questions about the project and am happy with the answers. ☐
- 3 I understand that I can choose whether or not I will take part in this discussion and that I can choose not to answer any question or stop taking part at any time, without having to give a reason. ☐
- 4 I agree that what I say can be used in reports and publications about this work (including the new Scottish Government Palliative Care strategy) and know that my name or any information that can identify me or another individual will not be used. ☐
- 5 I give permission for Healthcare Improvement Scotland and Scottish Government to hold relevant personal data about me and I understand that my comments are anonymous and confidential.
- 6 I agree to take part in this project. ☐

Name	
Preferred contact details e.g. email or phone number	
Local Authority area	
Signature	
Date	

Appendix 3 – Equality Monitoring form

About this Equality Monitoring form

We are capturing equality monitoring information, including data relating to sex, sexual orientation, disability, age, religion and ethnic group to ensure we gather feedback from people from a range of backgrounds and contexts. We want to understand how representative the people we talk to are. You are not required to answer any questions you do not wish to answer. The information you provide is not linked to your name or any other personal details and will be kept anonymous.

1. What is your sex?

- ☐ Female
- ☐ Male
- ☐ Prefer not to say

2. Do you consider yourself to be a trans person or have a trans history?

Trans is an umbrella term to describe people whose gender does not correspond with the sex they were registered at birth.

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

If you answered yes, please tell us your preferred terms - e.g. non-binary, trans man, trans woman (optional).

3. Which age group do you belong to?

- ☐ Under 16
- ☐ 16-25
- ☐ 26-35
- ☐ 36-45
- ☐ 46-55
- ☐ 56-65
- ☐ 66 and over
- ☐ Prefer not to say

4. If you are under the age of 26, please can you tell us whether you have ever had any experience of being in care? This can include foster care/supported care, kinship care, residential care, looked after at home (supervision order).

- ☐ Yes, I have had experience of being in care
- ☐ No, I have not had experience of being in care
- ☐ Prefer not to say
- ☐ Not applicable

5. Do you consider yourself to be disabled?

(The Equality Act 2010 defines a disability as a physical or mental impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities. Substantial means the effect is more than minor or trivial and long-term means the condition has lasted or is likely to last 12 months or more).

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

If yes, please include any more information you are happy to share:

6. Can you use British Sign Language (BSL)?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

7. Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical/mental ill-health/disability; or
- problems related to old age?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

8. Which of the following best describes your sexual orientation?

- ☐ Bi/Bisexual
- ☐ Gay/Lesbian
- ☐ Heterosexual/straight
- ☐ Prefer not to say
- ☐ Something else. Please write in:

9. How would you describe your religion, religious denomination or belief?

- ☐ Buddhist
- ☐ Christian - Church of Scotland
- ☐ Christian - Roman Catholic
- ☐ Christian - another denomination
- ☐ Hindu
- ☐ Jewish

- ☐ Muslim
- ☐ Sikh
- ☐ Pagan
- ☐ None
- ☐ Prefer not to say
- ☐ Other, please write in:

10. What is your ethnicity?

- ☐ African, African Scottish or African British
- ☐ Arab, Arab Scottish or Arab British
- ☐ Bangladeshi, Bangladeshi Scottish or Bangladeshi British
- ☐ Black, Black Scottish, Black British
- ☐ Caribbean, Caribbean Scottish or Caribbean British
- ☐ Chinese, Chinese Scottish or Chinese British
- ☐ Indian, Indian Scottish or Indian British
- ☐ Mixed or multiple ethnic groups
- ☐ Pakistani, Pakistani Scottish or Pakistani British
- ☐ Roma
- ☐ Showman/Showwoman
- ☐ White Gypsy/Traveller
- ☐ White Irish
- ☐ White British
- ☐ White Polish
- ☐ White Scottish
- ☐ Prefer not to say
- ☐ Other, please write in:

11. Do you usually have enough money each month to pay bills, buy the food, clothing and essentials you need and participate in your community?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

12. Please use this space to tell us anything else you would like us to know about how you identify in relation to any of the above questions.

Appendix 4 – Equality Monitoring Data

Gathering Views Equalities Monitoring Results

Response rate

Providing equality monitoring information is optional, and 30 out of the 42 participants (71%) completed this (N=30).

Equalities monitoring questions, in the form of an online survey, were shared with the participants, either before or during the discussion. We also offered alternative ways to provide this information, via email or through a paper copy.

Participant characteristics (N=30)

- Sex: 25 of the people we engaged with are female and four male.
- Gender reassignment and gender identity: 1 of the 29 participants who answered this question considered themselves to be trans or have a trans history, 27 said they did not and one preferred not to answer.¹⁵
- Sexuality: 29 said they were heterosexual/straight.
- Age: 2 participants were between 26-35, 3 between 36-45, 8 between 46-55, 11 between 56 and 65 and 6 66 years old and over.
- Care experience: None said that they have had any experience of being in care, such as foster care.
- Disability and long-term health conditions: As described in the Equality Act 2010 5 participants said they consider themselves to be disabled or have a long-term health condition and are limited a lot, seven are limited a little and sixteen do not have a disability. 1 preferred not to say.
- Use of BSL: 1 said that they use British Sign Language (BSL).
- Carers: 21 said they look after or support family members.
- Religion and beliefs: 4 participants are Christian Church of Scotland, three are Christian Roman Catholic, five are Christian of another denomination, one is Muslim, two are Pagan, twelve said they have no religion or religious beliefs. 3 preferred not to say.
- Ethnicity: 1 participant is Pakistani, Pakistani Scottish or Pakistani British, twelve are White British and fifteen are White Scottish.
- Deprivation: 21 said they usually have enough money each month for essentials and to participate in their community, five said they don't and four preferred not to say.

¹⁵ Due to the voluntary nature of completing equality monitoring forms, our monitoring may not fully capture all protected characteristics, especially regarding gender identity. Our approach to engaging with trans and non-binary individuals involved outreach through relevant groups for participation.

You can read and download this document from our website.
We are happy to consider requests for other languages or formats.
Please contact our Equality, Inclusion and Human Rights team on 0141 225 6999
or email his.equality@nhs.scot

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