healthwatch
Trafford

Palliative Care Report

March 2026

Contents

Executive Summary

Healthwatch Trafford undertook this project to provide an opportunity to understand how national ambitions and local strategy have translated into lived experience for people receiving palliative care in Trafford, and for the family members and carers who support them.

The project was informed by a review of national and local policy and evidence relating to palliative and end of life care. An online survey was conducted, receiving 26 responses from individuals with experience of palliative care in Trafford. These included people receiving care and family members or carers supporting someone who was receiving or had recently received palliative care.

Overall, many respondents described compassionate and respectful care, particularly in relation to pain and symptom management. District nurses and community-based services were frequently praised for their support.

However, concerns were raised about access to services, coordination between providers, and clarity about who to contact for help. A significant proportion of respondents reported that services did not work well together, highlighting ongoing challenges around communication and joined-up care.

Respondents emphasised that being pain free, treated with dignity, and having fast access to care whenever it is needed were most important to them.

The findings reflect national priorities for person-centred, coordinated care. They give insight into how strategic ambitions are translating into lived experience for people in Trafford, and where further improvement may be needed.

Healthwatch Trafford recommends that:

- A named or single point of contact is introduced for patients receiving palliative care in Trafford, particularly those supported at home, to improve coordination and reduce duplication.
- Communication pathways between community nursing, primary care, hospices and care homes are reviewed to strengthen information sharing and reduce delays.
- A clear and accessible information pack is developed and provided early in the palliative care pathway, outlining available services, how to access support, out-of-hours contacts, and financial or practical assistance.
- Community and night-time palliative care provision is reviewed to ensure timely and equitable access across Trafford, including consideration of workforce capacity.

- Support for carers is strengthened through routine offers of emotional support, clearer information about respite options, and signposting to bereavement services.
- Earlier and more consistent Advance Care Planning conversations are encouraged to ensure patients' documented wishes are shared appropriately across services.

Introduction

Palliative care plays a vital role in supporting people living with life-limiting illness and those important to them. In Trafford, services are delivered across a range of NHS, community, hospice and voluntary sector providers within the wider Greater Manchester health and care system.

Healthwatch Trafford undertook this project as part of its statutory role to represent the views of people using health and social care services, and to influence service improvement. The project seeks to understand the experiences of patients and carers accessing palliative care locally. While national policy sets out clear ambitions for coordinated, person-centred care, it is important to assess how these ambitions translate into practice within Trafford.

This report draws on survey responses from palliative care patients and carers to identify what is working well, where challenges remain, and where improvements are required. The findings are considered in the context of national and local policy frameworks and are intended to inform the development of services and partnerships across Trafford.

Literature Review

What is Palliative Care?

Palliative care is an approach to care that aims to improve the quality of life of people living with a life-limiting illness, as well as their families. It focuses on the prevention and relief of suffering through early identification, assessment and treatment of pain and other physical, psychological and practical needs.

The World Health Organisation defines palliative care as care that 'improves the quality of life of patients and their families facing the problems associated with life-threatening illness'. Palliative care can be provided alongside life-prolonging treatment and may begin at the point of diagnosis.

Palliative care is distinct from end-of-life care. While the two terms are often used interchangeably, end-of-life care refers specifically to care provided in the final months of life, when a person is considered likely to be in the last year of their life. Palliative care, on the other hand, may be provided for many years. This distinction is important, as confusion around terminology can affect whether individuals identify their care as 'palliative' and therefore whether they engage with palliative care services.

National Policy Context

National policy over the past decade has placed emphasis on improving the quality, coordination and person-centred nature of palliative and end-of-life care.

The NHS England Long Term Plan (2019)[1] recognises the importance of personalised care and improved community-based services, including better support for people with complex needs and stronger integration between health and social care providers. It highlights the need for joined-up care and improved support for people to remain at home if that is their preference.

The framework *Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026*,[2] developed by the National Palliative and End of Life Care Partnership, sets out six ambitions for local authorities to work towards:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

While separate from the NHS Long Term Plan (2019), the six ambitions align with the Long Term Plan's commitment to personalised care, strengthened community services and better integration between providers. The ambitions emphasise dignity, equity of access, good communication, coordinated services and support for carers – all themes that are central to evaluating local palliative care provision.

The Care Quality Commission (CQC) also regulates providers of health and social care in England and assesses services against standards including safety, effectiveness, responsiveness and whether care is well-led. Dignity and respect, person-centred care, and safe discharge arrangements are key expectations.

Together, these national frameworks establish clear expectations that palliative care should be person-centred, coordinated across providers, accessible and equitable,

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[1] https://stroke-education.org.uk/wp-content/uploads/NHS-Long-Term-Plan-2019.pdf

[2] https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf

delivered with compassion, and supported by clear communication and provision of information. These standards provide a benchmark against which local experiences of palliative care can be considered.

Local Policy Context

Palliative care in Trafford is delivered through a combination of NHS services, community providers, hospices and voluntary sector organisations operating within the wider Greater Manchester health and care system.

Under the Greater Manchester Integrated Care Partnership, Trafford forms part of an integrated care system designed to improve collaboration between NHS organisations, local authorities and voluntary sector partners. Integrated Care Systems are intended to strengthen joined-up working, reduce fragmentation between services and improve health outcomes.

The Trafford Local Care Organisation plays a key role in delivering community health services, including district nursing and community-based palliative care support. Hospice services and specialist palliative care providers, including charitable organisations, contribute to care provision across Trafford.

As well as locality-level planning, palliative and end-of-life care provision in Trafford is influenced by provider-level strategies across Greater Manchester. Manchester University NHS Foundation Trust (MFT), which offers specialist hospital and community services across the region, follows their *Supportive, Palliative and End of Life Care Strategy 2021-2026*. This strategy is largely based on the *Ambitions for Palliative and End of Life Care* national framework, and sets out priorities for improving coordination, communication, carer support and quality of care across MFT services.[3]

Trafford's locality and Better Care Fund plans seek to prioritise:

- Supporting people to remain at home where possible
- Reducing avoidable hospital admissions
- Improving discharge pathways
- Strengthening collaboration between health and social care
- Supporting carers

These priorities align with national ambitions and wider Greater Manchester provider strategies aimed at delivering coordinated and person-centred palliative care.

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[3] https://democracy.manchester.gov.uk/documents/s53262/Palliative%20and%20End%20of%20Life%20Care.pdf

However, national and regional evidence suggests that variation can exist in access to community nursing, hospice provision and bereavement services. Workforce pressures, communication challenges between organisations and inequalities in access remain recognised issues across England.[4]

For example, a 2017 Macmillan-commissioned YouGov study showed that 64% of cancer patients would prefer to die at home with the right support. However, 2015 ONS data showed that only 30% of cancer patients died at home, with many dying in hospital against their wishes. Furthermore, patients in more deprived areas are more likely to die in hospital than those from the least deprived areas.[5]

Aims

The central aim of the project was to understand people's experiences of palliative care services in Trafford. This included:

- Identifying which services patients and carers are involved with
- Understanding how satisfied people are with the care provided
- Exploring whether patients and carers understand what to expect from palliative care
- Examining whether experiences meet expectations
- Identifying areas for improvement

Methodology

Approach

A mixed methodology was used to understand patient experiences of palliative care in Trafford. The project combined a desk-based review of relevant literature and policy and an online survey. This approach ensures that as well as qualitative data, we also gain insight into the lived experience of participants.

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[4] https://arc-eoe.nihr.ac.uk/sites/default/files/uploads/files/Hospice%20care%20access%20inequalities%20a%20systematic%20review%20and%20narrative%20synthesis_2.pdf and https://publications.parliament.uk/pa/cm5901/cmselect/cmhealth/632/report.html

[5] https://www.macmillan.org.uk/_images/MAC16904-end-of-life-policy-report_tcm9-321025.pdf

Literature Review

A desk-based review of national and local policy documents was conducted to provide context to survey findings, and also identify the ambitions against which local experiences of palliative care should be considered. Key documents reviewed included:

- The NHS Long Term Plan (2019)
- Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026
- Care Quality Commission standards relating to palliative care
- Relevant Trafford and Greater Manchester policy documents

Findings from the survey were compared against national and local ambitions in order to identify strengths and weaknesses of Trafford's palliative care provision.

Survey Design

An online survey was developed to explore:

- Where palliative care is received
- Which services are involved in providing care
- Experiences of access, communication, and coordination
- Whether physical, emotional and practical needs were met
- Awareness of advance care planning
- Areas for improvement
- Areas of good practice

The survey included a mix of closed questions (multiple choice and scaled responses) and open-text questions to allow respondents to describe their experiences in their own words. Demographic questions were included to understand which groups were represented in the responses.

Survey Distribution

The survey was open from 12 October 2025 to 6 January 2026. It was promoted through Healthwatch Trafford networks, local partners, and stakeholder organisations including community services and carer groups. Responses were collected anonymously.

Respondents

A total of 26 responses were received. The majority of respondents were family members or carers of someone receiving, or who had received, palliative care. One respondent reported receiving palliative care themselves.

Although the sample size was modest, responses included detailed qualitative feedback from individuals with direct experience of local services, and is therefore still valuable.

Data Analysis

Quantitative data was analysed using percentages and frequency counts. Qualitative data from open-text responses were reviewed and analysed thematically. Recurring themes were identified, including:

- Access to services
- Coordination between providers
- Communication and information provision
- Emotional and practical support
- Areas for improvement
- Areas of good practice

Where appropriate, anonymised quotes have been included to illustrate key themes.

Limitations

There are several limitations to this project:

- The number of responses was relatively small and may not be representative of all individuals receiving palliative care in Trafford
- Palliative care is a sensitive subject, which can reduce participation
- There may be confusion about the definition of palliative care; some individuals may associate it purely with end-of-life care and therefore not consider the survey to be relevant to them
- Participation was voluntary, meaning responses may reflect individuals with particularly positive or negative experiences
- The survey relied on self-reported experiences, which may be influenced by recall bias
- Palliative care is a broad and complex subject area; this project focused on selected aspects of patient and carer experience and does not represent all areas of local provision

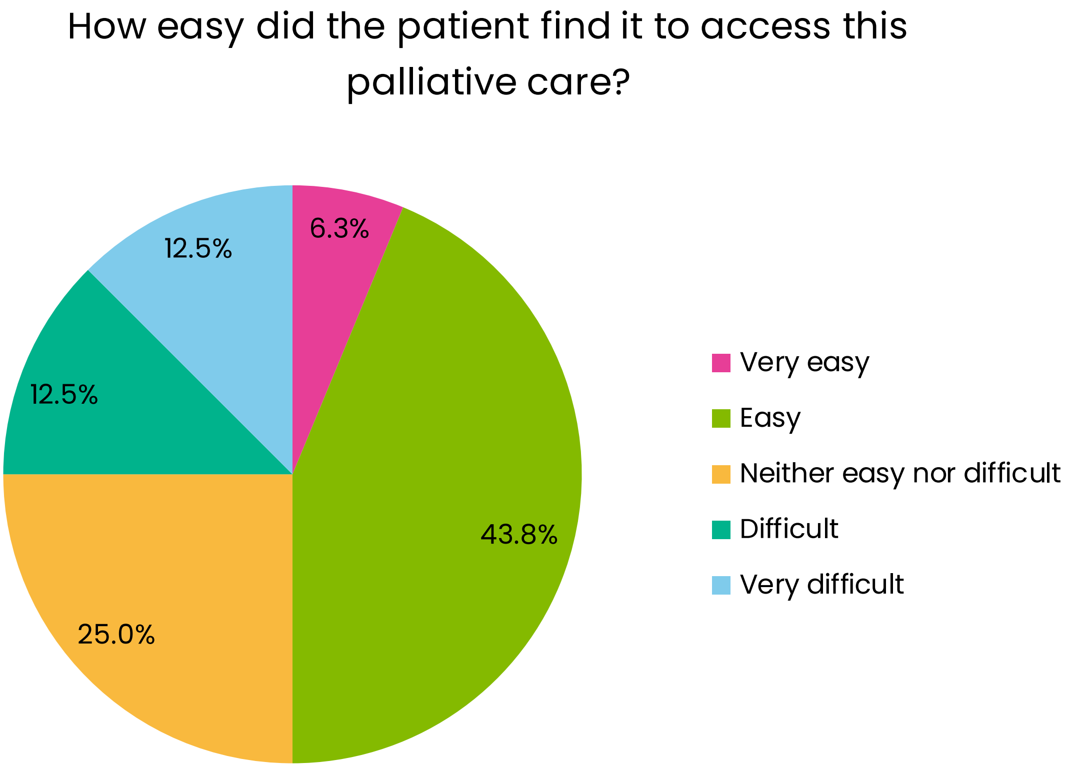
Despite these limitations, the findings provide valuable insight into the palliative care experiences of carers and patients in Trafford.

Findings

A total of 26 responses were received. The majority of respondents were family members or carers of someone receiving, or who had received, palliative care. One respondent reported receiving palliative care themselves. Most respondents were women aged 50 and over. 82% identified as White British, and 9% as Asian/Asian British: Pakistani. Demographic questions were completed by 11 respondents, except for question 19 which had 9 respondents, and therefore do not provide a comprehensive profile of all participants. A full demographic breakdown is provided in Appendix 1.

Respondents were at different stages within the palliative care pathway. While 38% considered the person to be approaching the end of their life, 29% did not and 33% were unsure. This reflects both the diversity of medical conditions treated within palliative care, and potential uncertainty about how 'palliative' and 'end of life' are defined.

Access to Palliative Care



Half of respondents (50%) reported that accessing palliative care was easy. However, a quarter (25%) felt it was neither easy nor difficult, and a further 25% reported that access had been difficult. Open-text responses highlighted:

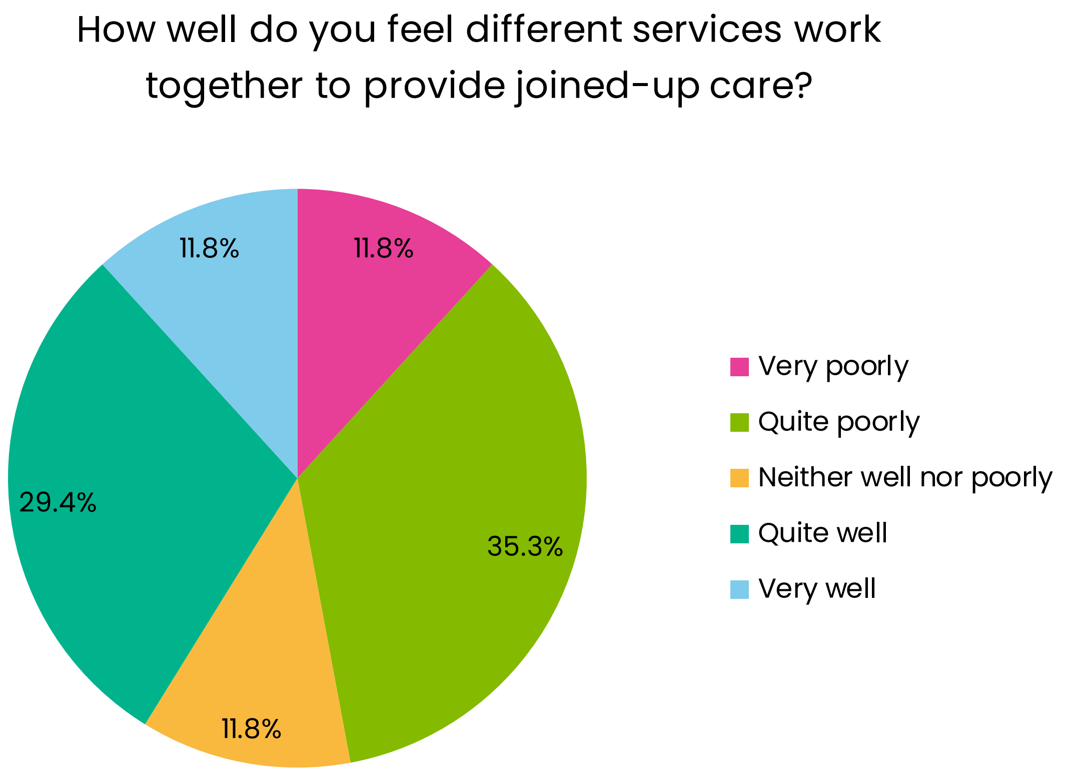
- Delays in district nurse visits
- Difficulties accessing night-time support

- Uncertainty about who to contact
- Concerns regarding availability of Marie Curie services

Care was delivered by a range of providers. 44% of respondents said that family and friends provided care, 39% NHS community nurses, 22% Macmillan and 17% St Ann's Hospice (now known as Moya Cole Hospice). Respondents also mentioned care and nursing homes, such as Flixton Manor and Faversham House. One mentioned their GP, another said that Arielle Care came to their home to provide care, and another stated that carers came to provide treatment but did not specify where from. This highlights the complexity of the local care landscape and the reliance on informal carers.

While many respondents ultimately received the care they were seeking, some described delays and barriers that increased stress during an already difficult period. These findings suggest variation in how accessible community-based support is perceived to be.

Coordination and Communication Between Services


How well do you feel different services work together to provide joined-up care?

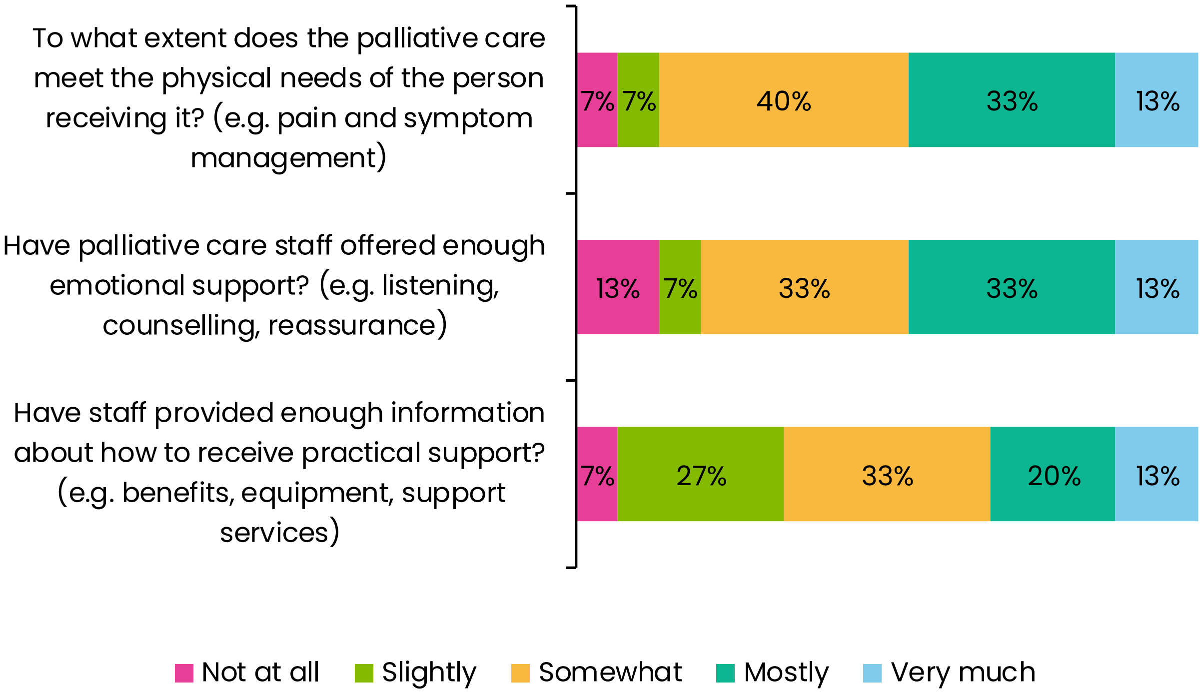
Almost half of respondents (47%) reported that services did not work well together. Only a minority felt that care was consistently well-coordinated. Comments suggested:

- Communication gaps between providers
- Carers needing to chase services
- Repeating information to multiple professionals

- Lack of a single point of contact

Better integration and communication between different service providers should be an area of improvement for Trafford's palliative care offering. Having a named contact or clearer communication pathway would improve coordination. This is a theme which aligns with national and local ambitions for integrated and joined-up care.

Meeting Physical, Emotional and Practical Needs

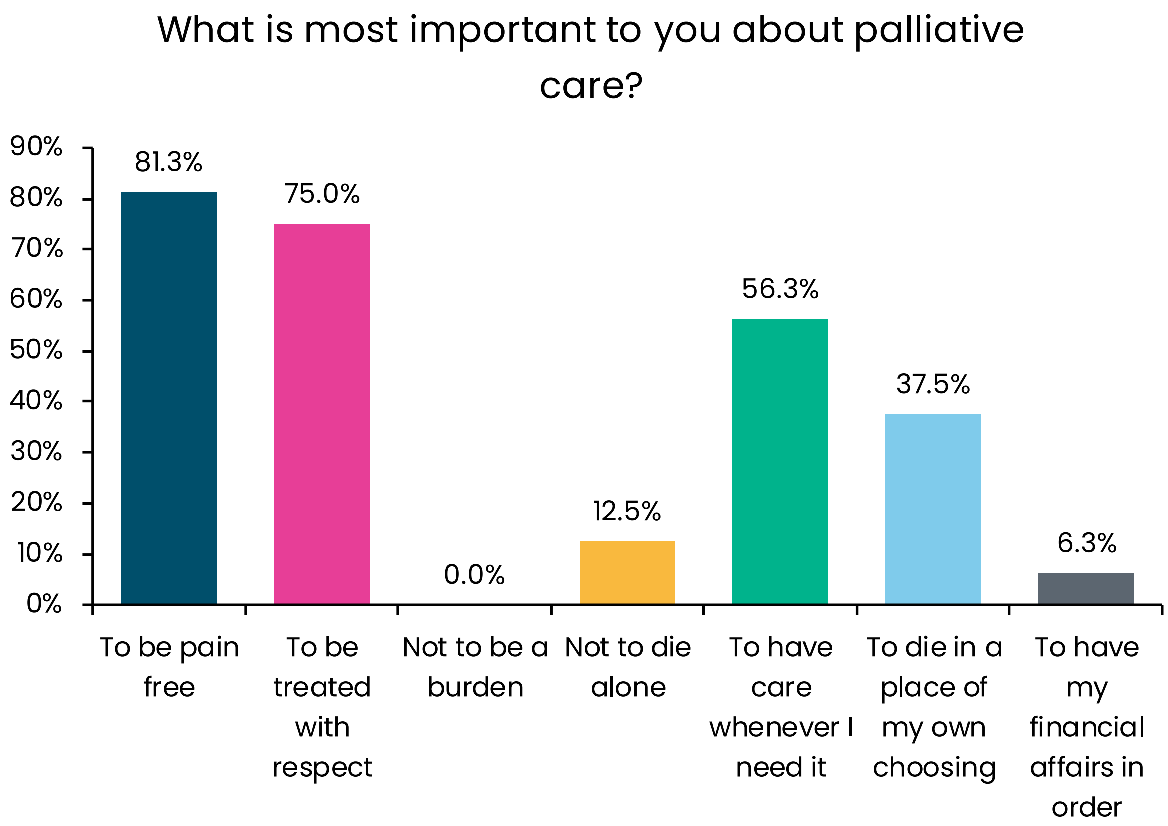


When asked to what extent the physical, emotional and practical needs of the patient were met, 13% of respondents answered 'very much'. When asked to what extent palliative care met the physical needs of the patient, 33% said it 'mostly' did, 40% said it did 'somewhat' and 14% said 'slightly' or 'not at all'.

In terms of emotional support, 33% each said that palliative care staff either 'mostly' or 'somewhat' met the needs of the patient. 7% said that they did 'slightly', and 13% said that they did not offer emotional support at all.

When asked if staff provided enough information about how to receive practical support, only 20% said they 'mostly' did, 33% said they 'somewhat' did, and approximately 34% said that they did only 'slightly' or 'not at all'. These results show that there is room for improvement across each of these three areas, but information about how to receive practical support such as benefits, equipment and support services was particularly lacking.

What Matters Most to People



For survey respondents, the most important two things about palliative care were to be pain free and to be treated with respect, with 81% and 75% choosing these options respectively. 56% chose 'to have care whenever I need it', and 38% highlighted the importance of dying in a place of their own choosing. Only 6% decided that having their financial affairs in order was in the top three most important aspects of palliative care, and nobody selected 'not to be a burden'.

These priorities align closely with the Six Ambitions for Palliative and End of Life Care, particularly in relation to dignity, comfort and coordinated support.

Planning Ahead

Approximately 88% of respondents had an Advance Care Plan, although 24% said that their family or friends were not aware of it. 65%, however, had an Advance Care Plan that their family or friends were aware of.

Every respondent was aware of Power of Attorney, and 65% had used it before.

While awareness of Advance Care Planning was relatively high, the findings suggest that communication and consistent sharing of plans across providers and family members requires strengthening.

Positive Experiences

Many respondents mentioned the high quality of care given to palliative care patients by doctors and nurses, either in their own home or in a nursing home. District nurses in particular are singled out for the level of care they provide, and they are the main source of support for many families with a palliative care patient. One respondent said that they 'would have floundered without the support of the district nurses' as they offered both practical and emotional support. Macmillan nurses are also mentioned as offering useful advice, although one respondent 'really had to push to get to see a Macmillan nurse' and Macmillan nurses do not carry out any practical care. Generally, though, there was praise for Macmillan nurses who were 'great' and 'empathetic'.

A recurring theme from the survey respondents was that, as carers, they can become overwhelmed having to support their terminally ill family members. The care provided by nurses allowed them to have a break from this, which the carers were very grateful for. One respondent describes how they were 'desperate' for help, and carers came in 4 times a day to assist.

Another area of good practice in palliative care was the way in which doctors and nurses listened to family members; one respondent who cared for their non-verbal husband with Alzheimer's said: 'the GP practice and staff on the nursing wing respected my input into his care'. Another respondent also noted how the care home communicated 'excellently' between the family, the doctors and themselves.

These positive examples show that high-quality care is being delivered in Trafford and is valued by those who receive it.

Areas for Improvement

Some respondents requested better access to palliative care services provided at the patient's home. One respondent highlighted the lack of access to Marie Curie services, which they were unable to access but believed would have been 'invaluable, especially for night care so I could get some sleep'. Although Marie Curie offers palliative care services in parts of Greater Manchester, these services are not typically commissioned in Trafford, meaning that Trafford residents do not have the same access to services as those in neighbouring boroughs. One carer said that they would like the person they care for to be visited by a professional to see how the care could be improved. Another point raised was that of bereavement support; one respondent did not complain about the palliative care itself, but rather the lack of support after the patients in question passed away. They described this experience as being akin to 'drowning'. Another respondent also requested that access to physiotherapy for palliative care patients be made easier.

Another issue raised in the responses was that of the quality of care received by the patients. One respondent said that NHS community nurses did not treat her husband with dignity, instead leaving him in a wet bed. The respondent alleged that the 'nurse spent more time talking about her own issues' rather than providing good care to the patient. Management of symptoms such as pain and sickness was also mentioned as being lacking in some cases. One example given was a carer phoning the district nurses several times over the course of a day to request anti-sickness medication be administered to the patient. Despite being told they would be visited by a nurse within the hour, this never happened. One respondent also complained about private care companies in particular, suggesting that their 'management have no interest in the client and what is best for them'. Instead, the respondent believes these private care companies prioritise the business rather than the patient.

Another concern raised by respondents was that of suitable housing for palliative care patients, for example in nursing homes. One respondent said that their husband was supposed to be discharged to a nursing home by a hospital, but he was instead sent to a care home, which was not suitable for him and could not provide the level of medical treatment required. The respondent had to complain several times before he was moved to a nursing care wing which had the correct level of treatment available. The respondent commented that 'his lack of initial care still haunts me'.

Other responses showed a desire for improved communication of what palliative care options are available in Trafford. One respondent said they wanted to be notified of what sort of care is available for them to access. Another respondent also suggested that services would be improved by having one point of contact for palliative care services in Trafford, rather than having to contact each organisation (e.g., Macmillan, district nurses, GPs) separately. In this respondent's experience, each of these organisations 'often seem to say it is the responsibility of one of the other parties', and 'it feels as though you are chasing for support'.

So, while many respondents did have positive experiences of palliative care, experiences did vary and this can be seen particularly in relation to access and coordination of care.

Recommendations

1. Improve Coordination Through a Named Point of Contact

The fourth ambition of the Ambitions for Palliative Care framework is for care to be coordinated. Our survey findings showed that 47% of respondents felt services did not work well together. Carers described needing to chase providers, and they were not always certain about who they should contact for assistance.

Therefore, it is recommended that a named or single point of contact should be introduced for patients receiving palliative care in Trafford, particularly those being supported at home. This will reduce duplication, improve communication between services, and provide reassurance to carers.

This supports Trafford's priority to strengthen collaboration between health and social care and reduce fragmentation between services.

2. Strengthen Communication Between Providers

Also relating to coordination of care, respondents described gaps in communication between community nursing, GPs, hospices and care homes.

Therefore, current communication pathways between community nursing teams, primary care settings, hospices and care homes should be reviewed to identify opportunities to improve information sharing and reduce delays, for example reviewing handover processes.

This aligns with Trafford's priority to improve discharge pathways and strengthen partnership working across providers.

3. Improve Information for Patients and Carers

The first ambition of the Ambitions for Palliative Care framework is for each person to be seen as an individual, and the second ambition calls for fair access to care. Survey feedback indicates that information about financial support, equipment and available services was not always proactively provided.

It is recommended that a clear and accessible information pack is developed for patients and carers outlining:

- Available services
- How to access support
- Out-of-hours contacts

- Financial and practical assistance

This should be provided early in the palliative care pathway.

This supports Trafford's priorities around fair access to care and enabling people to remain at home where possible.

4. Address Inequality in Community and Night-Time Support

The second ambition of the Ambitions for Palliative Care framework is for fair access to care, and the third is to maximise comfort and wellbeing. However, some respondents reported difficulty in accessing district nurses and night-time support, which does not align with these ambitions.

It is recommended that local provision of community and night-time palliative care support is reviewed to ensure a fast response and equitable access across Trafford. This should include consideration of workforce capacity, achievement of national caseload standards for district nursing, and consistent seven-day access to specialist palliative care services, in line with the priorities supported by Trafford ICB.[6]

This recommendation supports Trafford's priorities to reduce avoidable hospital admissions and enable more people to remain at home where possible.

5. Strengthen Support for Carers

The sixth ambition of the Ambitions for Palliative Care framework is for each community to be prepared to help. Carers described emotional strain and limited post-bereavement support.

To address this, it is recommended that carers are routinely offered:

- Emotional support
- Clear information about options to have a break from their caring responsibilities
- Signposting to bereavement services

This aligns with Trafford's priority to support carers.

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[6] https://gmintegratedcare.org.uk/wp-content/uploads/2025/11/20260217-trafford-locality-board.pdf

6. Promote Early and Shared Advance Care Planning

The first ambition of the Ambitions for Palliative Care framework is for every person to be seen as an individual. Although awareness of Advance Care Plans was relatively high, not all respondents reported having shared their plans.

Therefore, it is recommended that earlier and more consistent conversations about Advance Care Planning are encouraged. This should ensure that documented wishes of patients are shared across the relevant providers and with family members if consent is given.

This supports Trafford's ambition for coordinated, person-centred care and improved planning across services.

Conclusion

The survey gives insight into the lived experiences of carers and patients accessing palliative care in Trafford. While many respondents reported compassionate and supportive care, experiences were not consistent across services. Access and coordination were the most significant concerns, particularly in relation to community-based and out-of-hours support. Communication between service providers remains a key area where improvements could reduce stress for carers.

Physical care needs were generally well-met, but awareness of information and practical support were more varied.

Respondents' priorities of being pain free, being treated with dignity, and being cared for in a place of their own choosing closely align with national ambitions for palliative care. Although the number of responses was modest, the themes identified are consistent with national evidence which suggests problems with coordination and pressures on the workforce.

Implementing the recommendations in this report would support progress toward the Six Ambitions for Palliative and End of Life Care within Trafford. It is important to continue to engage with patients and carers to ensure services remain person-centred and responsive to change.

Recent national policy developments also highlight the growing priority placed on improving palliative and end-of-life care. In November 2025, the Minister of State for Care announced that the government is developing a *Palliative Care and End of Life Care Modern Service Framework for England*, planned for publication in Spring 2026. This framework aims to address challenges across the sector, including workforce pressures, variations in commissioning, and gaps in 24/7 provision. The framework will "drive improvements and enable ICBs to address these challenges through the delivery of high-quality, high-value, personalised and equitable care".[7]

The experiences shared by Trafford residents in this report provide valuable insight into how these national ambitions may be realised locally.

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[7] https://questions-statements.parliament.uk/written-statements/detail/2025-11-24/hcws1087

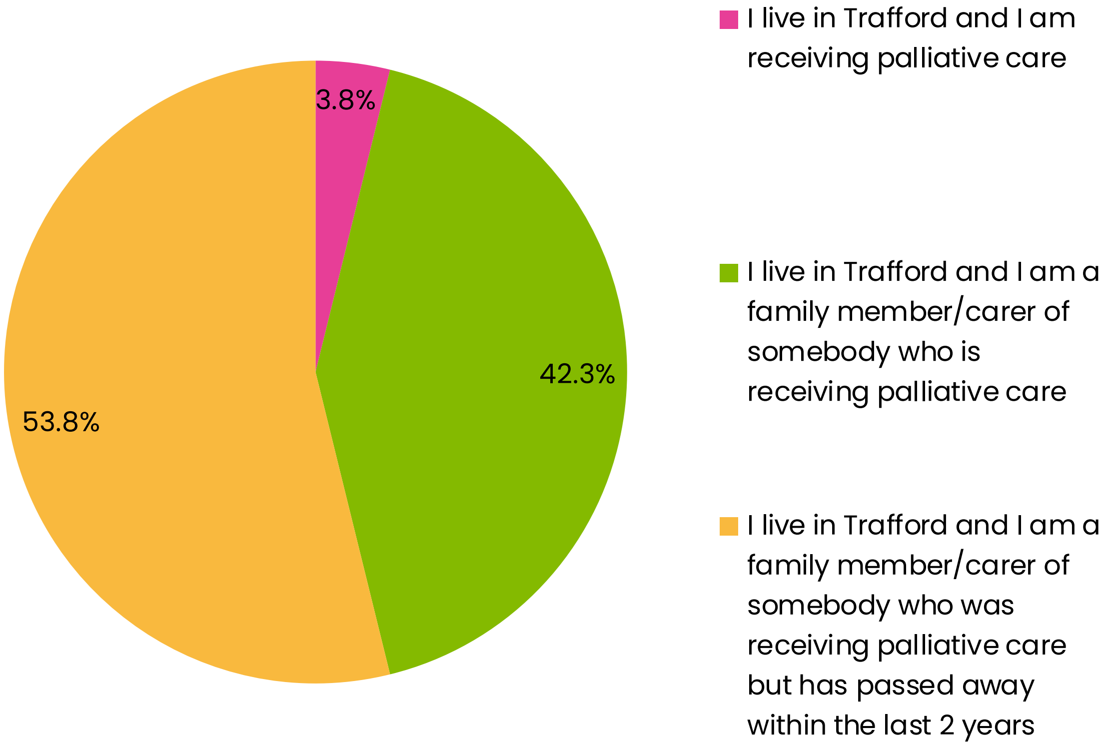
Appendix: Survey Responses

1: Circumstance of survey respondent (26 respondents)

I am receiving palliative care: 3.8% (1 respondent)

I am a family member/carer of somebody who is receiving palliative care: 42.3% (11 respondents)

I am a family member/carer of somebody who was receiving palliative care but has passed away within the last 2 years: 53.8% (14 respondents)

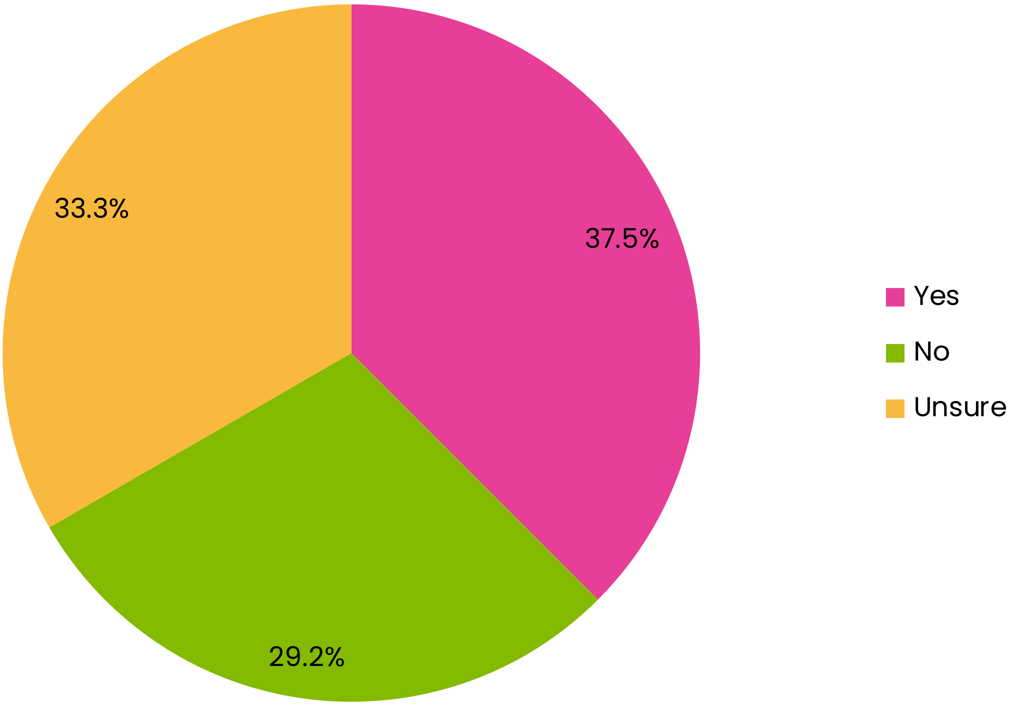


2: Is the person considered to be approaching the end of their life and currently receiving end-of-life care? (24 respondents)

Yes: 37.5% (9 respondents)

No: 29.2% (7 respondents)

Unsure: 33.3% (8 respondents)



3: Who provides the palliative care? Please choose all that apply (18 respondents)

NHS Community Nurses: 38.9% (7 respondents)

Macmillan: 22.2% (4 respondents)

St Ann's Hospice: 16.7% (3 respondents)

Marie Curie: 0% (0 respondents)

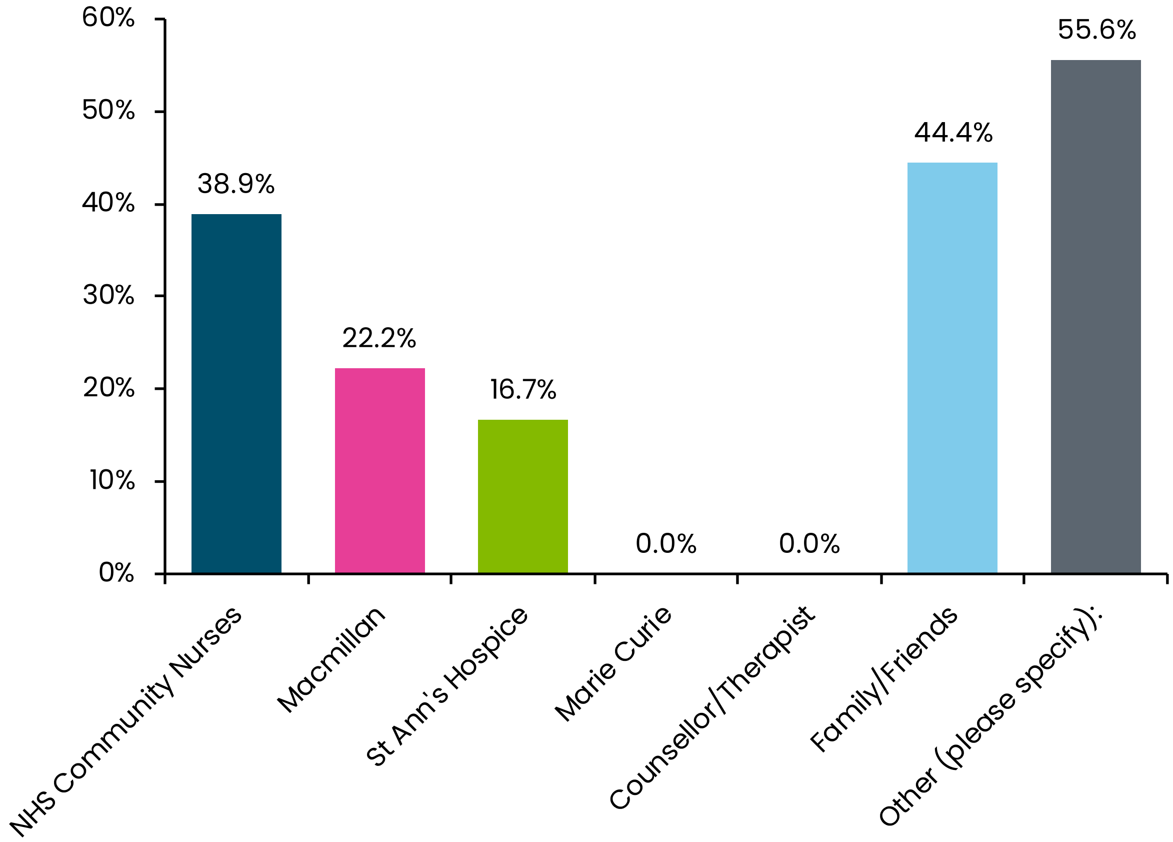
Counsellor/Therapist: 0% (0 respondents)

Family/Friends: 44.4% (8 respondents)

Other (please specify): 55.6% (10 respondents)

- Doctor
- Care Home
- Faversham House Nursing Home
- Arielle Care
- We did have carers for a short period
- Flixton Manor
- N/a
- Wife family and nursing home
- Now living in a nursing home

- Care/nursing home



4: How easy did the patient find it to access this palliative care? (16 respondents)

Very Easy: 6.3% (1 respondent)

Easy: 43.8% (7 respondents)

Neither easy nor difficult: 25% (4 respondents)

Difficult: 12.5% (2 respondents)

Very difficult: 12.5% (2 respondents)

5: What is most important to you about palliative care? Please select 3 options at most (16 respondents)

To be pain free: 81.3% (13 respondents)

To be treated with respect: 75% (12 respondents)

Not to be a burden: 0% (0 respondents)

Not to die alone: 12.5% (2 respondents)

To have care whenever I need it: 56.3% (9 respondents)

To die in a place of my own choosing: 37.5% (6 respondents)

To have my financial affairs in order: 6.3% (1 respondent)

6: How well do you feel different services work together to provide joined-up care? (17 respondents)

Very poorly: 11.8% (2 respondents)

Quite poorly: 35.3% (6 respondents)

Neither well nor poorly: 11.8% (2 respondents)

Quite well: 29.4% (5 respondents)

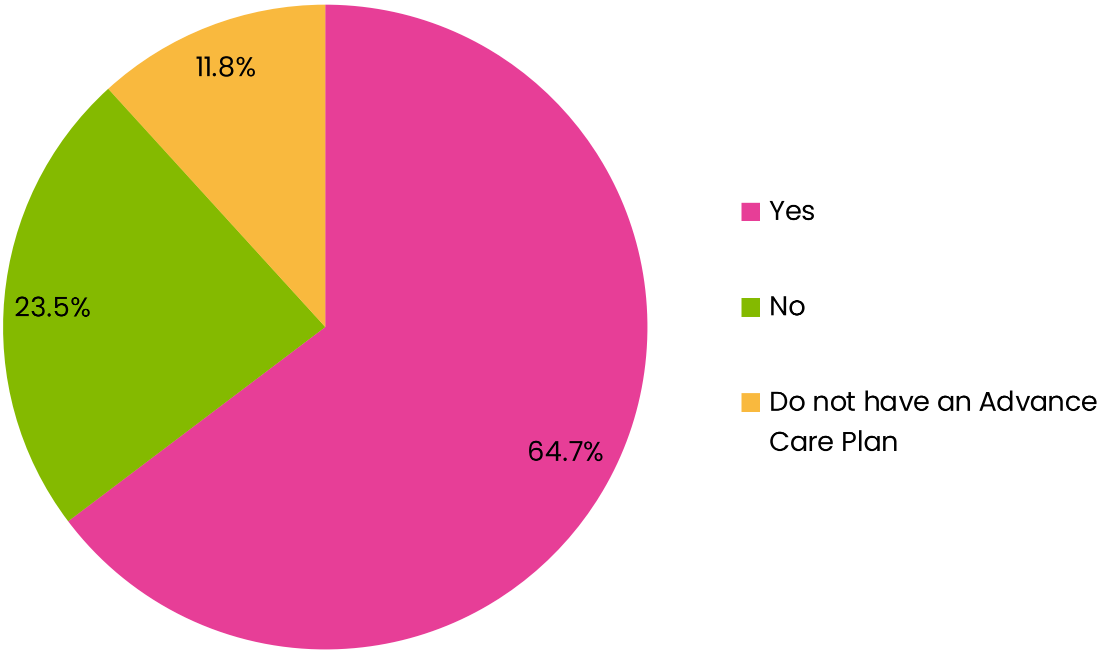
Very well: 11.8% (2 respondents)

7: Are your family or friends aware of your Advance Care Plan, if you have one? (17 respondents)

Yes: 64.7% (11 respondents)

No: 23.5% (4 respondents)

Do not have an Advance Care Plan: 11.8% (2 respondents)

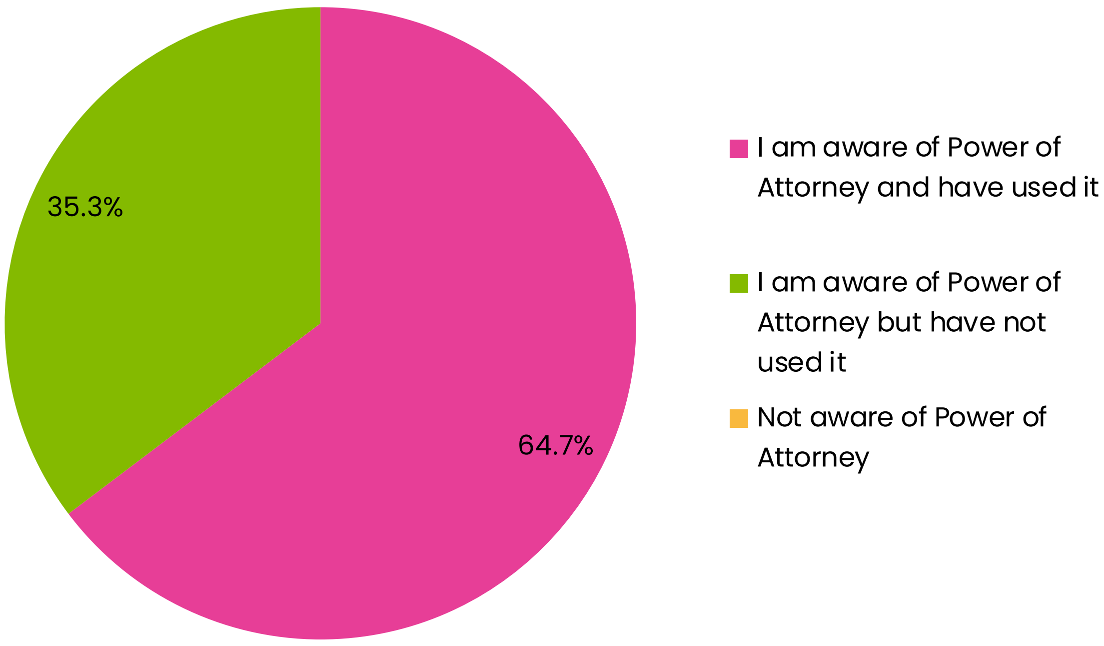


8: Are you aware of Power of Attorney? If so, have you used it? (Either as a patient or carer/family member) (17 respondents)

I am aware of Power of Attorney and have used it: 64.7% (11 respondents)

I am aware of Power of Attorney but have not used it: 35.3% (6 respondents)

Not aware of Power of Attorney: 0% (0 respondents)



9: To what extent does the palliative care meet the physical needs of the person receiving it? (e.g. pain and symptom management) (15 respondents)

Not at all: 6.7% (1 respondent)

Slightly: 6.7% (1 respondent)

Somewhat: 40% (6 respondents)

Mostly: 33.3% (5 respondents)

Very much: 13.3% (2 respondents)

10: Have palliative care staff offered enough emotional support? (e.g. listening, counselling, reassurance) (15 respondents)

Not at all: 13.3% (2 respondents)

Slightly: 6.7% (1 respondent)

Somewhat: 33.3% (5 respondents)

Mostly: 33.3% (5 respondents)

Very much: 13.3% (2 respondents)

11: Have staff provided enough information about how to receive practical support? (e.g. benefits, equipment, support services) (15 respondents)

Not at all: 6.7% (1 respondent)

Slightly: 26.7% (4 respondents)

Somewhat: 33.3% (5 respondents)

Mostly: 20% (3 respondents)

Very much: 13.3% (2 respondents)

12: Is there anything you feel could be done to improve palliative care? (10 respondents)

- Staff need to be better trained and supervised. Care staff visited but left my husband in a very wet bed. They did not treat him with dignity. The Macmillan nurse spent more time talking about her own issues.
- Be notified what is available
- We have been lucky in that my mum's care home have arranged what has been needed and informed the family along the way however when my in laws passed away after palliative care we felt like we were drowing
- Physiotherapy, suitable housing, better attension by medical staff to minimise pains
- Access to Marie Curie services in Trafford. These are not available and would have been invaluable, especially for night care so I could get some sleep
- As my husband has been a type one diabetic since he was a child and is now 88 years of age, I would like my husband to be visited by a professional to see how we can manage better with his medical issues.
- Get the private care companies to think more about the person/client and not about the business. Management have no interest in the client and what is best for them
- Yes when the person is being sick and you have been promised the district nurses would come out within the hour to administer anti sickness - it would be great if this happened - rather than myself phoning after two hours to be told it was not recorded so no visit scheduled and if patient was not being sick now to phone if it started happening again - and later the same day (7pm) to be told that no district

nurse was available to advise on sickness till 10pm and they would phone then so you wait up till midnight for the phone call that never came – disgraceful

- To ensure patient goes to nursing care if that is what discharge from hospital directed, not to a care home. Then after several complaints on the care to find that my husband was then moved onto the nursing care wing. The care was then so much better and may or may not have saved my husband from such serious infections and submitting a formal complaint before he was moved to the nursing care. His lack of initial care still haunts me.
- it would be helpful to have one point of contact. It feels as though you are chasing for support - and each area, Macmillan, District Nurses and GPs often seem to say it is the responsibility of one of the other parties

13: Is there anything you feel was done particularly well in relation to palliative care? (10 respondents)

- Pain relief
- Doctor is amazing
- The care home have liaised between the family, the doctors and themselves excellently
- Visit by carers 4 times a day. Also a respite for me for 4 hours, 3 times a week. Only this year I was given 14 days holidays which was a good break for me.
- District nurses were amazing. They were our main source of support (along with GPs). We had to really push to get to see a Macmillan nurse. They didn't do any practical care and most of their advice, we already had in place. Would have floundered without the support of the district nurses - both practical help and advice and emotional support.
- The care received from Arielle was excellent.
- Mcmillan and regular district nurses have been helpful and empathic
- The carers coming in 4 times a day and came out to clean her up when vomit was everywhere and I was desperate for help
- Yes listening to family, both the staff and doctors did this, even though my husband by this time couldn't speak for himself. I had cared for him for 20 years with Alzheimer's and the GP practice and staff on the nursing wing respected my input into his care.
- Once you have the Macmillan nurses in place, they are great

Demographics:

14: Please tell us your gender (11 respondents)

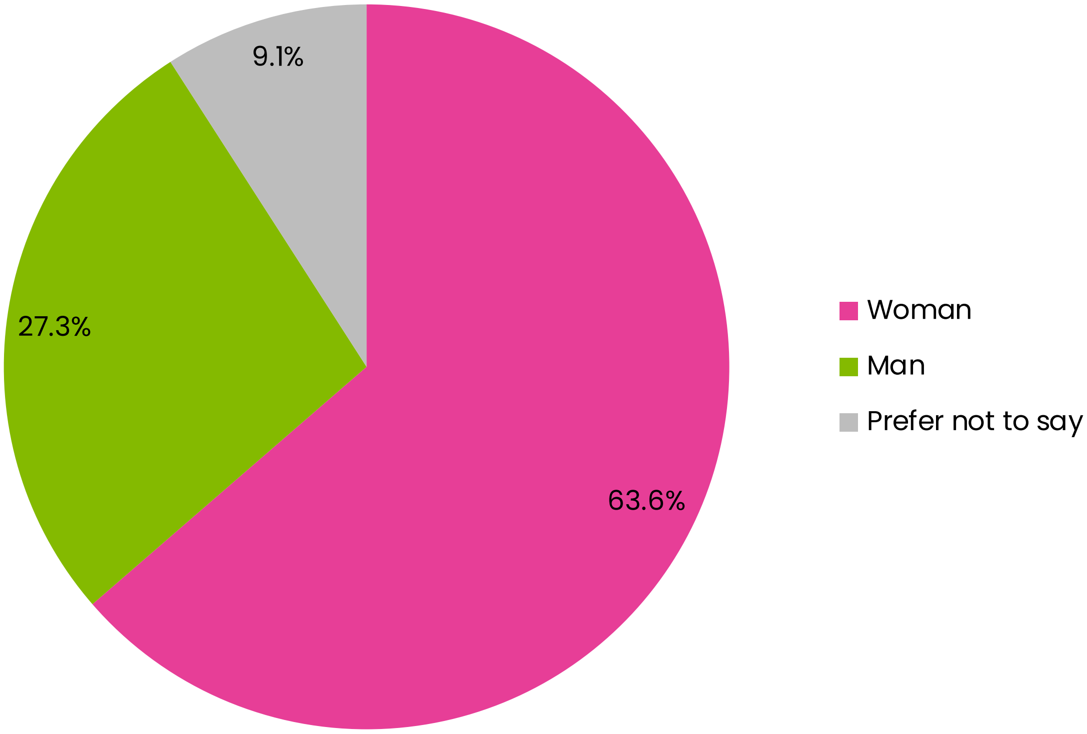
Woman: 63.6% (7 respondents)

Man: 27.3% (3 respondents)

Non-binary: 0% (0 respondents)

Prefer not to say: 9.1% (1 respondent)

Prefer to self-describe: 0% (0 respondents)

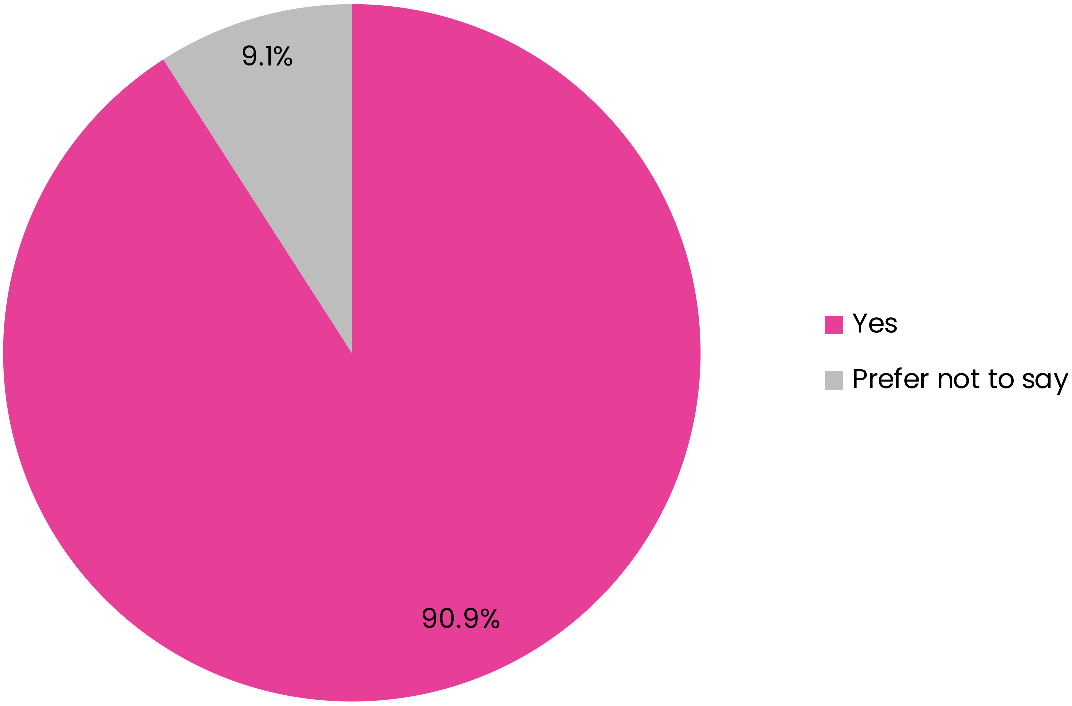


15: Is your gender identity the same as your sex recorded at birth? (11 respondents)

Yes: 90.9% (10 respondents)

No: 0% (0 respondents)

Prefer not to say: 9.1% (1 respondent)



16: Please tell us which sexual orientation you identify with (11 respondents)

Asexual: 9.1% (1 respondent)

Bisexual: 0% (0 respondents)

Gay man: 0% (0 respondents)

Heterosexual/straight: 63.6% (7 respondents)

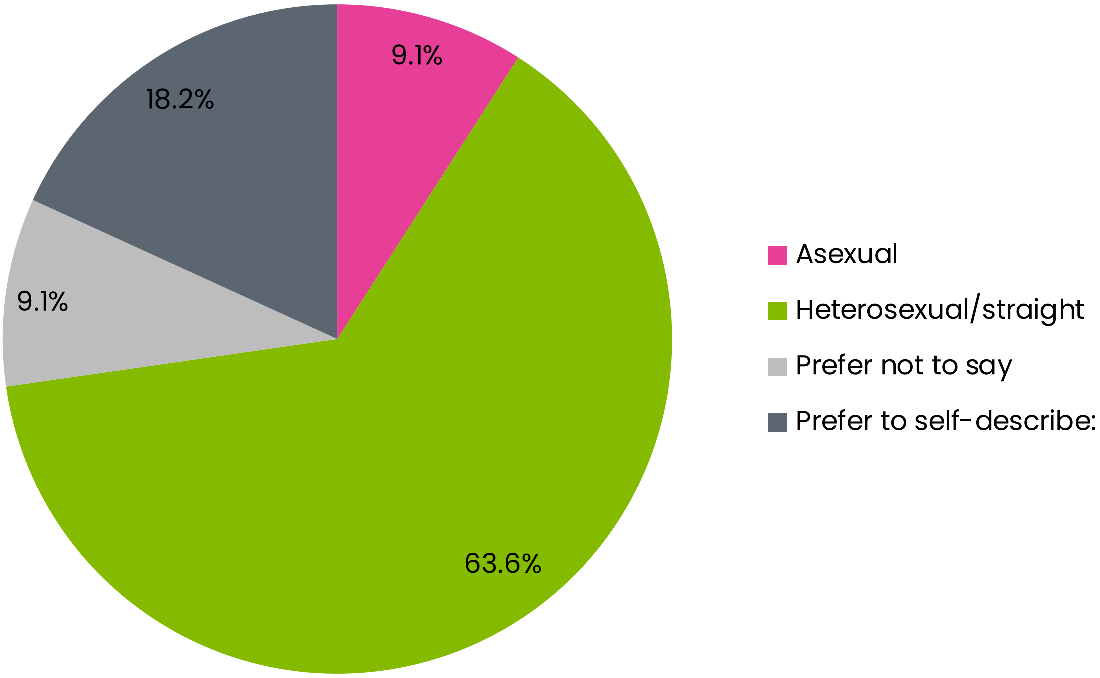
Lesbian/Gay woman: 0% (0 respondents)

Pansexual: 0% (0 respondents)

Prefer not to say: 9.1% (1 respondent)

Prefer to self-describe: 18.2% (2 respondents)

- Normal
- Strong belief on nature



17: Please tell us your age (11 respondents)

13-15 years: 0% (0 respondents)

16-17 years: 0% (0 respondents)

18-24 years: 0% (0 respondents)

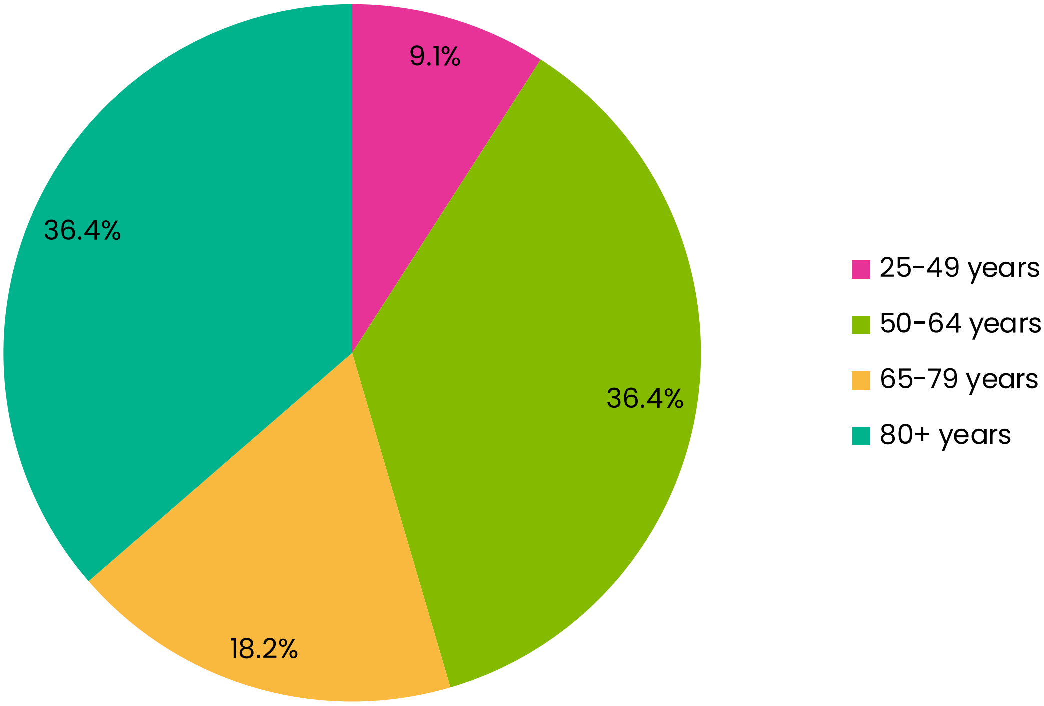
25-49 years: 9.1% (1 respondent)

50-64 years: 36.4% (4 respondents)

65-79 years: 18.2% (2 respondents)

80+ years: 36.4% (4 respondents)

Prefer not to say: 0% (0 respondents)



18: How would you describe your marital or partnership status? (11 respondents)

Single: 9.1% (1 respondent)

Cohabiting: 0% (0 respondents)

In a civil partnership: 0% (0 respondents)

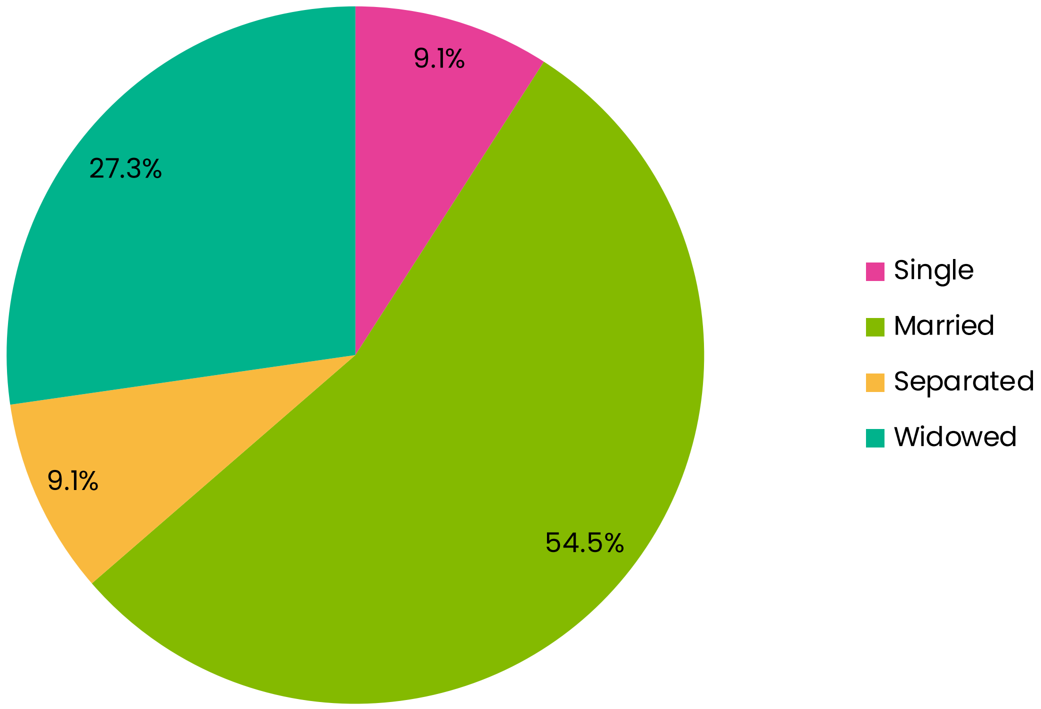
Married: 54.5% (6 respondents)

Separated: 9.1% (1 respondent)

Divorced/Dissolved civil partnership: 0% (0 respondents)

Widowed: 27.3% (3 respondents)

Prefer not to say: 0% (0 respondents)



19: Pregnancy and maternity (9 respondents)

This question does not apply to me: 100% (9 respondents)

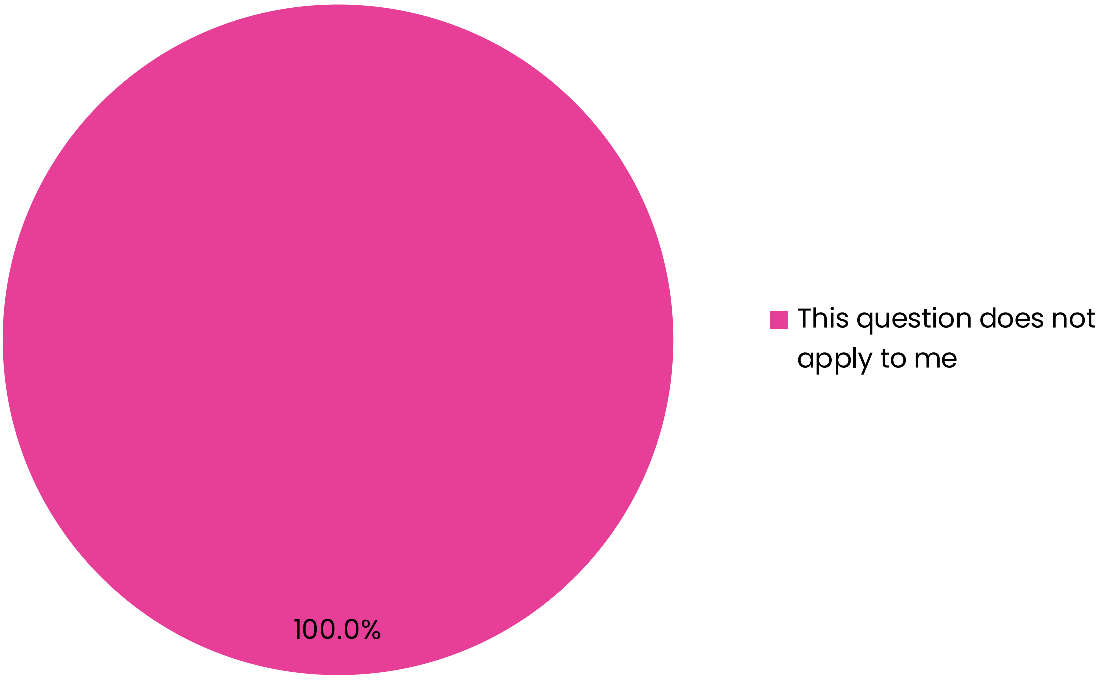
I am currently pregnant: 0% (0 respondents)

I am currently breast-feeding: 0% (0 respondents)

I have given birth in the last 26 weeks: 0% (0 respondents)

Prefer not to say: 0% (0 respondents)

Not known: 0% (0 respondents)



20: Please select your ethnicity (11 respondents)

Arab: 0% (0 respondents)

Asian/Asian British: Bangladeshi: 0% (0 respondents)

Asian/Asian British: Chinese: 0% (0 respondents)

Asian/Asian British: Indian: 0% (0 respondents)

Asian/Asian British: Pakistani: 9.1% (1 respondent)

Asian/Asian British: Any other Asian/Asian British background: 0% (0 respondents)

Black/Black British: African: 0% (0 respondents)

Black/Black British: Caribbean: 0% (0 respondents)

Black/Black British: Any other Black/Black British background: 0% (0 respondents)

Mixed/multiple ethnic groups: Asian and White: 0% (0 respondents)

Mixed/multiple ethnic groups: Black African and White: 0% (0 respondents)

Mixed/multiple ethnic groups: Black Caribbean and White: 0% (0 respondents)

Mixed/multiple ethnic groups: Any other Mixed/Multiple ethnic group background: 0% (0 respondents)

White: British/English/Northern Irish/Scottish/Welsh: 81.8% (9 respondents)

White: Irish: 0% (0 respondents)

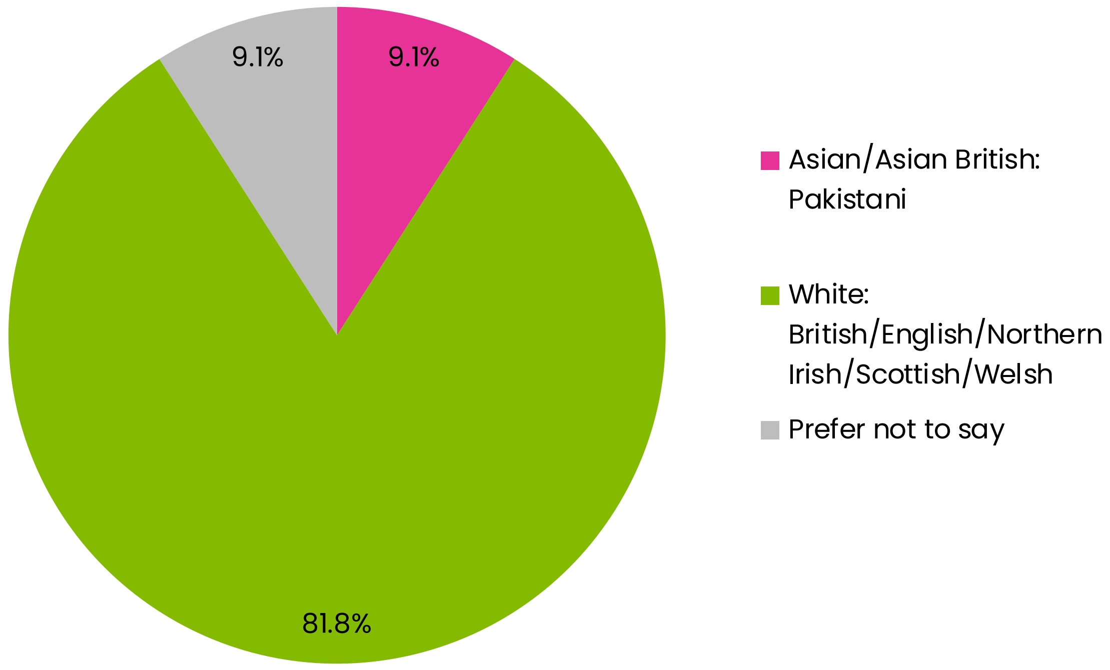
White: Gypsy, Traveller or Irish Traveller: 0% (0 respondents)

White: Roma: 0% (0 respondents)

White: Any other White background: 0% (0 respondents)

Prefer not to say: 9.1% (1 respondent)

Other (please specify): 0% (0 respondents)

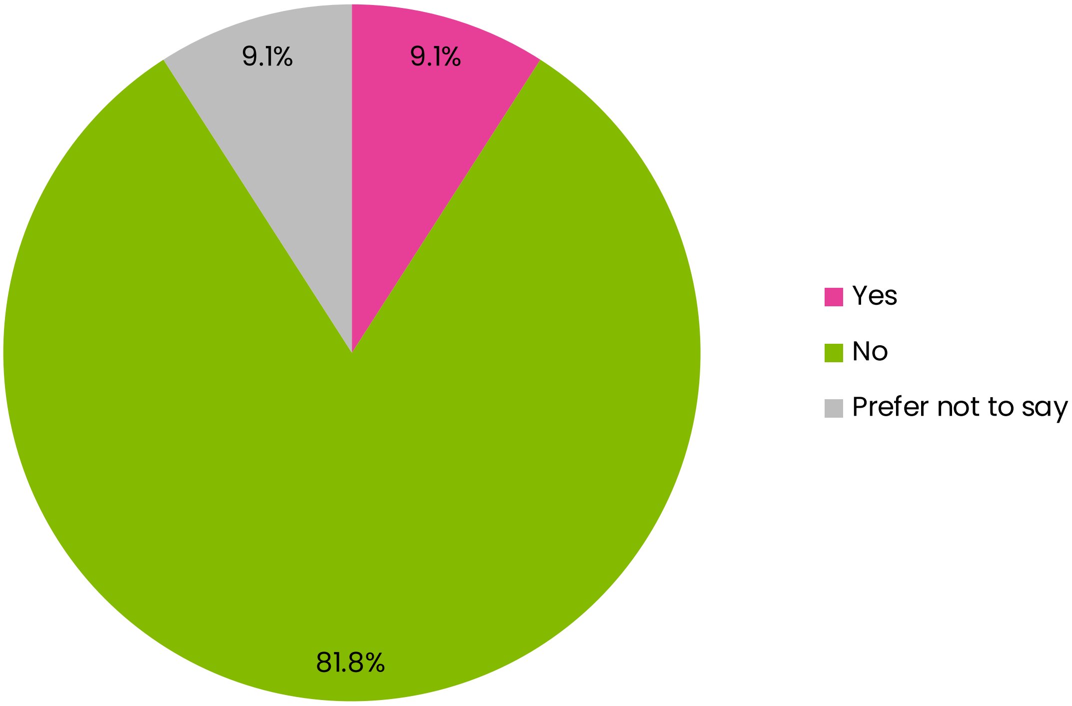


21: Do you have a disability or long-term health condition? (11 respondents)

Yes: 9.1% (1 respondent)

No: 81.8% (1 respondent)

Prefer not to say: 9.1% (1 respondent)


9.1%
9.1%
81.8%
Yes
No
Prefer not to say