

**Fife Health
& Social Care
Partnership**



Fife Dementia Local Action Plan

Participation & Engagement Feedback Report

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Table of Contents

1. Introduction..... 3

2. Engagement Purpose 3

3. The Engagement Timeline 3

4. Stakeholder Engagement..... 4

 4.1 Designing the Consultation 4

 4.2 Engagement Methods 4

 4.3 Engagement Reach 5

5. Themes from Feedback..... 8

6. Conclusion 20

 6.1 Next Steps 20

 Appendices 21



1. Introduction

The **National Dementia Strategy for Scotland: Everyone's Story**

(www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/documents/) sets out a ten-year vision for improving dementia care, support, and services across Scotland. Developed collaboratively with people with lived experience and wider partners over eight months, this strategy emphasises a collective effort to enhance the delivery of dementia support, ensuring a person-centred approach that reflects real needs and aspirations.

National Vision: Our vision is of a Scotland where people living with dementia have their strengths recognised, their rights upheld, and where they, their families and care partners/unpaid carers are supported to live an independent life, free from stigma and with person centred treatment and care, when and where they need it.

In Fife, we recognise the importance of local ownership of this vision. To ensure the strategy is meaningful and effective in our communities, we have established a **local Dementia Strategy Working Group**. This group includes people responsible for delivering dementia services and support, alongside local organisations and individuals with lived experience.

To help shape the local action plan, we wanted to gather views from people living with dementia, their families, their carers, professionals and the wider community in Fife.

This report provides a summary of the feedback which was captured during the consultation period.

2. Engagement Purpose

The purpose of the engagement was to give the people of Fife, including people living with dementia, carers, professionals and the wider community, the opportunity to share their experiences of services and their views on the identified themes and priorities to ensure that our approach:

- **Reflects local needs** and priorities.
- **Builds on existing strengths** in dementia care and support.
- **Addresses gaps and challenges** unique to Fife.

A consultation was designed to capture the experiences of people who have used dementia services and to ask for views to establish if the themes and priorities that we have identified for Fife cover what is important for people living with dementia, their families and their carers.



3. The Engagement Timeline

The engagement timeline shown below outlines the planning, delivery and reporting process that has been undertaken.



4. Stakeholder Engagement

4.1 Designing the Consultation

The consultation was designed by the Project Team and the Participation and Engagement Team and was structured to capture views and experiences of people in Fife.

4.2 Engagement Methods

Engagement took the form of a survey (Appendix 1) which was made available to members of the public and key stakeholders (Appendix 2) both online and in paper form. The survey was live from 20th of June until 30th of September 2025. Engagement was extended beyond the initial planned period to allow for further responses to be received to the online survey, to enable additional face to face engagement to take place and to introduce a social media campaign in the form of **“A Question a Day”** which focused on the four identified priorities and captured individual experiences of dementia services.

Face to Face Engagement Sessions were held with stakeholders during that period (Appendix 2). It was acknowledged that people impacted by dementia gain significant benefits from attending groups and therefore the approach was flexible and aligned with the needs of the groups. In these group sessions there was no expectation that everyone would answer all the questions and therefore some of the feedback presented is a **consensus from the groups**.

From 22nd September – 26th September 2025, **“A Question a Day”** was shared on social media by Fife HSCP to allow people to share their experiences and views on the identified priorities in an interactive way.

An “Easy Read” version of the survey was available but was not requested and no paper copies of the survey were returned.



4.3 Engagement Reach

During the live engagement period, a total of **312 responses** were received across all methods of consultation. This included:

- **60 responses** to the online survey
- **116 people** who shared their views during **face-to-face engagement** sessions
- **136 responses** to the “**A Question a Day**” social media campaign, averaging **27 responses per day** over 5 days.

From the 60 responses received for the online consultation, 75% of those who responded told us that they had been impacted by dementia. People were able to **choose more than one answer** and from those who had been impacted the breakdown of responses is shown below:

- **33 people** (53%) have a family member who has been diagnosed with dementia
- **21 people** (34%) cared for someone who has been diagnosed with dementia
- **5 people** (8%) have a friend who has been diagnosed with dementia
- **3 people** (5%) had previously cared for someone who had dementia

Of the 60 people who responded to the online survey:

- **30 people** (50%) described themselves as Unpaid Carers
- **16 people** (27%) described themselves as a member of the public
- **14 people** (23%) described themselves as a person who works or volunteers to provide Health and Social Care.

In addition, **116 people** were able to share their views as part of a face-to-face session and the detail of the sessions is below:

Group/Organisation	Location	Participant	Total No of people
STAND Groups	Kinghorn, Dunfermline, Kirkcaldy, Methilhaven Cupar	People with a diagnosis, family members and staff	51
STAND Young Onset Group (Carers)	Kirkcaldy	Carers and staff	23

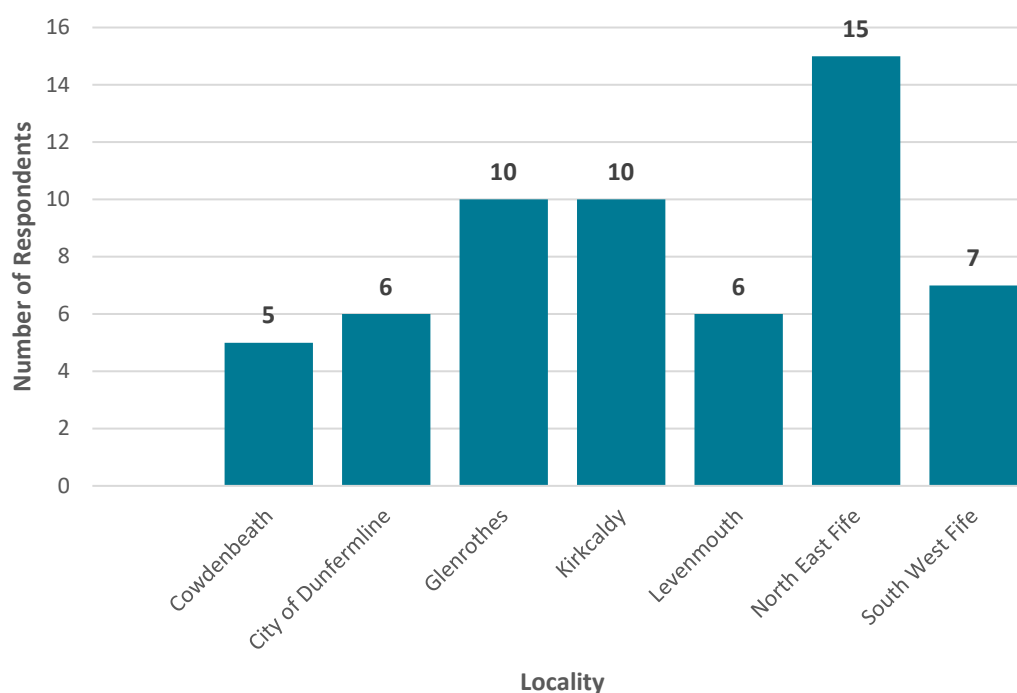


Abbotsford Care Homes	Dunfermline and Tayport	Care home residents and staff	10
Fife Forum Action Groups	Kirkcaldy, Leven and Glenrothes	Members of the public and staff	13
Later Life Choices	Glenrothes	People with a diagnosis, staff and volunteers	19

A link to the survey was shared with the organisations listed in Appendix 2 and the Participation and Engagement Officer contacted key staff members across all sectors to raise awareness of the consultation and offer support to enable them to share it within their own networks.

Localities

Responses to the online survey were received from all 7 localities across Fife's communities. The responses per locality are shown below:





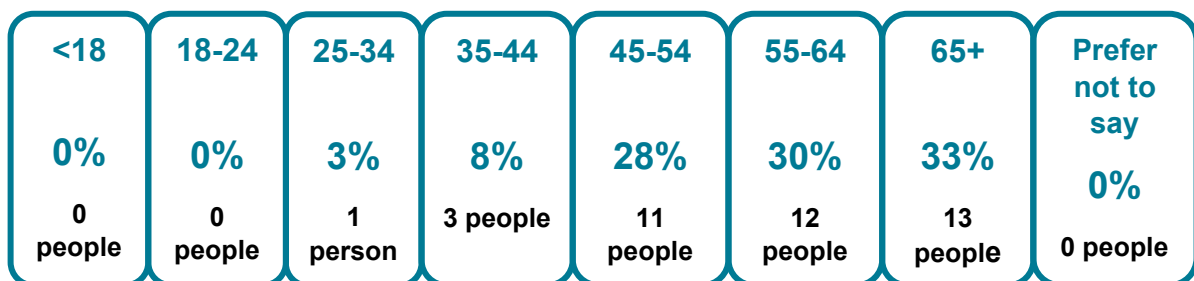
Equality, Diversity and Inclusion

38 people (66%) completed the **Equalities, Diversity, and Inclusion** question on the online survey, which provided an understanding of respondents **age**, **gender**, and **ethnicity**, which is used for monitoring and statistical purposes in the planning and delivery of health and social care services in Fife.

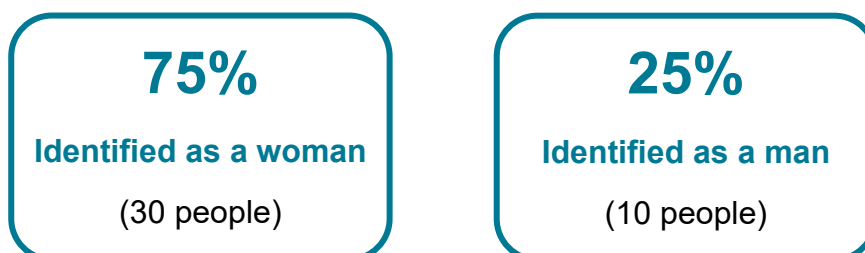
Key points from the equalities data are summarised below with further data shown in Appendix 3.

Equalities data was not collected in the Face-to-Face Engagement Sessions or from the social media “A Question a Day” interactive week.

Age: A detailed breakdown is shown below from the online survey responses.



Gender: A detailed breakdown is shown below from the online survey responses.



Sexual Orientation: A detailed breakdown is shown below from the online survey responses:

30 people (83% of those who answered) said that they were Straight/Heterosexual

1 person (3% of those who answered) said that they were Asexual

5 people (14% of those who answered) preferred not to say



Ethnicity: A detailed breakdown is shown below from the online survey responses:

38 people (97% of those who answered) said they were **white** (Scottish, English, Northern Irish or Other British)

1 person (3% of those who answered) preferred not to say.

5. Themes from Feedback

We asked if people had heard about the National Dementia Strategy: Everyone's Story:

16 people (27%) who responded to the online survey and around a quarter of those who attended the face-to-face sessions had heard of the National Strategy. Most people had heard about it either online, through STAND, Third Sector organisations or in a professional capacity.

The themes from the National Strategy that Fife is looking to include in its local dementia action plan are:

- 1. Human Rights & Dignity** - Ensuring people with dementia are treated with respect and fairness.
- 2. Prevention & Post Diagnostic Support** - Helping people reduce risks and live well after diagnosis.
- 3. Inclusion & Community Support** - Keeping people connected to their communities.
- 4. Personalised Care** - Tailoring support to individual need and preferences.

5.1 We asked which themes were most important to people living with dementia, their families and carers.

Respondents to the online survey were able to select multiple options. The most frequently selected theme was *Personalised Care* (chosen by **53 respondents, or 88%** of participants), followed closely by *Prevention and Post Diagnostic Support* (**47 respondents, 78%**) and *Human Rights and Dignity* (**46 respondents, 77%**). *Inclusion and Community Support* was selected by **39 respondents (65%)**.



Theme	Number of Selections	% of Respondents who selected this theme
Personalised Care	53	88%
Prevention and Post Diagnostic Support	47	78%
Human Rights and Dignity	46	77%
Inclusion and Community Support	39	65%

In the face-to-face sessions the consensus was that themes were all **equally important**.

5.2 We asked why people answered that way:

People who responded feel that these themes are all important for those receiving dementia care, as they reflect what matters to people living with dementia, their carers and families.

Quotes

“These are all important, but the personalised care is most important as it can have a profound effect on the person and their carer”.

“Meeting all 4 themes will create and provide care, support and guidance that is of a good quality, is person-centred, trauma-informed and meets the varying needs of individuals and their carers and families living with Dementia”

“All of the above are necessary to ensure our loved ones are treated fairly and get the best from local services, the information and help need to be easily accessed”.

5.3 We asked if there were other themes that we have not covered that are important for people living with dementia, their families and their carers in Fife.

34 people (57%) who responded to the online survey felt that all themes were covered and **26 people** (43%) of people who responded felt that the other themes included:

- Support for Carers



- Equity of service and support across Fife
- Future Planning
- Aftercare when loved ones die or move into care
- Workplace support for young onset dementia

There were no other themes identified in the face-to-face sessions as discussions highlighted that much of what was important to them was covered in the identified themes and priorities.

Identified Priorities

Fife Health and Social Care Partnership have identified four priorities from the National Strategy for inclusion in a local dementia action plan. These are set out below:

- **Priority 1 - Information, Awareness Raising and Tackling Stigma.**
People will get the information they need in a way they understand to help them make choices about care, treatment and support. There will be more awareness and understanding of dementia in the community which will help to reduce stigma.
- **Priority 2 - Prevention and Early Intervention.**
People will have increased awareness of brain health to help delay the onset of dementia and the information will be easy to find and understand. Improving diagnosis rates for dementia will help people to be diagnosed quicker and get support sooner.
- **Priority 3 - Support.**
People will get the help and support they need, when they need it no matter their age or where they live. People with dementia will feel safe at home and be part of their community.
- **Priority 4 - Carers Support.**
Families, care partners and unpaid carers of people living with dementia will be supported to manage their caring role and have a life alongside caring that allows them to do the things that are important and meaningful to them.



5.4 We asked people to consider each priority and whether they feel it covers what is important for people living with dementia, their families and their carers in Fife, and why they answered that way.

Priority One: Information, Awareness Raising and Tackling Stigma

Source	Agreement Level
Online Survey	<p>Fully Covers 62% of Respondents agreed that this Priority fully covers what is important.</p> <p>Partially Covers 35% of Respondents agreed that it partially covers what is important.</p> <p>Does not cover at all 3% responded that it did not cover at all.</p>
Face to Face Engagement	There was a consensus in the sessions that this should be a priority for Fife.
A Question a Day	32 Respondents agreed that this should be a priority.

Key Themes identified from Priority One

Information

- Must be **clear, accessible, and free of jargon** to ensure meaningful impact
- Should be available in **multiple formats**, including verbal delivery by a named worker
- Needs to be in **plain English, large font, and concise** for better understanding

Awareness Raising

- **Intergenerational work by STAND** has been positive
- Raising awareness in **local communities** helps to create inclusive communities that understand dementia
- Support needs to differ between **community and care home settings** - this must be acknowledged addressed



Tackling Stigma

- Mixed feedback from **online survey** - some people questioned if stigma exists in Fife.
- **Face-to-face groups** reported that stigma is still present and prevents people with early-stage dementia from seeking support.
- There is a need for **education and open conversations** to reduce discomfort and misunderstanding around dementia and its impact.

Quotes

“Information and awareness are key in helping people understand the illness.”

“Even when your memory starts to play tricks on you, you are still a person and still have the right to make choices.”

“More personalised information required as every journey is different.”

“This doesn’t even appear to be an issue in Fife... I’ve seen no stigma”

“Yes. As it should be for all illnesses/conditions and disorders.”

Priority Two: Prevention and Early Intervention

Source	Agreement Level
Online Survey	<p>Fully Covers 50% of Respondents agreed that this Priority fully covers what is important.</p> <p>Partially Covers 40% agreed that it partially covers what is important.</p> <p>Does not cover at all 10% responded that it did not cover at all.</p>
Face to Face Engagement	There was a consensus in the sessions that this should be a priority for Fife.
A Question a Day	27 Respondents agreed that this should be a priority



Key Themes identified from Priority Two

Prevention:

- Education on **brain health** should start in school and be available for all age groups
- **Awareness of dementia symptoms** must improve - dementia impacts individuals differently and is not just about memory loss, early recognition will help people to seek support sooner.
- The **school curriculum** should include brain health education to promote lifelong understanding of how to keep the brain healthy

Early Intervention:

- **Diagnosis takes too long** – many individuals deteriorate before they get support, quicker diagnosis is essential.
- **Limited resources and long waiting lists** leave people unsupported leading to further decline and increased stress for carers.

Quotes

“It is important that we have the knowledge to look after our own brain health as with all health conditions”.

“Yes, I definitely agree that this needs to be a priority. Prevention is important but recognising early signs of deteriorating cognitive abilities and more timely diagnosis is vital as this is the gateway to support”

“Yes, I agree with this fully – if there are ways to prevent dementia, we should be spreading awareness in schools and in the community – campaigning for people to be tested early, especially if there is dementia in the family. However, in our experience it’s only when people start to behave differently, that’s when the investigation starts but by then it’s probably too late to prevent/cure”.

“Prevention is not the priority as I don’t think you can successfully stop the onset so helping people who have dementia should get more focus”.



Priority Three - Support

Source	Agreement Level
Online Survey	<p>Fully Covers 60% of Respondents agreed that this Priority fully covers what is important.</p> <p>Partially Covers 32% agreed that it partially covers what is important.</p> <p>Does not cover at all 10% responded that it did not cover at all.</p>
Face to Face Engagement	There was a consensus in the sessions that this should be a priority for Fife.
A Question a Day	33 Respondents agreed that this should be a priority

Key Themes identified from Priority Three

Support

- **Local support and community groups** are vital to support people with dementia and their carers
- Support should be **equally accessible** to everyone regardless of age, social circumstance or location.
- **Post Diagnostic Support** must be more flexible in timing, so it is at the right time for individuals
- Organisations like **STAND** provide crucial support in connecting people and providing both support and information
- **Navigating systems is challenging** - clearer signposting and access to support is a priority.

Quotes

“Navigating modern primary, secondary and health and social care services is very difficult for staff and patients. A strategic joined up approach for Fife is a priority to make sure people can access the right care in the right place is a priority”.

“Having local services are so important to enable people to access”



“Access to proper support is essential, not only for the person with dementia but also their loved ones. This should not be linked to where they live or how much they can afford to pay for support. There are a lot of excellent dementia groups run and these should be available to all who need them. Access to support should not be a postcode lottery”.

Priority Four – Carers Support

Source	Agreement Level
Online Survey	<p>Fully Covers 57% of Respondents agreed that this Priority fully covers what is important.</p> <p>Partially Covers 37% agreed that it partially covers what is important.</p> <p>Does not cover at all 6% responded that it did not cover at all.</p>
Face to Face Engagement	There was a consensus in the sessions that this should be a priority for Fife.
A Question a Day	25 Respondents agreed that this should be a priority

Key Themes identified from Priority Four

Unpaid Carers

- Support must be **easy to find and access** for Unpaid Carers
- People **don't always identify as carers** so they miss out on support.
- **Limited and inflexible support** for those with a diagnosis increases stress on their carer
- **Young onset dementia** presents unique challenges – carers often give up work leading to financial strain
- **Fife Carers** are recognised for provide good support
- Support often arrives **too late** with carers reaching crisis before intervention
- **Care home residents** sometimes provide support to others with dementia and need support



Quotes

“This is vital. We had to search for support. It’s really hard to care for people with dementia”.

“Carers are often forgotten and left to get on with it they need support to care for a loved one. think that should be at the top. The most important”.

“Paying carers or providing time for respite is vital. If the carer becomes exhausted or unwell, there are then two people needing care. Carers save money for the social and health care sector by keeping the person at home rather than in an institution”.

Other Priorities

We asked if there were any other priorities that we have not covered that are important for people living with dementia, their families and their carers in Fife. Further key themes included:

- **Support** for those who do not want to assume a caring role
- Increased **financial** resource
- Workforce development to **improve staff knowledge** of dementia
- **Dedicated website** for people impacted by dementia
- Options for **advanced dementia care**, including residential care

Your Experiences

5.5 We asked people to tell us what good dementia care and support looks like for them.

48 people (80%) responded to this question from the online survey and during the face to face sessions, group members shared their views through discussion. The themes from the online survey and face to face engagement were:

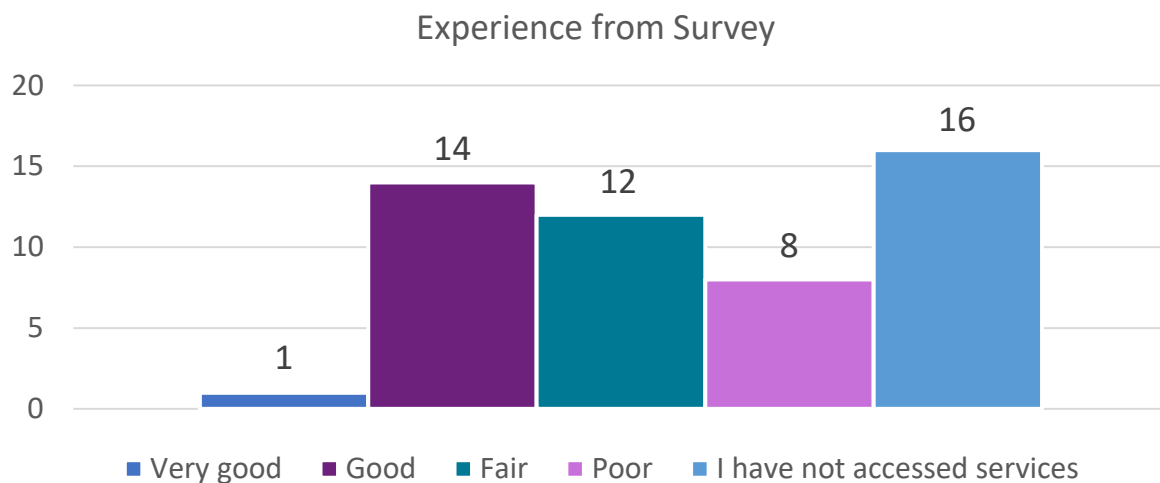
- **Support and Care** – a focus on practical, responsive and co-ordinated services that are accessible and reliable
- **Person Centred Approach** – care tailored to individual needs respecting personal circumstances and preferences
- **Compassion and Respect** – kindness, dignity, empathy and emotional support in all care interactions.



- **Continuity and Communication** – the need for consistent support and clear information throughout the journey
- **Carer experience** – a focus on recognising and supporting unpaid carers with options like respite and choice.

5.6 We asked people to tell us what had been their experience of accessing dementia services in Fife.

60 people (100%) responded to this question from the online survey. The breakdown of responses from the online survey is below:



Mixed experiences were reported during the face-to-face engagement sessions with some people reporting good support from organisations like STAND in Fife and Fife Carers. Others felt there was a lack of support, delays in diagnosis and inflexible options so that support was not provided when it was really needed. Groups found it hard to comment on dementia services overall when their experiences with different organisations and staff members had been variable.

19 people responded to the ‘**A Question a Day**’ although almost half had not used services. The themes from those who did respond were similar to those shared in the survey and face to face sessions.

Summary of the key themes from the feedback were:

What was Very Good or Good:

People said that being signposted to the right services and having supports and groups available locally contributed to a positive experience.



What was Fair:

People reported that they had positive experiences with some organisations including STAND, Alzheimer Fife, Fife Carers and Social Work. They also experienced delays in diagnosis, lack of support pre-diagnosis and inflexible post diagnostic support.

What was Poor and Very Poor:

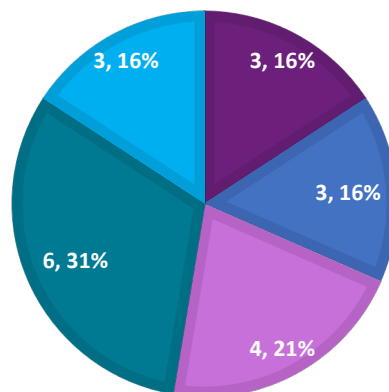
People told us that they had experienced a lack of accessible information and guidance, poor or inflexible post diagnostic support, delayed diagnosis, lack of support and respite for carers, long waiting lists for support and intervention at crisis point rather than when it would have been more helpful.

5.7 We asked people to share their experience of admission to hospital in the last year.

16 people (27%) of those who responded to the online survey shared their experiences and **3 people** shared experiences in the face-to-face sessions. Not all respondents shared why they answered that way. The feedback was as follows:

HOSPITAL EXPERIENCE IN THE LAST YEAR

■ Very Good ■ Good ■ Fair ■ Poor ■ Very Poor



Summary of the key themes from the feedback were:

Positive experience:

- Provided with a separate room and received good service

Negative experiences:

- Lack of care or understanding from staff for dementia patients
- Poor communication



5.8 We asked if there are any gaps in dementia services and support that need urgent attention:

36 people (60%) of those who responded to the online survey felt that there were gaps. People attending the face-to-face engagement also highlighted gaps and the themes are as follows:

- Tailored, **personalised approach** to support
- **Flexible** Post Diagnostic support to suit individual needs
- Clear, **accessible** information
- **Well trained** workforce who are knowledgeable about the impacts of dementia
- **Holistic** care
- **Co-ordinated** care and support
- **Education** about brain health and impacts of dementia

5.9 We asked people what their preferred way of accessing information is and the most popular methods are:

Leaflets

Online

Facebook/Instagram

Face to Face

Voice of Unpaid Carers

30 people (50%) who responded to the online survey described themselves as **Unpaid Carers** and approximately 40% of people who took part in the face-to-face engagement sessions were Unpaid Carers. **The voice of Unpaid Carers** runs strongly through all the feedback included in this report and the issues they face have been captured and highlighted.

Voice of people with a diagnosis of dementia

There were no responses received to the online survey from people with dementia but during the face-to-face sessions approximately **30%** of those who attended had a diagnosis of dementia and the feedback included:

- People enjoyed seeing friends and **feeling part of the group** they were attending
- Attending groups helped them **feel connected** to the community
- **Taking part** in activities made people happy
- Being **part of the group** with caring staff and volunteers present helped people to feel cared for and respected
- In some groups, people enjoyed knowing that their family member/carer was **getting some time to themselves**



6 Conclusion

The feedback gathered through the engagement process has provided an insight into the lived experiences, priorities, and aspirations of people affected by dementia across Fife. The themes and priorities identified in the National Dementia Strategy for inclusion in Fife Health and Social Care Partnership's Local Dementia Action Plan resonate with local communities and the majority of people who participated in the engagement agree that these are right for Fife.

Respondents consistently emphasised the importance of timely diagnosis, accessible information, and flexible support that is tailored to individual needs. The voices of unpaid carers were particularly prominent, highlighting the critical role they play and the need for better recognition, resources, and respite care.

While many respondents acknowledged positive experiences with local organisations and community groups, there were also clear calls for improvement - especially in the areas of post-diagnostic support, workforce training, and system navigation. The feedback highlights the need for a coordinated, person-centred approach that is responsive to the realities of living with dementia in Fife.

This report provides feedback which will contribute to the shaping of a Local Dementia Action Plan for Fife that is grounded in real experiences. The insights shared will inform future service development, ensuring that dementia care in Fife is compassionate, equitable, and reflective of what matters most to those it serves.

6.1 Next Steps

The Dementia Strategy Working Group will

- Use the feedback to support the development of the Local Dementia Action Plan for Fife
- Provide an update in Summer 2026 to inform all stakeholders of changes/improvements to services in line with the "You Said, We Did" approach.
- Share the report's findings on the impact of dementia on Unpaid Carers to the wider Carers Strategy Group
- Share the report's findings on the impact of dementia on Unpaid Carers to the wider Care Home Collaborative Group
- Discuss how a local reference group might link with the strategy group



Appendices

Appendix One - Survey

Appendix Two – Stakeholder List

Appendix Three – Equality, Diversity and Inclusion Data



Appendix 1 - Survey



The **National Dementia Strategy for Scotland: Everyone's Story** sets out a ten-year vision for improving dementia care, support, and services across Scotland. The strategy can be found here: <http://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/documents/>

The national strategy was developed collaboratively with people with lived experience and wider partners over eight months, with an emphasis on a collective effort to enhance the delivery of dementia support, ensuring a person-centred approach that reflects real needs and aspirations. In Fife, we recognise the importance of local ownership of this vision. To ensure the strategy is meaningful and effective in our communities, we have established a **local Dementia Strategy Working Group**. This group includes people responsible for delivering dementia services and support, alongside local organisations and individuals with lived experience. Together, we will shape how Fife responds to the national vision, developing a local dementia action plan that ensures high-quality, person-centred dementia support.

To help shape the local dementia action plan, we would like to invite you to complete this survey to help us gather views from people living with dementia, their families, their carers, professionals and the wider community to ensure that our approach reflects local needs and priorities, builds on existing strengths in dementia care and support and addresses gaps and challenges which are unique to Fife.

Feedback will be used in public presentations, reports and documents, but the information you provide will be **anonymised** and you **will not be identified**. You can read more about data protection and how we use your information on our website: www.fife.gov.uk/kb/docs/articles/privacy-notice/health-and-social-care

If you would like this form in a different format or would like help to complete the questionnaire, please contact

Email: HSCP.ParticipationEngagement@fife.gov.uk

Telephone: 03451 55 55 55 ext. 493731

Address: Participation & Engagement Team, 6th Floor, Fife House, North Street, Glenrothes KY7 5LT

The closing date for the survey is: 29th of August 2025



Thank you for taking the time to complete this form, your feedback is very important to us.

Questions

1. Have you been impacted by dementia?

- ☐ Yes
- ☐ No

2. If yes, please tell us how you have been impacted by dementia:

- ☐ I have been diagnosed with dementia
- ☐ A family member has been diagnosed with dementia
- ☐ A friend has been diagnosed with dementia
- ☐ I care for someone who has been diagnosed with dementia
- ☐ Other - please provide details:

National Dementia Strategy for Scotland: Everyone's Story

We have included a link to the National Dementia Strategy for Scotland: Everyone's Story in the section above, however, we know not everyone will have heard about or read the Strategy previously. As this consultation asks for your views on what you feel the most important aspects are and if you agree that Fife should align with the priorities of the National Strategy, we have identified key themes and priorities for Fife's action plan in this consultation. The outcomes for Fife's action plan below:

Outcomes

1. There will be improved access to services, e.g., dementia advisors, peer support, increased public awareness and reduced stigma around dementia.
2. People will have information to help delay the onset of dementia and will be diagnosed and given support earlier.
3. Fife will have stronger dementia-friendly communities (businesses, transport, and services more inclusive).
4. There will be better recognition of carers' needs (respite care, training, and financial support).



3. Have you heard about the National Dementia Strategy: Everyone's Story?

- ☐ Yes
☐ No

4. If yes, please tell us how you heard about it:

Key Themes

5. Fife is looking to include the key themes (listed below) from the National Strategy into its local dementia action plan.

- 1. Human Rights and Dignity** - Ensuring people with dementia are treated with respect and fairness
- 2. Prevention and Post Diagnostic Support** - Helping people reduce risks and live well after diagnosis
- 3. Inclusion and Community Support** - Keeping people connected to their communities
- 4. Personalised Care** - Tailoring support to individual need and preferences

Which themes do you think are most important to people living with dementia, their families and their carers? (you can choose more than one)

- ☐ **Human Rights and Dignity** - Ensuring people with dementia are treated with respect and fairness
- ☐ **Prevention and Post Diagnostic Support** - Helping people reduce risks and live well after diagnosis
- ☐ **Inclusion and Community Support** - Keeping people connected to their communities
- ☐ **Personalised Care** - Tailoring support to individual need and preferences

6. Please share with us why you answered this way:



7. Are there any other themes that we have not covered that are important for people living with dementia, their families and their carers in Fife?

- ☐ Yes
☐ No

8. If Yes, please tell us what other themes we should cover that are important for people living with dementia, their families and their carers in Fife:

Priorities

Fife is looking to align with the priorities of the National Strategy, to create a local dementia action plan that reflects local needs and priorities. We want to ensure the identified priorities cover what is important for people in Fife and find out if there are any other priorities we should include in our local dementia action plan.

Priority 1 - Information, Awareness Raising and Tackling Stigma

People will get the information they need in a way they understand to help them make choices about care, treatment and support. There will be more awareness and understanding of dementia in the community, which will help to reduce stigma.

Priority 2 - Prevention and Early Intervention

People will have increased awareness of brain health to help delay the onset of dementia and the information will be easy to find and understand. Improving diagnosis rates for dementia will help people to be diagnosed quicker and get support sooner.

Priority 3 - Support

People will get the help and support they need, when they need it no matter their age or where they live. People with dementia will feel safe at home and be part of their community.

Priority 4 - Carers Support

Families, care partners and unpaid carers of people living with dementia will be supported to manage their caring role and have a life alongside caring that



allows them to do the things that are important and meaningful to them.

9. Priority 1 – Information, Awareness Raising and Tackling Stigma

People will get the information they need in a way they understand to help them make choices about care, treatment and support. There will be more awareness and understanding of dementia in the community, which will help to reduce stigma.

Does this priority cover what is important for people living with dementia, their families and their carers in Fife?

- ☐ Fully covers
- ☐ Partially covers
- ☐ Does not cover at all

10. Please tell us why you answered that way:

11. Priority 2 - Prevention and Early Intervention

People will have increased awareness of brain health to help delay the onset of dementia and the information will be easy to find and understand. Improving diagnosis rates for dementia will help people to be diagnosed quicker and get support sooner.

Does this priority cover what is important for people living with dementia, their families and their carers in Fife?

- ☐ Fully covers
- ☐ Partially covers
- ☐ Does not cover at all

12. Please tell us why you answered that way:

13. Priority 3 - Support

People will get the help and support they need, when they need it no matter their age or where they live. People with dementia will feel safe at home and be part of their community.



Does this priority cover what is important for people living with dementia, their families and their carers in Fife?

- ☐ Fully covers
- ☐ Partially covers
- ☐ Does not cover at all

14. Please tell us why you answered that way:

15. Priority 4 - Carers Support

Families, care partners and unpaid carers of people living with dementia will be supported to manage their caring role and have a life alongside caring that allows them to do the things that are important and meaningful to them.

Does this priority cover what is important for people living with dementia, their families and their carers in Fife?

- ☐ Fully covers
- ☐ Partially covers
- ☐ Does not cover at all

16. Please tell us why you answered that way:

17. Are there any other priorities that we have not covered that are important for people living with dementia, their families and their carers in Fife?

- ☐ Yes
- ☐ No

18. If Yes, please tell us what other priorities we should cover that are important for people living with dementia, their families and their carers in Fife:



Your Experiences

We would like you to share your experiences of dementia services and support in Fife.

19. What does good dementia care and support look like for you?

20. What has been your experience of accessing dementia services in Fife?

- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very Poor
- ☐ I have not accessed dementia services in Fife

21. Please tell us why you answered that way:

22. If you have experienced an admission to hospital in the last year, please tell us what that experience was like.

- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very Poor
- ☐ I have not accessed dementia services in Fife

23. Please tell us why you answered that way:



24. Are you aware of any gaps in dementia services and support in Fife that you think need urgent attention?

- ☐ Yes
- ☐ No

25. If Yes, please tell us what gaps in dementia services and support need urgent attention:

26. What is your preferred way of accessing information relating to the services and supports available to help delay the onset of dementia or to help you make choices about care, treatment and support?

- ☐ Internet
- ☐ Facebook
- ☐ Instagram
- ☐ Tiktok
- ☐ YouTube
- ☐ LinkedIn
- ☐ I don't access information online
- ☐ Leaflets
- ☐ Face-to-face
- ☐ Other

27. Would you like to be involved in shaping dementia services in Fife?

- ☐ Yes
- ☐ No

28. We are developing a lived experience network to help us to engage with people who use health and social care services. Would you be interested in finding out more about joining the network for people who have lived experience of dementia services?

- ☐ Yes
- ☐ No

29. Would you like to be added to our mailing list to be made aware of future engagement opportunities?

- ☐ Yes
- ☐ No



30. Would you like to know the outcome of this consultation?

- ☐ Yes
☐ No

31. If you answered yes to any of the above questions, please make sure you provide your contact details.

Please provide your name here:

32. Please provide your email address here:

33. Please provide any other contact details:

About You





34. Which area of Fife do you live?

- ☐ Cowdenbeath (includes Lochgelly, Kelty and Cardenden)
- ☐ City of Dunfermline
- ☐ Kirkcaldy (includes Burntisland and Kinghorn)
- ☐ Glenrothes (includes Thornton, Kinglassie and Leslie)
- ☐ Levenmouth (includes West Wemyss, Buckhaven, Methil, Methilhill, Kennoway and Leven)
- ☐ North East Fife (includes Auchtermuchty, Cupar, Taybridgehead, St Andrews, Crail and Anstruther)
- ☐ South West Fife (includes Inverkeithing, Dalgety Bay, Rosyth, Kincardine, Oakley and Saline)
- ☐ I do not live in Fife

35. Which of the following best describes you?

- ☐ A member of the public
- ☐ A person with dementia
- ☐ A person who works or volunteers to provide Health and Social Care
- ☐ An unpaid carer (*Unpaid carers provide care and support to family members, friends and neighbours. The people they care for may be affected by disability, physical or mental ill-health, frailty or substance misuse*)

Supporting Unpaid Carers in Fife

Unpaid carers provide care and support to family members, friends and neighbours. The people they care for may be affected by disability, physical or mental ill-health, frailty or substance misuse.

Since the Carers (Scotland) Act 2016 was introduced, we have made significant improvements in the scale and scope of the support we offer to unpaid carers. We know there is more we can, and we will do.

We want to ensure that carers have access to high quality information at a time and place that best meets their needs and enables them to make positive choices regarding their caring role. There are also a range of supports available that you may be entitled to apply for, as an unpaid carer:

- Carers income maximisation service
- Grants available to support carers experiencing financial crisis
- Adult Carer Support Plans (ACSP)
- Micro-breaks available to carers with an ACSP
- Short breaks services for carers and
- The development of a 'Fife Unpaid Carers Forum' offering unpaid carers a safe and welcoming space to share your experiences, seek advice and advocate for your rights.



36. Are you aware of what support is available to unpaid carers and who to ask for help?

- ☐ Yes
☐ No

37. Do you currently access support?

- ☐ Yes
☐ No

38. What support do you currently access?

39. Can you share some of the reasons why you don't access support?

40. What would be the best way of getting information about support for unpaid carers to you?

41. Would you like to join Fife Health and Social Care unpaid carers email network, so that we can invite you to take part in any future engagement opportunities, to ensure that we are capturing your 'carer' voice within our feedback?

- ☐ Yes
☐ No

42. As per our privacy statement, we also work with a range of organisations who are commissioned by Fife Health and Social Care Partnership to provide care and support, in particular Fife Carers Centre. Would you be happy for us to share your contact details with Fife Carers Centre, who support adult carers in their caring role, who will be able to offer relevant, straightforward



information as well as practical help? (If you are selecting yes, please make sure you complete the contact details below).

- ☐ Yes
- ☐ No
- ☐ I am already supported by Fife Carers Centre

43. If you answered Yes to the above questions, please provide your name here:

44. Please provide your email address here:

45. Please provide any other contact details here:

Equalities, Diversity, and Inclusion

Under the Equalities Act 2010 (Scotland) we continue to work to protect people from discrimination because of:

- age
- disability
- gender reassignment
- race
- religion or belief
- sex
- sexual orientation
- marriage and civil partnership
- pregnancy and maternity

We strive to ensure that people who identify with these protected characteristics can participate in any events that are of interest to them.

We will use the information in this section to understand who is responding to our consultation and engagement exercises. The information will help us to ensure we have representation from the broadest set of people within Fife and we are reaching every part of our community.

The information will be used for monitoring and reporting purposes relating to this consultation and for no other reason.



Any information you provide will remain anonymous and each question is optional.

The Fife Council Privacy Notice includes more details about the information we collect and how it is used. This is the link:

<https://www.fife.gov.uk/home/privacy-policy>

Fife Council Data Protection Officer can be contacted at: dataprotection@fife.gov.uk

46. Would you like to continue to provide us with feedback to help us better understand who we are engaging with?

☐ Yes ☐ No

Thank you for agreeing to continue to provide feedback. Any information you provide will remain anonymous and each question is optional.

47. What is your age?

- ☐ Under 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65 and older
- ☐ Prefer not to say

48. How would you describe your gender?

- ☐ Man
- ☐ Woman
- ☐ Trans man
- ☐ Trans woman
- ☐ Non-binary
- ☐ Identity not listed
- ☐ Prefer not to say

49. If you would like to specify your identify, please use the following text box

50. How would you describe your sexual orientation?

- ☐ Asexual
- ☐ Bi-sexual



- ☐ Fluid
- ☐ Gay man
- ☐ Lesbian
- ☐ Pansexual
- ☐ Queer
- ☐ Straight / Heterosexual
- ☐ Identity not listed
- ☐ Prefer not to say

51. If you would like to specify your identity, please use the following text box

52. Which of the following best describes your ethnic group or background

☐ **White:**

- ☐ Scottish ☐ English ☐ Welsh ☐ Northern Irish ☐ Other British ☐ Irish ☐ Polish
- ☐ Gypsy / Traveller ☐ Roma ☐ Showman / Showwoman ☐ Other:

☐ **Mixed or multiple ethnic groups:**

Please write in:

☐ **Asian, Scottish Asian or British Asian:**

- ☐ Pakistani, Scottish Pakistani or British Pakistani ☐ Indian, Scottish Indian or British Indian
- ☐ Bangladeshi, Scottish Bangladeshi or British Bangladeshi ☐ Chinese, Scottish Chinese or British Chinese ☐ Other:

☐ **African, Scottish African or British African:**

Please write in (for example, Nigerian, Somali):

☐ **Caribbean or Black:**

Please write in (for example, Scottish Caribbean, Black Scottish):

☐ **Other ethnic group:**

- ☐ Arab, Scottish Arab or British Arab
- ☐ Other, please write in:

☐ **Prefer not to say**

53. What is your religion or belief?

- ☐ None
- ☐ Church of Scotland



- ☐ Roman Catholic
- ☐ Other Christian
- ☐ Muslim
- ☐ Hindu
- ☐ Buddhist
- ☐ Sikh
- ☐ Jewish
- ☐ Pagan
- ☐ Prefer not to say
- ☐ Other:

54. Would you describe yourself as having a health condition and / or a disability?

- ☐ Yes ☐ No ☐ Prefer not to say

55. Do you have any of the following, which have lasted, or are expected to last, at least 12 months? (Tick all that apply)

- ☐ Deafness or partial hearing loss
- ☐ Blindness or partial sight loss
- ☐ Full or partial loss of voice or difficulty speaking (*a condition that requires you to use equipment to speak*)
- ☐ Learning disability (*a condition that you have had since childhood that affects the way you learn, understand information, and communicate*)
- ☐ Learning difficulty (*a specific learning condition that affects the way you learn and process information*)
- ☐ Developmental disorder (*a condition that you have had since childhood that affects motor, cognitive, social, and emotional skills, and speech and language*)
- ☐ Physical disability (*a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting, or carrying*)
- ☐ Mental health condition (*a condition that affects your emotional, physical, and mental wellbeing*)
- ☐ Long-term illness
- ☐ Disease or condition (*a condition, not listed above, that you may have for life, which may be managed with treatment or medication*)

56. What is your relationship status?

- ☐ Single
- ☐ Married
- ☐ Divorced
- ☐ Civil Partnership
- ☐ Widowed
- ☐ Separated
- ☐ Living with a partner



☐ Prefer not to say

57. Are you currently breastfeeding, pregnant, or recently given birth?

☐ Yes

☐ No

☐ Prefer not to say

58. Please specify if you are:

☐ Pregnant

☐ Breastfeeding

☐ Recently given birth

☐ Prefer not to say

Thank you for taking the time to complete this form.



Appendix 2 - Stakeholder List

Fife HSCP Adult Social Work Teams
Fife Council Housing
Fife Council Very Sheltered Housing/Extra Care Service
IJB Carers Representative
IJB Public Representative
NHS Fife Dementia Services and Mental Health Teams
Consultant Old Age Psychiatry
Consultant Medicine of the Elderly
Consultant Neurologist
Nurse Consultant for Older adults and Frailty
Head of Nursing HSCP
Director of Nursing (Acute)
OT Team Leader NHS Fife
OT Service Manager NHS Fife
Social Work OT Team Managers
Head of Older Adults Psychology
Clinical Psychologist and Co-lead of Dementia Education Leadership Group
Head of Nursing Care Homes
Head of Nursing HSCP and Lead for Dementia
NHS Fife Post Diagnostic Teams
GP Practices
Alzheimer Scotland
Fife Carers Centre
Citizens Advice and Rights Fife
Scottish Dementia Working Group (SDWG)
Local Authority Care Homes
Kingdom Housing Association
Scottish Care
Fife Housing Group
Glen Housing Association
Trust Housing Association
Blackwood Homes and Care



Barchester Healthcare
Balhouse Care Group
Abbotsford Care homes
Fife Housing Register
Fife Voluntary Action
Fife Forum
Fife Centre for Equalities
Age Scotland
Fife Sports and Leisure Classes
Later Life Choices
Crossroads Fife
Sporting Memories
Memory Makers Fife
Fife Council Safer Communities
Scottish Fire and Rescue Service
Dunfermline Advocacy
DEEP
STAND
Participation and Engagement Subscribers List
Participation and Engagement Unpaid Carers Subscribers List

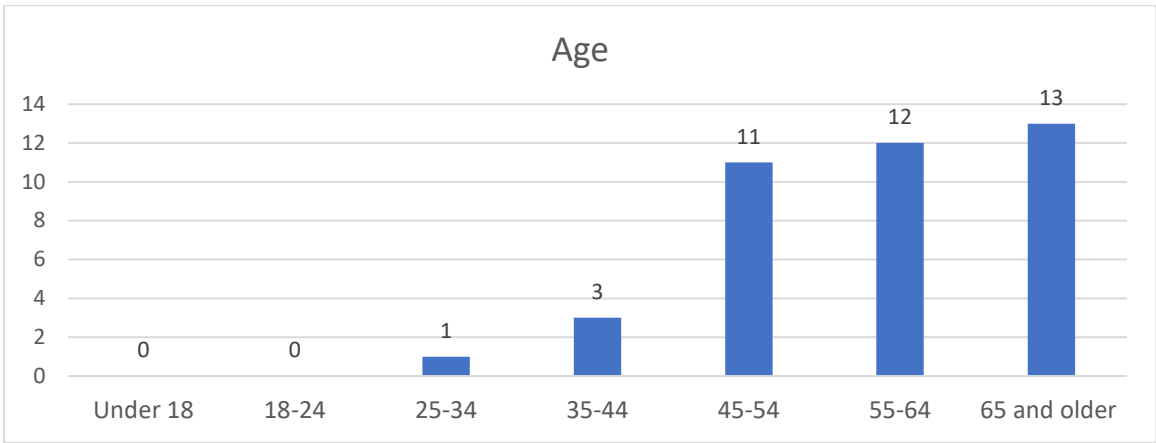
Face To Face Engagement Sessions

Stand Dementia Friendly Meeting Spaces
STAND Young Onset Dementia Group
Later Life Choices Glenrothes
Fife Forum Action Groups – Kirkcaldy, Glenrothes and Leven
Abbotsford Care Homes Dunfermline and Tayport

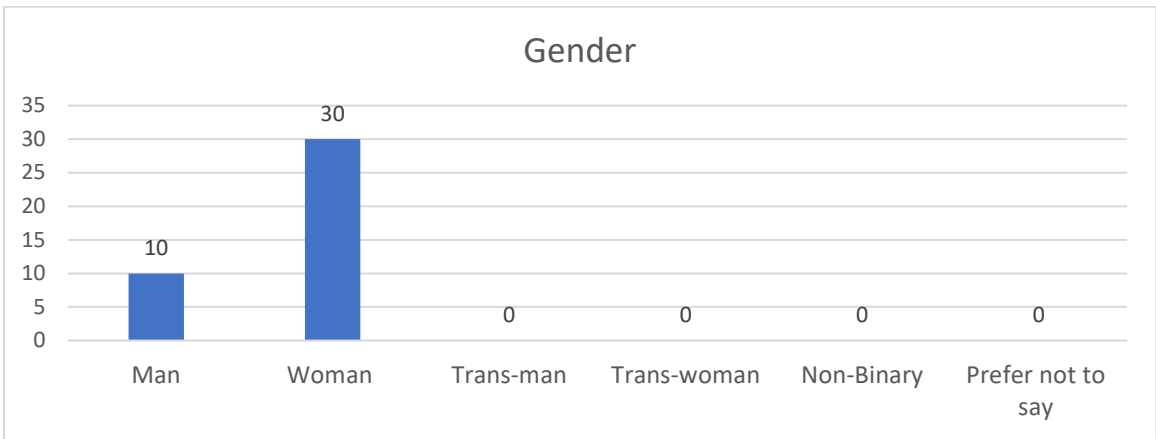


Appendix 3 - Equality, Diversity and Inclusion Data

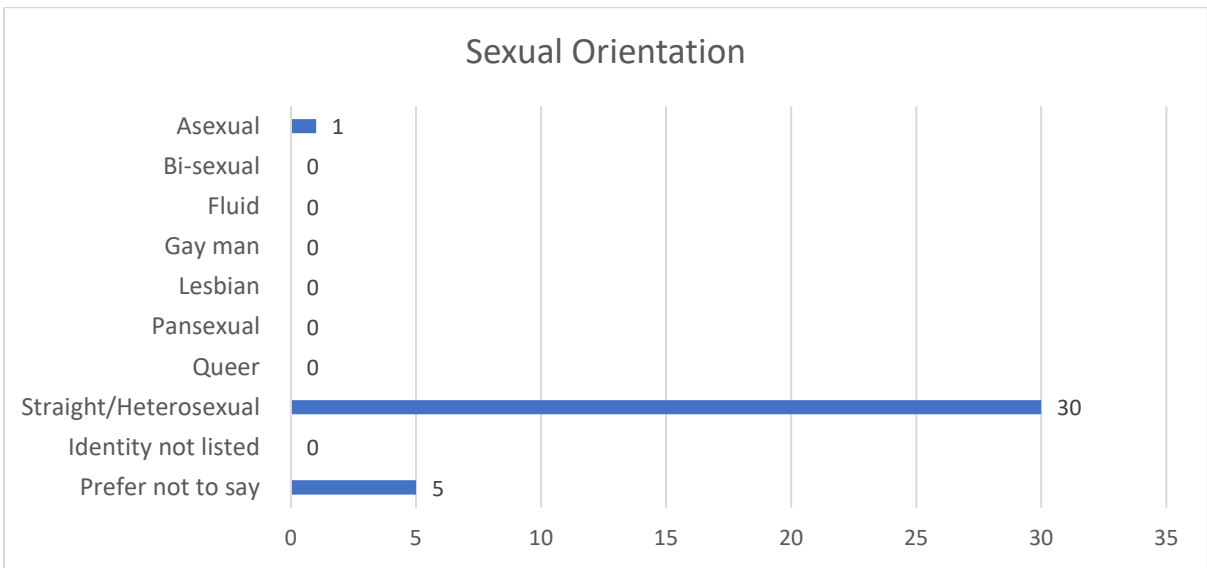
Age



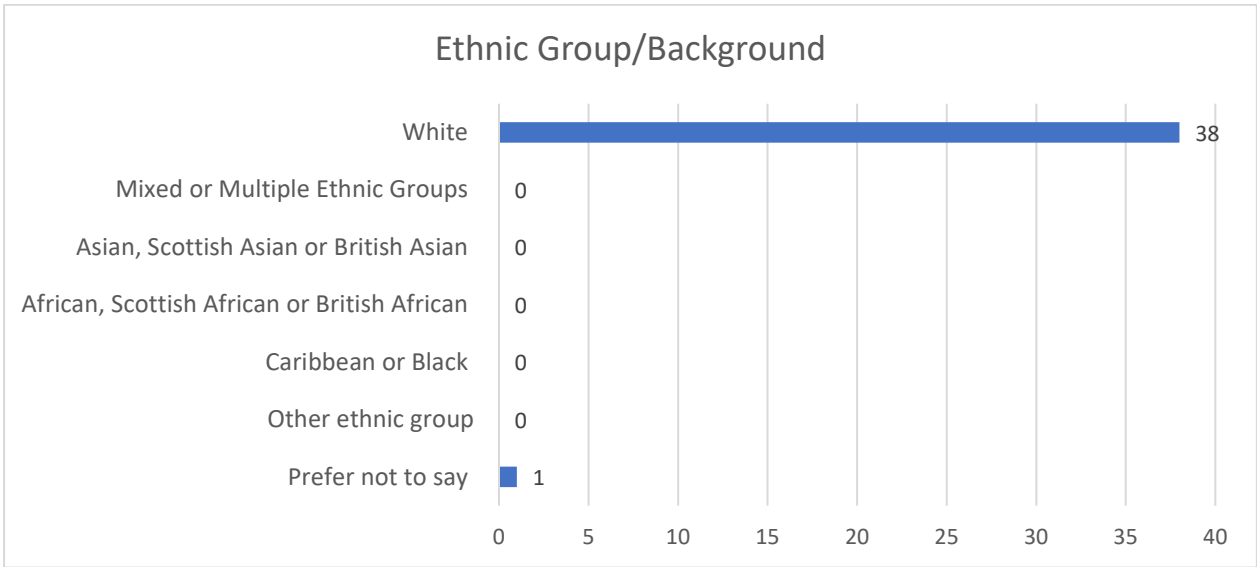
Gender



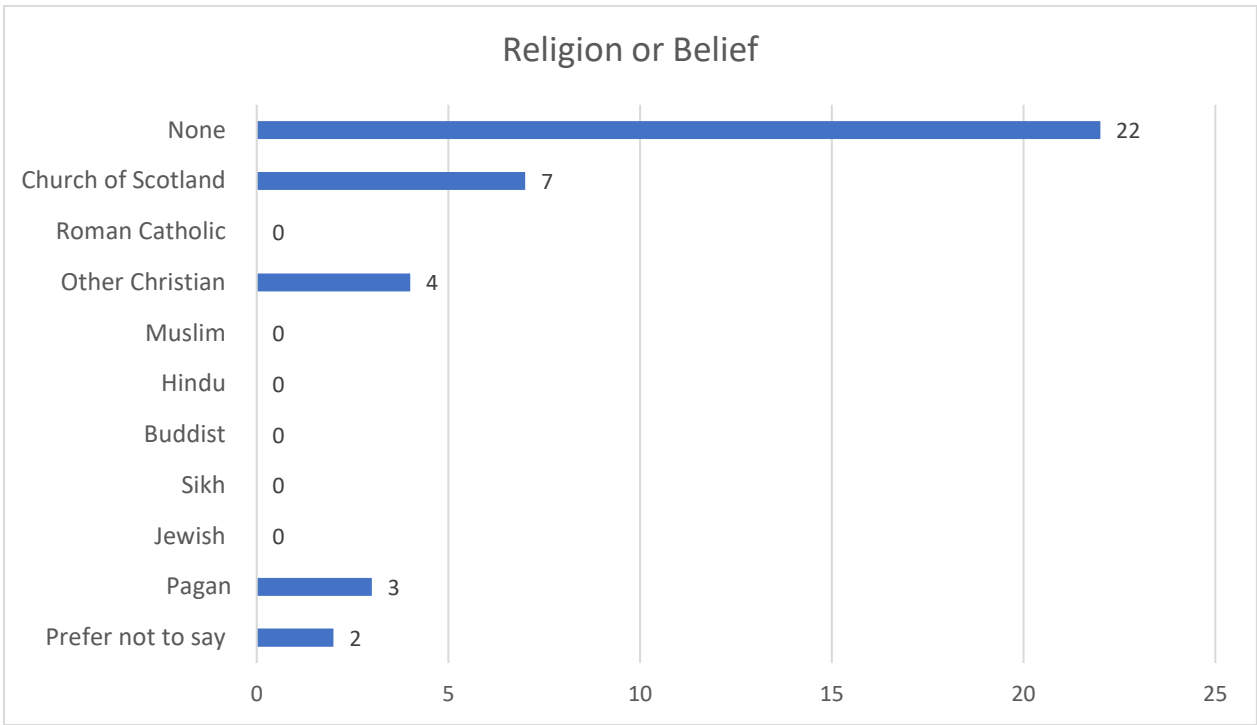
Sexual Orientation



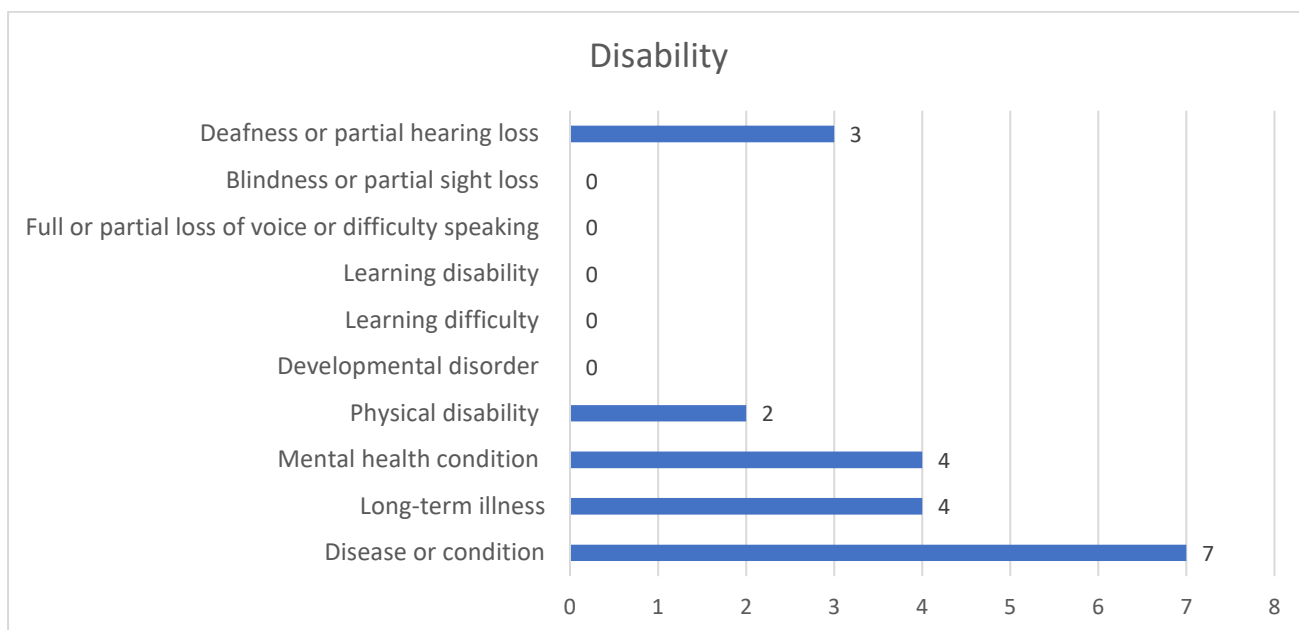
Ethnic Group/Background



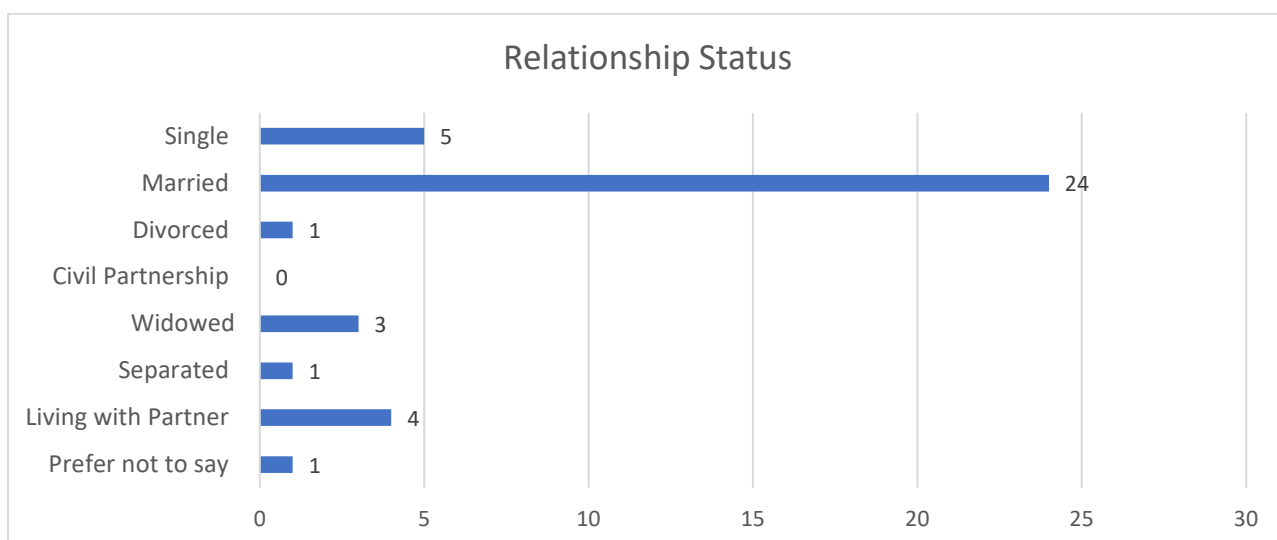
Religion or Belief



Disability



Relationship Status



Pregnant, breastfeeding or recently given birth

