



## LGBTQ+ COMMUNITIES & DEMENTIA

ENGAGEMENT REPORT  
JUNE 2018

The Brighton & Hove Clinical Commissioning group has commissioned Switchboard (formerly 'Brighton and Hove LGBTQ Switchboard') to conduct a series of consultation and engagement activities with Brighton & Hove and Sussex-based lesbian, gay, bisexual, trans and queer (LGBTQ+) people affected by dementia, and the professionals and volunteers supporting them. This engagement work will be used to inform how LGBTQ people affected by dementia can be best supported; and to identify areas where improvements to patient experience can be made.

*Please note, the following report presents information about the consultation and engagement work conducted by LGBTQ Switchboard, and should not be taken as a position statement of Brighton and Hove LGBTQ Switchboard or of any participating organisation.*

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# Executive Summary

## Background

According to one estimate, there are **around 56,000 lesbian and gay people living with dementia in the UK** (McParland & Camic 2016). However, **taking into account trans, non-binary, bisexual, queer and other (non-cis, non-heterosexual) sexual and gender identities, the number is likely to be significantly higher**. This figure would also not take into account numbers of those living with, but undiagnosed, with dementia, and the large numbers of those who care and support a family member, partner or friend with dementia.

Brighton & Hove CCG indicates that there are 1811 patients with dementia aged 65+ currently on their lists, and that there may be approximately 1000 more who are as yet undiagnosed. Utilising the common '1 in 10' statistic regarding LGBTQ+ identity, this means there may be at least **280 LGBTQ+ people living with the condition in Brighton and Hove alone**. Again, however, adding to this carers and those under 65 living with the condition, the number is likely to be much higher.

While the Department of Health's 2009 National Dementia Strategy helped to raise the profile of dementia and promote it up the national agenda, it did not make any reference to the particular needs of LGBTQ people. Indeed, while a current **lack of standardised monitoring of sexual orientation, gender identity and trans status** on both local and national levels, means that the **actual statistics of LGBTQ+ people affected by dementia are unknown**, it is clear from the estimated statistics this group represents a sizeable population. However, as Roger Newman (2012), an LGBTQ+ dementia activist and former carer of a partner with the condition, notes, it is **a population that remains "largely invisible to both policy makers and practitioners"**.

In the past five years, however, there has been significant research and engagement activity within the voluntary sector and academia to understand the needs and experiences of this under-served group, from which this report draws to inform its recommendations. It is Switchboard's hope that this piece of engagement can further extend the body of research around LGBTQ+ needs and dementia, to help **inform the discussion on better serving the intersectionally diverse communities represented within this broad group at both local and national levels**.

## Overview of Engagement

From April to June 2018, Switchboard's Health and Inclusion Project (HIP) carried out **engagement with the LGBTQ+ community and health and social care providers on the subject of LGBTQ+ people affected by dementia: their experiences in relation to living with the condition and of accessing care and support**. The aim of the engagement was to understand the specificities of LGBTQ+ experiences in relation to dementia, and the challenges and opportunities of these communities in accessing dementia care and support in Brighton and Hove and Sussex.

As part of this engagement, we carried out **two online surveys: one for LGBTQ+ people affected by dementia**, for which we received 14 valid responses, and **one for the professionals and volunteers who support them**, for which valid responses from 21 individuals were gathered.

We also **reviewed existing literature and engagement on LGBTQ+ experience and dementia**, and drew from Switchboard's experience through the Rainbow Café – a monthly social meet-up for LGBTQ+ people affected by dementia or concerned about memory loss.

# Key Findings

The findings of Switchboard's surveys echoed and extended many of the existing findings of other organisations' engagement and research with LGBTQ+ people on the topic of dementia, and included the following key points.

**LGBTQ+ people continue to face significant barriers to accessing dementia care and support**, with 64% of LGBTQ+ respondents providing at least one example of an LGBTQ+ based barrier, including having experienced homo-, bi- or trans-phobia from staff (20%). Among other reported barriers, it was found that more than two thirds reported a lack of LGBTQ specific information and resources as a barrier, followed by hetero- and cis-normativity, at nearly 1 in 3 respondents.

Echoing the findings of HIP's Inclusion Award engagement, **confidence and trust in health and social care services** to provide LGBTQ+ inclusive care was relatively low, with just short of a quarter of LGBTQ+ respondents saying they did not have trust or confidence in any of the professionals they worked with, and nearly half said they did so only with 'some'. It was found that, as a whole, service providers' confidence meeting LGBTQ+ needs outpaced their professional experience working with these communities, and LGBTQ+ people's confidence in staff to meet their needs was lower than professionals' confidence to serve them.

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*64% of LGBTQ+ people affected by dementia surveyed said they had experienced some form of gender or sexual orientation based barrier to accessing dementia care and support.*

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NEARLY **1 IN 4** LGBTQ+ PEOPLE SAID THEY DID NOT HAVE TRUST OR CONFIDENCE IN ANY OF THE PROFESSIONALS THEY HAD WORKED WITH

**Heteronormativity** as a key barrier to accessing support came through strongly in the LGBTQ+ engagement, and was also reflected through some responses to the professional and volunteer survey, where both hyper-individualising and hyper-generalising approaches to support meant that individuals' LGBTQ+ status, and related inequalities, needs and experiences, were not adequately addressed.

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*"My sexuality and the sexuality of my partner seems either wrongly assumed or not deemed relevant"*

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The **Intersectional Engagement Challenge** of engaging individuals who experience marginalisation and/or inequalities in relation to accessing health and social care across an intersecting range of characteristics. In addition to sexual orientation and/or trans status and dementia diagnosis, these may include age (for older people affected by dementia) and often other factors, such as other forms of disability, carer status, race and ethnicity, immigration status and more. Engagement strategies must therefore be diverse and flexible to help reach and engage a diversity of groups.

**Single and socially isolated** LGBTQ+ people affected by dementia face particular challenges, including delays to accessing diagnostic support due to a lack of social support. LGBTQ+ people are likelier to be single and/or socially isolated than their heterosexual peers, and this therefore constitutes an inequality, as well as an additional engagement challenge.

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*“As the LGBTQ community has a greater proportion of single people [...] then the fear of having dementia and being alone must be even greater and consequent anxiety levels heightened.”*

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**LBTQ+ women**, in particular, are currently under-represented among those engaging with research and consultation into dementia, despite being the majority of those both living with the condition, and providing care for those who do.

**Young-onset dementia** is an issue for the LGBTQ+ community, with younger LGBTQ+ people affected by the condition facing additional barriers to diagnosis and appropriate support and care. Yet, at present, services are geared primarily towards older people in a way some feel to be at the expense of those with younger-onset manifestations of the condition.

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*“NHS and support services seem not to recognise the existence of people with early on-set dementia who are not in their old age. The system seems geared towards old age people and there is very little support for those who are not well into retirement. Being in a different generation needs to be recognised as the nature of support and the way it is delivered needs to reflect the cultural and life experiences of the person living with dementia.”*

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**HIV-associated neurocognitive disorder (HAND)** is a form of HIV-related dementia disproportionately affects men who have sex with men and sex-working LBTQ+, particularly trans, women. Some form of this condition affects up to half of people with HIV (Alzheimer’s Society 2018). HIV-related dementia may then also contribute to LGBTQ+ people being over-represented among those with a young onset of the condition.

**Trans people affected by dementia and memory loss** have particular needs, which health and social care providers have a duty to meet. For those living with the condition, this may include being supported to express and navigate their gender identity and expression as capacity lessens and there is an increasing reliance on others to perform this function for them. Support around medications, such as HRT, may also be required. Professionals’ confidence serving trans people’s needs was relatively low, and further training in this area was particularly desired.

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**HIV-associated neurocognitive disorder (HAND) affects up to half of people with HIV**

a condition that disproportionately affects MSM and sex-working LBTQ+ (particularly trans) women (Alzheimer’s Society 2018)

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*“Nobody has any support or idea how to help a 22 year old trans woman with memory loss so I have to learn everything myself”*

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**LGBTQ+ carers face additional pressures** due to a tendency of some professionals, volunteers and family members to de-value their LGBTQ+ relationships and commitments and therefore expect these individuals to take on greater responsibilities of care. Partners who are carers face particular challenges, often related to heteronormative assumptions that mean their relationships are overlooked or de-valued.

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*“Professionals and my wider extended family assume I can always be available to care for Mum because my relationships are either invisible to or less valued by them than a conventional heterosexual monogamous marriage would be.”*

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While more than half of LGBTQ+ respondents rated their **quality of care** in the NHS at 8 or 9 out of 10, more than a third rated their care at 5/10 or less, and 14% of LGBTQ+ people surveyed felt that they or the person they cared for had not been treated with dignity or respect throughout their care (including in non-NHS settings). LGBTQ+ respondents also said they would have liked to have received more signposting and information regarding support groups and resources.

**The need for LGBTQ+ inclusive later-life care**, particularly in residential settings, was a high priority for LGBTQ+ people, who are likelier to rely on formal care support in later life due to less access to traditional familial and social support systems. A strong narrative of fears of being ‘forced back into the closet’ runs throughout existing literature on LGBTQ+ older people, and it important to LGBTQ+ people that they are free and safe to be themselves in care settings.

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**14%** of LGBTQ+ people surveyed felt that they or the person they cared for **had not been treated with dignity or respect** throughout their care

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*“I worry for myself and my queer friends that when we are older we might have no choice but to go into care homes or use care facilities that are not LGBTQ affirmative. This is quite a big concern for us and we often discuss whether we could make alternative arrangements to be looked after in queer community of some kind.”*

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LGBTQ+ respondents named **eliminating heteronormativity and increasing LGBTQ+ visibility, information and resources as top priorities for inclusion**. These findings are echoed in existing research and engagement with LGBTQ+ affected by dementia, and indicate continued room for development around training, organisational culture and resource provision.

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*“It is important to understand that those of us who are members of minority groups are always looking for signs that we are ‘included’. Failure to show such signs sends a message that our needs are neither considered nor met, and even, perhaps, that we are not welcome at all” (Roger Newman 2010 in ‘Meeting the Needs of LGBT People Affected by Dementia’)*

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Supporting existing research and engagement, it was found that **LGBTQ+ specific community support was highly valued**, for those living with dementia, concerned about memory loss and carers alike. Services like Switchboard’s Rainbow Café are therefore seen as very important resources by the community, who find a sense of belonging in community to be essential to their wellbeing.

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*“As much community support as can be provided. The need to engage with others is imperative”*

*“Helps to be part of a community that understands”*

*“The LGBT community have been my main source of support throughout my time caring for my parents. I would not have coped without them and am truly grateful to them”*

*“As an LGBTQ carer, I'd like to have been offered any info about any peer support communities (online or [in real life]) for LGBTQ carers of people with memory loss/dementia.”*

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# Recommendations

Below is a brief summary of the recommendations emerging from this engagement, a more detailed version of which can be found at the end of this report.

## 1. Sexual Orientation, Gender and Trans Status Monitoring

Implement monitoring of Sexual Orientation, Gender and Trans Status at patient intake and other key points of patient contact, alongside other equalities monitoring.

## 2. LGBTQ+ Specific Group and Individual Support

We recommend further developing and supporting LGBTQ+ specific group support, and having a designated person as a point of contact throughout a person's journey with dementia.

## 3. LGBTQ and T Awareness Training

LGBTQ+ awareness training should be included in clinical and non-clinical staff training as standard, with a particular focus on trans\* inclusion. This should include general LGBTQ+ awareness, as well as specific training in relation to the needs of LGBTQ+ people affected by dementia.

## 4. Clarify communications around end of life care – including 'next of kin' and 'power of attorney'

Governance processes, admissions documents and other paperwork should be adapted to change the language of 'next of kin', with its heteronormative implications, to explicitly recognise and include informal support networks and families of choice. The distinction between next of kin and power of attorney should be explained carefully and with sensitivity to the particular circumstances of any given LGBTQ+ person.

## 5. Visible LGBTQ+ Inclusivity & LGBTQ+ Affirmative Communication

LGBTQ+ affirmative and inclusive language should be used in patient communications as a matter of course, and visible LGBTQ+ affirming signifiers, like leaflets, information guides and posters should be freely and visibly available.

## 6. LGBTQ+ Affirmative Accreditation

Brighton & Hove CCG should pursue LGBTQ+ affirmative accreditation for health and social care services, such as Switchboard's [LGBTQ+ Inclusion Award](#)

# Terminology

**‘PERSON AFFECTED BY DEMENTIA’** is used throughout to refer to individuals who have either received or are exploring a diagnosis of dementia, and those who are concerned about memory loss, as well as individuals who care for and support them in a non-professional capacity, such as partners, friends, and family members.

**‘LGBTQ+’** refers to lesbian, gay, bisexual, trans\*, queer and other sexual orientation and gender minority groups.

**‘Cis’/ ‘CIS-GENDER’** refers to individuals whose current gender matches the gender they were assigned at birth.

**‘HETEROSEXISM’ AND ‘CISSEXISM’** refer to the tendency to value, implicitly or explicitly, heterosexuality or cis-gender status, respectively, more highly than other sexual orientations or trans and/or non-binary genders.

**‘HETERONORMATIVITY’ AND ‘CIS-NORMATIVITY’** refer to the promotion of the worldview of heterosexuality or cis-gender status, respectively, as the normal or ‘neutral’ sexual orientation or gender identity.

# Introduction

It is estimated that there are around 1.2 million older gay and lesbian people in the UK (Equality and Human Rights Commission 2010) and, according to one estimate, around 56,000 lesbian and gay people living with dementia in the UK (McParland & Camic 2016). However, taking into account trans, non-binary, bisexual, queer and other (non-cis, non-heterosexual) sexual and gender identities, the number is likely to be significantly higher. This figure would also not take into account numbers of those living with, but undiagnosed, with dementia, and the large numbers of those who care and support a family member, partner or friend with dementia.

Brighton & Hove CCG indicates that there are 1811 patients with dementia aged 65+ currently on their lists, and that there may be approximately 1000 more who are as yet undiagnosed. Utilising the common '1 in 10' statistic regarding LGBTQ+ identity, this means there may be around 280 LGBTQ+ people living with the condition in Brighton and Hove alone. Again, however, adding to this carers and those aged under 65, the number is likely to be much higher.

While the National Dementia Strategy (Department of Health 2009) helped to raise the profile of dementia and promote it up the national agenda, it did not make any reference to the particular needs of LGBTQ people. Indeed, while a current lack of standardised monitoring of sexual orientation, gender identity and trans status on both local and national levels, means that the actual statistics of LGBTQ+ people affected by dementia are unknown, it is clear from the estimated statistics this group represents a sizeable population. However, as Roger Newman (2012), an LGBTQ+ dementia activist and former carer of a partner with the condition, notes, it is a population that remains "largely invisible to both policy makers and practitioners".

As Newman also points out, when a person receives a diagnosis of dementia, they are often reduced – at least in the public consciousness – to their diagnosis, thereby 'obliterating other defining personal features and social identities, apart from those highlighted by the condition'. As such, bringing LGBTQ+ experiences of dementia into focus is essential for humanising and personalising care and support of those affected by the condition.

In the past five years, however, there has been significant research and engagement activity within the voluntary sectors and academia to understand the needs and experiences of this under-served group, from which this report draws to inform its recommendations. It is Switchboard's hope that this piece of engagement can further extend the body of research around LGBTQ+ needs and dementia, to help inform the discussion on better serving the intersectionally diverse communities represented within this broad group at both local and national levels.

## Engagement Overview

Switchboard carried out two strands of engagement to learn about the needs, challenges and experiences of LGBTQ+ people affected by dementia and the services that support them:

1. LGBTQ+ people affected by dementia or memory loss, including those who provide informal and unpaid care and support, such as partners, friends and family members
2. Health and Social Care professionals and volunteers who support LGBTQ people affected by dementia, including carers

We chose to broaden the criteria from those with a diagnosis of dementia to also include those concerned about memory loss because, as the early stages of engagement and research indicated, the path to receiving a dementia diagnosis is potentially a long and challenging one, and that many individuals may live with the condition for considerable time before receiving a formal diagnosis.

We chose to open the surveys to individuals and organisations within both Brighton & Hove and the wider Sussex area, due to the small sample size and engagement challenges of reaching a more isolated population, with the view that experiences of those in nearer locations will also be relevant for the CCG's consideration in taking the experiences of this group into account in future commissioning. Since Brighton and Hove has a particularly young population (Brighton & Hove City Council 2014), this approach also meant a greater likelihood of capturing the experiences of individuals in neighbouring towns with older populations, who are likelier to be affected by dementia.

## Methodology

### Online Surveys

Two online surveys were carried out as part of the engagement. One was aimed at professionals and volunteers supporting people affected by dementia, and the other was for LGBTQ+ people affected by dementia, including partners/family members/friends of LGBTQ+ people affected by dementia.

The surveys were conducted using SurveyMonkey over a period of six weeks in May - June 2018. Both surveys were live and promoted intensively over Dementia Action Week 2018 (21-28 May), using the #DAW2018 hashtag. Paper copies of the survey were also advertised alongside links to the SurveyMonkey online form and offered to local community organisations for distribution to their clients and workers/volunteers, with a number of these being requested.

The surveys were promoted and distributed through a variety of channels including Switchboard's LGBT HIP, Older People and Community Group members' mailing lists, Switchboard's social media channels on Facebook and Twitter, email lists for Community Works, Community Base and all LGBT Switchboard staff and volunteers.

Lisa Douglas, the commissioner for dementia services also assisted by circulating both surveys through professional contacts at key dementia support providers, including the Memory Assessment Service and the Carers Centre. We also reached out directly to the local Dementia Action Alliance and the Alzheimer's Society to circulate the surveys. However, Switchboard did not meet the Alzheimer's Society's criteria for supporting research-related activities, and as a result, unfortunately the AS declined to circulate the surveys through their networks. However, some individuals in the organisation were reached through Switchboard's general social media outreach campaign and responded to the survey. Switchboard also promoted the engagement and surveys by attending May's Rainbow Café, and by liaising with the HOP 50+ project.

Survey responses have been analysed and reviewed by Switchboard's LGBTQ Engagement Officer, Sophie Barnes, and qualitative responses have been reviewed to identify key themes and extend quantitative findings.

### *Limitations and challenges*

The sample of both surveys was relatively small. 21 individuals passed the exclusion criteria and went on to complete the survey for professionals and volunteers, and 14 individuals did so for the LGBTQ+ community survey.

No LGBTQ+ identified individuals with a current diagnosis of dementia responded, although several respondents concerned about memory loss did, as did several LGBTQ+ carers. While this small sample limits the reliability of results, this challenge to engage is in itself indicative of one of the most pressing issues facing LGBTQ+ people affected by dementia: isolation. Indeed, for the LGBTQ+ community survey, engaging individuals with the multiple stigmas and isolating factors of LGBTQ+ identity, dementia, carer-status and/or older-age was a particular challenge. The 'Over the Rainbow' project reported a similar problem reaching and engaging LGBTQ people with dementia themselves (2015), despite significant planning and scale of engagement.

Although one person living with dementia and their partner was engaged at Switchboard's Rainbow Café, they declined to participate in the survey. Although they did not say why, it is understandable that the distressing nature of reflecting on the challenges one faces in accessing care as an LGBTQ+ person with the condition would be prohibitive for many people.

# LGBTQ+ & Dementia:

## What We Already Know

### LGBTQ+ Health Inequalities and Dementia Risk Factors

A number of health inequalities experienced by LGBTQ+ communities also constitute dementia risk factors, meaning that these communities may be particularly vulnerable to the condition. Adding to this the cumulative health inequalities of older age, and other possible axes of marginalisation such as disability and ethnicity, an individual's sexual orientation and/or trans status may have significant implications for the likelihood of developing dementia.

#### Lifestyle factors: Diet, Exercise, Smoking and Substance Use

Lifestyle factors such as smoking, alcohol consumption, a lack of a healthy diet and regular exercise have all been identified as risk factors for dementia, and are also issues which disproportionately affect the LGBTQ+ community, as has been demonstrated and explored in previous HIP reports (Switchboard/ HIP 2017, 2016) and existing research.

The heightened stress levels endured by LGBTQ+ people associated with social, familial and economic marginalisation (often termed 'minority stress'), coupled with a lack of appropriate support, mean that these communities are likelier to rely on substances, such as tobacco, alcohol and recreational drugs, as coping strategies. For example, according to research by the LGBT Foundation, 29% of lesbians and bisexual women binge drink at least once a week compared to 15% of women in general, and a Trans Mental Health Study carried out in 2012 found that 47% of trans people drank at high and potentially problematic levels.

#### HIV

HIV, a condition disproportionately affecting men who have sex with men (including gay, bi and queer men) and sex-working lesbian, bisexual, queer and – particularly – trans women, has also been linked to a higher likelihood of developing dementia (NAT 2015). HIV infection can also cause a number of different problems in the brain, which fall under the umbrella term of HIV-associated neurocognitive disorder (HAND). Some form of this condition affects up to half of people with HIV (Alzheimer's Society 2018). However, this situation is improving: according to the Alzheimer's Society only around 2% of people living with HIV now experience dementia, whereas this figure was 20-30% before antiretrovirals were available.

#### Hormones

A lack of research means that the effects of hormone replacement therapy for trans individuals who choose this as part of their transition (it is important to remember that some trans and/or non-binary people will not choose to take hormones) are as yet unknown, and so any possible connections between this and a vulnerability to dementia are still unknown, and require further research.

## LGBTQ+ Inclusion Barriers in Mainstream Services

### Low levels of confidence and trust

In addition to health inequalities experienced by LGBTQ+ people, existing research and engagement reveals that low levels of confidence and trust in staff to be LGBTQ+ aware, inclusive and affirmative are a key barrier. Switchboard's HIP report on the Kitemark Scheme (now 'Inclusion Award': Switchboard/ HIP 2016) revealed that trust and confidence in primary healthcare services, including GP surgeries, to be LGBTQ+ aware and inclusive was low. The 2018 HIP report into sexual orientation, gender and trans status monitoring reinforced this finding, and points in particular to issues around not only accessing services, but feeling uncomfortable to disclose one's sexual orientation or trans status upon engagement with healthcare professionals and reception staff due to concerns and fears about staff response and possible discrimination.

For LGBTQ+ people with dementia, particularly those who are older, this is particularly problematic, as there may be additional barriers to feeling comfortable sharing information about sexual orientation and trans status related to fear of stigma and prejudice, based on socially and politically exclusive and prejudicial attitudes to sexual and gender variance experiences earlier in life.

This is further supported by research, reported by Newman (2012) which has found that practitioners in dementia care are unaware of how to respond appropriately to LGBT service users (Manthorpe and Price 2003; Price 2005, 2007, 2010, 2011; Ward 2000; Ward, Pugh and Price 2011). As a result, LGBTQ+ service users must manage additional anxieties related to this response to their sexuality (or lack thereof) – often including the service providers' as well as their own.

### Poor LGBTQ+ representation in resources and publicity

Though simple and easily remedied, the importance of visible LGBTQ+ inclusivity in information resources and publicity should not be underestimated, and its lack has been cited as a key barrier to inclusion for LGBTQ+ people affected by dementia.

LGBTQ+ dementia activist Roger Newman (2012), who founded the now closed LGBT Dementia Support Network with the Alzheimer's Society, writes of the 'consistent use' of 'non-inclusive images' used in dementia literature, primarily (in this case) from the Alzheimer's Society, wherein publicity materials showed "Caucasian people surrounded by loving, supportive [opposite sex] spouses and, presumed biological, families."

Newman continues that he enquired of the Society whether he "was the only person caring for someone with dementia who wasn't married, or who wasn't the same gender as the person with dementia they cared for," and adds:

*"It is important to understand that those of us who are members of minority groups are always looking for signs that we are 'included'. Failure to show such signs sends a message that our needs are neither considered nor met, and even, perhaps, that we are not welcome at all"*

The Alzheimer's Society has since gone on to improve its engagement with LGBTQ+ issues and communities, and is currently undertaking an 'LGBT Dementia' project to further this aim.

### Heteronormativity and Cisnormativity

The implicit and explicit valuing of cis-heterosexuality as the normal or preferred sexual orientation and gender identity, and the subsequent de-valuing of LGBTQ+ identities and experiences emerged as widespread problems throughout health and social care in existing research and engagement.

Unlike some other forms of marginalisation along lines of, for example, skin-colour, age, and certain forms of disability, LGBTQ+ status is not always visible, apparent or legible to others. Where LGBTQ+ status is not marked by the person with traditional or stereotypical signifiers of their respective identity (and even when it is), others can make the hetero- and/or cis-normative assumptions that the person is heterosexual and cisgender 'until proven otherwise'.

As a result, LGBTQ+ people are placed in a position of needing to decide whether to 'come out' (that is, to disclose their sexual orientation and/or gender) to service providers, and to manage the attendant anxieties of uncertainty about the response they will receive. Cultures of heteronormativity and cisnormativity place the onus of disclosure on the LGBTQ+ person, adding additional anxieties to the existing considerable challenges a person with a diagnosis of dementia or their carer may be managing.

Assumptions that individuals are heterosexual; unduly questioning the commitment, longevity and stability of LGBTQ+ relationships; and refusing LGBTQ+ partners access to information or contact with one another on the basis of their relationships not being seen as real or legitimate are all common examples of inclusion barriers rooted in heteronormativity experienced by LGBTQ+ people throughout literature on these communities' experiences in accessing dementia care.

The Dementia Action Alliance roundtable report on LGBTQ+ people and dementia presented a case study of a lesbian couple, Sue and Sandi, affected by dementia, who spoke of struggling with heteronormativity in their attempts to access care:

*"Following Sue's diagnosis, Sandi would spend lots of time trying to explain her relationship to social services and others, who struggled to understand the basic fact that they are in a relationship. This was a frustrating and time-consuming experience.*

*They found that they faced a lot of pushback and aggression from health and social care staff e.g. asking Sandi "who are you?" They think it would have been different if they were a heterosexual couple.*

*Sometimes they used to lie and say they were sisters before it was legal.*

*Sandi has been asked repeatedly by health and social care professionals if she is planning on staying with Sue, despite them knowing they have been married for over 20 years. Sandi feels like a heterosexual couple would not be asked the same kind of question."*

#### Mainstream activity barriers

Post-diagnostic support and activities focusing on biography and life story can have particular and at times difficult meanings for older LGBTQ+ people living with dementia. Many grew up (particularly people aged 65+: Morrow, 2001) in a time when LGBTQ+ relationships were illegal and punishable by law, and when these identities and experiences were considered indicative of mental illness, a view which was enshrined in the Diagnostic Statistical Manual until 1973.

Trans communities continue to face pathologisation, stigmatisation and exoticisation in mainstream media and political discourse throughout the UK and internationally, and may face particular barriers to engaging with activities relying on individuals' memories, backgrounds and life stories, some of which they may not wish to share, and may for individuals with a dementia diagnosis, create distress, dysphoria and confusion.

If sexuality and gender have not been openly discussed in a care and support setting, or if the environment is not felt to be LGBTQ+ affirmative, individuals may not feel safe disclosing some of



the most important information about their lives related to these areas, for fear of negative responses from staff and other residents. Avoidance of or failure to reference and value LGBTQ+ identity in these activities is indicative of heteronormativity, and, prior engagement work has indicated, leaves LGBTQ+ people feeling excluded and uncomfortable (DAA 2017, University of Worcester 2015).

The Dementia Action Alliance roundtable report iterated this point, stating “Care homes often have support groups (the majority of which are not LGBT specific), which LGBT people may feel uncomfortable attending due to references to their family. Someone who identifies as LGBT may feel uncomfortable or fearful when discussing their personal life, which may include a same sex partner and/or an unsupportive family” (DAA roundtable report 2017, p4).

Engagement and research has also indicated a preference for LGBTQ+ people to engage in activities and support with fellow community members (DAA 2017, University of Worcester 2015), finding that LGBTQ+ exclusive spaces were felt to be safer to explore the challenging issues faced by them through dementia.

#### Care settings

LGBTQ+ unaware or actively exclusive staff in care settings may intentionally or unintentionally suppress individuals’ ability express their gender and/or sexuality, meaning that some LGBTQ+ older people feel they are forced ‘back into the closet’ in later life (National Care Forum 2016). Further to this the DAA Roundtable report stated:

*“being admitted in to hospital, a care home or receiving homecare with dementia can be a frightening experience for anyone, and may be even more daunting for LGBT people with dementia. While the Equality Act guarantees protection from discrimination based on your sexuality or gender, prejudice and stigma is still widespread in care settings, which results in many places not providing appropriate, sensitive and person-centred support to LGBT people with dementia. As a consequence, in many cases their needs are not met.” (2017, p3)*

Even where this issue is not service-wide, individual care-givers in a given setting may express homo/bi/trans-phobic views, requiring an appropriate plan for challenging this kind of behaviour. The DAA report continues:

“Even if a care setting is inclusive and providing good quality care, a pervading issue within the sector is certain staff members’ views of homosexual and trans people. Some care setting staff members are unaccepting of LGBT people, due to religious or cultural views of homosexuality in their home countries. As a result, there have been many recorded instances of staff members discriminating against LGBT residents with dementia. This is why many LGBT people with dementia often do not disclose their sexuality to care staff, which leads them to hiding their sexuality or gender upon entering a care setting.” (DAA roundtable report, p4-5)

The DAA Roundtable report also shared the experiences of a gay couple, Mike and Tom, in a case study, as they discussed their fears and concerns about accessing care. Both experienced homophobic abuse when young, at a time when it was illegal to be gay, and expressed how important it is for them to be free to be who they are, and that any care would support this:

*“They are worried about if they get separated, one will go into a care home by themselves.*

*When they were looking for a care home for Tom, they struggled to find places that advertised themselves as being LGBT friendly, and sometimes felt uncomfortable asking questions. This meant many of the homes seemed unsuitable for their needs.*

*They find that typical, heterosexual support services are insufficient as they feel they cannot be as open about their lives, their experiences and who they, as heterosexual people wouldn't be able to relate as much to homosexual people.*

*They struggle with having to come out to health and social care professionals, as this can be an emotional and difficult thing to do repeatedly, especially when they are unsure of the response that they will receive - 'coming out' is an ongoing process."*

#### Engagement Challenges and Intersectionality

It is important to take an intersectional approach to understanding the multiple ways in which LGBTQ+ individuals face barriers to engaging with services. This means recognising that multiple facets of an individual's identity may present particular challenges and opportunities, privileges and disadvantages, in different contexts.

There are a number of challenges to engaging LGBTQ+ people affected by dementia, and particularly those with the condition, pre- or post-diagnosis. Some of these are outlined above, as with individuals feeling uncomfortable accessing primary care services or sharing their sexual orientation or trans status when they do so.

However, a particularly significant barrier to inclusion is the isolation experienced not only by many sectors of the LGBTQ+ community, but also older people, those with dementia, and those with a disability/disabilities. As noted by the NHS 'dementia rarely travels alone', and many individuals with dementia will likely also have at least one other disability, whether that's a mental health condition, long-term health condition, sensory impairment, neurodivergence, developmental condition or any other form of disability.

#### Single LGBTQ+ People and Social Isolation

Social isolation is particularly acute among single individuals, and research has found that LGBTQ+ individuals are likelier to be single in later life than their heterosexual peers (YouGov and Stonewall 2011). Those who are not partnered in later life, and especially those who are also socially isolated, may face additional challenges to accessing and engaging with care and support due to a lack of motivational and encouraging support from those close to them, and additional difficulties managing appointments and getting out and about due to disability/ies, including, for example, physical and sensory impairments and mental health conditions. As a result, many single and/or socially isolated LGBTQ+ people may easily 'slip through the cracks' between initial assessment and referral to support.

LGBTQ+ people are also more likely to be estranged from their family of origin, more likely to live alone and less likely to have children than their non-LGBT peers (Westwood & Price 2016). As such, LGBTQ+ people are therefore much likelier to rely on families of choice, as Monks and Shaw note in their research on the topic:

*"Family and informal carers provide the majority of care to people with dementia, but in the case of LGBT people this is more likely to be from families of choice than families of origin and these families are more likely to be single-generational. Such families of choice and other social networks may lack the legal certainties of "next of kin" biological or marriage relationships." (Monks, S. & Shaw, A., 2017, p 12)*

Furthermore, "some biological families may be unwilling to acknowledge or honour the sexual or gender identity of the person." (Ibid.) and, as a result, may be more likely to need to rely on formal care (National Care Forum 2016). This means that care settings have a particular responsibility to be

welcoming and inclusive of LGBTQ+ communities, who are likelier to have nowhere else to turn for support.

Being single and/or socially isolated also presents a challenge for identifying memory loss and the early stages of dementia. As one participant at the Switchboard's rainbow café put it: *'how do you know if you have memory loss if you have no one who is observing you on a daily basis?'*

### Sexual Orientation, Gender and Trans Status Monitoring

A recent HIP report into sexual orientation, gender and trans status monitoring (Switchboard/ HIP 2018) also highlighted a lack of monitoring as a barrier to engagement – both for LGBTQ+ accessing services, and for services in attempts to engage LGBTQ+ individuals.

It was found that LGBTQ+ people were less likely to feel comfortable approaching and accessing primary health care in part due to a lack of recognition of their particular needs related to sexual orientation and/or trans status – something it was felt equalities monitoring was a key strategy to addressing. In turn, a lack of consistent monitoring of these characteristics by services meant that they were unaware of the numbers and circumstances of LGBTQ+ individuals accessing (or not accessing) services, so that they could design outreach and engagement strategies accordingly.

Although it is often feared that asking these questions will be considered inappropriate or intrusive, HIP's engagement findings echoed those of the LGBT Foundation, which found that the vast majority of LGBTQ+ people were happy to be asked, as long as they understood how and why the information would be used.

### Next of Kin Recording and Power of Attorney

In addition to equalities monitoring, other forms of information capture – particularly next of kin recording – are also important to effective engagement, support and care. This is particularly the case in the later stages of dementia when the individual living with dementia may lack capacity to make decisions about their care, and reliance on others for guidance around best interest decision come into play. As such, it is important that health and social care services record information in a way that accurately captures the reality of LGBTQ relationships and living situations.

Although by law, one's allocated 'next of kin' does not have to be someone one is in a legally recognised relationship to (such as a child or spouse), this is a common misconception, both among staff and patients (DAA 2017, University of Worcester 2015, Opening Doors and Compassion in Dying 2018). The legalistic language of 'next of kin' may indicate this to LGBTQ+ individuals, and it may therefore be beneficial to find a more neutral way of wording this.

This is also often confused with 'power of attorney' and it is not often well understood what the distinctions and rights of these two categories entail, or the processes involved in allocating POA.

### Legal Issues and Planning Ahead for End of Life Care

Some people affected by dementia may need to think about planning ahead for what they would like to happen if or when they no longer have the capacity to make their own decisions about their care. This is a difficult and sensitive thing to consider, and LGBTQ+ individuals and communities may face particular challenges in approaching this.

A resource for LGBTQ+ people planning ahead for end of life care created by Opening Doors in partnership with the charity Compassion in Dying outlines some of the needs and experiences of these communities. In addition to highlighting the ambiguity of 'next of kin' language, and clarifying the meaning of this, the resource also explains that, as LGBTQ+ older people are likelier to be single

and to not have children (who traditionally may support their care and decision-making in later life) it is likely that individuals will grant legal decision-making power (such as Lasting Power of Attorney) to a friend or partner, rather than a family member or spouse.

LGBTQ+ people should be supported in exploring their options, and resources such as the above could be shared with patients to support this. It is also important that LGBTQ+ individuals are supported to share who they would like (and would not like) disclosure and discussion of health information to be shared with. For instance, some LGBTQ+ estranged from their families may not wish for certain family members to be included in discussions and decisions about healthcare, or to have medical information shared with them.

#### Challenges for LGBTQ+ carers

LGBTQ+ dementia activist Roger Newman writes that “research to date suggests that caring for a person with dementia, as a gay man or lesbian woman, presents a range of challenges and associated well-founded anxieties that are, arguably, unique.”

For instance, as LGBTQ+ individuals are likelier to live in a different geographical location than their family of origin, they may be likelier to face challenges with traveling to provide care, and difficulties accessing adequate support in either location.

LGBTQ+ carers, particularly women, Newman also reports from his experience running the now closed National LGBT Dementia Helpline, are also likelier to be more heavily relied upon and expected to carry out caring roles for biological/ family-of-origin members as they are perceived as ‘single and therefore more free to do the work’.

Those who care for a partner living with dementia face particular challenges in terms of heteronormativity and lower valuing of their relationships, resulting in reports of individuals who are refused access to visit their partner due to a lack of legally recognised relationship, who are dismissed as ‘concerned friends’ or whose relationship validity and longevity is unduly questioned.

## LGBTQ+ Specific Impacts of Dementia

### Identity Issues

Dementia can have a significant impact on a person's personality and sense of identity, but this can be particularly amplified for LGBTQ people, for whom identity may have been a particularly strong – and possibly challenging – theme throughout their life. Due to the neurological changes incurred through dementia, some people may come to experience their gender and/or sexuality differently. While this is also true for cis-heterosexual people, LGBTQ+ individuals may bring a lifetime of experience of their gender and/or sexuality being a subject of much closer social and public scrutiny, and may therefore be understandably more sensitised to these changes. Some LGBTQ people with dementia may become more, or less, inhibited in expressing their gender and/or sexuality as the condition progresses, and may need particular support from loved ones and professionals to help them maintain their sense of self, relationships and identity throughout their condition.

### Trans Experiences

Trans individuals face different and particular challenges than cis-gender LGBTQ+ individuals when they develop dementia, and may also face additional challenges of being LGBTQ+.

A common issue reported throughout the literature on trans individuals with dementia was the experience of 'reverting' to gender identity and expression assigned at birth. This creates dysphoria and distress both for the individual concerned, and for loved ones, who may need to support the person to express their gender in a way that is unfamiliar to them.

Emphasising the need for a person-centre approach, and outlining some of the key issues for trans people with dementia, the DAA's Roundtable Report (2017) states:

*"For trans people with dementia who have reverted back to the gender that they were born with, several specific issues may arise in care settings. Namely, should a male or female clean them and how should they be dressed? Additionally, trans people with dementia may be living with medical issues relating to the gender that they were born with that begin to emerge when the person ages. For instance, a trans woman with dementia may get a diagnosis of prostate cancer. It is therefore extremely important that their health is cared for properly. For a trans resident with dementia it may be difficult to remember to take their hormone treatment or other vital drugs and this can have a negative impact on the mental health of the person if this is not rigorously controlled. Trans people may cross-dress as a result of their dementia, because of confusion relating to their gender expression, or because they have repressed the urge their entire life and now feel liberated to do so. Regardless of the reason, a care setting should have plans in place for when this happens. They should not be stopped, reprimanded or judged. It is the person's decision to do so and they should be made to feel as comfortable as possible." (DAA roundtable report, p5-6)*

The report also found that trans people often felt excluded and marginalised within LGBTQ+ discussions on dementia and that their particular needs and experiences were often overlooked. It was noted in the discussion that participants felt a balance needed to be struck between being explicitly inclusive and welcoming, and yet avoiding drawing excessive attention to trans individuals in a way that might be experienced as 'othering'.

### Young Onset Dementia

While dementia disproportionately affects older people, particularly those over 65, younger people may also develop the condition, and face particular challenges related to their age, as well as their LGBTQ+ status.

HIV, which disproportionately affects men who have sex with men and LGBTQ+ sex workers, a disproportionate amount of whom are trans women, has been linked to dementia, as described above. Indeed, an untreated HIV diagnosis can lead to HIV-associated neurocognitive disorder (HAND), which can affect individuals of any age.

A webinar hosted by the Alzheimer's Society in May 2018 featured a guest presenter, Patrick, a 34 year old gay man with a diagnosis of young-onset frontal lobe atrophy. Patrick has a diagnosis of HIV and lives with a number of mental health issues, including schizophrenia. Originally from Barbados, he has lived in the UK for many years. He spoke of his struggle for several years to receive a formal diagnosis and therefore to receive the support and care he required, with diagnosticians failing to take his symptoms seriously enough, which he felt was linked to his age, and even his aesthetic presentation, with his GP giving the man's smart dress sense as an indicator that he could not have dementia. Patrick has found the support services to be completely geared for older people living with dementia and this has led him to feeling isolated in dealing with his diagnosis, and unable to access adequate support. Patrick's main fear is being on his own – and what this means for him and his future – and he spoke of the challenges of finding a partner as a young person living with frontal lobe atrophy.

The problems experienced by Patrick are shared by many younger LGBTQ+ people living with dementia, who are more likely to live alone and without access to the support systems cis-heterosexual people are likelier to enjoy.

It is therefore important to understand that LGBTQ+ people may be over-represented among individuals with younger onset dementia, and particular care should be made to engage these groups and understand the health inequalities they face that may contribute to a diagnosis of younger-onset dementia.

## Switchboard's Rainbow Café

In February 2018, Switchboard launched the Rainbow Café: a monthly social meet-up for LGBTQ people living with dementia or concerned about memory loss. Funded by an £11,725 grant awarded by the Rainbow Fund, the Café provides an opportunity to come together and socialise over tea, coffee and cake, and to take part in a variety of activities, which vary monthly. Through the Rainbow Café, Switchboard also aimed to raise awareness of dementia within the LGBTQ+ community and put LGBTQ+ experiences and needs in relation to dementia on the map for services.

The launch of the Rainbow Café hosted a performance of a one-man play entitled 'The Purple List', which told the story of a man support his partner living with dementia, and the highs, lows and challenges of their experiences as a gay couple.

The group meets monthly at Brooke Mead on Albion Street, Brighton, BN2 9PY, and – at the time of writing the report – is undergoing engagement with the community to learn about how the group can better serve the needs of its participants.

The group has been regularly attended by 5-6 individuals.

However, it became clear throughout the group that the needs and experiences of the group members varied greatly – from those in the early stages of concern about memory loss, to those at a more progressed stage of diagnosed dementia. This has presented a challenge for the group facilitators in attempting to keep the group inclusive, supportive and enjoyable for members with such a wide range of experience and need.

While participants stated that they valued having a space to come together as LGBTQ+ people, the group is disproportionately attended by men, and there are issues around serving the needs of all attendees in a differentiated way. It has also been found that those in the very early stages of concern about memory loss have somewhat dominated the group discussions, creating an environment that is less inclusive and enjoyable for those attending with a more advanced form of the condition, and those supporting them.

Engaging LGBTQ+ people with a diagnosis of dementia is a widespread challenge that Switchboard also encountered. Through the ongoing engagement, conducted via interviews with participants, Switchboard aims to discover how these groups might more effectively be reached.





## Review of Existing LGBTQ+ Dementia Engagement and Research

Monks, S. & Shaw, A. LGBTQ+ Dementia Research

# LGBT and dementia: what do we know?

LGBT people's needs are often overlooked in dementia care. **Sarah Monks** and **Angie Shaw** explain the problem and one way to solve it

Monks and Shaw (2017) facilitated a 2.5 hour workshop to capture conversations and ideas for best practice for people with personal and professional experience of the intersection of LGBTQ+ identity and dementia. This was a collaboration between a hospital dementia team and its LGBT staff network, Alzheimer's Society and the LGBT Foundation, and an 'expert by experience'. More than 30 individuals attended – 'some' of whom were LGBT, the report said.

Recommendations emerging from the engagement included:

- Improved visibility of LGBT people living with dementia in educational and promotional literature, including visual representations of non-heterosexual families as a matter of course.
- Specific education and training in awareness of gender and sexuality issues
- Improvements in monitoring to inform services of local need and to enable the capture of information in a sensitive and timely manner.
- Governance processes to be adapted to recognise and include informal support networks and families of choice, changing the language of "next of kin" with its heteronormative implications to more inclusive categories such as "significant other" or "partner in care". For this to be reflected in admissions documents.
- Specific training and guidance on the physical health needs of people who have had genital reconstruction and other surgeries as well as the implications of long-term hormone replacement.

The project developed plans to implement a scoping exercise for the development of a LGBT and Dementia Network Alliance in the region revealed significant interest. Further meetings are planned to formalise the structure and purpose of the alliance.



## The Alzheimer's Society: LGBT Dementia Project

The Alzheimer's Society undertook a piece of community engagement with LGBTQ+ people to better understand their needs and experiences, with a view to developing their offer for these communities.

Their engagement with LGBTQ+ people across the UK yielded the following findings:

### 1. Need for a 'go-to' place for support. Existing services don't take into account the needs of LGBTQ+ people affected by dementia.

- People don't know where to go for help, particularly at first, and particularly if they are on their own

*'There's no go-to place – where do I start?'*

*'I don't feel connected.'*

- People find it easier to be open with those in a similar situation. Many LGBTQ+ people affected by dementia may have experienced stigma or ignorance, both within health and social care settings, and within peer groups.

*'I need to feel safe, comfortable and secure in the environment before I feel I can talk about those things.'*

*'I've experienced ignorance within groups from those with dementia. They didn't understand my situation and how I had no carer or partner to support me.'*

- Services are not 'geared up' for LGBT+ people

*'When they only refer to heterosexual couples in scenarios, it makes me feel excluded, not offended, but not entirely inclusive...Can't they just say 'partner' instead?'*

*'A cultural change is needed for services.'*



### 2. Existing services are not sufficiently LGBTQ+ aware – issues with stigma, prejudice and fears of poor treatment

- Being made to feel uncomfortable and frustrated:

*'I'm constantly asked if we're going to stay together: by doctors, social workers and so on. Heterosexual couples I've spoken to aren't asked this.'*

*'If I'd experienced prejudice from my GP, I would have withdrawn.'*

*'It is assumed that we are friends or sisters, and not partners or a married couple. If we want to be seen, we have to come out again and again, unsure of people's response. We have enough to deal with without that as well!'*

- Concerns around discrimination and prejudice in care homes

*'There's homophobia and transphobia – it's a huge issue for care staff who have religious or cultural views.'*

### 3. Barriers to LGBTQ+ individuals and couples having wishes respected around long-term planning for care.

- Legal situations for LGBTQ+ people affected by dementia are not understood by everyone

*'We have to put an enormous amount of work into wills, lasting power of attorney, final decisions, finances and so on.'*

*'My siblings are legally my next of kin. I want it to be my partner. I'm worried that my siblings will appeal against her being my lasting power of attorney, as we're not married. Our solicitor advised us to have a civil partnership which we didn't want to have to do.'*

*'If you are transgender, the law may not recognise your gender identity unless you go through a formal process to have it recognised.'*

- Encouragement and understanding around long-term planning

*'I need to be told the truth so I can plan early.'*

*'People need to be equipped with knowledge and be assertive about their rights.'*

### 4. Need to recognise the specific experiences of LGBTQ+ individuals affected by dementia rather than a 'one-size-fits-all' approach

- Lack of knowledge and awareness around unique needs of LGBTQ+ people affected by dementia

*'There's discrimination but there's also lack of awareness, understanding and knowledge – it's not always deliberate. It's the absence of information.'*

- In the wider context of health

*'People don't know much about HIV-related dementia – there are links but it isn't highlighted properly publicly.'*

- Trans communities have some even more complex needs and experience further sets of challenges, including reverting to their previous gender, medical implications and stigma.



## Dementia Action Alliance: LGBT+ Community 'Seldom Heard Groups' Roundtable

The Dementia Action Alliance held a roundtable discussion as part of a campaign to improve care and support for people affected by dementia from seldom heard groups.

The key issues emerging from the discussion included:

### Under-representation and stigma

This is partly, the report found, due to sexual orientation and gender identity not being monitored when they receive a diagnosis, get admitted to hospital or enter a care home. Further to this, continuing LGBTQ+ stigma, particular among over 65s, means that some people will choose not to disclose for fear of prejudice.



### Heteronormativity

Heteronormativity (a world view that promotes heterosexuality as the normal or preferred sexual orientation) was also found to be at play in many care and support settings. Examples included marketing materials showing images exclusively of heterosexual couples and gendered language around partners suggesting heterosexual partners only.

### Activities

Heteronormativity, as discussed above, can also exclude LGBTQ+ individuals from certain activities, particularly those around sharing memories, background and life stories. Where there is a lack of explicit LGBTQ+ inclusion, individuals may feel uncomfortable or unsafe sharing about some of the most important aspects of their identity and experience.

### The support of families-of-origin

A family-of-origin of an LGBTQ+ person affected by dementia may not be supportive of that individual's sexual orientation or gender identity, and may attempt to influence health and social care providers to deter them from expressing these aspects of their identity.

Families of choice (for example, groups of close friends) are more prevalent among LGBTQ+ communities, and these individuals should be involved and communicated with regarding provision of care (with consent of the person affected).

### Staff

Even where care settings are relatively inclusive as a whole, individual staff members may harbour anti-LGBTQ+ views and beliefs, and may discriminate against LGBTQ+ individuals. Care settings

should nominate a Diversity and Equality champion to help ensure that any instances of homo-/bi-/trans- phobia are suitably challenged, and that the care setting is inclusive as possible.

### Partners

Partners of LGBTQ+ people affected by dementia should be supported to engage in all of the caring and supporting activities expected between cis-heterosexual partners, including helping with bathing, expressing physical affection and intimacy.

### Trans people affected by dementia

Trans people are faced with specific challenges when they develop dementia and require specific support. This can include 'reverting' to identify with the gender assigned at birth, and may feel anxious, confused and upset and the form of addressed used for them and, if they have undergone any surgical interventions as part of their transition, may also experience dysphoria in response to their present embodiment.

Trans individuals may also require additional support with taking hormones as part of HRT treatment, and, in residential care settings, should also be supported to choose whichever forms of dress they choose.

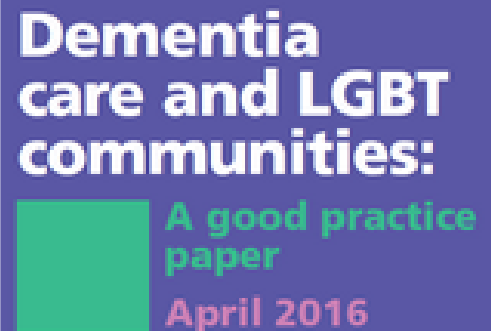


## National Care Forum, Voluntary Organisations Disability Group and the National LGB&T Partnership: “Dementia care and LGBT communities”

Working in partnership, the National Care Forum, Voluntary Organisations Disability Group and the National LGB&T Partnership, produced a report entitled “Dementia care and LGBT communities” (2016), which included several case studies of LGBTQ people affected by dementia.

Key learning points from the engagement included:

- “establishing a clear purpose that an organisation is LGBT-friendly, and ensuring that this aim is supported at board-level
- educating the workforce; developing specialist LGBT training materials for staff, such as guidelines encouraging the use of gender neutral pronouns
- promoting diversity, inclusion and presenting the environment as non-discriminatory; with same-sex couples in marketing materials, for example
- designing support sessions such as reminiscence activities sensitively and appropriately, to avoid returning people to a challenging period in their sexuality or gender identity
- recognising the value of peer-led networks and lived experience – both as a support for individuals supported and as a sounding board to advise on policy
- an awareness that LGBT people might have a wide support network involving those who are not conventional family members
- ensuring that partnership approaches to support – for example, those involving care staff, social services, healthcare professionals and voluntary sector agencies – enable all partners to collaborate on care and support plans.” (NCF 2016)



## University of Worcester: 'Over the Rainbow' Report

The Over the Rainbow project was created in partnership with the University of Worcester Association for Dementia Studies, Birmingham LGBT Centre for Health and Wellbeing and PACE Health London. The project was funded by DEEP, which is led by Innovations in Dementia in Partnership with the Mental Health Foundation. The aim of the Over the Rainbow DEEP project was to develop a support and advocacy group for LGBTQ people with dementia (February 2014 - February 2015). It aimed to offer:

- 1) An opportunity for LGBT people with dementia and carers to come together in safe spaces
- 2) The facilitation of intergenerational dialogue, support and advocacy
- 3) The voices of LGBT people with dementia to be heard (through ongoing 'dementia rainbow friends' buddying, and online representation).

While a total of 11 eligible individuals participated in the project, none of these were LGBTQ+ individuals with dementia themselves, but rather carers. "The lack of engagement from LGBT people with dementia underscores the challenges of accessing this very hard to access group."

A conversation was facilitated around the topic: "What are the particular issues for LGBT people with dementia?" The following key themes emerged:

- Loss of family connections
- LGBTQ+ scene may be youth-oriented and not inclusive for some older people and those with dementia
- Some LGBTQ people 'back in the closet' in care settings

The following recommendations were made:

- Quality Care Commission to audit care homes on LGBT friendliness: '*compulsory provision on the part of all inspectors to ask the question: "what are you doing for LGBT people?"*'
- Training for care home staff to carefully and sensitively determine the sexual orientation of all residents
- Explicit recognition that not all LGBTQ+ people will have partners and may be likelier to rely on friendship support networks.
- Explicit recognition that some LGBTQ+ people may have partners and be in legally recognised relationships with them, including civil partnership and marriage.



### "Over the Rainbow" Lesbian, Gay, Bisexual and Trans People and Dementia Project

#### Summary Report

#### Report on the LGBT people and dementia support and advocacy project

February 2015

The project is funded by DEEP, which is led by Innovations in Dementia in partnership with the Mental Health Foundation. DEEP is funded by the Joseph Rowntree Foundation and Comic Relief.





## ‘Meeting the Needs of LGBT People Affected by Dementia: The Story of the LGBT Dementia Support Group’ Roger Newman and Elizabeth Price

Chapter in *Lesbian, Gay, Bisexual and Transgender Ageing: Biographical Approaches for Inclusive Care and Support* (2012) Richard Ward, Ian Rivers, Mike Sutherland (eds.)

Roger Newman, LGBTQ+ dementia activist and former carer of his late partner who had a diagnosis of dementia, worked with the Alzheimer’s Society to establish the LGBT Dementia Support Network. The Network took the tagline “Gay or Straight: Dementia Doesn’t Discriminate” and aimed to be a resource of information, solidarity and support for LGBTQ+ people facing dementia throughout the UK, offering a nation-wide helpline service. The network faced many challenges throughout its time, and was reluctantly closed only when the Alzheimer’s Society redirected its funding elsewhere.

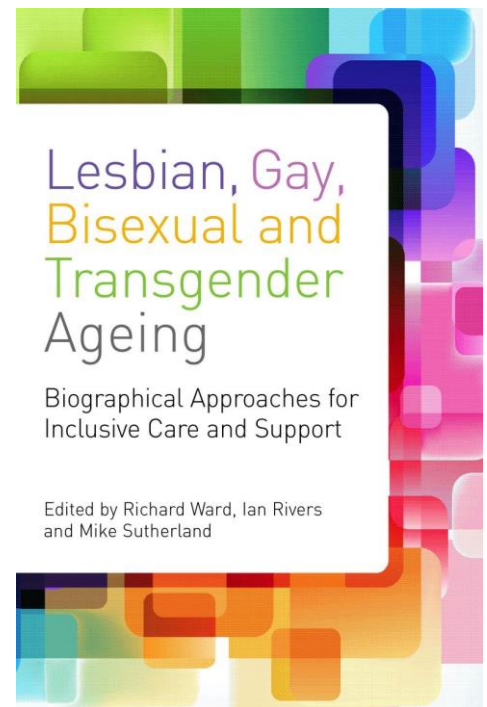
Newman speaks about his difficulties interacting with health and social care providers who were not comfortable or equipped to respond empathically or appropriately to a gay male couple affected by the condition. Supporting his partner when he was first diagnosed, in the early 90s, he writes:

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*“During the eight years of caring, I can honestly say [...] that no service provider related to me in a straightforward or empathic way. My partner’s doctor refused to see me even though we had taken out mutual powers of attorney; his designated social worker refused to respond to numerous phone calls because, they said, I was ‘simply a concerned friend’; following his sectioning he was tested for HIV without any reference to me; after his diagnosis I was told to leave him to the hospital and to go away and simply forget about him; and, after a few weeks in a mental health ward, I discovered that he had been moved to a residential home without reference to me. I read, I think correctly, that each act of apparent mistreatment, rejection, misunderstanding, dismissal and the neglect of both my partner’s and my own feelings, was a direct result of a lack of appreciation of the ways in which our sexual identities impacted on our experiences of dementia. Even now, I can hardly believe how resilient I had to be in order to deal with each unexpected challenge. My only support was from local gay friends who had no greater knowledge of dementia than I did, but were there for me simply because they were good friends.”*

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Newman also emphasises how current understandings of what it means to live with and care for someone with dementia are “limited to a model which relied heavily on the biological family unit”, with assumptions often made that those with the condition will have biological family networks to lean into, and that carers will primarily be one’s biological children (usually female). It is not simply



that the experiences of LGBTQ+ carers and people with dementia are the same as heterosexuals', with the addition of discrimination, but that they are qualitatively different experiences.

Through the LGBT Dementia Helpline, Newman reported several key themes from carers, including service providers not being able to use or understand appropriate language when working with LGBT service users; prevalence of LGBT stereotypes; myths about the nature of LGBT relationships; and a general misunderstanding and lack of valuing of the importance of families of choice.

Among the challenges the network faced was the 'defensive stance' from other service providers that they saw no value in an LGBBT specific service as they considered that they 'treated everyone equally' whoever they were. Trans inclusion was another issues. Although the helpline had touted itself as 'LGBT', the organisers' "knowledge, understanding and expertise in working with the trans community had been neither researched nor tested".





# Survey: Professionals and Volunteers Supporting People Affected by Dementia

## Summary

The target audience of the survey was professionals and volunteers whose work involved supporting people affected by dementia or concerned about memory loss (of any sexual orientation or gender), including carers. It was open to individuals working in practices, agencies or organisations based in Brighton and Hove and Sussex. This included both clinical and non-clinical staff.

The survey was live over a three week period across May/ June 2018, coinciding with Dementia Action Week 2018. In addition to promotion through the LGBT HIP and Groups newsletters and the LGBT Switchboard's Facebook and Twitter accounts, the engagement topic and survey was promoted via email through the Community Works list and via direct email to a range of dementia-related services and organisations.

Organisations who helped distribute the survey for professionals/ volunteers included:

- Care for the Carers (Sussex, not B&H)
- Dementia Action Alliance B&H
- Alzheimer's Society
- Lisa Douglas, Dementia Commissioner, who shared the survey with the Memory Assessment Service and Carers' Centre

While 32 initially responded, only 21 both passed the initial exclusion question and went on to respond to the majority of survey questions.

## Demographics

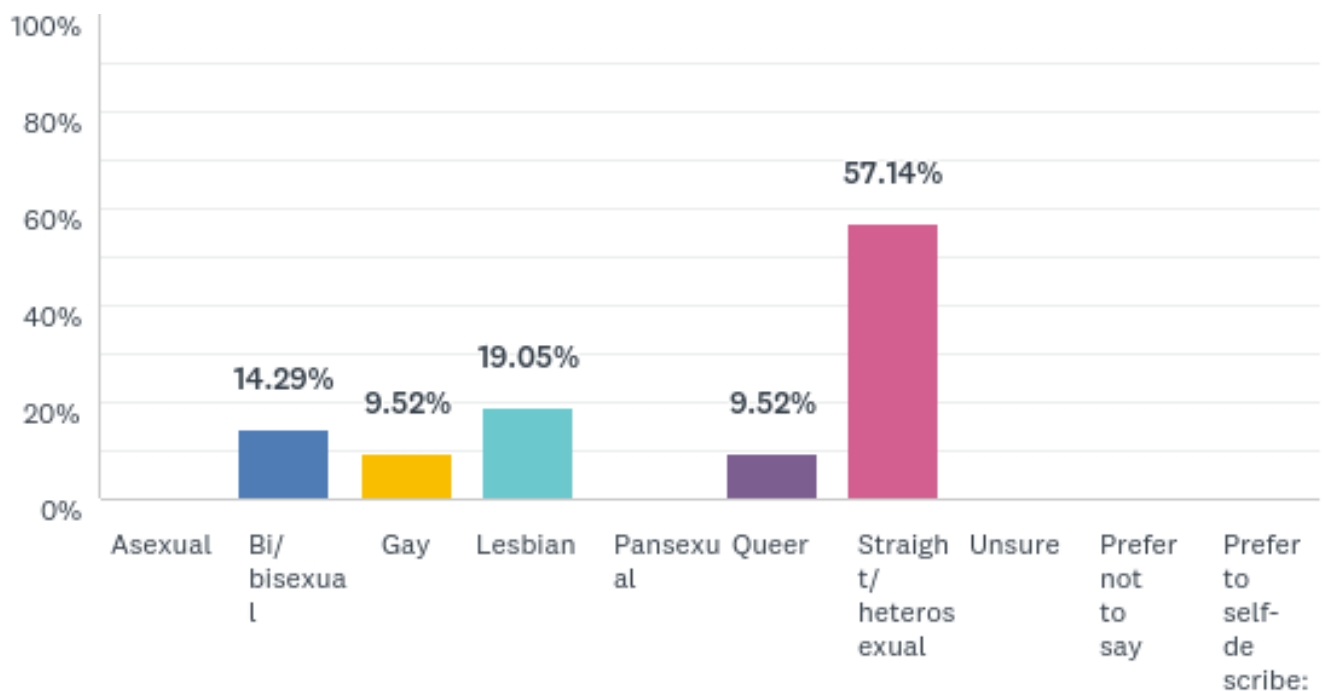
### Neighbourhood: 21 answers

We asked respondents to provide the first part of their postcode.

33% (7) were located in BN1, while 29% each (6 each) were located in BN2 and BN3 respectively.

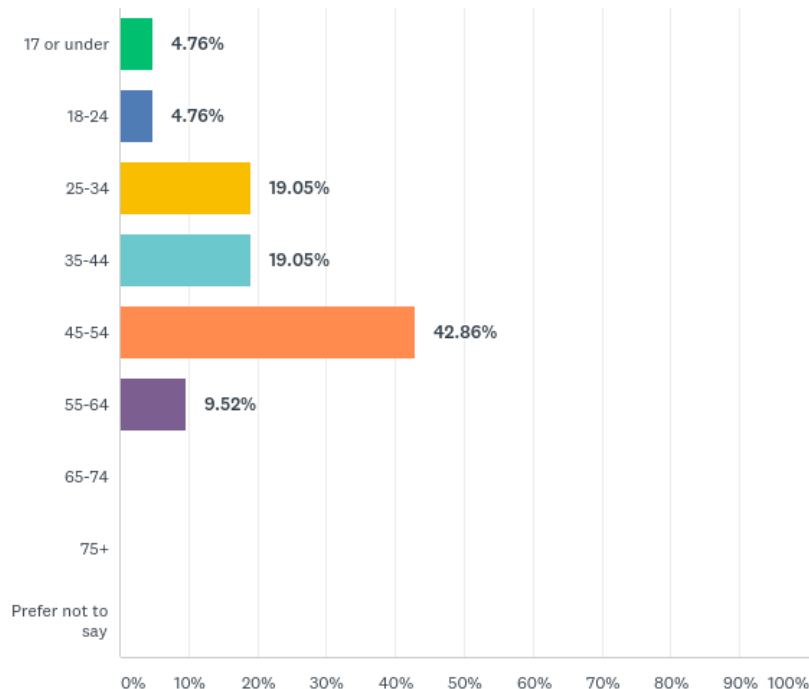
### Sexual Orientation: 21 answers

We asked respondents “How would you describe your sexual orientation?” Participants were provided with a free text field to provide their preferred term under ‘prefer to self-describe’. The majority of respondents identified themselves as ‘heterosexual/ straight’, at 57% (12). 11 respondents identified somewhere under the LGBTQ+ umbrella, with the largest proportion of these identifying as lesbian (19%, 4), followed by bisexual (14%, 3), gay, and queer (10%/ 2 each).



### Age: 21 answers

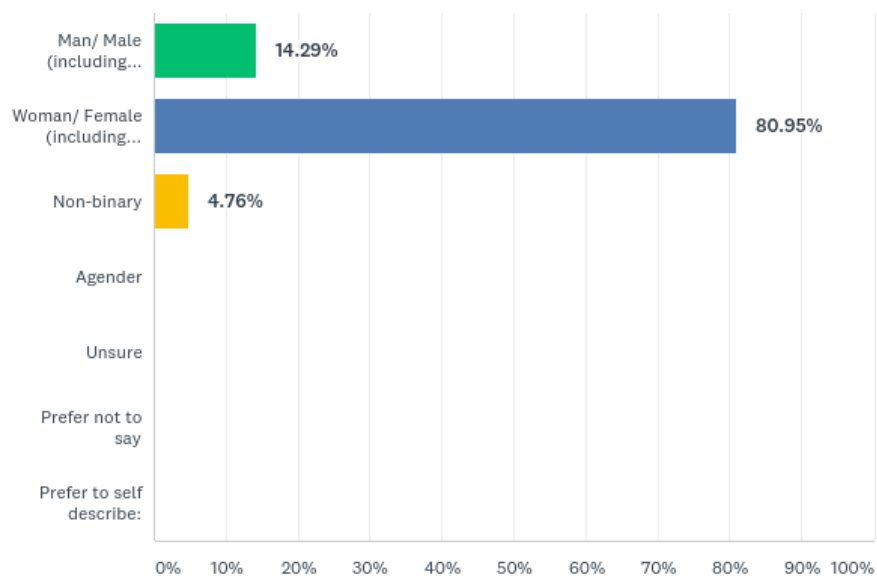
We asked respondents : ‘What was your age at your last birthday?’ The largest proportion of those responding were aged 45-54 (43%, 9), followed by 35-44 and 25-34 equally (each 19%, 4). 1 participant each (5%) was aged 17 or under or 18-24. 10% of respondents (2) were aged 55-64. No respondents were aged 65 or over.



### Gender: 21 answers

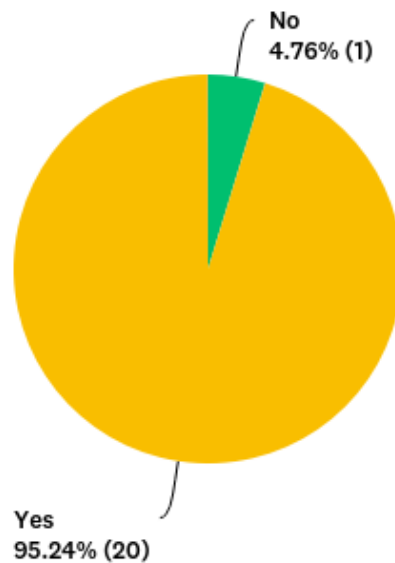
We asked respondents “How would you describe your gender?” We offered the options ‘female/ woman (including trans woman)’, ‘male/ man (including trans man)’, ‘non-binary’, ‘agender’, ‘unsure’, ‘prefer not to say’, and ‘in another way’, with a free text field in which to self-describe.

The majority of respondents identified as female/ women (81%, 17), followed by male/ men (14%, 3). 1 respondent was non-binary (5%).



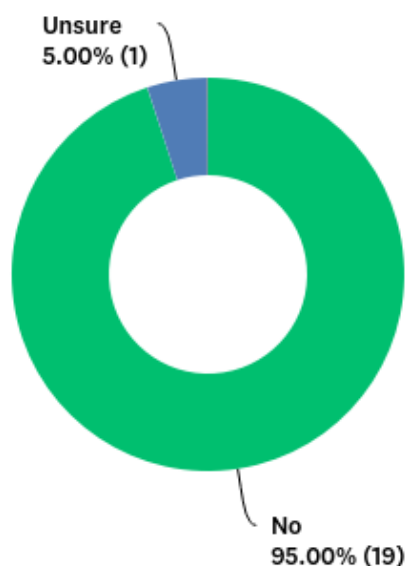
*Trans Status: 21 answers*

To discern the trans status of respondents, we asked “Is your gender the same as the gender you were assigned at birth?” 95% (20) of respondents selected ‘yes’, and 5% (1) answered ‘no’.



*Intersex Status: 20 answers*

We asked respondents “Do you have an intersex variation? Intersex is a term for people born with atypical physical sex characteristics. There are many different intersex traits or variations.” 95% of respondents selected ‘no’ (19), and one selected ‘unsure’ (5%).



*Disability: 20 answers*

We asked respondents “Do you live with a health condition, impairment, learning difference, or neurodivergence that shapes your day to day activities?” 65% (13) of respondents reported that they had no known health condition, impairment, learning difference or neurodivergence, while 35% reported that they had some form of the above. The specific types of health condition, impairment,

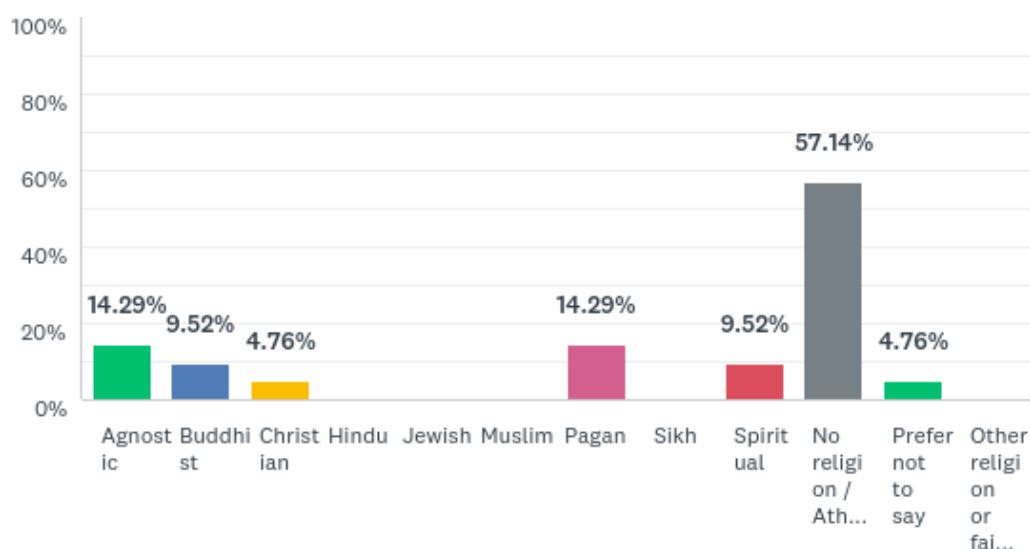
learning difference or neurodivergence of respondents are listed in the table below. One participant selected 'prefer to self-describe' and shared that they have a severely disabled child.

ANSWER CHOICES	RESPONSES	
No known health condition, impairment, learning difference, or neurodivergence	65.00%	13
A long standing illness or health condition such as cancer, chronic heart disease, diabetes, epilepsy, or HIV	5.00%	1
A mental health difficulty, such as depression or anxiety disorder	10.00%	2
A physical impairment or mobility issues, such as difficulty using your arms or using a wheelchair or crutches	5.00%	1
A neurodivergence, meaning that your brain or mind works significantly differently from social expectations of what is 'normal'. This can include AD(H)D, Asperger's syndrome/other autistic spectrum disorder, bipolar, dyscalculia, dyslexia, dyspraxia, or Tourette syndrome	10.00%	2
A social/communication condition such as a speech and language impairment or Asperger's syndrome/other autistic spectrum disorder	5.00%	1
A specific learning difficulty (SpLD) such as AD(H)D, dyscalculia, dyslexia, or dyspraxia	10.00%	2
Blind or have a visual impairment uncorrected by glasses	0.00%	0
D/deaf or have a hearing impairment	5.00%	1
Prefer not to say	10.00%	2
Prefer to self-describe:	5.00%	1
Total Respondents: 20		

Religion, faith and spirituality: 21 answers

We asked respondents "What is your religion or faith?"

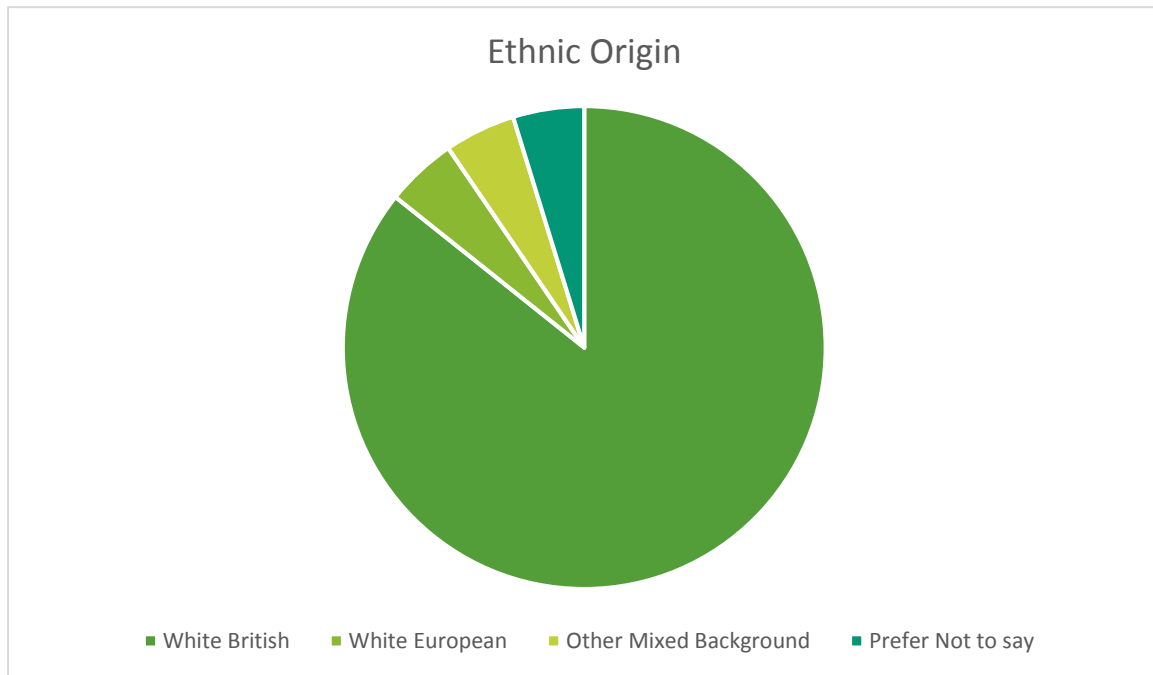
57% (12) reported that they were either atheist or had no religion. Three (14%) respondents each identified as agnostic or pagan, while two each (10%) identified as Buddhist or Spiritual. One participant each (5%) identified as Christian or preferred not to say.



### Ethnic Origin: 21 Answers

We asked respondents: “What is your ethnic group?”

86% (18) were white British, and 5% (1) was white European. A further 5% (1) each chose ‘Other mixed background’ and ‘prefer not to say’.



## Survey responses

### Q1: Exclusion question: 32 *Answers*

Question 1 of the survey was an exclusion question designed to filter out any respondents who did not meet the above criteria.

32 individuals responded to the survey, and of these 29 satisfied the criteria of the exclusion question and went on to complete the survey.

### Q2: Job roles: 23 *Answers*

We asked “What is your job/ role title?” Responses were clustered as follows:

- Support Worker (22%, 5)
- Carer (18%, 4)
- Management role (13%, 3)
- Centre worker/ group facilitator (9%, 2)
- Nurse (9%, 2)
- Health Advisor (9%, 2)
- Cafe worker (5%, 1)
- PA to frontline psychological support worker (5%, 1)
- Psychiatrist (5%, 1)
- Occupational therapist (5%, 1)
- CEO (5%, 1)

### Q3: Organisations and services: 23 *Answers*

Responses were received from the following services. Numbers have not been provided so as to help protect respondent anonymity.

- B&H Carers Centre
- Brighton & Sussex University Hospitals
- Open Strings Music
- Impact Initiatives/ Hop 50+
- Alzheimer’s Society
- Here / B&H Memory Assessment Service
- Terrence Higgins Trust
- Somerset Centre/ Older and Out
- Sussex Partnership Mental Health Service
- MacLeod Pinsent Care Homes
- Sussex Partnership NHS Foundation Trust
- Care for the Carers

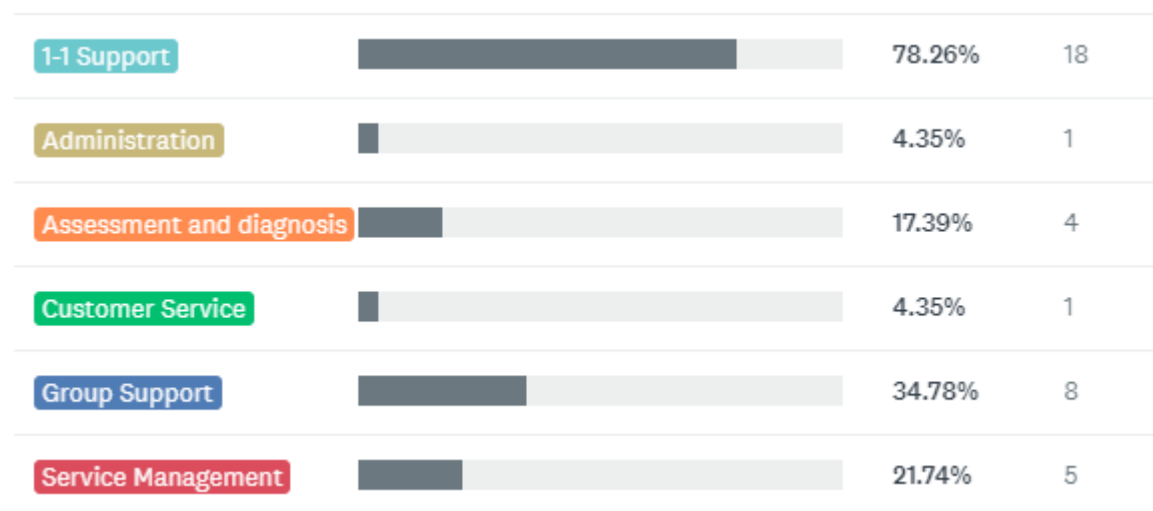
### Q4: Respondents’ types of work with people affected by dementia: 23 *Answers*

We asked “Please briefly summarise what your role supporting people affected by dementia entails”. The intention of this question was to gain a picture of the types of work respondents were engaged with, to better understand the meaning of the survey results, and any potential gaps.

The majority of respondents' roles (78%, 18) involved a 1-1 support element, while 35% (8) involved group support.

22% (5) had roles directly involving service management, while only 17% (4) of respondents' roles involved assessment and diagnosis, indicating that the assessment and diagnostic process may be an area requiring further attention in relation to LGBTQ needs.

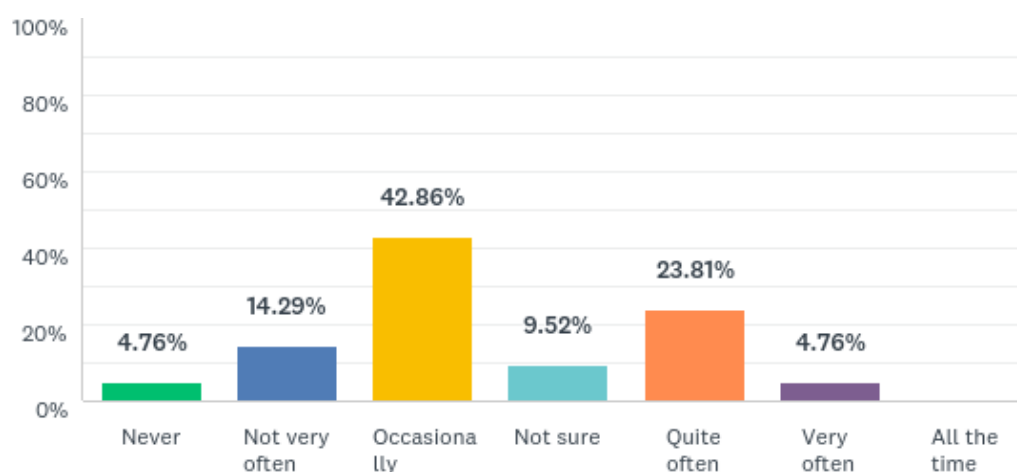
One respondent's (4%) role was a customer-facing role that included serving individuals affected by dementia, and a further single respondent's main role involved managing administration of a dementia service.



#### Q5: Awareness of contact with the LGBTQ+ community: 21 Answers

We asked "How frequently, in your work with people affected by dementia, are you aware of coming in contact with individuals who are from the LGBTQ community?"

The largest proportion of respondents (43%, 9) said they 'occasionally' come into contact with LGBTQ+ people through their work with people affected by dementia. Five (24%) said "quite often", and one (5%) said "very often". Three (14%) said "not very often" and one (5%) said "never". Two (10%) said they were not sure.





### Comments:

Five respondents provided comments.

Of these, three mentioned being aware of 'one or two' LGBTQ+ individuals in their care, and indicated that they were only aware of this when told specifically by the person themselves.

*"I wouldn't know unless they specifically told me. I know of 2 that use the service."*

One lesbian-identified respondent said she came out to LGBTQ carers when appropriate to help build empathy in the supporting relationship:

*"As a lesbian myself, I do come out (when appropriate) to carers from the LGBTQ community in a 1-2-1 situation which builds empathy."*

One respondent indicated noticing that one of their client's expression of his sexual orientation was changing as his dementia progressed:

*"I have at least one gentleman I care for who is more openly gay as his dementia has progressed."*

One stated they did not understand the meaning of the question.

### Analysis:

It is positive that most professionals and volunteers (72%) were aware of coming into contact with LGBTQ+ people at least occasionally. However, this does leave more than a quarter (28%) who either are finding they are not coming into contact with LGBTQ+ people at all or not very often, are not aware of doing so, or are unsure.

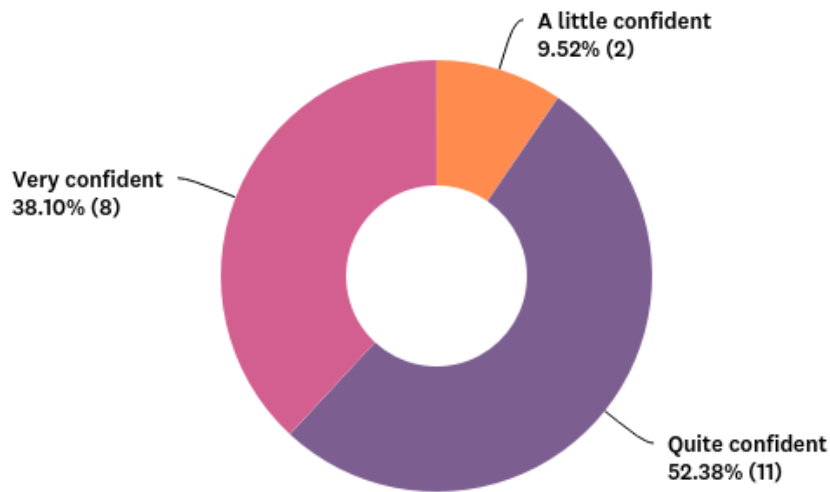
This may indicate that services need to work on becoming more accessible and inclusive of LGBTQ+ people, so that they are likelier to access services and feel comfortable sharing about their sexual orientation and/or gender identity if they wish to do so. It may also indicate an opportunity to strengthen monitoring of these characteristics, particularly for those who were unsure.

It might be speculated that the 19% (4) of responses indicating that they either 'never' or 'not very often' came into contact with LGBTQ+ people may be related to the 'closeting' effect of people with dementia, and of older people – that heteronormativity (the tendency to believe individuals are heterosexual until otherwise stated) is amplified in relation to these groups, and assumptions are more often made that these individuals will be heterosexual and/or cisgender.

### Q6: Confidence providing LGBTQ+ support: 21 Answers

We asked "In general, how confident do you feel in providing support (clinical or emotional, or providing information, signposting, etc.) to LGBTQ individuals and their carers?"

Most respondents (52%, 11) said they were “quite confident” doing so, while 38% (8) said they felt “very confident”. Two (10%) said they were “a little confident”.



#### Comments:

One comment was provided stating that the worker’s own LGBTQ+ identity gave them a link to a network of professional and personal LGBTQ+ information and support.

#### Analysis:

These results are promising, in that no volunteers or professionals stated they felt lacking in confidence supporting LGBTQ+ people to any degree.

It is of note, however, that although 28% said they rarely or never came into contact with LGBTQ+ people through their work, all of these individuals would feel at least a little confident supporting LGBTQ+ people. This begs the question of the basis of this confidence. It may be that this has been gained outside of the professional context (for example through personal experience, such as the commenter’s), or through other work or training. However, further results later in the survey suggest that respondents had relatively low levels of LGBTQ+ awareness training to draw from in building this confidence.

However, it may also be an indication of the often widespread view that LGBTQ+ people require the same support as ‘everyone else’, i.e. heterosexual and/or cisgender individuals. While this perspective is usually well-meant, it tends to erase the particular experiences, needs and inequalities faced by LGBTQ+ people.

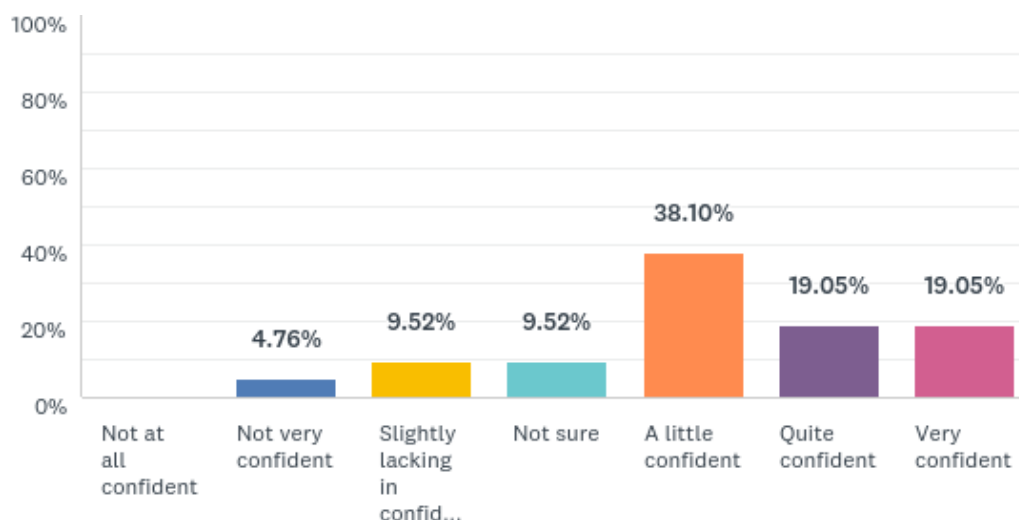
Another possibility is that a selection bias is at play, in which only LGBTQ+ confident individuals chose to respond to the survey. Despite anonymity and confidentiality, social desirability may have also played a part, with some individuals feeling they ‘should’ be confident and choosing answers that reflect this.

These are speculations, however, and it is also possible that the respondents answers reflect a genuine and well-earned confidence in relation to providing LGBTQ+ support.

Q7: Confidence supporting trans individuals: 21 Answers

We asked respondents “In general, how confident do you feel about acknowledging the needs of and providing support to trans individuals (those whose gender identity is different from the gender they were assigned at birth)?”

The largest proportion of respondents said they were ‘a little confident’ supporting and acknowledging the needs of trans individuals (38%, 8), followed by 19% each equally (4) who said they were either ‘quite’ or ‘very’ confident. 10% (2) and 5% (1) respectively said they were ‘slightly lacking in confidence’ or ‘not very confident’ in this area, while 10% (2) said they were not sure.



#### Comments:

Three respondents provided comments, which tended to centre around the need for training in this area, and a sense that this was one of the most challenging areas for workers supporting people affected by dementia. One said they did not have any experience in this area with clients/ patients, but indicated some confidence based on working with trans individuals as colleagues or non-dementia-related service users.

*“I feel this is one of the most difficult things we can come across in our work and I think we would all benefit from a training session, or several, to help us to better acknowledge the needs of trans individuals on receiving a diagnosis of dementia, and how these needs then change as the disease progresses.”*

*“No experience in dealing with trans individuals with dementia or trans individuals who are carers although I have had many positive experiences dealing with trans individuals (either service users who do not have dementia or colleagues).”*

#### Analysis:

In contrast to Q6, which asked about confidence support LGBTQ+ people in general, this question about supporting trans individuals specifically revealed some indications of lacking confidence in this area. However, overall levels of reported confidence were still relatively high, at 78% being at least ‘a little confident’, and 40% of these either ‘quite’ or ‘very’ so.

The above comments expand on this discrepancy, focusing on the need for training to understand the needs of trans individuals affected by dementia. Again, as with Q6, there is an indication that individuals’ actual experience of supporting trans individuals affected by dementia may be low, while confidence is relatively high.

#### Q8: Confidence support LGBTQ+ couples: 21 Answers

We asked “How confident do you feel in supporting the needs of LGBTQ couples (e.g. being able to acknowledge their partners as partners, and not friends or general family members)?”

Most respondents chose ‘very confident’ (10, 52%), while 48% (10) chose ‘quite confident’.

#### Comments:

Two respondents provided comments.

One highlighted their confidence in terms of providing person-centred care, treating each couple as unique:

*“This is a fairly frequent occurrence and I feel entirely comfortable with this. I also believe that my current direct colleagues are also comfortable with this. Essentially I would seek the views and direction of the patient and their partner or carers and treat each person and couple as unique.”*

Another highlighted that, based on their own LGBTQ+ experience, they understood “the importance of recognising partners/wives/husbands”.



#### Analysis:

Again, these results appear very positive, with all respondents feeling either ‘quite’ or ‘very’ confident support LGBTQ+ couples.

As the comments suggest, this may be based in part on individuals drawing from their personal, lived experience, and from taking a person-centred approach, treating each couple as unique.

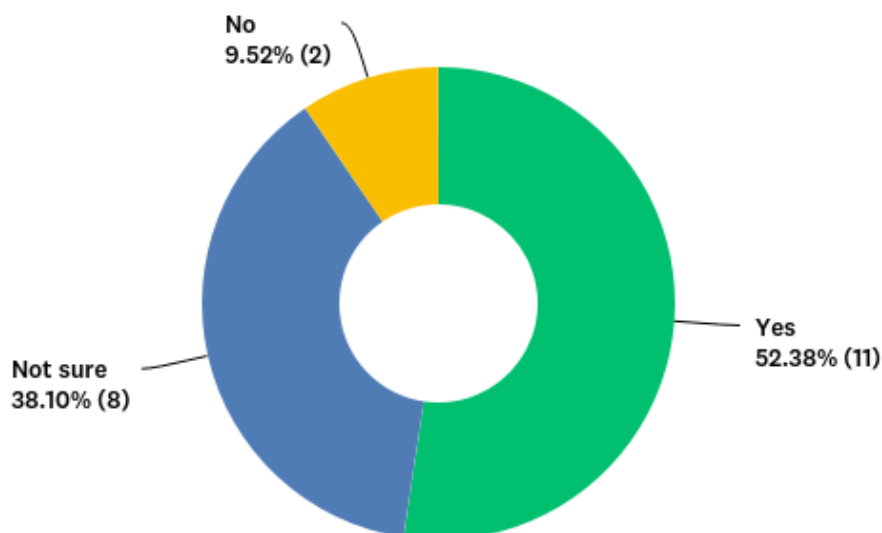
While a person-centred approach is highly commendable and important, it is also important to note how LGBTQ+ individuals face challenges and barriers that are not related to their personal individuality, so much as systemic inequalities at a community level. As such, at times, stating that each individual and couple is treated only and completely ‘as an individual’ can be just as problematic as claiming to treat LGBTQ+ people ‘the same as everyone else’. While both may be

based on positive intentions, the outcome can be to miss systemic inequalities that play out in relation to specific LGBTQ+ identities.

#### Q9: Monitoring sexual orientation: 21 Answers

We asked: “Do you regularly monitor the sexual orientation of patients/clients/service users in your service or department?”

52% (11) said ‘yes’, they did, while 36% (8) were not sure. Two (10%) said they did not.



#### Comments:

Four respondents provided comments.

Three of these stated that formal equalities monitoring was not taken, but that this information I gathered on an ad hoc basis, or remembered and kept in mind in relation to specific individuals, when directly shared.

*“I don't do so myself and have not observed this, but internally I have a knowledge base in my head.”*

*“I don't personally but this information is captured if the patient or family is willing to share”*

*“This question is included in formal assessment, but may or may not be specifically asked. Often if someone is LGBT and in relationship, we would be liaising closely with carer partner so the fact of someone's sexual orientation might be clear from initial assessment or when arranging an appointment.”*

One stated they use equality monitoring forms in their service.

#### Analysis:

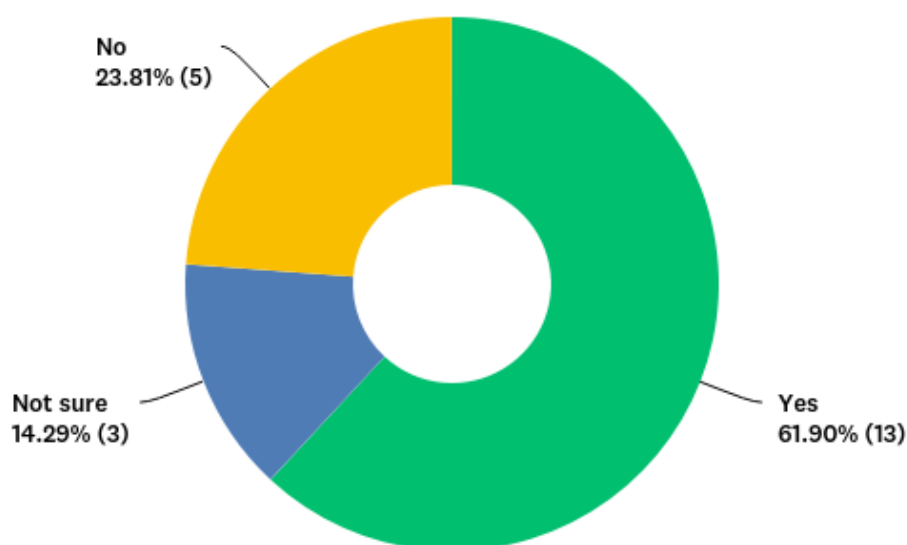
It is promising that more than half of those who responded said they were monitoring sexual orientation. However, the fact that nearly half were either aware they did not monitor this characteristic, or were not sure, indicates room for development around monitoring. As comments indicated, workers rely on information gleaned from day-to-day interactions with patients/ clients affected by dementia. While this may under many circumstances be the most appropriate and sensitive course, it is also important to highlight that the opportunity to provide one's sexual orientation via equalities monitoring can send a message to individuals that it is 'okay' and 'safe' to

share about their sexual orientation (Switchboard: HIP, 2018), leading them to be more open about this in relation to services in a way that might be appropriate to the care and support they receive. It is also important to note, as the background research and LGBTQ+ community survey suggest, many LGBTQ+ people do not feel comfortable verbally disclosing, and the onus remaining on them to do so can create additional anxiety and concerns around how any disclosure will be received and responded to.

#### Q10: Monitoring trans status: 21 Answers

We asked: “Do you regularly monitor whether patients/clients/service users in your service or department are trans?”

62% (13) said ‘yes’, they did, while 14% (3) were unsure and 24% (5) said ‘no’, they did not.



#### Comments:

Five respondents provided comments.

Three stated that there was no formal monitoring, but that they took this information on board and into account in their one-to-one relationships with clients/patients on an as-relevant basis.

*“I don't personally but this information is captured if the patient or family is willing to share”*

One commenter supported this point, and highlighted the importance of a person-centred approach, but also indicated some lack of clarity about the distinction between sexual orientation and trans status:

*“Again, the question of sexuality is in our assessment, but may or may not be asked, and relies on the practitioner's judgement. We would hope to have a conversation about sexuality as relevant and appropriate to the piece of work we are doing with the patient, as this is person-centred and being sensitive to what a patient wishes to disclose.”*

One respondent shared that they were particularly aware of doing so due to their own lived experience.

Two stated that this was part of formal, recorded equalities monitoring.

### Analysis:

It is of note that considerably more respondents said they monitored trans status (62%, 13) than sexual orientation.

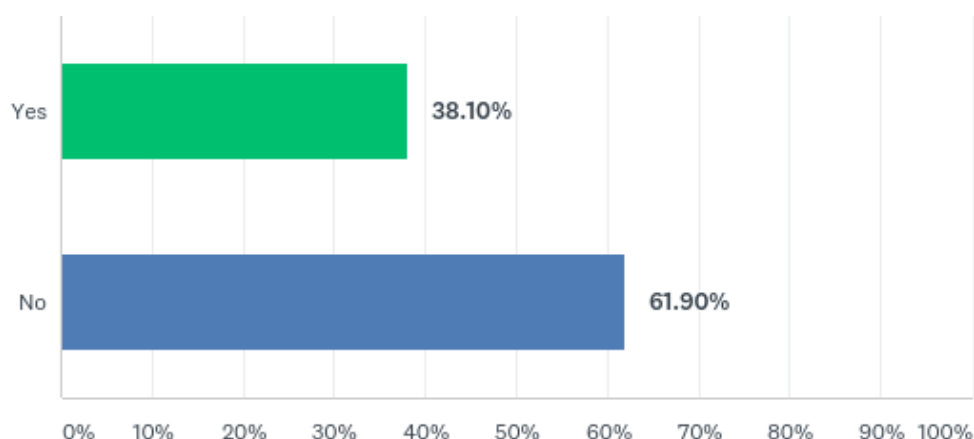
However, where this monitoring is not formal, this may be based on the perception that it is 'obvious' when a person is trans, and may be based on binary assumptions of gender, or assumptions based on the worker's perceptions rather than the client's statement.

One comment indicated some possible lack of clarity about the distinction between a person's trans status and their sexual orientation as being distinct and different aspects of experience and identity. This is also reflected in respondents reporting much higher levels of confidence around 'LGBTQ+' awareness versus 'trans' awareness: even though 'LGBTQ' includes 'trans', this is often conflated with sexual orientation and not considered a separate facet of identity.

#### Q11: Past LGBTQ+ and dementia training: 21 Answers

We asked "Have you received any information or training that you can draw on to help you support LGBTQ people affected by dementia?"

The majority, 62% (13) said 'no', they hadn't, while 38% (8) said 'yes', they had received training that could help them support LGBTQ+ people affected by dementia.



### Comments:

We asked those who had received training to specify what this had entailed. Answers clustered around the following themes:

- LGBTQ+ specific training from previous roles (5)
- General equalities training in this or past roles (2)
- Drawing from personal interactions with LGBTQ+ individuals (1)
- Drawing from personal experience as an LGBTQ+ person (1)
- LGBTQ+ specific training in current role (1)
- LGBTQ+ and dementia training via the Alzheimer's Society (1)
- General Dementia Training (1)



*"I have had training externally from my work around working with LGBTQ folk and am also a member of the community, and I mix this with my knowledge of dementia and how it can affect things such as inhibitions as it progresses."*

#### Analysis:

7 in 21 of respondents had received LGBTQ+ specific training, although 5 of these had been from previous roles, where the information may not have been directly relevant to a dementia support context. 1 in 21 respondents had received LGBTQ+ and dementia specific training (through the Alzheimer's society).

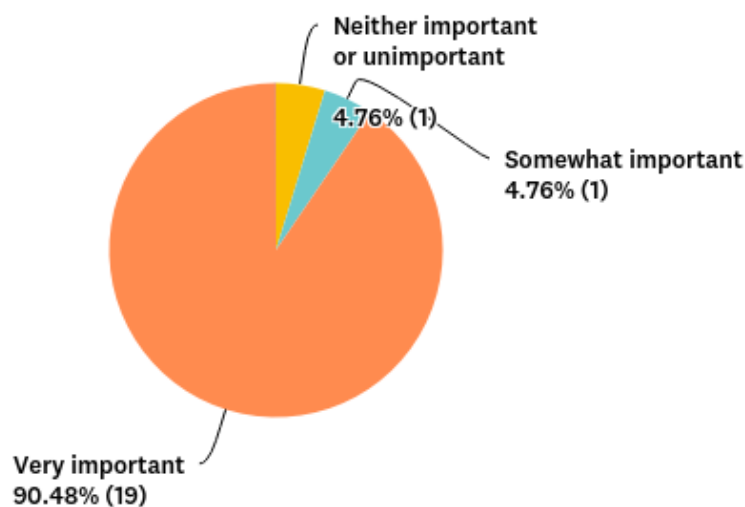
This indicates a gap in dementia specific and role-specific LGBTQ+ training provision. As noted above, it is also of interest that confidence serving LGBTQ+ people was so high given that training experience was less consistent and somewhat lower.

#### Q12: Perceived importance of understanding LGBTQ+ issues: 21 Answers

We asked: "Do you consider an understanding of someone's sexual orientation and/or gender identity to be important in delivering the best possible dementia care?"

The vast majority of respondents (19, 91%) said they considered an understanding of someone's sexual orientation and/or gender identity to be 'very important' in delivering the best possible dementia care.

One respondent (5%) each said they considered this either 'somewhat important' or 'neither important nor unimportant'.



#### Comments:

Five comments were provided, which all centred around emphasising the importance of understanding sexual orientation and gender identity for the client. The importance of seeing the individual as a whole, and the particular relevance in relation to memory

*"When providing any caring role, especially when it comes to matters of the brain, it is important to see a person as a whole and our sexual orientation and gender identity are a huge part of who we are."*

*“When doing memory work it is good not to be heteronormative and cisnormative when working. For example saying “I bet you were a hit with the ladies” when a service user is openly not straight it could add to their confusion or just make them feel awkward.”*

*“Sexual orientation is part of a person's identity and therefore an integral part of personal support”*

*“The main aim is to deliver positive holistic care which incorporates all aspects of a person and what is important to them.”*

#### **Analysis:**

It is promising that no respondents said they considered an understanding of someone's sexual orientation and/or gender identity to be ‘not at all’ or ‘not very’ important in delivering the best possible dementia care, with the comments underscoring this. This also bodes well for future engagement and training around this issue, indicating an enthusiasm and valuing of LGBTQ+ issues for providing the best possible care.

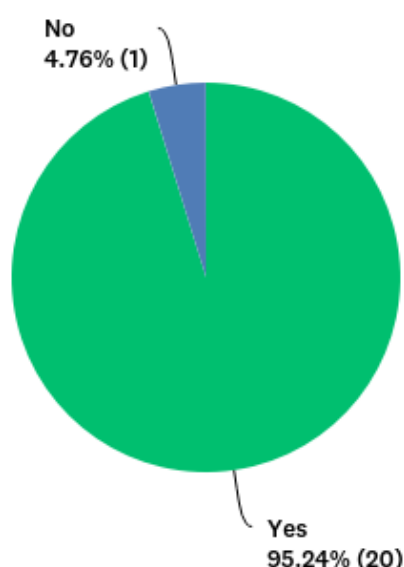
It is also positive to note the sensitive and considered responses related to appreciating the importance of sexuality and gender to identity, and the need to avoid slipping into heteronormative and cisnormative assumptions.

As mentioned previously, there is a possibility of a self-selection bias of individuals responding who are already engaged with LGBTQ+ issues and interested in the intersection of these identities with dementia.

#### **Q13: Desire for LGBTQ+ and dementia training: 21 Answers**

We asked: “Would you like to access further training, support or information in regards to working with LGBTQ people affected by dementia?”

The vast majority (20, 95%) of respondents said they would like to access further LGBTQ+ and dementia specific training. One (5%) said they would not like to access this.



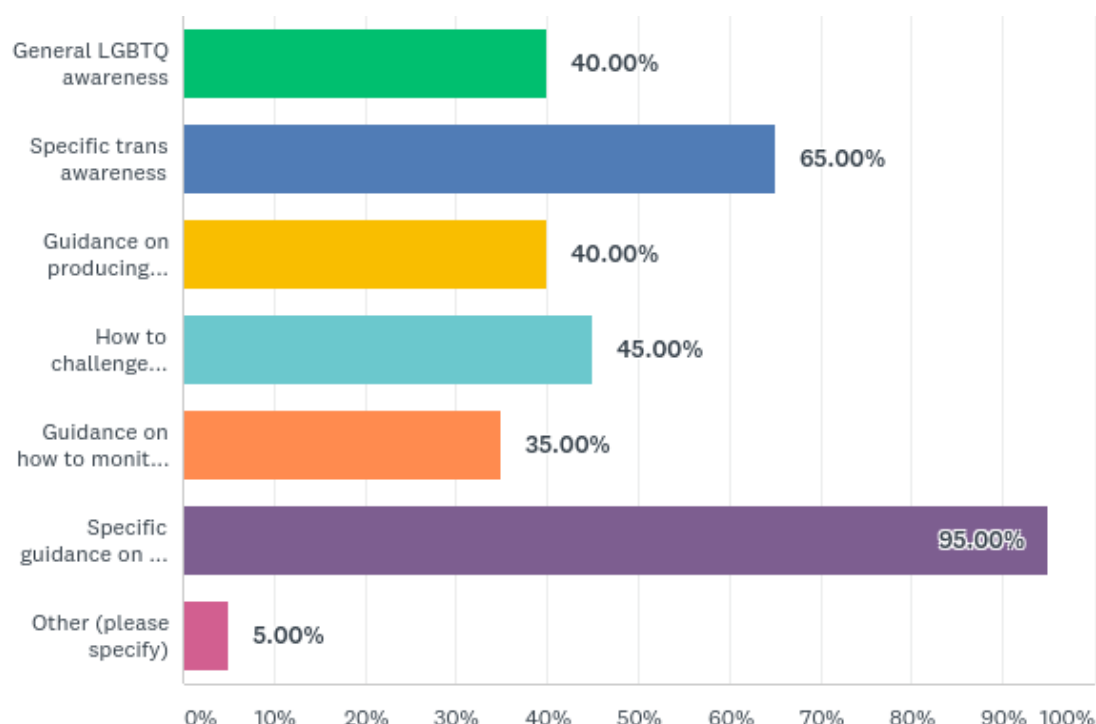
**Analysis:** This supports previous findings about the high valuing of understanding LGBTQ+ identity in relation to providing the best quality dementia care, and suggests an appetite for further training, which the following question expands on in more detail.

#### Q14: Preferences for training content: 20 Answers

We asked: "If yes, what kind of content would you find most useful? Select all that apply."

The vast majority (95%, 19) said they would like specific training on LGBTQ+ and dementia, followed by 65% (13) who would value specific trans awareness training. Just less than half (45%, 9) said they would like training on how to challenge homo/bi/transphobia, while 40% (8) each equally would value general LGBTQ+ awareness training, and guidance on producing LGBTQ+ literature, posters and other resources. Just over a third (35%, 7) wanted further guidance on monitoring sexual orientation, gender and trans status.

One participant selected 'other' and stated they would like training on *"Supporting LGBTQ people and their carers in planning future care. Eg moving to a care home, organising care. I believe this is also very important to offer training to care homes in this area."*



#### Analysis:

The fact that almost all respondents wanted to receive specific LGBTQ+ and dementia training highlights the high valuing of understanding this aspect of identity, as demonstrated in earlier questions.

The high demand for trans-specific awareness training echoes the finding that there are lower levels of confidence in relation to supporting trans individuals as compared with cisgender non-heterosexual people.

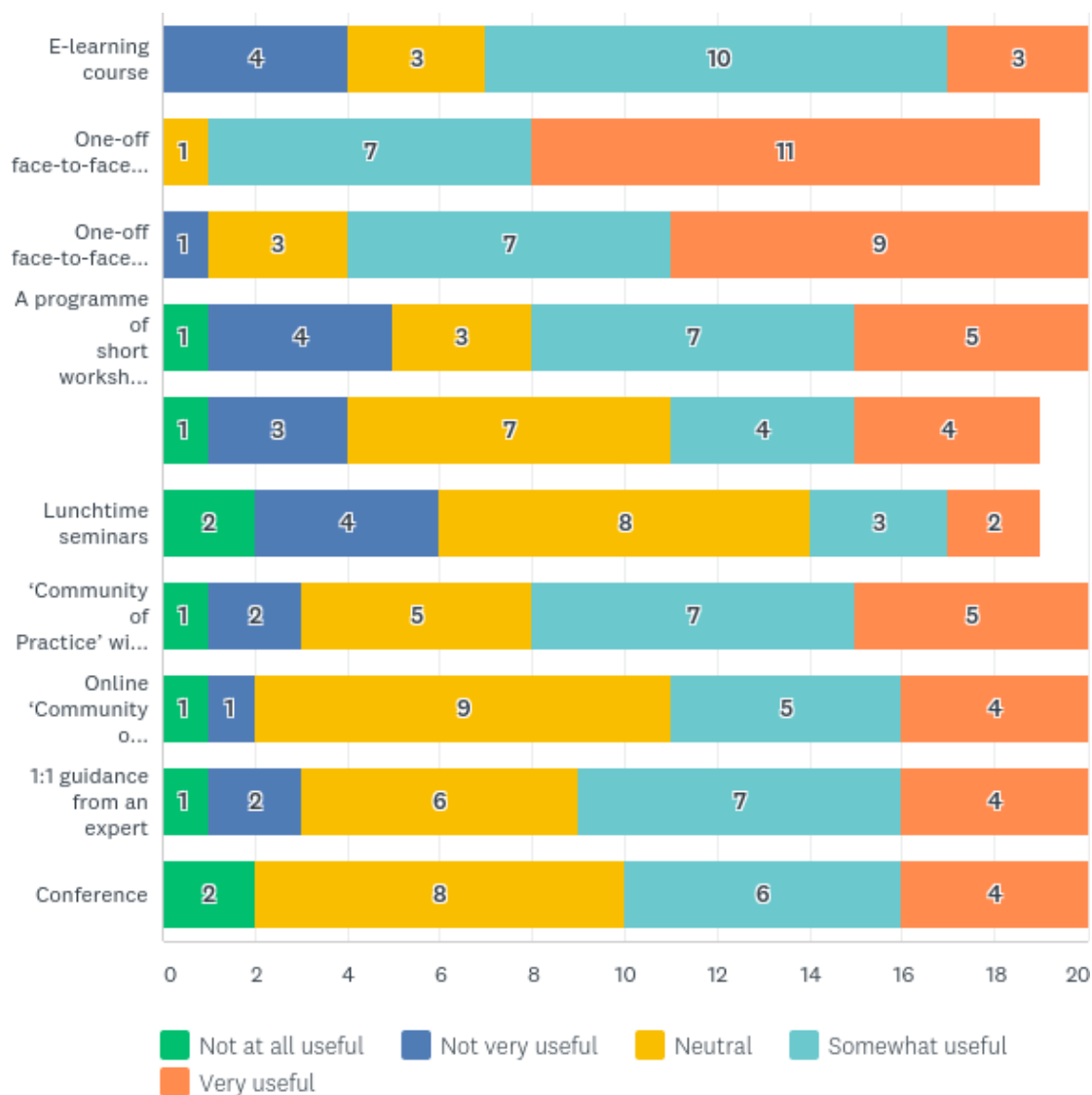
The relatively lower demand for training around monitoring sexual orientation, gender and trans status, combined with relatively low levels of sexual orientation and trans status monitoring, may mean that this is an area that may require more work and awareness. Switchboard's recent consultation into monitoring (Switchboard: HIP, 2018) demonstrated overall low levels of awareness and confidence in relation to the value of monitoring sexual orientation, gender and trans status across health and social care, and this is likely to be just as present across dementia care services.

Q15: Training delivery options: 20 Answers

We asked: "How useful do you think the below options for training and support would be to you? (please tick one rating per idea in the table below)"

The options provided were:

- E-learning course
- One-off face-to-face open course
- One-off face-to-face in-house course
- A programme of short workshops (in-house)
- A programme of short workshops (open)
- Lunchtime seminars
- 'Community of Practice' with invited speakers (including LGBTQ people affected by dementia)
- Online 'Community of Practice'
- 1:1 guidance from an expert
- Conference



A one-off face to face open course was the most popular option, with more than half (11, 58%) rating this as 'very useful', and 7 (37%) as 'somewhat useful'. An in-house one-off face to face course was the second favourite, with 45% (9) saying this would be 'very useful', and 35% (7) saying 'somewhat useful'.

An e-learning course was also highly rated, with half of respondents (10) saying this would be 'somewhat useful' and 3 (15%) 'very useful'. While 15% (3) said this would be 'neutral' and a further 4 (20%) said this would be 'not very useful', no respondents said this would be 'not at all useful', the only option without this response.

1:1 guidance from an expert was also relatively highly valued, as either 'somewhat' (6, 30%) or 'very' (7, 35%) useful for more than half of respondents (11, 55%). 6 (30%) considered this neutral, 2 (10%) 'not very useful' and 1 (5%) not at all useful.

A 'community of practice' with invited speakers (including LGBTQ people affected by dementia) was rated as either 'somewhat' (5, 25%) or 'very' (4, 20%) useful by just under half of respondents. 5 (25%) considered this neutral, 2 (10%) 'not very useful' and 1 (5%) not at all useful.

A programme of short workshops (in house) was rated as 'somewhat' useful by 7 (35%) respondents, and 'very' useful by 5 (25%), while 3 (15%) considered this option 'neutral'. 4 (20%) considered this 'not very useful' and 1 (5%) 'not at all useful'.

A programme of short workshops (open) was slightly less popular than the in-house equivalent, with 22% (4) equally considering this option 'somewhat' and 'very' useful respectively, while 37% (7) considered this option 'neutral'. A further 16% (3) found this 'not very useful' and 1 (5%) found it 'not at all useful'.

Lunchtime seminars were the least popular option, with 14/19 of those who answered this option considering them 'neutral' (8), 'not very useful' (4) or 'not at all useful' (2), and only 5 considering them 'somewhat' or 'very' useful.

#### **Comments:**

One comment was provided, which highlighted the value of a one-off workshop for making this training accessible to workers with busy schedules:

*"Options like programmes of workshops I'm sure would be useful but I think realistically I would struggle to find the time in my role to attend lots of sessions - a one off session would be easier to actually get to, and a point of contact for expert support if needed."*

#### **Analysis:**

One-off and in-person trainings were the most highly valued options. Whether these were preferred to be in-house or open seemed to depend on whether they were one-off (open preferred) or a series of sessions (in-house preferred). This may be due, as the commenter highlighted, to the perception that an in-house series would be more sensitive to the time demands on individuals' roles and be more accommodating of workers' schedules.

Accessing 'expert' support was also highly valued as an option, as was the 'community of practice' suggestion, suggested a high valuing of sharing information resources and hearing from those with lived and expert professional experience.

## Q16: Barriers to dementia care: 21 Answers

We asked: "In your experience, what (if any) barriers do LGBTQ people experience in accessing dementia care, support and/or information?"

Answer options were as follows:

ANSWER CHOICES	RESPONSES	
A lack of LGBTQ specific information and resources e.g. posters, leaflets	71.43%	15
Assumptions being made that all patients are heterosexual and cisgender (i.e. people whose gender is the same as the gender assigned at birth)	61.90%	13
Healthcare professionals not being LGBTQ-aware and inclusive	61.90%	13
Experiencing homo-/ bi- / transphobia from professionals	28.57%	6
Experiencing homo-/ bi- / transphobia from peers in residential or extra-care living settings	52.38%	11
LGBTQ partners (including civil partners or spouses) not being recognised as 'next of kin'	47.62%	10
Trans people being mis-gendered by professionals (referred to by a pronoun or form of address, that does not correctly reflect the gender with which they identify)	47.62%	10
LGBTQ people being afraid to disclose their sexual orientation or gender identity because of fears about homo-/ bi- / transphobia	66.67%	14
'Next of kin' recording not taking into account non-legally-binding significant relationships (e.g. partners, informal support networks and families of choice)	42.86%	9
None of the above	14.29%	3
Other (please specify)	9.52%	2
Total Respondents: 21		

A lack of LGBTQ+ specific information and resources was rated as the most significant barrier by a majority of respondents (71%, 15).

LGBTQ+ people's fears of homo/bi/transphobia in relation to disclosing sexual orientation and/or gender identity was given as the second most prevalent perceived barrier, at 67% (14).

An equal number, 62% (13), considered assumptions being made that all patients are heterosexual and cisgender and healthcare professionals not being LGBTQ-aware and inclusive as key barriers.

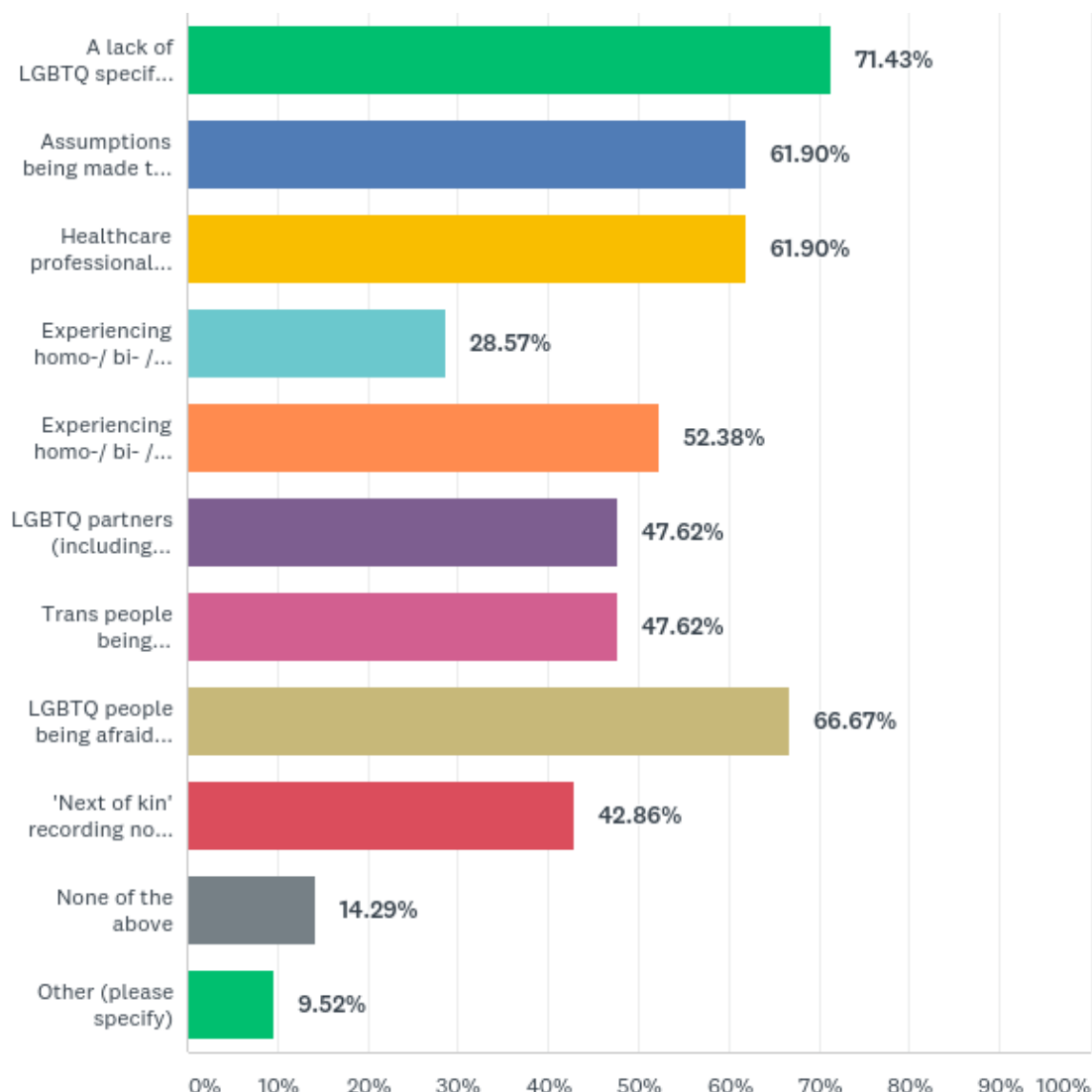
More than half, 52% (11), felt that experiencing homo-/ bi- / transphobia from peers in residential or extra-care living settings would be an important barrier.

An equal number, just under half, 48% (10), considered LGBTQ partners not being recognised as 'next of kin', and trans people being mis-gendered by professionals (referred to by a pronoun or form of address, that does not correctly reflect the gender with which they identify) as key barriers.

'Next of kin' recording not taking into account non-legally-binding significant relationships (e.g. partners, informal support networks and families of choice), was considered a barrier by 43% (9).

Less than a third, 29% (6), said they thought experiencing homo-/ bi- / transphobia from professionals was a barrier for LGBTQ+ people.

14% (3) said they felt none of the above barriers existed for LGBTQ+ people accessing dementia care.



#### Comments:

Two comments were provided.

One emphasised the need for support, including written information, about planning future care or choosing a care home, that was tailored to LGBTQ+ people's needs.

The other stated that, although they did not have direct experience of the listed barriers, they could see how any of them could be at play at a given time for an LGBTQ+ person attempting to access a dementia care service:

*"I have not had any specific experience of people not accessing services because of these issues, but I imagine that all of these issues would be barriers to someone accessing services."*

#### Analysis:

It is of note that LGBTQ+ actually *experiencing* homo/bi/trans-phobia from staff was the lowest-ranked barrier. This may reflect the generally high levels of confidence held by staff about their

LGBTQ+ awareness. However, it may also reflect a tendency to locate the barriers primarily in LGBTQ+ people's perceptions and within the community and peers themselves, rather than in those with a duty of care.

It is also notable that more than 1 in 10 were not aware of any of the above barriers being an issue, indicating a need for further training and awareness around the inequalities and barriers experienced by LGBTQ+ people in relation to accessing care.



# Survey: LGBTQ+ People Affected by Dementia

## Summary

The target audience of the survey was LGBTQ+ people directly affected by dementia or concerned about memory loss, and those who support and care for them in a personal capacity. This includes those without, or just beginning to explore, a formal dementia diagnosis, as well as those who care for them, such as partners, friends and family members.

It was open to individuals who live, work, study or socialise in Brighton and Hove and Sussex.

The survey was live over a three week period across May/ June 2018, coinciding with Dementia Action Week 2018. In addition to promotion through the LGBT HIP newsletter, the Older People's Mailing List, Groups Mailing List, the survey was promoted via Switchboard's Facebook and Twitter accounts. Paper copies were printed and distributed to the Memory Assessment Service, and a printable PDF was shared with all services so that they could provide a paper copy where this was preferred.

While 25 initially attempted to respond to the survey, only 14 went on to pass the exclusion question and actively complete the majority of the survey.

## Demographics

### Neighbourhood: 14 answers

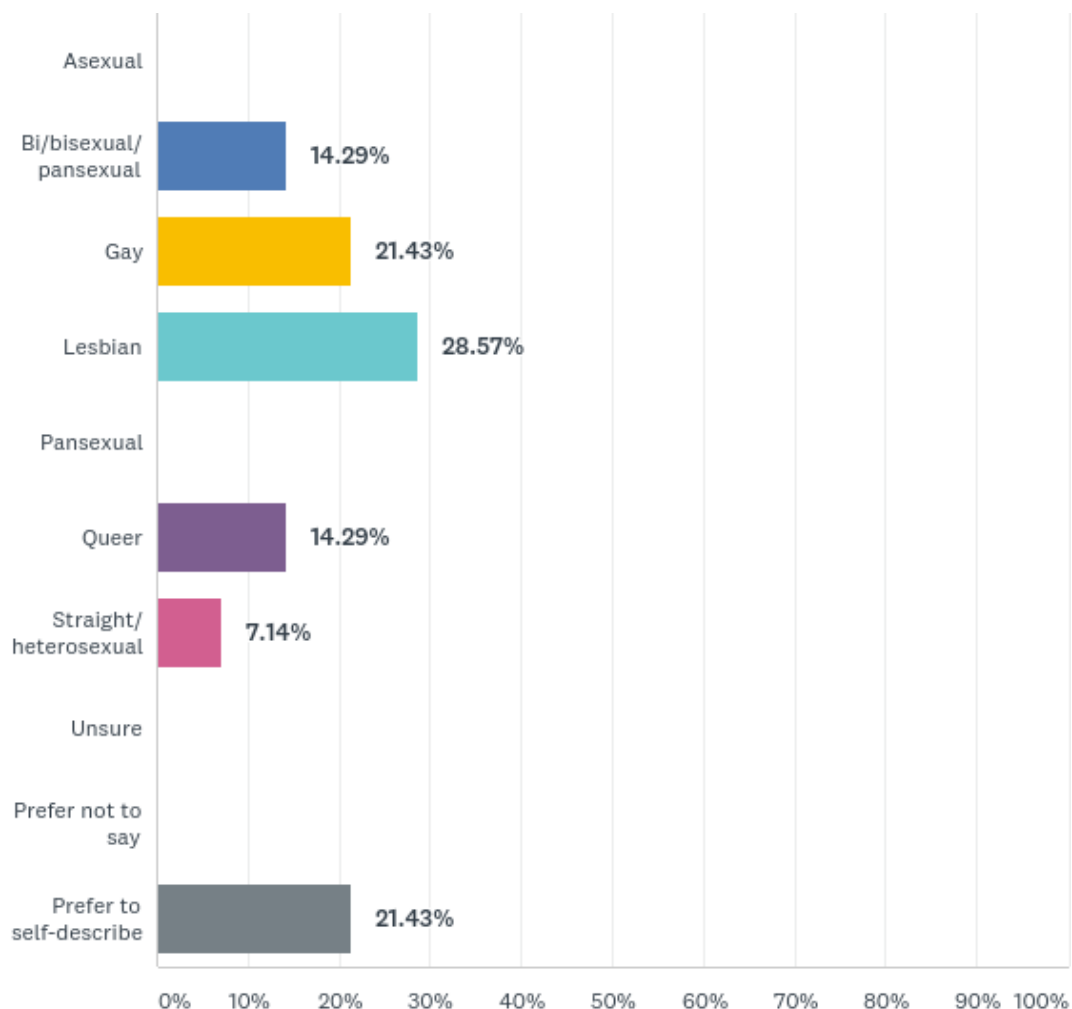
We asked respondents to provide the first part of their postcode. Geographical location was distributed across respondents as follows:

- BN1: 36% (5)
- BN2: 28% (4)
- BN3: 7% (1)
- Outside of Brighton and Hove: 29% (5)

### Sexual Orientation: 14 answers

We asked respondents “How would you describe your sexual orientation?” Participants were provided with a free text field to provide their preferred term under ‘prefer to self-describe’.

The largest proportion of respondents identified as ‘lesbian’, at 29% (4), followed by gay (21%, 3), Bisexual/ pansexual (14%, 2), and queer (14%, 2). 1 respondent (7%) identified as heterosexual/straight.



3 respondents (21%) preferred to self-describe, and stated:

*"Depends on who I am speaking to. This will depend on the person asking! "I am a member of the LGBT Community" is what I say - if required"*

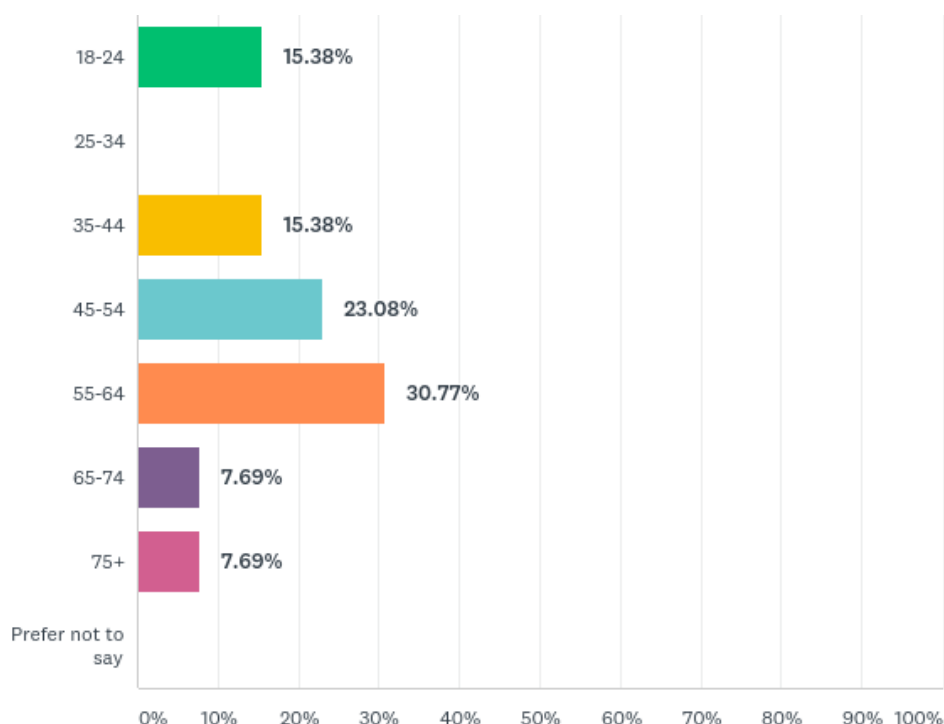
*"Gay woman"*

*"Bisexual"*

*Age: 13 answers*

We asked respondents: 'What was your age at your last birthday?' The largest proportion of those responding were aged 55-64 (31%, 4), followed by 45-54 (23%, 3).

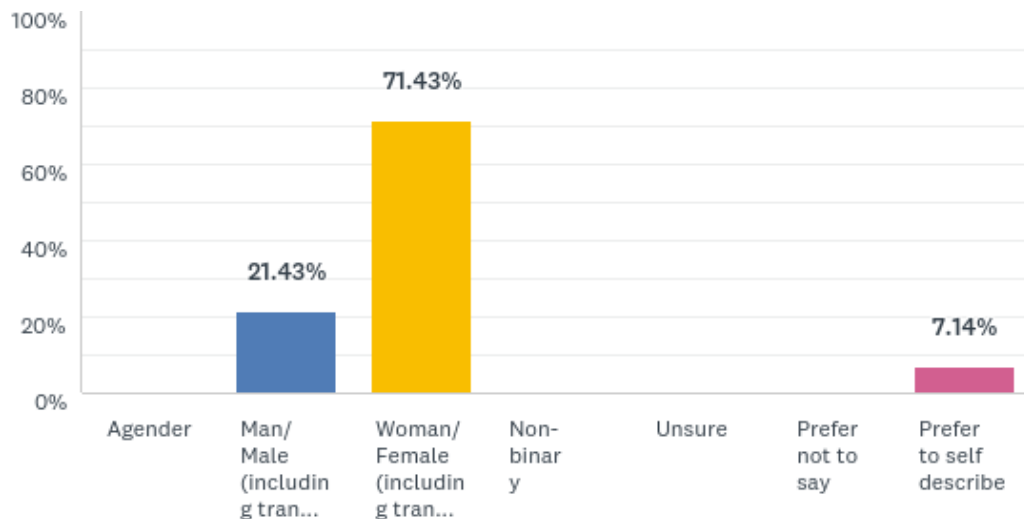
2 participants each (15% each) were aged 18-24 and 35-44 respectively. One participant (8%) was aged 65-74 and a further one was aged 75+.



*Gender: 14 answers*

We asked respondents "How would you describe your gender?" We offered the options 'female/ woman (including trans woman)', 'male/ man (including trans man)', 'non-binary', 'agender', 'unsure', 'prefer not to say', and 'in another way', with a free text field in which to self-describe.

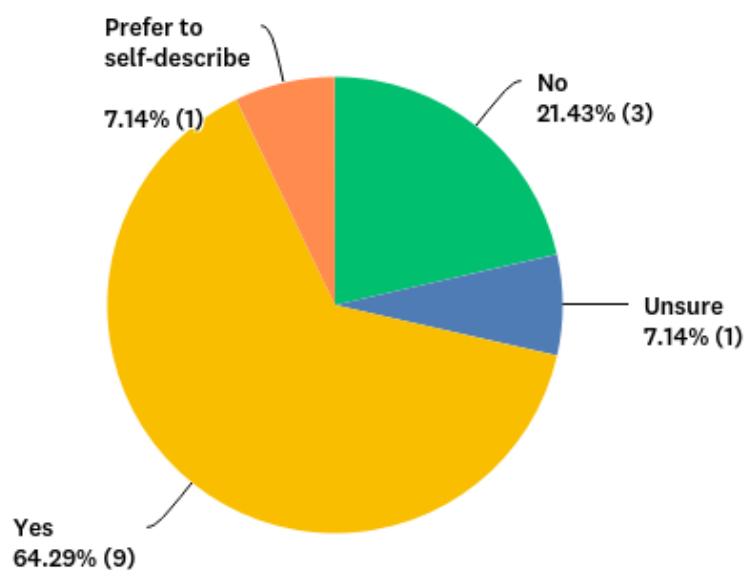
The majority of respondents identified as female/ women (71%, 10), followed by male/ men (21%, 3). 1 respondent (7%) chose to self-describe and stated: *"Biologically female"*



Trans Status: 14 answers

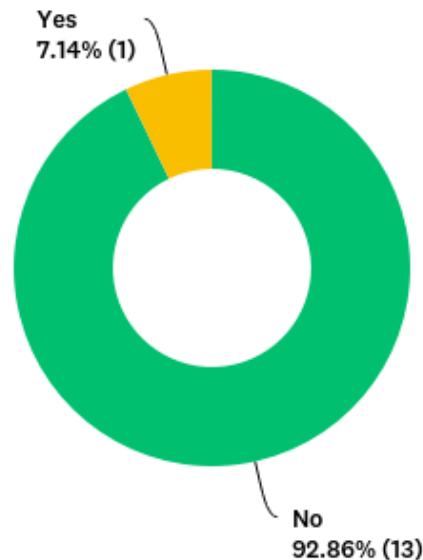
We asked “Does your gender identity match the one you were assigned at birth?” 64% (9) of respondents selected ‘yes’, and 21% (3) answered ‘no’. 7% (1) said ‘unsure’ and a further respondent preferred to self-describe, and stated:

*“I don't have a gender identity, that is a patriarchal construct. I do have a biological sex which was of course apparent from birth.”*



Intersex Status: 14 answers

We asked respondents “Do you have an intersex variation? Intersex is a term for people born with atypical physical sex characteristics. There are many different intersex traits or variations.” 93% of respondents selected ‘no’ (13), and one selected ‘yes’ (7%).



Disability: 14 answers

We asked respondents “Do you live with a health condition, impairment, learning difference, or neurodivergence that shapes your day to day activities?”

The majority of respondents (64%, 9) said they lived with some form of mental health difficulty. 36% (5) had a long-term illness or health condition, and 4 respondents (29%) were D/deaf or had a hearing impairment. 3 respondents (21%) had some form of neurodivergence, and a further 3 had some form of social or communication condition. 2 (14%) had a specific learning difficulty and 21% (3) of respondents reported that they had no known health condition, impairment, learning difference or neurodivergence, meaning that 79% (10) respondents had some form of disability.

One participant selected ‘prefer to self-describe’ and stated: “*older age!*”

ANSWER CHOICES	RESPONSES	
No known health condition, impairment, learning difference, or neurodivergence	21.43%	3
Long-term illness or health condition (e.g. cancer, chronic heart disease, diabetes, epilepsy, HIV)	35.71%	5
Mental health difficulty (e.g. addiction, anxiety, depression, eating disorders)	64.29%	9
Physical impairment or mobility issues (e.g. difficulty using your arms, using a wheelchair)	14.29%	2
Neurodivergence, meaning your brain or mind works very differently from social views of what is 'normal' (e.g. AD(H)D, Asperger's syndrome/ other autistic spectrum condition, bipolar, dyscalculia, dyslexia, dyspraxia, Tourette syndrome)	21.43%	3
Social or communication condition (e.g. a speech and language impairment, Asperger's syndrome/ other autistic spectrum condition)	21.43%	3
Specific learning difficulty (SpLD) such as AD(H)D, dyscalculia, dyslexia, or dyspraxia	14.29%	2
Blind or visual impairment that can't be fixed with glasses	0.00%	0
D/deaf or a hearing impairment	28.57%	4
Prefer not to say	0.00%	0
Prefer to self-describe	7.14%	1
Total Respondents: 14		

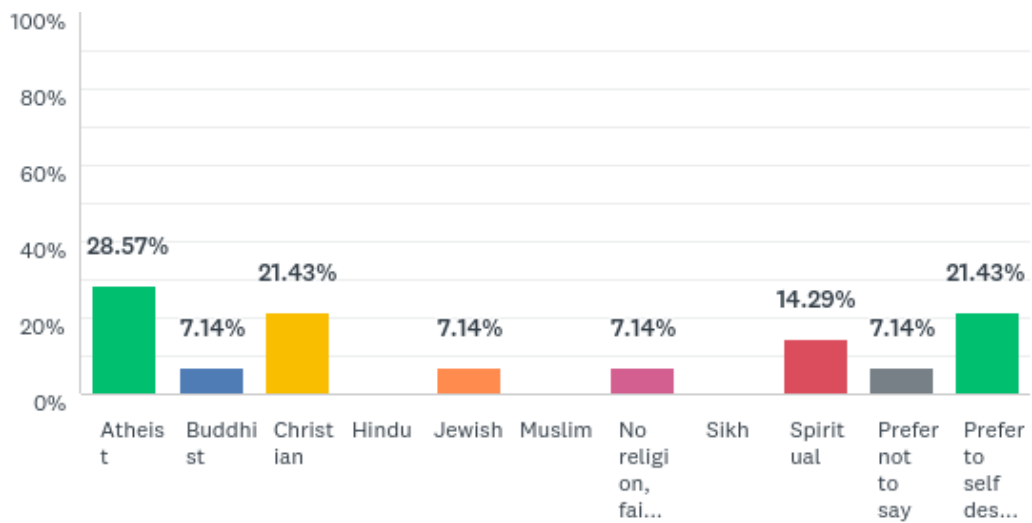
### Religion, faith and spirituality: 14 answers

We asked respondents “What is your religion or faith?”

29% (4) of respondents identified as atheist, and a further 7% (1) stated they had no religion, faith or spirituality.

Three (21%) respondents identified as Christian, and two identified as spiritual (14%). One respondent each (7% each) identified as Buddhist and Jewish respectively, and one preferred not to say.

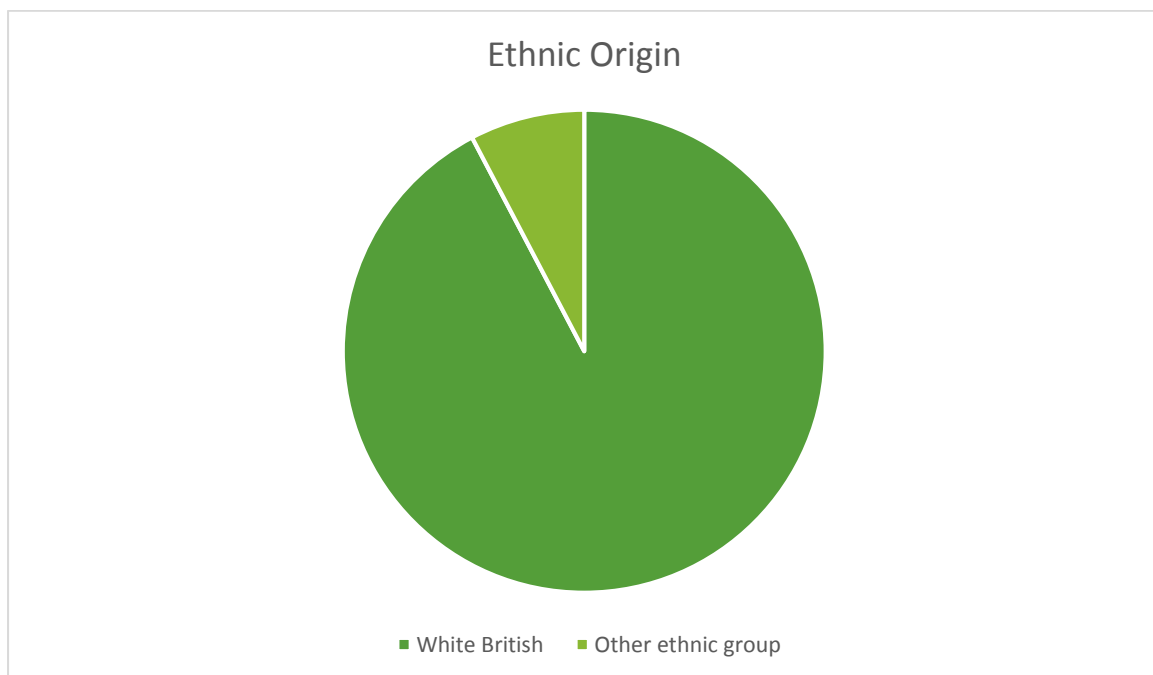
Three chose to self-describe. Two stated 'pagan' and one said 'not active'.



### Ethnic Origin: 13 Answers

We asked respondents: "How would you describe your ethnic origin?"

92% (12) were white British, and one chose 'other ethnic group' (8%) and stated "Anglo Irish Indian"



## Survey responses

### Q1: Exclusion questions: 25 answers

The first question was an exclusion question designed to filter out participants who were not eligible to respond. We said:

*“This survey is for LGBTQ (lesbian, gay, bisexual, transgender, queer or questioning) people affected by dementia and memory loss in Brighton & Hove and Sussex. By this, we mean:*

*Those living with dementia or memory loss - with or without a formal diagnosis*

*Those who are concerned about memory loss and/or are exploring a diagnosis of dementia*

*Those who care for an LGBTQ person affected by dementia or memory loss (of any sexual orientation or gender identity), such as partners, friends or family members*

*Does this describe you?”*

Of the 25 who responded, 20 said ‘yes’ and continued to complete the survey, while 5 said ‘no’ and were unable to complete the survey.

### Q2: How respondents are affected by dementia or memory loss: 14 Answers

We asked: “How are you affected by dementia or memory loss?”

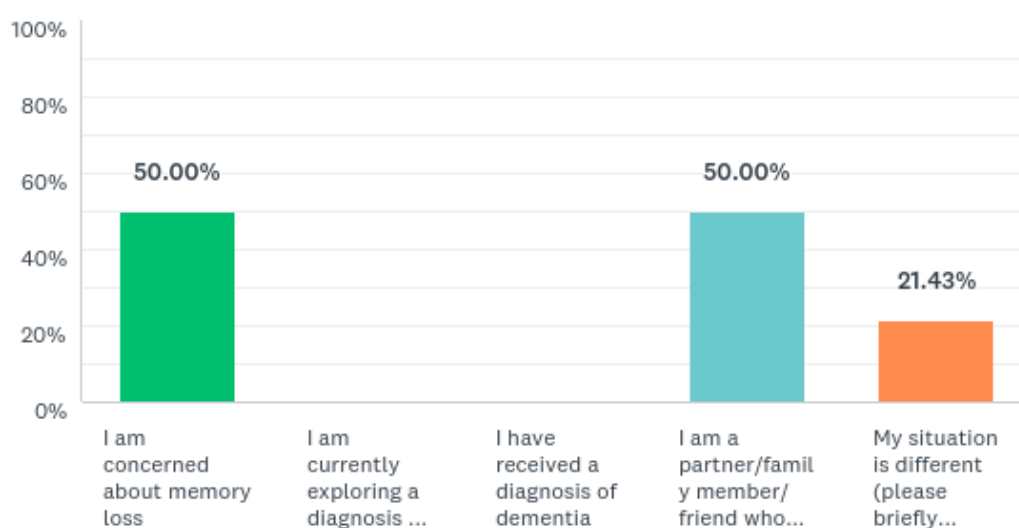
An equal number of participants, 50% (7), said that they were concerned about memory loss, and/or were a partner/ family member/ friend who supports someone with dementia or memory loss.

21% (3) said their situation was different and shared the following:

*“I am suffering major memory loss although ‘dementia’ has not yet been mentioned”*

*“After 30 years of M.E. / fibromyalgia I have recently had a stroke and a cluster of mini strokes”*

*“I have retrograde amnesia caused by head trauma”*



### Analysis:

It is of note that no respondents either currently have, or are exploring, a diagnosis of dementia.



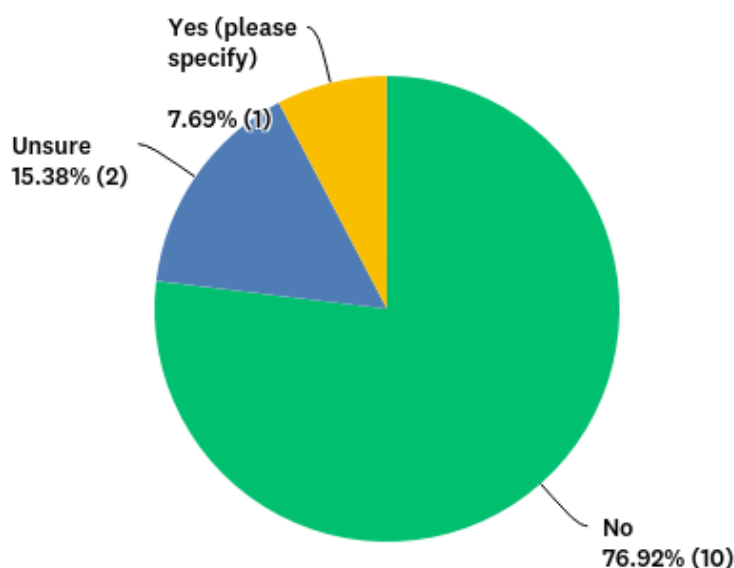
As noted by previous research, and outlined in the literature review, reaching and engaging individuals with the double, and sometimes triple, stigma and isolation of LGBTQ+ identity, dementia and often older age, is a significant challenge. Many will also experience other intersecting forms of marginalisation based on ethnicity, disability, and other factors.

While two of the respondents described situations in relation to memory loss ascribed to other conditions than possible dementia, their input is still valuable, in that they may still have contact with services like the Memory Assessment Service, Carers Centre, receive care and support, and other resources related to supporting with memory loss.

### Q3: Monitoring: 13 Answers

We asked: "Was your/ the person you support's sexual orientation, gender identity or trans status ever monitored when accessing care or support? For example, at your GP surgery, the memory assessment clinic, the carers centre, or at any support groups you attended?"

More than three quarters, 77% (10) said 'no', they were not aware of any monitoring having taken place. 2 (15%) were unsure, and 1 (8%) said 'yes', specifying that this had been conducted via a registration questionnaire.



### Analysis:

It is notable that almost all respondents were not aware of monitoring having taken place, or were unsure, a strong contrast to the findings of the survey for professionals and volunteers, which suggested a much higher rate of monitoring. This mis-match may suggest further work is required around monitoring, as even where monitoring practices exist, these may not be being fully utilised or shared with service users/ clients.

#### Q4: Information about support and social groups: 13 Answers

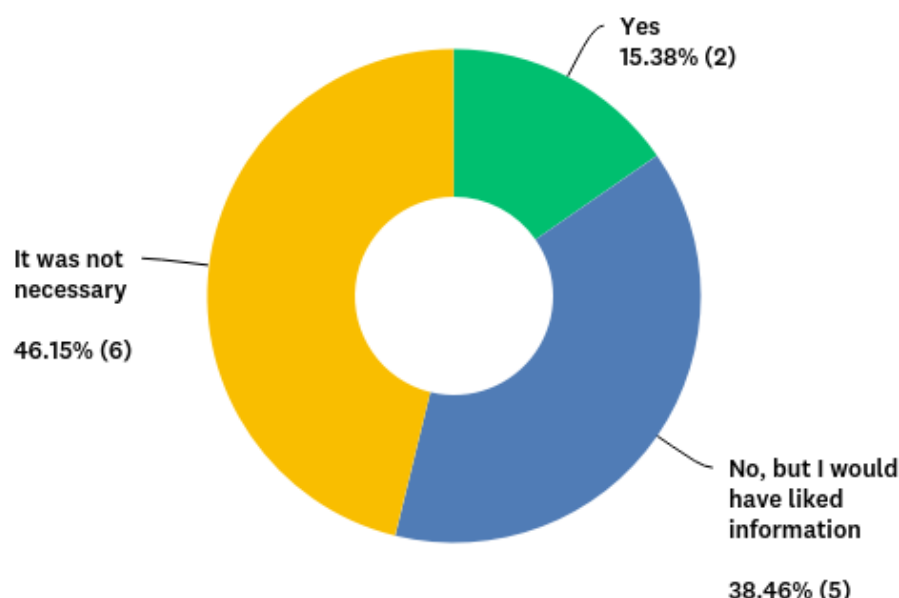
We asked: "Did you/ the person you support receive information about support or social groups for people affected by dementia?"

The largest proportion of respondents, nearly half (46%, 6) said it was not necessary to receive information about support or social groups, while 38% (5) said they did not, but would have liked to have received this. 15% (2) said they did receive this information.

#### Comments:

One comment was provided, which focused on the challenges of long-distance care for carers who live in a different place to the individual they support, including barriers to accessing support services in either location

*"Mum (living with dementia) and Dad (main carer) have been given a lot of support. It's harder for me to access support groups because I live in a different area (West Sussex) to them (London) - I stay with them one or two days a week to care for Mum and give Dad a break. But that makes it hard to access support in either London or Sussex. But there must be plenty of other long-distance carers how could do with support."*



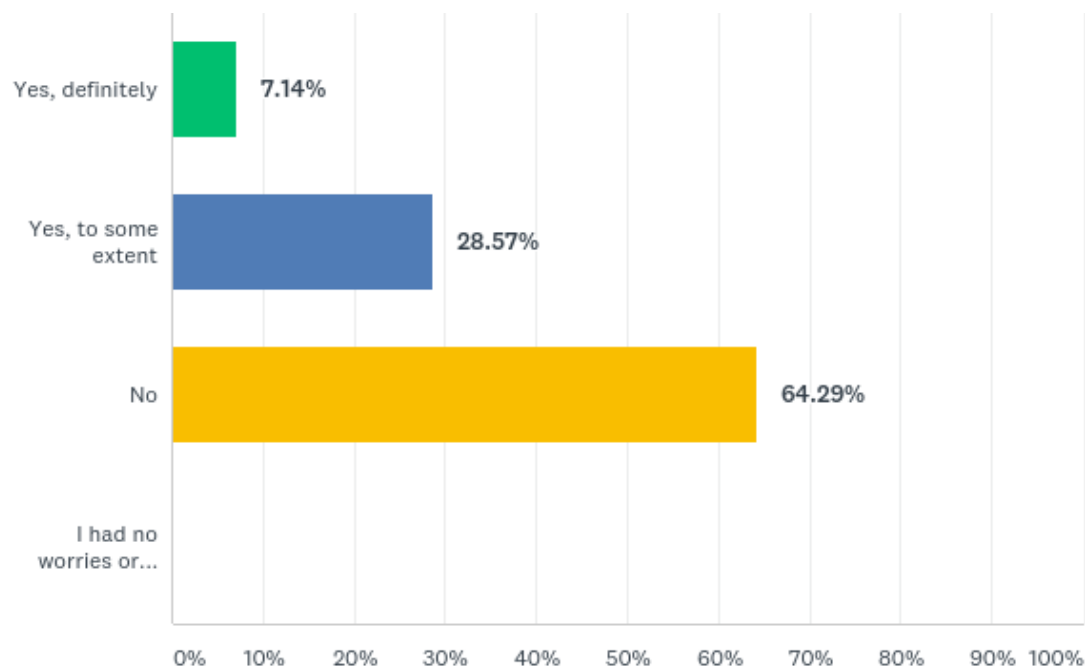
#### Analysis:

It is notable that more than a third would have liked but did not receive information about support services and groups, indicating that communicating about and signposting to relevant support – particularly of an LGBTQ+ inclusive nature – would be a valuable focus for services.

#### Q5: Being asked about worries and fears: 14 Answers

We asked: "Have healthcare staff spoken to you/ the person you support about your worries and fears?"

64% (9) said 'no' they had not been asked about this, while 29% (4) said they had been asked 'to some extent'. Only one respondent (7%) felt they had 'definitely' been asked about this.



**Comments:**

One comment was given, which stated that the respondent hadn't yet spoken to health professionals.

**Analysis:**

The fact that nearly two thirds had not been spoken to about their worries and fears indicates that this is an area requiring some work. It is important to note that no respondents said that they had no worries or fears, reinforcing that this is indeed a need that should be addressed by services.

Of those who did feel they had been spoken to, this was, for most, only 'to some extent', indicating that a more thorough approach could have been taken. It is positive that one respondent felt they had definitely been responded to in this way, and suggests that there may be 'good practice' examples to draw from in addressing this issue.

**Q6: Confidence and trust in professionals: 13 Answers**

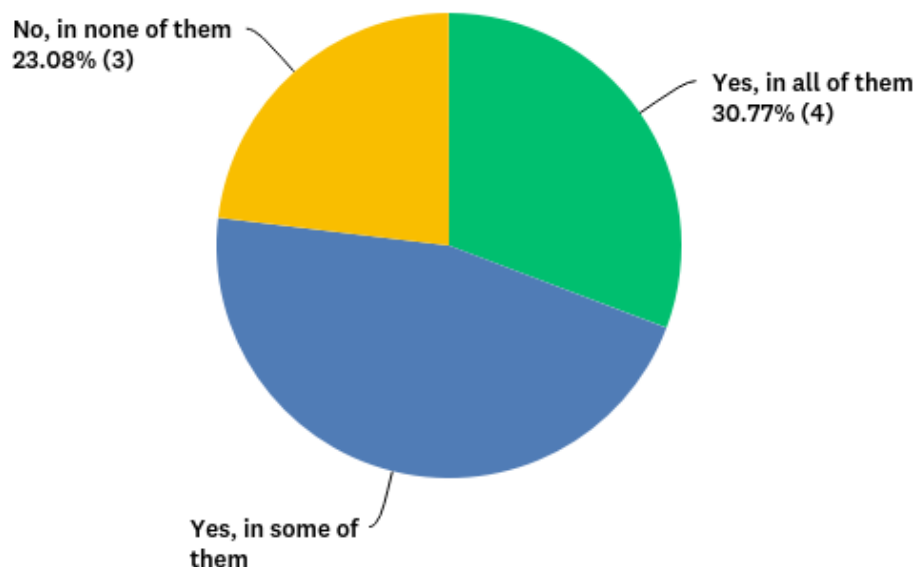
We asked: "Do you have confidence and trust in the professionals who have supported you/ the person you support?"

Nearly half of respondents (46%, 6) said 'yes, in some of them', while 31% (4) said they had confidence in all of the professionals who had provided support.

Just less than a quarter (23%, 3) said 'no' they did not have trust or confidence in any of the professionals they had worked with.

**Comments:**

One commenter stated "There are so many different people involved in Mum's care!" and other that they did not yet have experience of contact with professionals around dementia or memory loss.



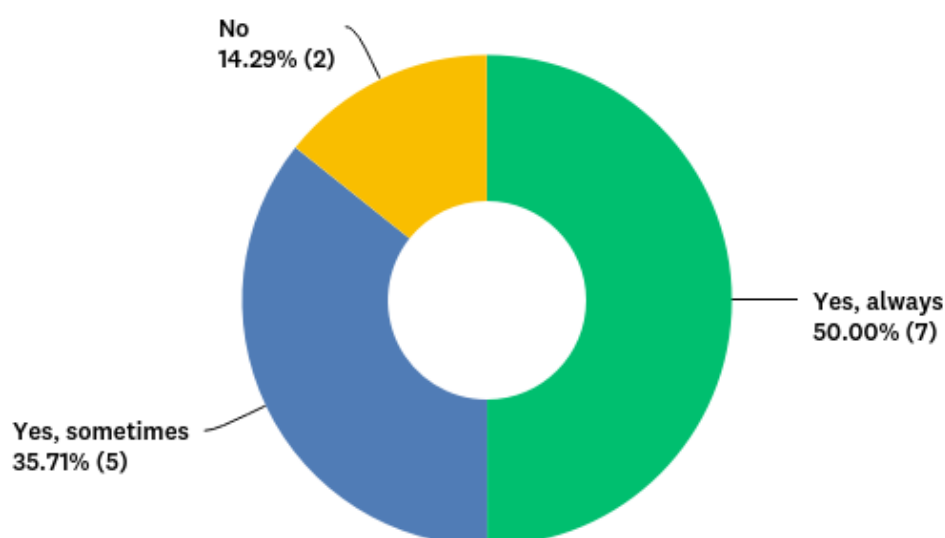
#### Analysis:

As the commenter noted, it is likely that there will be a large number of professionals involved in an individual's care, and as such, it is not surprising that the largest proportion of respondents said they had confidence trust only in 'some' of these individuals.

It is promising that more respondents said they had confidence in all of the professionals they had come into contact with than those that said they had trust in none (4:3). However, 3 in 13 respondents feeling that they do not trust any of the professionals they have come into contact with, in addition to those who had mixed experiences of professionals, indicates significant room for improvement around trust and confidence in relation to LGBTQ+ experience and dementia.

#### Q7: Respect and dignity in care: 14 Answers

We asked: "Overall, do you feel that you/ the person you support have been treated with respect and dignity throughout your/their care?"



Half of respondents (50%, 7) said that they felt they had 'always' been treated with dignity throughout their care or the care of their loved on. 36% (5) said that this had 'sometimes' been the case, and 14% (2) said 'no', that overall they did not feel they or their loved one had been treated with a sense of dignity and respect.

### Comments

One commenter said: *"Not as a younger person some 30 years ago!"*

### Analysis

It is of interest that a larger proportion of respondents felt they had 'always' (7, 50%) been treated with respect and dignity than those who felt they had trust and confidence in 'all' (4, 31%) professionals. This may indicate that there is more to trust and confidence in practitioners than being treated with respect alone.

It is of concern that 2 respondents felt they or their loved one had not been treated with respect and dignity throughout their care, overall. It is also notable that some older LGBTQ+ individuals, like the commenter above, may avoid seeking support from professionals in later life due to negative experiences with professionals as a younger person.

However, it is positive to note that, in addition to the 50% who felt they had 'always' been treated with respect and dignity, 36% (5) felt they had received this at least 'some' of the time. The fact that there was room for improvement in 50% of cases, indicates, however, that treating all LGBTQ+ clients with respect and dignity – in addition to building trust and confidence – is an area requiring some attention.

### Q8: Barriers to accessing dementia care: 14 Answers

We asked: "Have you experienced any of the following barriers in accessing dementia care, support and/or information?"

The response options offered were as follows:

ANSWER CHOICES	RESPONSES	
A lack of LGBTQ specific information and resources e.g. posters, leaflets	35.71%	5
Assumptions being made that people are heterosexual and cisgendered (i.e. people whose gender matches the gender they were assigned at birth)	28.57%	4
Healthcare professionals not being LGBTQ-aware and inclusive	21.43%	3
Experiencing homo-/ bi- / transphobia from professionals	21.43%	3
Experiencing homo-/ bi- / transphobia from other people affected by dementia	7.14%	1
LGBTQ partners (including civil partners or spouses) not being recognised as next of kin	7.14%	1
Trans people being mis-gendered by professionals (referred to by a pronoun or form of address, that does not correctly reflect the gender with which they identify)	7.14%	1
LGBTQ people being afraid to disclose their sexual orientation or gender identity because of fears about homo-/ bi- / transphobia	14.29%	2
Healthcare professionals not being confident to discuss LGBTQ issues	21.43%	3
None of the above	35.71%	5
Other (please specify). Please tell us about any/all of the barriers you have experienced.	28.57%	4
Total Respondents: 14		

A lack of LGBTQ specific information and resources was the most prevalent barrier experienced, as 36% (5). However, an equal number (5), said they had not experienced any of the above barriers.

This was followed by hetero- and cis-normativity as a barrier: assumptions being made that people are heterosexual and cisgendered, at 29% (4).

An equal number (21%, 3 – each) reported that healthcare professionals not being LGBTQ-aware and inclusive, experiencing homo-/ bi- / transphobia from professionals, and healthcare professionals not being confident to discuss LGBTQ issues respectively were key barriers they had experienced.

14% (2) of respondents said being afraid to disclose their sexual orientation and/or gender identity in anticipation of homo/bi/trans-phobia was a barrier they had experienced.

One respondent each said that experiencing homo-/ bi- / transphobia from other people affected by dementia, LGBTQ partners (including civil partners or spouses) not being recognised as next of kin, and trans people being mis-gendered by professionals, respectively, were barriers they had experienced.

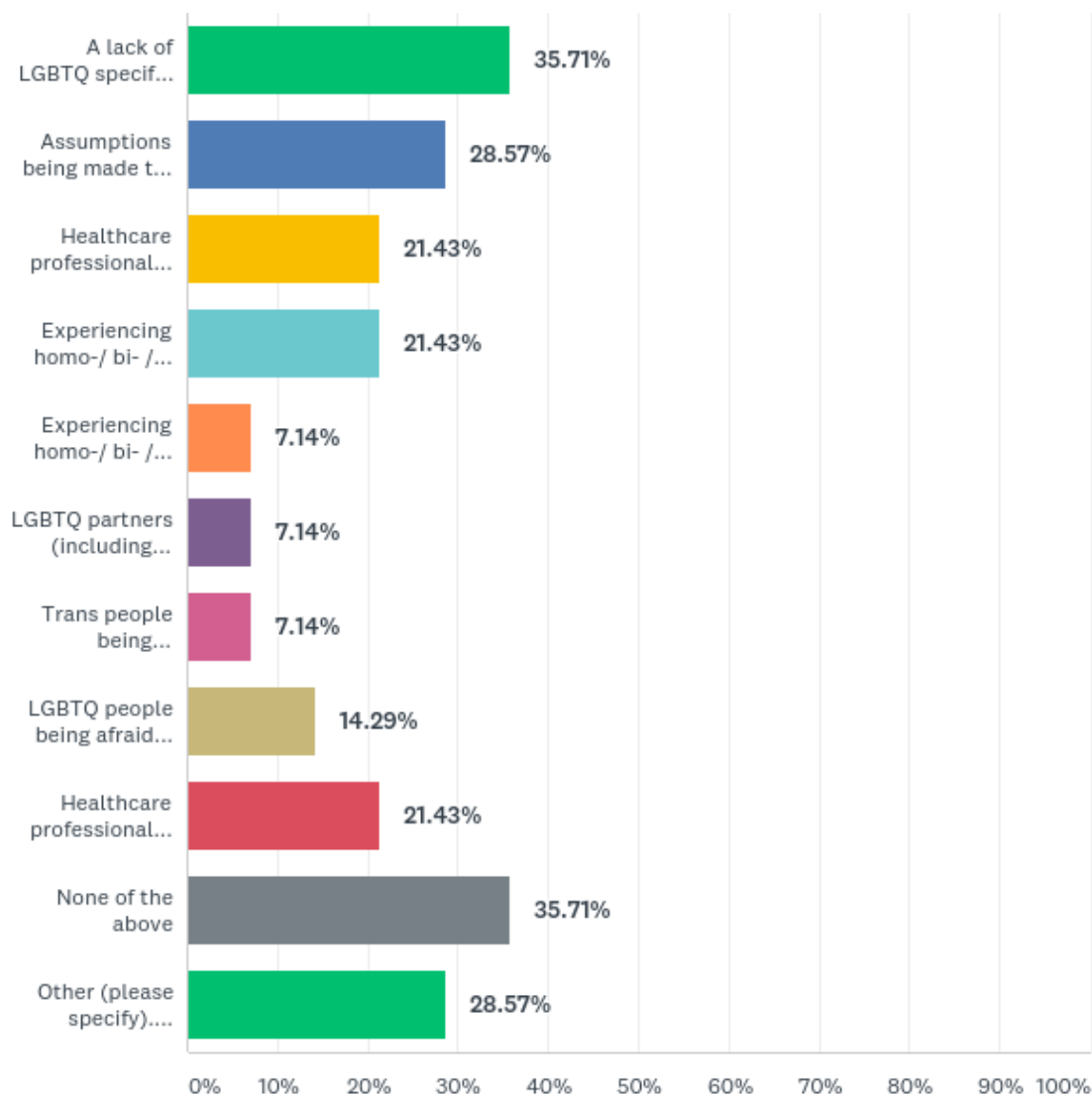
29% (4) of respondents stated ‘other’ and provided the following responses:

*“(none) recently”*

*“As a carer of a straight, cis person, she has not needed any LGBTQ-specific resources, and I have not needed them either in my caring role.”*

*“Being trans as the cause of all problems - i.e, not because of the car crash I was in, it's the fact I'm taking HRT”*

*“Professionals and my wider extended family assume I can always be available to care for Mum because my relationships are either invisible to or less valued by them that a conventional heterosexual monogamous marriage would be.”*



### Analysis:

It is notable that 64% of respondents had experienced some form of barrier to receiving dementia care of support, for themselves or a loved one, related to LGBTQ+ identity.

A lack of resources was given as the most prevalent barrier experienced, followed by hetero- and cis-normativity, indicating that these are key areas in need of attention. These are issues that a previous HIP report connected with a need to improve monitoring of sexual orientation, gender and trans status – an area indicated as requiring attention in the surveys both for dementia professionals and for the LGBTQ+ community. Without effective monitoring, it is easier for hetero- and cis-normativity to go on unchecked, for inaccurate assumptions to be made, and for individuals to therefore receive

inappropriate support, or miss out on particular forms of support and signposting. With better and more embedded monitoring practices also comes a greater understanding of the types of resources and information that service users need.

This may also be linked to being afraid to disclose sexual orientation and/or gender identity in anticipation of homo/bi/trans-phobia, which was reported as a barrier by 2 respondents (14%). Indeed, previous HIP reports (Inclusion Award, 2016; Monitoring, 2018) have highlighted a presence of visible LGBTQ+ information and resources, in addition to equalities monitoring, as facilitative of trust in healthcare professionals, and could possibly help allay fears of disclosing.

In contrast to the perceptions of dementia professionals and volunteers, who perceived clients'/patients' peers as a greater barrier than professional staff, more respondents (3) said they had experienced homo/bi/trans-phobia from staff than they had from peers affected by dementia (1). This indicates a mismatch between the experiences of LGBTQ+ people experienced by dementia and the staff who support them.

However, one of the highest-proportion single responses (5, 36%) was that respondents had not experienced any barriers related to LGBTQ+ identity. One of these respondents explained that this was because the person they cared for is heterosexual and cisgender, and that they did not feel that they had required any particular support as an LGBTQ+ carer. Another stated that they had not experienced any barriers "recently", indicating that there may have been barriers in the past, but that these have not been active in recent interactions with professionals and services. That said, the fact that several respondents had not experienced any barriers indicates that there are already examples of good practice that could be tapped in developing further training and support in the areas with room for improvement.

While only one respondent gave being mis-gendered as a barrier, it is important to take account of the very small number of trans respondents surveyed. One commenter also stated that, in their experience, problems attributable to a clear cause are instead attributed to taking hormone replacement therapy. This indicates a diminished sense of trust and confidence in professionals, and an experience of professionals not taking their stated health concerns seriously, as well as problematizing their trans status.

While a person designated 'next of kin' need not be someone to whom one is in a legally recognised relationship, like a spouse or child, other literature on LGBTQ+ and dementia has recognised that this is a common misconception.

LGBTQ+ partners not being recognised as next of kin, although not legally enforced, has been identified as an issue in literature and research on LGBTQ+ people with dementia, and the fact that one respondent reported this issue indicates that this may still be an active issue in some dementia care settings.

The commenter who stated that they find assumptions are made by professionals and family members that they will be available to care for their mum because their relationships are less visible and valued points to the issues LGBTQ+ carers of individuals with dementia may face. A de-valuing of non-heterosexual and non-monogamous relationships may mean that some LGBTQ+ carers do not receive appropriate support, or are over-stretched.



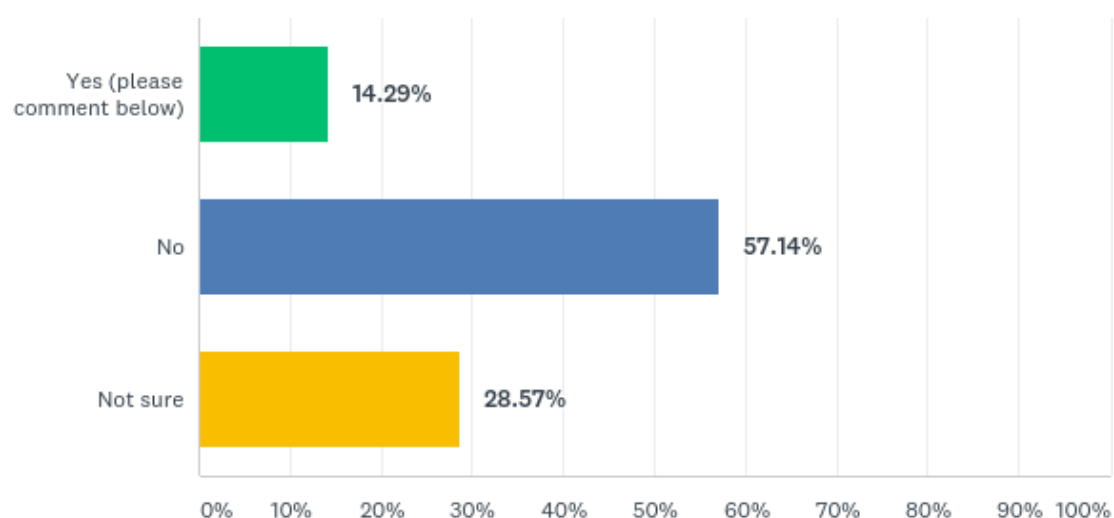
### Q9: Sexuality, Gender and Challenges to accessing support: 14 Answers

We asked: "Have you/ the person you support experienced any barriers or challenges in accessing information, care or support relating to your sexuality or gender?"

The majority of respondents said 'no', at 57% (8). 4 said they were not sure (29%) and 2 (14%) said yes, stating the following:

*"My sexuality and the sexuality of my partner seems either wrongly assumed or not deemed relevant"*

*"Nobody has any support or idea how to help a 22 year old trans woman with memory loss so I have to learn everything myself"*



### Analysis:

It is interesting to note that, while 64% of respondents gave at least one example of an LGBTQ+ based barrier to accessing dementia care or support in question 8, only 14% confirmed that they definitely had in question 9. However, it is notable that 29% also stated that they were 'not sure' possibly indicating a lack of confidence about identifying their previously reported barriers as a legitimate sexuality or gender based challenge.

One of the two comments provided indicated assumptions being made about sexuality as a barrier, pointing to possible heteronormative assumptions, identified as a prevalent barrier in question 8.

The second of the two comments pointed to the particular challenges of younger individuals experiencing memory loss, particularly those who are trans, and the burden this places on individuals to conduct research and learn about their condition for themselves. This experience of lacking appropriate support due to younger age was also echoed by a man in his early 30's with young-onset dementia, who spoke at an LGBTQ Dementia Webinar, organised by Alzheimer's Society in May 2018.

### Q10: Other information and support needs: 13 Answers

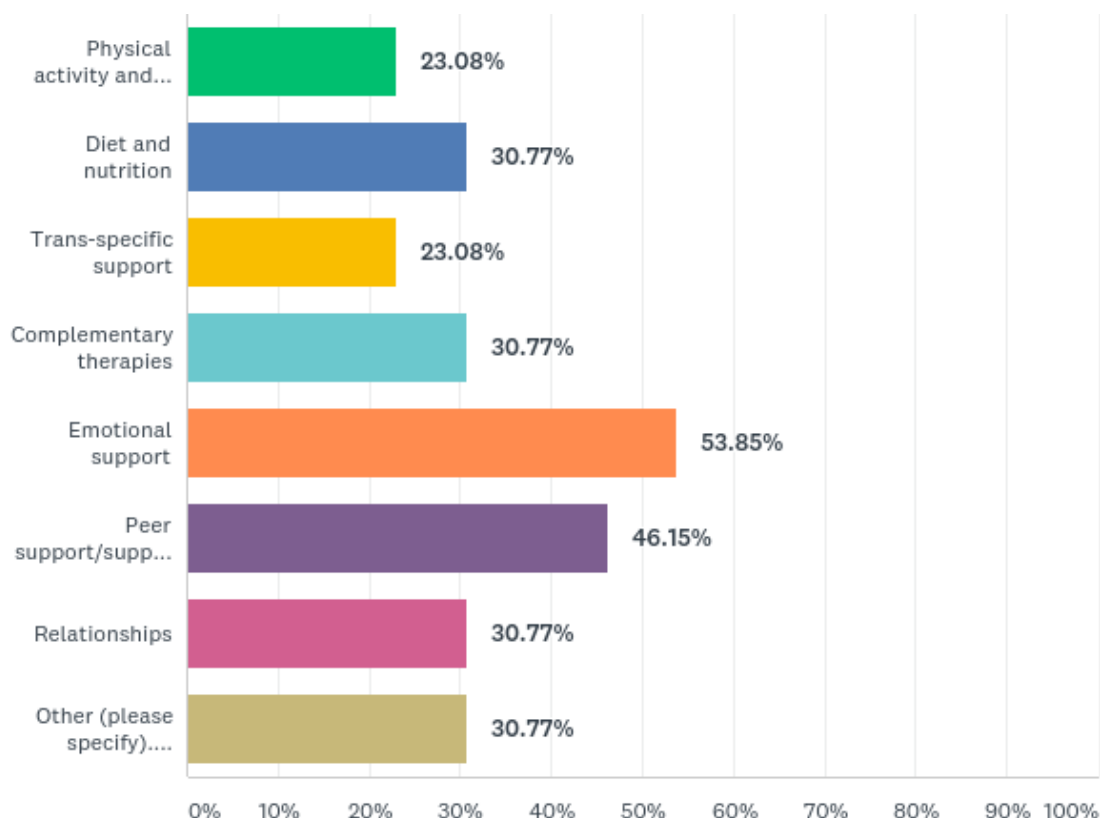
We asked: "Is there any information or support you/ the person you support felt you/ they needed at any point but did not have?"

The majority of respondents, 54% (7), said they would have valued, but did not receive, more emotional support. 46% (6) said they would also have liked more access to peer support or other forms of support group.

An equal number of respondents, 4 (31%) each, said they would have valued more information and support about diet and nutrition, relationships and complementary therapies.

3 (23%) said they needed and did not receive trans-specific support.

4 (31%) selected 'other' – comments, where provided, are given below.



#### Comments:

*"I'm in West Sussex and feel isolated from LGBTQI+ community"*

*"As an LGBTQ carer, I'd like to have been offered any info about any peer support communities (online or IRL) for LGBTQ carers of people with memory loss/dementia."*

*"General physical health"*

#### Analysis:

Emotional and peer support came through as the most needed and least served areas for respondents, indicating that this is an area to build on through LGBTQ+ specific training around providing non-physical and non-practical emotional and relational support through the process of managing memory loss or caring for someone in this process. This is supported by the commenter who said they would like to access LGBTQ+ specific support for carers of people with memory loss/dementia.

Support around relationships would have been valued by nearly a third of respondents (31%, 4), and this could also indicate an opportunity for training around LGBTQ+ and relationship-diversity inclusivity to be embedded in any improvements in this area.

As one commenter noted, certain geographical locations (in this case, in West Sussex) have less access to LGBTQ+ support and resources, and in these cases, emotional and peer/ group support may be particularly needed and valued.

It is also notable that all trans respondents said they needed, but did not receive, trans specific support, echoing previous comments related to issues around trans awareness.

#### Q11: NHS Care rating: 13 Answers

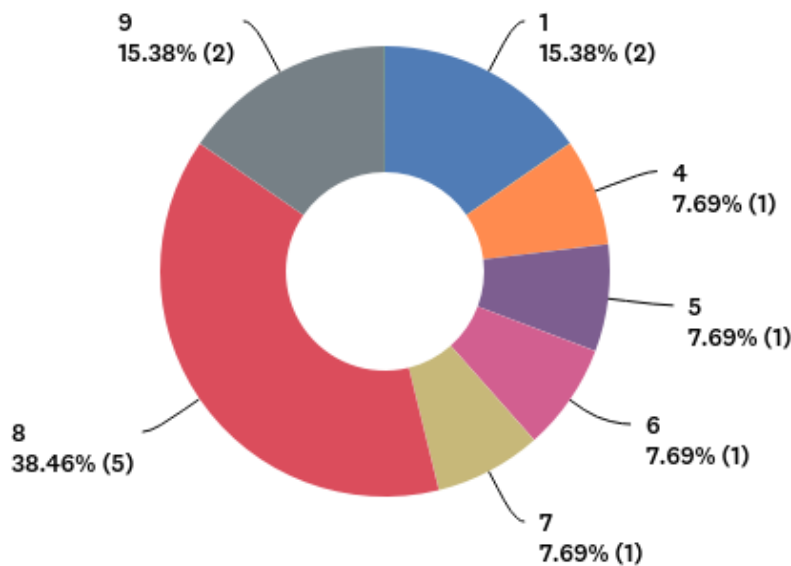
We asked: “Q11: Overall, how would you rate the care you/ the person you cared for received from the NHS?” and offered a rating scale from 0 = ‘very poor’ to 10 = ‘very good’.

The largest proportion of respondents (5, 38%) rated their NHS care as 8/10, and 2 (15%) rated their care 9/10.

2 (15%) rated their care 1/10.

One respondent each (8% each) rated their care 4, 5, 6, and 7 out of 10 respectively.

No respondents gave the lowest (0) or highest (10) rating.



#### Comments:

Two comments were provided. One stated that, while they highly valued and rated the individuals involved in NHS care, they felt that the NHS, at a systemic level, was performing poorly.

*“The people involved try their best and are generally lovely but it's systemically failing everyone”*

Another highlighted self-reliance, in contrast to the question about receiving NHS care, and being personable with professionals, possibly as a way of ensuring care needs are met:

*"I am quite capable of looking after myself after 76 years on this planet, as an elderly person, I am always polite and cheerful and well mannered - to everyone! Works every time!!!"*

**Analysis:**

It is promising to find that the overall rating of NHS care was good-very good. However, this finding comes in contrast to results indicating lower levels of trust and confidence. This may, however, indicate that many of these experiences were taking place outside of the context of NHS services, in care settings, for example.

Even with this positive result, it is still noteworthy that 4 in 13 respondents rated their care as 5/10 or less, indicating that some NHS care had been experienced as lacking, below a 'fair' rating. It is not clear, however, whether this is connected to individual professional interactions or interacting with the NHS on a more general and systemic level.

**Q12: Additional comments on LGBTQ+ and dementia: 14 Answers**

We asked: "Do you have any particular comments, concerns or experiences in relation to LGBTQ issues and dementia/ memory loss that you would like to share?"

Four respondents (26%) provided answers to this question.

One point raised was the need to acknowledge young-onset dementia, and provide appropriate support that takes into account the individual's cultural and life experiences:

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*"NHS and support services seem not to recognise the existence of people with early on-set dementia who are not in their old age. The system seems geared towards old age people and there is very little support for those who are not well into retirement. Being in a different generation needs to be recognised as the nature of support and the way it is delivered needs to reflect the cultural and life experiences of the person living with dementia."*

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Another comment centred around concerns about facing memory loss or dementia in the future, and fears that they would be forced to resort to non-LGBTQ+ affirmative resources and care facilities. In the face of this, there are questions of whether arrangements could be made within and by the queer community itself, rather than accessing mainstream services:

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*"I worry for myself and my queer friends that when we are older we might have no choice but to go into care homes or use care facilities that are not LGBTQ affirmative. This is quite a big concern for us and we often discuss whether we could make alternative arrangements to be looked after in queer community of some kind."*

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One trans commenter with memory loss affirmed that the experience did not affect their gender identity, and also indicated a sense that they may have felt that they needed to 'prove' their gender identity for this to be believed and taken seriously.

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*"It hasn't affected my gender identity at all - I was trans before (proved in pictures and diaries, I'm not just making it up!) and I still am now."*

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One trans-identified carer of their mother, who has dementia, spoke about the specific challenges of supporting a heterosexual and cisgender parent. In particular, they remarked on the tension this creates between supporting their mother in her community and simultaneously needing to have access to their own, which their mother is no longer able to recognise or support due to her dementia. A feeling that their non-heterosexual and non-monogamous relationships are also less valued adds to this difficulty, they said:

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*"Mum's attitudes have gone back in time as her memory has failed so she can be homophobic, homophobic and transphobic which is painful even though I know she can't help it. She forgets to use my chosen name rather than my birth name. I either have to keep coming out to the ongoing stream of new professionals involved in her care or be assumed to be straight and monogamous - it's a bit exhausting."*

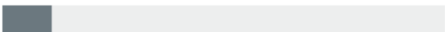
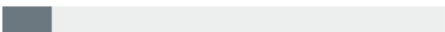
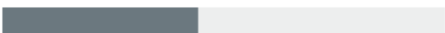
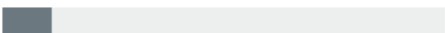
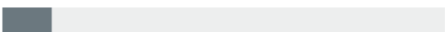
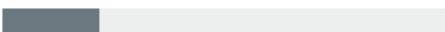
*"I don't feel that my commitments to my family of choice are as recognised or as valued as a conventional heterosexual monogamous marriage would be. Because Mum, the person I care for, is Heterosexual I feel like I am torn between two worlds. I want to support her to remain as active as possible in her community. But I also want to have the time and energy left to engage with my own community."*

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Q13: Additional comments on LGBTQ+ and dementia: 14 Answers

We asked: "Do you think there are any particular strengths or challenges LGBTQ people experience from within the LGBTQ community when it comes to dementia and memory loss? For example, in attitudes towards dementia, or the community support available."

9 responses were provided, which centred around the following themes:

Isolation		11.11%	1
Lack of information		11.11%	1
Positive community		44.44%	4
Sexism		11.11%	1
Single		11.11%	1
Youth-centric		22.22%	2

Four commenters made reference to the **positive community** influence of belonging in the LGBTQ+ community, including the support available, and how important this has been for them in their own journey with memory loss, or as a carer.

*“As much community support as can be provided. The need to engage with others is imperative”*

*“Helps to be part of a community that understands”*

*“Community support available for older lesbians”*

*“The LGBTQ community have been my main source of support throughout my time caring for my parents. I would not have coped without them and am truly grateful to them”*

On the theme of **single-status**, one respondent remarked on the added challenges for LGBTQ+ people as result of the higher incidence of being single in later life, and the **isolation** that can result from this:

*“As the LGBTQ community probably has a greater proportion of single people, or people not in a long established relationships, then the fear of having dementia and being alone must be even greater and consequent anxiety levels heightened.”*

One commenter said that it wasn't their sexual orientation so much as their gender as a woman that felt relevant to them in relation to being treated equally when accessing dementia care:

*“I am female and have always been a 2nd class citizen!!! Memory loss of the beginning of memory loss knows no boundaries.”*

One commenter remarked on the lack of information in general in the LGBTQ+ community about dementia, stating that, in the community, there is *“Just a lack of knowledge or experience around it all”*

Two commenters noted a **youth-centric** tendency in some areas of the LGBTQ+ community, and the challenges this faces for all older people, including those affected by dementia:

*“I do think LGBTQ culture is very youth-centric and glorifies youth, perhaps at a cost to older people including those dealing with memory loss or dementia.”*

*“Older people can be invisible in the LGBTQ community.”*

# Key Findings

## *An intersectional engagement challenge*

Reaching and engaging individuals with the multiple intersecting stigma, and isolating factors, of LGBTQ+ identity, dementia and often older age, is a significant challenge, and has been evident throughout this engagement. Many will also experience other forms of marginalisation based on ethnicity, disability, and other factors, compounding this difficulty. Indeed, it is of note that the vast majority of LGBTQ+ respondents to our community survey affected by dementia or concerned about memory loss – nearly 8 in 10 – had at least one form of disability. More than 6 in 10 of these live with some form of mental health difficulty and nearly 4 in 10 had a long-term illness of health condition. BAME communities were notably under-represented, with only 1 in 13 LGBTQ+ respondents being of a BAME background. The remaining 12 in 13 LGBTQ+ respondents who provided their ethnic origin were white British, indicating a need to consider engagement strategies of LGBTQ+ BAME individuals (work currently being carried out by Switchboard as part of its BHCC commissioned 'Intersectionalities' engagement topic) in engagement around dementia.

As such, strategies for identifying and engaging LGBTQ+ people affected by dementia, and the complex intersections of these identities with other protected characteristics, is groundwork that must be undertaken before the core recommendations about properly serving these communities can be best carried out. This report draws on previous literature and engagement and highlights effective sexual orientation, gender and trans status monitoring, in tandem with improving LGBTQ+ competence and inclusivity in services, as one key to improving identification of and engagement with LGBTQ+ people affected by dementia, who may otherwise 'slip through the net'.





### *Single and socially isolated LGBTQ+ people*

As LGBTQ+ individuals are likelier to be single and/or socially isolated, particularly in later life, engaging these groups is particularly challenging. Those without close support networks may take considerably longer to present at their GP for assessment, as they may not be aware of early signs of dementia, such as memory lapses, without close individuals to notice this for them. Post-assessment, those without support may not attend follow-up appointments or support due to a lack of motivating support from close loved ones, difficulties getting out and about by themselves, and inclusion barriers in services (explored elsewhere in this report, such as heteronormativity).

### *Engaging LGBTQ+ women*

According to the Alzheimer's Society, 65% of people living with dementia are women. Yet, through the Rainbow Café project, Switchboard has found it more challenging to engage LGBTQ+ women than men, with Switchboard's project mirroring issues found in many others of gay men being the most prevalent group represented, while women are notably under-represented. While women of all sexual orientations tend to be over-represented in caring and support roles (81% of professional and volunteer respondents were women) they appear to be under-represented among those accessing care, at least in the case of LGBTQ+ dementia services. Anecdotally, this is a shared situation across many LGBTQ+ dementia support groups throughout the UK. Furthermore, while 71% of the survey respondents were women, and although two women concerned about memory loss responded to the survey, it was notable that none of these had received a formal diagnosis, and most were responding in their capacity as carers. Engaging LGBTQ+ women, therefore needs to be identified as a priority, and further work is required to learn more about the engagement inclusion barriers specific to LGBTQ+ women.

### *Young-onset dementia*

LGBTQ+ people may be over-represented among those with young-onset dementia. One respondent to our community survey was an individual in their 20s concerned about memory loss. Furthermore, in a webinar hosted by the Dementia Action Alliance on LGBTQ+ dementia, both individuals with lived experience were gay men who had developed the condition before 65 (one in his 50s, one in his early 30s). One of these was HIV-related and one was not. Support services are geared overwhelmingly to older people affected by dementia, and younger people may face particular challenges receiving a diagnosis and accessing appropriate support. These challenges for younger people with dementia are also likelier in LGBTQ+ individuals to be compounded by additional factors of social isolation and inclusion barriers such as low confidence and trust in services.

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*"NHS and support services seem not to recognise the existence of people with early on-set dementia who are not in their old age. The system seems geared towards old age people and there is very little support for those who are not well into retirement. Being in a different generation needs to be recognised as the nature of support and the way it is delivered needs to reflect the cultural and life experiences of the person living with dementia."*

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### *HIV and dementia*

HIV, which disproportionately affects men who have sex with men (including gay, bi and queer men) and sex-working lesbian, bisexual, queer and – particularly – trans women, has also been linked to a higher likelihood of developing dementia (NAT 2015). HIV infection can also cause a number of different problems in the brain, which fall under the umbrella term of HIV-associated neurocognitive



disorder (HAND). Some form of this condition affects up to half of people with HIV (Alzheimer's Society 2018). HIV-related dementia may then also contribute to LGBTQ+ people being over-represented among those with a young onset of the condition.

#### *Additional pressures for LGBTQ+ carers*

A number of LGBTQ+ people responded to our community survey in their capacity as carers of a person with dementia, and spoke of the particular challenges they faced, including their commitments and relationships being less valued by the person for whom she cares and those involved in her support, due to them not following a traditional heterosexual framework. As a result, some LGBTQ+ carers may be finding that they are particularly over-stretched, and lack adequate experiences of empathy and support for other important aspects of their life.

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*"I don't feel that my commitments to my family of choice are as recognised or as valued as a conventional heterosexual monogamous marriage would be. Because Mum, the person I care for, is Heterosexual I feel like I am torn between two worlds. I want to support her to remain as active as possible in her community. But I also want to have the time and energy left to engage with my own community."*

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As LGBTQ+ individuals are likelier to live in a different geographical location than their family of origin, they may also be likelier to face challenges with traveling to provide care, and difficulties accessing adequate support in either location.

#### *Barriers to accessing services*

When selecting barriers to services they were aware of for LGBTQ+ people, individuals experiencing homo/bi/trans-phobia from staff was the lowest-ranked barrier. This may reflect the generally high levels of confidence held by staff about their LGBTQ+ awareness, but it may also reflect a tendency to locate the barriers primarily in LGBTQ+ people's perceptions and within the community and peers themselves, rather than in those with a duty of care.

However, this came in contrast with the results of the community survey, where more than 2 in 10 LGBTQ+ survey respondents said they had experienced homo, bi or trans-phobia from staff in these services. More than 1 in 10 were not aware of any barriers LGBTQ+ people would experience to accessing services.

While 64% of LGBTQ+ respondents gave at least one example of an LGBTQ+ based barrier to accessing dementia care or support, only 14% confirmed that they had experienced some barrier to accessing care related to their sexual orientation, gender or trans status. However, it is notable that 29% also stated that they were 'not sure' possibly indicating a lack of confidence about identifying their previously reported barriers as a legitimate sexuality or gender based challenge.

#### *Quality of Care*

The overall rating of NHS care was 'good' to 'very good', but around a third rated their care as 5/10 or less, indicating that some NHS care had been experienced as lacking, below a 'fair' rating.

More than 1 in 10 (14%) or LGBTQ+ people surveyed felt that they or the person they cared for had not been treated with dignity or respect throughout their care (including in non-NHS settings), and further roughly 4 in 10 (36%) said they felt they had only 'some' of the time.

More than a third of LGBTQ+ people surveyed also said they would have liked to have received more signposting and information regarding support groups and resources.

These findings indicate room for improvement in care and support settings both within and outside of the NHS, and also an untapped resource of examples of 'good practice' with more than 1 in 10 (15%) rating their care as 9/10 or 'very good'.

#### *Confidence and Trust*

It was found that, as a whole, service providers' confidence meeting LGBTQ+ needs outpaced their training or professional experience working with these communities, with 28% of professionals and volunteers saying they either rarely came into contact with LGBTQ+ people through their work or were unsure, while 90% said they were either 'quite' or 'very' confident in their ability to understand the needs of and serve these communities. Confidence understanding the needs, specifically, of trans people affected by dementia was significantly lower, however, at 38%.

However, LGBTQ+ people's confidence in staff to meet their needs was lower than professionals' confidence to serve them, with just under a quarter of respondents saying they did not have trust or confidence in any of the professionals they worked with, and nearly half said they did so only with 'some'.

#### *Heteronormativity*

While, reassuringly, 90% of professional and volunteer respondents said they considered an understanding of LGBTQ+ as 'very important' for delivering the best possible LGBTQ+ care, the well-meaning but heteronormative view that LGBTQ+ people should either be treated 'the same as everyone else' (implicitly meaning heterosexual people) came through in comments. At the opposing extreme, some comments made reference to needing to treat each patient as an individual irrespective of their identity. While both approaches are well-meaning, both equally erase the realities of systemic LGBTQ+ health inequalities, either through a hyper-individualising or hyper-generalising approach. Individualised, tailored, person-centred care can and should be informed by an understanding of societal-scale, systemic-level health inequalities and access barriers affecting LGBTQ+ people at a community level.

#### *The need for LGBTQ+ inclusive later-life care*

Throughout the literature on older LGBTQ+ people, particularly those with dementia, a strong narrative of being 'forced back into the closet' runs throughout, with LGBTQ+ individuals finding themselves in residential care settings that are not inclusive of their experience and identity. Individuals therefore hide their sexual orientation, gender or trans status to stay safe in what feels like a threatening environment. As LGBTQ+ are likelier to be single and/or socially isolated and lack traditional support networks, they are therefore likelier to rely on formal, state-provided care than their heterosexual peers, thus underlining the need for this generic care to be LGBTQ+ aware and inclusive.

One LGBTQ+ survey respondent voiced fears about needing care in the future as an LGBTQ+ person:

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*"I worry for myself and my queer friends that when we are older we might have no choice but to go into care homes or use care facilities that are not LGBTQ affirmative. This is quite a big concern for us and we often discuss whether we could make alternative arrangements to be looked after in queer community of some kind."*

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### *Trans needs*

Trans individuals, whether or not they have chosen any surgical or medical intervention as part of their transition, have particular care and support needs in relation to dementia. These are particularly relevant to care and support providers, in terms of supporting and maintain a sense of identity and, for those with medical needs (such as HRT treatments), support with maintaining these are also important. However, as the survey with professionals and volunteers indicated, most lacks confidence to some degree in this regard, and therefore training is essential for ensuring trans individuals needs are understood and responded to at each stage of their care.

One trans survey respondent concerned about memory loss expressed frustration that, particularly as a younger person, she felt as if professionals 'didn't know what to do with her'.

### *LGBTQ+ Priorities for Inclusion*

The two highest ranked barriers to inclusion in dementia care services for LGBTQ+ people were heteronormativity and a lack of LGBTQ+ inclusive cues, information and resources. These were followed by experiencing homo, bi or transphobia from workers and volunteers, them not being LGBTQ+ aware and inclusive, or confident to talk about LGBTQ+ issues. These findings are echoed in existing research and engagement with LGBTQ+ affected by dementia, and indicate continued room for development around training, organisational culture and resource provision.

### *LGBTQ+ Community Support Highly Valued*

The survey for the community revealed a high valuing of LGBTQ+ community support, both for those concerned about memory loss and carers. Services like Switchboard's Rainbow Café are therefore seen as very important resources by the community, who find a sense of belonging in community to be essential to their wellbeing. This also supports the development of LGBTQ+ specific support groups, possibly in a peer support format.

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*"As much community support as can be provided. The need to engage with others is imperative"*

*"Helps to be part of a community that understands"*

*"Community support available for older lesbians"*

*"The LGBT community have been my main source of support throughout my time caring for my parents. I would not have coped without them and am truly grateful to them"*

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The DAA Roundtable report also shared a case study of a lesbian former carer and the value of LGBTQ+-specific support. The case study outlined the story of Rachael, who cared for her civil partner, Irene, who was diagnosed with dementia, and passed away in 2014:

*"Both constantly had to make judgements as to when they could come out for fear of people's reactions and how they might be treated."*

*Younger LGBT people may not understand how difficult it was for people in the past: in the 1970s it was illegal to be gay or lesbian, and this fear has stayed with them, even though it is now legal.*

*Rachel said a good way of helping straight people to understand what it's like for LGBT people is to ask them to consider how they would feel if they constantly had to think about whether or not they could be open about their relationships and families.*

*It's important for LGBT people to be around other LGBT people, as they share similar experiences."*

*"Alzheimer's Society created a new 'lifeline' for her – a group of LGBT carers."*

#### *Training*

Even with high levels of reported confidence, however, there was a significant appetite for further training – particularly around general LGBTQ+, especially trans, awareness, and specific training on the intersections of these identities with dementia, with 95% of respondents saying they would like to access further LGBTQ+ and dementia specific training.

Only a third of respondents had received LGBTQ+ specific training, although most of these had been from previous roles, where the information may not have been directly relevant to a dementia support context, indicating a gap in dementia specific and role-specific LGBTQ+ training provision. Others indicated that they mostly drew from their informal conversations with LGBTQ+ people in their social life, or from lived experience as an LGBTQ+ person. While these are valuable resources, however, it is important that they are not mistaken as a substitute for awareness training, which is likely to cover issues one may not have experienced oneself as an LGBTQ+ person, and also issues that LGBTQ+ friends and colleagues may not openly discuss.



# Recommendations

## 1. Sexual Orientation, Gender and Trans Status Monitoring

**B&H CCG to incentivise implementation of monitoring of Sexual Orientation, Gender and Trans Status at patient intake and other key points of patient contact, alongside other equalities monitoring, in health and social care settings, aiming for 100% compliance by April 2019, in line with the NHS England's Sexual Orientation Monitoring (SOM) Information Standard deadline.**

- Improvements in monitoring can inform services of local need and to enable the capture of information in a sensitive and timely manner. It can also inform signposting and improve overall engagement, thereby countering the tendency for LGBTQ+ people (particularly those who are single and/or socially isolated) to 'slip through the net' between initial assessment and follow up.
- LGBTQ+ women, in particular, are under-represented among those accessing LGBTQ+ specific dementia support, despite 65% of people living with dementia in the UK being women (Alzheimer's Society), and therefore particular efforts should be made to engage this group.
- Due to the continued stigma around LGBTQ+ identity (particularly among older populations) appropriate reassurance might be necessary to indicate that the information will not be used to discriminate against the patient, but rather than it will be taken as a positive opportunity to provide useful signposting and better respond to their individual situation and needs.
- Switchboard's recent [report into Sexual Orientation, Gender and Trans Status Monitoring](#) provides some pointers for Q&A good practice, highlights the value and importance of monitoring, and suggests that the most value is gained from monitoring all three characteristics together, along with pronouns and an 'Mx' title option.
- The LGBT Foundation have also developed a [Good Practice Guide](#) for monitoring sexual orientation

## 2. LGBTQ+ Specific Group and Individual Support

**B&H CCG and/or BHCC to fund LGBTQ+ specific group support for people affected by dementia. With funding, Switchboard could develop this in partnership with relevant partner organisations, as an extension of Switchboard's Rainbow Café project.**

**B&H CCG should explore the possibility of assigning a designated person as a point of contact for individuals going through the process of attaining a dementia diagnosis and accessing support, to help ensure that individuals (particularly those who are single and/or socially isolated) stay engaged with the diagnosis and support process.**

- Switchboard runs a monthly Rainbow Café for LGBTQ+ people affected by dementia or concerned about memory loss, which the CCG could further fund and support to develop this service to engage a larger number of service users and diversify its offer to meet the needs of different sub-groups of those affected by dementia, such as carers, and those in different stages of the condition.
- A possible extension of this could be the development of LGBTQ+ specific peer support, the need for which was discussed by LGBTQ+ people affected by dementia on the DAA's LGBT and Dementia Webinar Conference Call (24<sup>th</sup> May 2018) – as it is common for LGBTQ+

people to feel less safe or comfortable in predominantly heterosexual spaces, particularly when already feeling vulnerable.

### 3. LGBTQ and T Awareness Training

**B&H CCG should ensure compulsory LGBTQ+ awareness training, developed in partnership with LGBTQ+ people with lived experience of dementia, is provided for clinical and non-clinical staff (including reception staff and carers) as standard, with a particular focus on trans\* inclusion. This should include general LGBTQ+ awareness, as well as specific training in relation to the needs of LGBTQ+ people affected by dementia.**

**Additional specific training and guidance on trans people with a diagnosis of dementia should be provided for care providers in health and social care settings (including day and residential care settings), including training on the physical health needs of people who have had genital reconstruction and other surgeries as well as the implications of long-term hormone replacement.**

- A one-off face to face open course was the most popular option for training delivery among professionals and volunteers surveyed, favoured by 58%.
- Many service providers believe that treating LGBTQ+ people the same as heterosexual patients is the best way to demonstrate inclusivity, but this becomes a problem when LGBTQ+ peoples specific needs and health inequalities go un-noticed.
- Some others lack the knowledge and 'LGBTQ+ literacy' to feel confident interacting with LGBTQ+ patients openly about their identities, relationships and life situations
- Reception staff should also receive training to manage sensitive information relating to sexual orientation and gender identity tactfully and respectfully.
- Specific LGBTQ+ dementia training should focus on inclusive activities, sensitivity and awareness in managing personal care, challenging hetero- and cis-normativity/phobia among staff and peers, and proactively supporting gender and sexual orientation expression and identity.

### 4. Clarify communications around end of life care – including 'next of kin' and 'power of attorney'

**B&H CCG should communicate with local care and dementia support services to ensure that governance processes, admissions documents and other paperwork are adapted to change the language of 'next of kin', with its heteronormative implications, to explicitly recognise and include informal support networks and families of choice.**

**Guidance should be provided on the distinction between next of kin and power of attorney, and how these should be explained carefully and with sensitivity to the particular circumstances of any given LGBTQ+ person.**

- Many, staff and patients alike, have the misconception that a designated 'next of kin' must be someone to whom they have a legally recognised relationship (like a spouse or child). Many are also confused about the legal rights (or lack of) afforded to one's next of kin, and are not always aware of the processes around power of attorney, which may be particularly important for those LGBTQ+ individuals who do not wish for their family-of-origin to be involved in decisions about their care.

- LGBTQ+ people are likelier to rely on families of choice and informal support networks over traditional family-of-origin networks and legally sanctioned partnerships than their heterosexual and/or cisgender peers. The legal status of these informal and non-traditional kinship relationships are ambiguous, and often unfamiliar to services and their staff. This ambiguity and uncertainty creates problems for accessing end of life care, and navigating power of attorney and next of kin.
- Care settings should involve and communicate with the chosen family in regards to provision of care (with the consent of the person affected), as partners should be involved in every aspect of communication and care.

## 5. Visible LGBTQ+ Inclusivity & LGBTQ+ Affirmative Communication

**B&H CCG should work with dementia care and support providers to ensure LGBTQ+ affirmative and inclusive language is used in patient communications as a matter of course, and visible LGBTQ+ affirming signifiers, like leaflets, information guides and posters should be freely and visibly available. This communication could be reinforced through LGBTQ+ awareness training, and pre-existing resources should be shared.**

**An LGBTQ+ dementia information and resource pack would be a valuable and effective way of sharing information and signposting for LGBTQ+ individuals affected by dementia. Many excellent resources – such as pamphlets, guides, and websites – already exist (many of which are included in the ‘resources’ section of this report), which could be included or linked to in the pack.**

- Many LGBTQ+ people, particularly those who are older, may feel fearful of ‘coming out’ in case they are discriminated against. Many older people have experienced the illegality, stigmatisation and pathologisation of LGBTQ+ identity and relationships in their lifetime.
- Mainstream services must therefore make a particular and visible effort to demonstrate LGBTQ+ inclusivity and awareness, to help counter the fear of stigma arising from an existing lack of LGBTQ-specific support.
- This should include improved visibility of LGBTQ+ people living with dementia in educational and promotional literature, including visual representations of non-cis-heterosexual families, couples and individuals. The gender neutral term ‘partner’ should be used in communications rather than assuming the gender or marital status of a person’s significant other.
- There are several excellent resources for LGBTQ+ people affected by dementia to learn more about the condition and planning ahead for care (linked at the end of this report) which could helpfully be integrated into the existing resources shared with individuals with a diagnosis of dementia.

## 6. LGBTQ+ Affirmative Accreditation

**B&H CCG should fund LGBTQ+ affirmative accreditation for health and social care services, such as Switchboard’s Inclusion Award.**

- This would provide an opportunity for health and social care organisations to upskill and demonstrate their commitment to equality for LGBTQ+ people in order to provide a “safe space”, improving access and engagement.



- Switchboard is currently building a proposal for further developing the Inclusion Award, and recommends the Memory Assessment Service, Carers Centre and all other services relevant to take this up should the project receive further funding.
- Switchboard's report into, and pilot of, the [LGBTQ+ Inclusion Award](#) also ties the above recommendations together, and is a way of visibly marking, communicating and celebrating a service's LGBTQ+ competence and friendliness
- Following the Seldom Heard Groups Roundtable, the Dementia Action Alliance set out [recommendations for improvised LGBTQ+ inclusivity](#) in dementia care, and named a 'gold standard' of LGBTQ+ care for dementia as a priority – something the Inclusion Award offers as part of its tiered Bronze, Silver and Gold Award scheme.



# Resources

- Alzheimer's Society: *Supporting a lesbian, gay, bisexual or trans person with dementia* (Feb 2017)  
[https://www.alzheimers.org.uk/download/downloads/id/3555/supporting\\_a\\_lesbian\\_gay\\_bisexual\\_or\\_trans\\_person\\_with\\_dementia.pdf](https://www.alzheimers.org.uk/download/downloads/id/3555/supporting_a_lesbian_gay_bisexual_or_trans_person_with_dementia.pdf)
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[https://www.alzheimers.org.uk/download/downloads/id/3629/lgbt\\_living\\_with\\_dementia.pdf](https://www.alzheimers.org.uk/download/downloads/id/3629/lgbt_living_with_dementia.pdf)
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<http://dementiavoices.org.uk/wp-content/uploads/2015/03/Over-the-Rainbow-LGBTDementia-Report.pdf> (Elizabeth Peel and Sam McDaid)
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