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Safe Ageing No Discrimination LESBIAN, GAY, BISEXUAL, TRANS

Researching the hopes, fears, experiences, expectations of health & social care by older – and old - lesbian, gay, bisexual and trans people in Shropshire

"I want to be able to relax inside wherever I am"

This research project has been supported by Healthwatch Shropshire Research Grant funding

healthwatch Shropshire

March 2015

Sexuality, gender and identity

are complex, intimate and evolving components

of how we see ourselves

and how we present ourselves

to others[1]

Acknowledgement

We would like to thank everyone who has taken part in the research, the Two Fat Rascals Coffee Shop in Shrewsbury who hosted our dissemination event for research participants and Healthwatch Shropshire for the funding to enable it to happen.

The research was undertaken by **changes** on behalf of SAND
http://changesuk.net

It was a privilege to be included in the research sample and I am so impressed with your research report. Congratulations on producing a meticulously planned and executed piece of research and a comprehensive and highly readable report… The contents certainly gave me a lot to think about, especially the main findings and quotes which had been selected. It gave me a deeper understanding of issues (in the past or currently) and anxieties about the future faced by LGBT people who have had different life experiences from myself.

An important note from SAND:

- Whilst we know a fair amount and are diligent and honest in what we do, we would never claim to be experts. This is a vast and growing subject area and we have been delighted at the response we have received when we go and talk to people.
- Our own learning curve has been – and continues to be – immense.
- We continue our research and learning every day and are confident that we shall never know it all.

[1] http://www.gannett.cornell.edu/for/lgbt/

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Executive Summary

It is reassuring to know some things are being thought of in connection with old LGBT people who may need care.

Research participant

Older and old Lesbian, Gay, Bisexual and Trans people in Shropshire are at risk of marginalisation and isolation. Their story is similar to that of LGBT people all over the country and Shropshire has a potential head start in making improvements and being a beacon of good practice if health and social care providers take notice.

Past societal experiences of illegality, abuse, brutality, ridicule and intimidation mean that an older generation of LGBT people has adopted sophisticated 'risk assessment' processes to gauge personal and emotional safety. These same processes keep them hidden from health and social care providers.

This invisibility means that the issues commonly facing older and old LGBT people are not addressed; individuals are not receiving an equal service to their heterosexual, non-trans counterparts and their life experiences are not considered.

LGBT people have recorded difficult and variable relationships with their blood families – often the ones on whom reliance is built for care provision or information about an individual in later life. People have lost friends and family through disapproval or condemnation, or they may have families – or parts of families - in complete ignorance of their lives.

LGBT people are fearful of being 'outed' or made vulnerable in situations where they feel trapped. This can occur through speech or actions of self, partner, friends, staff, other patients/residents. Denial of sexuality is a denial of identity – a serious contravention of human rights and damaging to health and wellbeing. There is no evidence to suggest that health and social care providers recognise or take seriously the impact of this denial (by self or others), nor that they understand the hidden nature of sexuality.

Trans issues readily get subsumed into those impacting on lesbian, gay and bisexual people and yet there are distinct social, medical, psychological and physical implications of transition. These issues are not well researched.

Many people find a lot of these issues difficult to talk about and so choose to bury their heads in the sand and hope they go away. As one research participant said 'just because you can't see us, doesn't mean we are not here'.

Health and social care environments are a frightening prospect for older and old LGBT people who have learned experience of discrimination, negative experiences of authority, learned deception, secret/forbidden lives, been told to keep themselves to themselves, been witness to public denouncements of 'their kind' and denied their identity.

Doing this research has made the researchers and participants appreciate that it is absolutely critical that people in positions to make decisions and act in ways which impact on people's lives understand the reasons **why** it is important that they know about those lives.

Any progress needs health and social care providers, commissioners, other relevant organisations and sectors to build on the momentum created by this research and SAND's advances to engage with change. Shropshire CCG, Shropshire Partners in Care , Shropshire Council (incl Public Health), Shropshire Voluntary & Community Sector Assembly, Royal Shrewsbury Hospitals NHS Trust, Shropshire Community Health NHS Trust, South Staffordshire & Shropshire Healthcare NHS Foundation Trust, Staffordshire and Stoke-on-Trent Partnership Trust, the care home sector, Shropshire Solicitors for the Elderly Network, Severnside Housing, South Shropshire Housing Association, Stonham Housing Association, Bromford Housing, Sustain and the legal sector need to engage with SAND and commit to:

- increase confidence and capacity of older and old LGBT people in Shropshire to engage in a process of change
- invest in further research in Shropshire to explore care pathways of older and old LGBT people; trans experiences; barriers to accessing legal services and housing options
- equip staff with the skills and knowledge and structure their organisations to create safe environments for older and old LGBT people
- develop a kite-mark, Champions scheme, or similar way of publicising those services with raised levels of awareness about issues impacting on older and old LGBT people in Shropshire.

Why this research?

I don't mind people disliking me if they know me well enough to dislike me
Research participant

In 2013, SAND undertook desk research to find out what others were saying about the issues we were considering at the time. We looked at a range of publications produced in the UK by charities, the NHS, philanthropic organisations and community groups and identified 10 key themes for consideration:

1. LGBT people may be afraid to come out as they are unsure about the response they will get. Organisations then say 'there are no gay people here' so it isn't an issue
2. Coming out isn't a one-off – it's constant and can be very wearing
3. Growing up in homophobic families, workplaces, environments has an impact on LGBT people's mental health and how they manage situations
4. Being part of a group that is, in many parts of our society and many parts of the world, 'not normal', has an impact on how LGBT people see themselves and each other
5. Treating everyone 'the same' means that LGBT people's life experiences are unlikely to be considered
6. It's not always about being actively 'excluded', but more about not being 'included'
7. Isolation can be a serious issue amongst older LGBT people, and although not exclusive to them, they may have/feel they have less choice in accessing support networks
8. LGBT people don't necessarily know how to access information and support – if they don't see themselves represented on leaflets, posters etc they are likely to feel excluded
9. Being LGBT isn't all people are, but it can be a part of their identity that gets left out in order to survive in the world
10. The concept of 'family' may be very different for LGBT people

We also identified some notable barriers to gathering and getting these messages across to health and social care providers

- While it is easy to say 'we don't discriminate' or 'we treat everyone the same' this misses the subtleties and complexities faced by LGBT people which means that SAND faces a challenge – "to get people to get that there's something to get"
- Health and social care providers are difficult to engage in these conversations – and, to some extent so are older and old LGBT people who may already have gone back into the closet.
- As with many older and old people – LGBT people do not particularly want to think about future needs or face the possibility that they may become less independent

- Many LGBT people have lived experience of trying to change things and not getting anywhere. This can take its toll and means that many may be cynical about possibilities for change and reluctant to raise their own expectations.

To help bring this to life SAND wanted evidence and some local stories – from a rural Shropshire context - to take to health and social care providers in the hope that these will provoke an interest and willingness to engage. Once that has been achieved dialogue can begin about the things that LGBT people identify need to happen in order to affect positive change.

SAND wanted to know: how the experiences and lives of LGBT people impact on the issues they may face around health and social care, now and in the future. SAND is well-placed to undertake research of this nature, having good developing relationships with a broad spectrum of LGBT people in the County and with a growing reputation: SAND has recently been invited to take part in a national research pilot looking at housing options for older and old LGBT people and is also part of County-based LGBT activity which has led the National LGBT History Festival to consider Shropshire as a rural location for its 2016 Festival.

Shropshire is ahead of the game in consideration of these issues and the journey to change. We have an interested and engaged community of older and old LGBT people who increasingly understand the issues facing their community and want to be a part of change. Where other areas of the country are at the forefront of academic research, SAND is building a community of interest on the ground, assisted by this research.

Background

The research mustn't stop here

Research participant

The grains of SAND began in February 2012 when the Shropshire Rainbow Film Festival screened a thought-provoking film for LGBT History Month. Gen Silent is an American documentary about the silent generation of LGBT elders going back in the closet as they age. The film screening and panel discussion led to an expression of interest by members of the audience to find out what is happening locally – and to do something about it. An enthusiastic group began meeting to plan.

At about the same time, and unbeknownst to us in Shropshire, researchers at Nottingham University were putting together a proposal to explore end of life experiences and care needs facing older LGBT people – this project[2] funded by Marie Curie was to become the biggest study to date in this field, comprising 237 completed surveys and 60 in-depth interviews with older LGBT people. Their emerging themes include:

- the diversity of experiences suggests inconsistencies in policy and practice
- there is evidence suggesting that cultural and religious prejudices are carried into care situations
- there is evidence of knowledge gaps and over-attention to stereotypical health needs
- 74% of respondents are 'not very confident' or 'not very confident at all' that mainstream health and social care services provide sensitive and appropriate end of life care services for LGBT people
- for some LGBT people health and care settings do not represent safe spaces to disclose or enact aspects of their intimate relationships, at a time when they feel more vulnerable and in need of such intimacies
- inappropriate behaviour and assumptions are not limited to (some) health and care staff – behaviour of other service users may require attention and management

Various strategies were reportedly used by partners and significant others to navigate situations that arise in illness and at end of life including:

Not disclosing at all that they identify as LGBT or that they are in a same-sex relationship

…. passing as mother and daughter, father and son, sisters or brothers, carers and friends

(Not) displaying affection or intimacy in public

Doing nothing – assuming no explanation is necessary

[2] The Last Outing: http://www.nottingham.ac.uk/nmpresearch/lastouting/home.aspx

Conceding to normative processes (e.g. blood relatives favoured over significant others)

By July 2013, SAND had established an Action Group which began to meet monthly. This group developed an action plan based on the theory that:

If we can

- *Build the capacity of older and old LGBT people themselves, and straight allies*
- *Bring about change within organisations to change their working practices*
- *Tap into influential policy making channels*

Then we can fundamentally influence the ways in which older and old LGBT people experience – and expect to experience – later life.

Three recent initiatives help to illustrate the diversity and breadth of current interest in the issues SAND is working with:

At the beginning of 2013, the University of Surrey secured European funding for a series of seminars called Minding the Knowledge Gap[3], exploring the current levels of knowledge about LGBT ageing. They hosted 6 seminars over 2 years, in different locations around England, on subjects such as trans-aging; intergenerational working; health & social care and bisexuality. The research team is only now pulling together the findings, following their 'sell-out' final conference event in January 2015.

In December 2014, The University of Worcester Palliative Care Centre hosted a seminar as part of their Watershed Series, looking specifically at issues impacting on LGBT people and palliative care. The event, attended by nursing students, hospice staff and voluntary sector organisations supporting carers was notable because it openly offered 'training' on these issues. It was one of a series of seminars looking at traditionally 'unspoken' issues which may have a significant impact for some people and communities accessing health and social care.

The Campaign to End Loneliness undertook research with Age UK to consider responses to loneliness and isolation, culminating in their report: Promising Approaches to reducing loneliness and isolation in later life, published in January 2015. This report has a small section about lesbian, gay, bisexual and trans older people which interestingly notes the "… dearth of knowledge for specific interventions for Lesbian, Gay, Bisexual and Trans (LGBT) older people ….. Surveys suggest loneliness can be particularly acute among older lesbian and gay people, and the limited evidence available suggests that these groups experience problems in accessing mainstream provision, and lack confidence that these services will meet their needs. It is clear that more research will be needed to understand how best to meet the needs of LGBT people as they age."

[3] Minding the Knowledge Gap: http://www.surrey.ac.uk/sociology/research/researchcentres/crag/seminar_series/

Recent research[4] - complete with recommendations - has been undertaken by, Stonewall, the lesbian, gay & bisexual[5] campaigning charity. They were commissioned by YouGov in 2014 to undertake research into experiences impacting on older LGB people and received completed surveys from 1036 LGB people about their experiences and expectations of getting older. It examined their personal support structures, family connections and living arrangements. It also asked about how they feel about getting older, the help they expect to need, and what they would like to be available from health and social care services. Interestingly, Stonewall also surveyed a similar number of heterosexual people with the same questions so they could make a direct comparison with their results.

Stonewall found that:

Nearly half of LGB people would be uncomfortable being out to care home staff, a third would be uncomfortable being out to a housing provider, hospital staff or a paid carer, and approximately one in five wouldn't feel comfortable disclosing their sexual orientation to their GP.

Lack of support from conventional family is also an important issue for lesbian, gay and bisexual people as they get older. Lesbian, gay and bisexual people are more likely to be estranged from their biological family compared to heterosexual people, often because their biological family do not approve of their sexual orientation.

Lesbian, gay and bisexual people are less likely than heterosexual people to see their biological family members on a regular basis. Less than a quarter of lesbian, gay and bisexual people see their biological family members at least once a week compared to more than half of heterosexual people. One in eight lesbian, gay and bisexual people see their biological family members less than once a year compared to just 1 in 25 heterosexual people.

The reasons behind their increased worries about ageing are diverse, but frequently founded in an expectation of discrimination. Many have experienced ill-treatment due to their sexual orientation in the past, sometimes at work, from those in authority or their own family. This discrimination has a clear influence on their expectations for the future.

The Stonewall survey also found that Lesbian, gay and bisexual people over 55 are more likely to be single; more likely to live alone; less likely to have children; less likely to see biological family members on a regular basis; more likely to have a history of mental ill health.

[4] Lesbian, Gay & Bisexual People in Later Life: http://www.stonewall.org.uk/documents/lgb_in_later_life_final.pdf

[5] At the time of the research Stonewall had not adopted the 'T'

Older and old LGBT people in the 21st century have lived through acute public threats to their identity and themselves: Criminalisation; AIDs & HIV; Section 28; the first lesbian kiss on television; the Age of Consent debate; the Civil Partnership Debate; a Trans winner of the Eurovision Song Contest; the Same-sex marriage debate – all of which have allowed homophobic views to be voiced in the public domain – affecting how we see ourselves.

In Shropshire

Shropshire is a rural County covering 1,300 sq miles. We have more older people than average in England (20.7% of the population is aged 65 and over, compared with 16.4% for England and Wales, Census 2011), and the over 65's are growing faster than elsewhere (23.8% compared with 10.9% for England and Wales, Census 2001-2011).

Figures are notoriously unreliable but we can be pretty confident that there are at least 4,200[6] LGBT people over the age of 65 living in Shropshire and that over 300[7] of these are statistically likely to be in nursing or residential beds.

Given these figures, it is concerning that SAND has only been able to identify 2 of these to date and care home managers and staff repeatedly suggest they do not have any LGBT people resident in their establishments[8] – so where are they all?

SAND is on a long journey to find out, and the initial stages involve widening our circle of stakeholders and uncovering the issues which impact on the younger-older LGBT people that we can find, as well as capturing their ideas about what needs to happen to improve things.

The findings in this Shropshire-based research resonate with those from larger national studies and reinforce previous desk research both in terms of the hopes and fears of older

[6] The Treasury estimated that 6% of the population is lesbian or gay when it was budgeting for the Civil Partnerships Act. Age UK Shropshire Telford & Wrekin state there are currently 71,100 people over the age of 65 in Shropshire (estimated to increase to 80,900 by 2020), 6% of this figure is 4,266. Add to this the numbers of Trans & Bisexual people and we have offered a conservative minimum.

[7] There are 5135 Nursing & Residential beds in Shropshire, Telford & Wrekin. 6% of this = 308

[8] SAND undertook a small-scale study in early 2014 which found that care home managers are confident that they have no LGBT people resident. Subsequent training delivered to care home staff received similar comments and the national Age UK officer who has been working on this for more than 10 years corroborates this.

and old LGBT people accessing health and social care, and also the lack of recognition of those issues by service providers. The research raises similar issues in Shropshire about family relationships and expectation of discrimination linked with past experiences which can make people mistrustful and cautious. This research also revealed the lack of information locally available about and for older trans people, as noted nationally.

Methodology

Thanks so much for getting the issues out there and creating the conditions for improvement in practice in future.

Research participant

Initially we intended to contact 50 – 75 LGBT people via an online survey

Survey pilot

We developed survey questions, referring to the survey conducted by Nottingham University's The Last Outing Project[9] and Jane Traies's research into 'The lives of British lesbians over sixty'[10] to inform how we framed the questions. We anticipated it would take approximately 20 minutes to complete.

The survey was piloted with 7 people aged 51 – 77. The figures below exceed 7 because the trans woman also identifies as lesbian:

- 3 gay men
- 4 lesbians
- 1 trans woman

The pilot revealed some issues with the proposed methodology.

Time – it took considerably longer to complete than anticipated, 2 respondents recording 30 – 40 minutes; 2 who left it after 30 minutes and returned at a later date. Only one respondent thought the length was about right.

I filled most of your Survey - took about half an hour. Then I lost it!

Subject – most of the respondents to the pilot had not thought about these issues before. Two, despite agreeing to be part of the pilot, did not open the survey – one felt too worried about what it might raise for them, the other wanted to respond to questions as part of a discussion rather than via an online survey. For others it was new territory or was difficult to interpret

I stumbled a bit at the first question because I haven't really given much thought to my concerns about ageing

A lot of the questions related to sexuality which is not usually an issue for a transgender person. They are more concerned about respect for and acceptance of their acquired gender, which is usually always apparent unlike sexual orientation which is only apparent if the individual chooses to make it so.

[9] http://www.nottingham.ac.uk/nmpresearch/lastouting/home.aspx
[10] http://sro.sussex.ac.uk/48420/1/Traies%2C_Jane.pdf

The questions did really make me stop and think.

I had to think about all the answers as a lot of these thoughts hadn't been in my mind prior to completing it.

Closed questions – the format of a survey with a mix of qualitative and quantitative questions did not give the flexibility to respond that people wanted

I found it impossible to enter anything apart from a X for a number of questions that needed elaboration

More information – people felt like they needed more to go on

Ideally the survey could use a pre-brief to people to say they do need to stop and think about it and the value from it will be from people making it as personal as possible to their experiences.

In response to these concerns we decided to change the methodology and returned to Healthwatch Shropshire for approval to change from the estimated 50 – 75 survey returns to fewer in-depth face-to-face discussions. These would give us opportunity to expand on questions, encourage more contextualised responses, develop relationships with respondents and offer reassurance.

We took a 'snowball' approach: advertised through existing networks and asked people to pass the word on via the Border Women lesbian network; Chill Out social group; Shropshire Rainbow Film Festival; Gay men's social group.

Sample

In fact, it was quite hard to get people to agree to talk about these things and some actively refused. We imagine that this was for a variety of reasons, not least that it brings up all sorts of things from the past as well as fears for the future. Some people we contacted were not in a position at this moment in their lives to engage with these issues.

We were mindful of this in the way that we pursued questions and this is a key reason for us deciding to make sure that the discussions were as informal as possible with groups of people who know each other and feel relatively comfortable talking in front of each other.

We were clear that all information would be anonymous and that we would be drawing out general themes from the research.

In June 2014, we held a launch event[11] for SAND where we started a dialogue about the issues that people thought they might face in later life; of the 40 attending 10 went on to be amongst the people we interviewed for this research.

We carried out single interviews, couples and small groups, in total, facilitating in-depth discussion with 24 people each lasting 90 – 120 minutes. Interviewees were aged from 51 – 85 with an average age of 62.

- 14 lesbian
- 7 gay men
- 3 bisexual
- 3 trans (included in sexuality numbers above)

Ages 50 – 59 (25%); 60 – 69 (54%); 70 – 79 (17%); 80 – 85 (4%)

All interviewees spend time in Shropshire at work, rest and play, and live in areas including: Ludlow, Baschurch, Monkhopton, Bridgnorth, Nesscliffe, Shrewsbury, Wellington, Telford, Shifnal.

Dissemination

At the beginning of February 2015 we invited all interviewees to come together to hear what we have learned and share their experience of the research. Of the 24 people who took part 23 wanted to continue participating as a consultative group for SAND.

19 research participants (4 had to give apologies due to illness or for family commitments) joined us for the dissemination event where they were led through the research findings and asked to flag up anything they felt to be misplaced or misinterpreted.

We then circulated a copy of the draft report to all participants and asked them specifically to check that statements made are true to their intent and that they are happy with quotations where they recognise them as their own.

We are quite happy with (and recognise!) comments from us. We think it is an amazing amount of work you have done and raised many long-term issues we have chosen to avoid to date. Hopefully, this is about to change!

This is absolutely brilliant! Really accessible, well-presented and well-argued, I sat up late to read it - I couldn't put it down!

With their approval we feel confident that the research findings in this report resonate with and represent the research participants' views and experiences.

[11] Funded by FRESh: Fairness Respect Equality Shropshire

LGBT people are perfectly able to see some ways forward to achieve improvement – and are willing to put their own efforts in. The responsibility for change needs to be shared and the challenge remains, to engage health and social care staff and policy makers in these discussions.

Notes of caution

It is inspiring to see that otherwise hidden issues are gaining some attention and momentum.

Research participant

During the research and preparation we identified some issues which feel important to flag up as they had an impact on the way in which we asked the questions – or they raise questions for the future

- We didn't want to frighten people – many people had not given any thought to how they may experience their futures as LGBT people – or they had deliberately avoided thinking about it.
- The research discussions raised questions for people – things they had not considered before – around finance, legalities and knowledge gaps – which they now want answers to.
- There is an intrinsic difficulty with researching LGBT people as a homogenous group when there are so many differences between them (and again for people as individuals). At its most basic – Gay men were criminalised through the law, lesbians are more likely to have been married (and had children), Bisexuals are hard to identify and there is very little research into specific issues and Trans experiences are about gender identity rather than sexuality. LGBT people are a varied and complex bunch – with different life experiences, different levels of confidence, different values, different cultures.
- The sample size is small and whilst the findings are supported by other research there are significant gaps – not least the absence of trans men in the study.
- We have not talked to older LGBT people in care homes as part of this research.
- Getting anything to change is the responsibility of all players – SAND, Healthwatch, the Clinical Commissioning Groups. Using an old adage – "we can lead a horse to water ….."

Alongside this Healthwatch Shropshire funded research, SAND was undertaking other related work which fed in and complemented the stories from a different perspective.

Research findings - Section 1

We choose to keep company that is totally accepting of us. I dread not being as open as I am now

Research participant

How the experiences and lives of LGBT people impact on the issues they may face around health and social care, now and in the future.

Pulling together qualitative information that illustrates the complex issues concerning LGBT people and ageing, what we have found – on the whole - resonates with existing research.

We are aware that there is a danger that people think that LGBT people want 'special' treatment, particularly as many of the issues facing them as they get older are pretty generic and shared by many. What we're trying to untangle is the way in which these generic issues are overlaid by the particular experiences of LGBT people and their expectations of the future.

If we take the general anxieties of ageing[12] as

Lack of independence / becoming dependent
Deteriorating health
Losing home
Losing faculties
Isolation
Losing a partner
Losing dignity and privacy

Then there is an additional layer – either above or below – if we are to include the experience of LGBT people.

Learned and experienced discrimination – physical violence and abuse because of sexual identity
Negative experience of authority/professionals
Learned deception
Secret/forbidden lives
We've been told to keep ourselves to ourselves – safety and conformity – so more self-contained
Sexuality equated with sex and dismissed as people age
Assumed heterosexuality, therefore denied and denial of own identity
Higher awareness and emphasis on identity – has been threatened / talked about
Do people take our relationships seriously?

[12] Gathered in conversation during research

Our research findings can be harnessed under distinct and related headings. Because we are dealing with human beings with complex lives there is some natural overlap between the sections which consider the factors which impact on LGBT peoples experiences and expectations of health and social care in later life:

- Levels of confidence
- Hurtful and painful pasts
- Family relationships
- Uncertain environments
- Legal and financial issues
- Tricky issues

Underlying all of these is an innate instinct to assess risk at every turn.

Our sexual orientation and gender identity are only a part of our identity. In an ideal world this wouldn't be an issue but, because it clearly is an issue for the rest of the world, LGBT people are put in the position of having to focus more attention than maybe is warranted – and then are accused of 'banging on about it!' A bit of a catch-22 no win situation! LGBT people are a varied and complex bunch

1.1 Risk assessment

There are lots of reasons why LGBT people may be 'hidden' or have (had) 'hidden lives', including:

- Personal Safety
- Fear based on past experiences
- Fear/expectations based on others' experiences
- Exhaustion from endlessly coming out
- Familiarity with living a double life in public/private spaces

We can safely say that 'coming out', 'being out' or being 'outed' as an LGBT person is never a one-off. It permeates all experiences and fears and leads to the development of some pretty sophisticated safety tactics.

Coming out can be emotionally and physically draining

all our lives we have to come out to people – to come out or drip it in – all that energy and each one makes my heart race

LGBT people undertake **micro** – day to day - risk assessment. Little things like people assuming you have a husband if you are a woman, and **macro** risk management – weighing up things for the future – who in my family do I come out to and why – related to 'big' decisions – do you tell your children, or siblings? What will the response be?

There are differences between telling someone that you have a vested interest in – someone you want to love you – someone who can take your children away from you or might never speak to you again – the amount of damage that might be caused – in your eyes. People you are dependent on for your care and wellbeing.

In our pilot survey we asked people how out they are to health professionals and even in this small sample there was a difference between coming out to a GP who they have more contact with and hospital staff they might see just once or fleetingly – many of our respondents would weigh this up.

There is an issue for lesbians, gay men and bisexuals who haven't told family members for 30 / 40 years about their sexuality. All their lives they have kept a secret – how do they now tell them when they have deceived them forever? Trans people we spoke to knew when they were children but went through the motions of marriage and children before partners died and transition felt possible – or until they could bear it no longer, or until they got caught out.

Before 1967 for gay men, and before 1999 for lesbians in the armed forces, participants in our research talked about the skill of being safe and avoiding arrest or dismissal

I was brilliant at being asexual[13]

LGBT people are well practiced at pretending and have every reason to be mistrustful and careful.

I know people who have had friendships since childhood and am very envious. I have not had much practice making friendships… … I don't trust anyone, am anxious to please. I don't have many friends – I am quite isolated

I have a general lack of trust, and worry about being ridiculed

This ongoing 'risk assessment' and 'personal editing' has implications for visibility.

[13] Here the research participant is stating their ability to behave in ways which present a lack of sexuality and which detract questions pertaining to sexuality or sexual activity. Note – in actuality, 'asexuality' is another minority sexual group. Unlike celibacy, which is a choice, asexuality is a sexual orientation. Asexual people have the same emotional needs as everybody else and are just as capable of forming intimate relationships. Asexual people do not experience sexual attraction.

LGBT people choose to stay hidden for all sorts of reasons and so no care provider can ever really be sure that they have no LGBT people in their care and should always behave as if they do. These are real issues which do not go away for people even if care staff choose to ignore them. Besides, if care is a positive and personalised experience – as much as it can be – for older and old LGBT people, then it should be good for everyone else and so provides a good benchmark.

1.2 Levels of confidence

Generally, the research found that, the more confident LGB people feel about being open and 'out' about their sexuality, the more confident they are likely to feel about their future. This didn't mean they had no fears, or didn't anticipate poor or adverse reactions from health & social care providers or peers, but they feel more equipped to challenge and deal with this. This is different for some of the trans people we spoke to who would choose to be absorbed into the mainstream in their 'new' gender but know that they cannot successfully pass[14].

LGB people often experience internalised homophobia. Years of negative images, deception and a world of heterosexuality as the 'norm' has led to internalised feelings that to be LGB is to be bad, immoral and just plain wrong.

I'm a confident lesbian and yet I have a layer of internalised homophobia – I've had it all my life

How assertive we are depends on how safe we feel; how tired we are; how much we trust the response we will get and whether or not we feel that we can deal with another rejection or 'cold shoulder'. For those of us in a relationship, it can also depend on whether or not our partner is still around.

While there are 2 of us we'll be OK

Our level of assertiveness is also dependent on how much we care about what people think. Does this change as we get older? Some people said that they care less about what others think of them as they themselves get older – others felt that they are more vulnerable and less able to deal with disapproval.

In many circumstances, it doesn't occur to LGB people to come out and yet the research made people wonder if this was a negative thing – that coming out and being visible might actually be modelling and allow others to feel more at ease.

[14] 'passing' is the ability to be recognised by the casual observer as the gender of preference

I volunteer with older people and it has never occurred to me to come out – but maybe that might make it easier for them – if they wanted to

Our level of optimism about the future is also dependent on our financial security. Research participants generally felt that they would be safer and have more choices if they had money to pay for care.

Levels of confidence make a significant difference to the experience and expectations of older and old LGBT people, whether about housing or about health and social care.

1.3 Hurtful and painful pasts

Being ignored and shunned, experiencing homophobia – that doesn't ever go away

Many participants had stories to tell about bullying, ridicule and violence – either targeted at them personally or someone they knew.

We have 2 gay men friends X (89) and Y (84) who have been together over 50 years. X's relative had him put into an institution and he had electric shock treatment. As a couple they are very contained. They worry.

Gay men spoke of police brutality and imprisonment.

Trans people spoke about the interminable hoops they have had to jump through to prove themselves and the nightmare of long waits before being taken seriously

there is an issue about how long you have got to wait - and it is harder as you get older, especially if you transitioned relatively late in life

People spoke about intimidation from neighbours, directly linked to their identity and others spoke of a time when they were young when it was totally impossible to be "who you are". This resonated with participants whether linked to sexuality or to gender identity.

These hurtful and painful pasts, not surprisingly have an impact on people's levels of trust, and their expectations

I am looking around all the time to check I am safe

… and mean that they are therefore much more likely to pick up on nuances of behaviour and responses from others – whether intended or unintended.

People fear that if they suffer with dementia in later life, they will only remember these painful pasts.

There is a danger of a regressive pathway as LGBT people get older. The confidence to manage and assess different situations can reduce as their identities are undermined. It may be possible to identify tipping points in the care pathway – points at which LGBT people reassess and make choices about whether to be 'out', whether to talk about gender identity, or whether to withdraw

1.4 Family Relationships

Family – there is a gap between what they see and what they know – they are willing but they don't get our world

Perhaps unsurprisingly the notions of 'family' were a key aspect of the discussions. People talked about blood families – reactions to them and their sexuality or gender identity – be-it acceptance or rejection, or a mix of both. In equal measure they talked about 'created' or 'friendship family' and for some, those were the ones central to their lives.

We need to be around people who know who we are, where we don't have to explain anything. Even good heterosexual friends – do they know that our feelings are the same as theirs?

If you lose a partner and are heterosexual then family tends to rally round – we're more reliant on friends. This could be a particular issue in a rural area if alone and getting older – less access to social stuff, LGBT activity, more reliant on a small group of people – especially if able to travel less. Might be completely trapped

46% of our research participants had been married to someone of the opposite sex and most of these have – or have had - quite complex relationships with their previous spouse and/or children. As a group they revealed a whole host of experiences, some have children,

some don't – of those that do, some are 'out' to their children and some are not. This has implications around money, property and concerns over children 'pulling rank' at times of crisis when critical decisions have to made over health and wellbeing. Participants in the research generally thought that these difficulties are quite subtle, yet with substantial potential implications stemming from an intrinsic belief in the heterosexual world that, somehow or other, non-heterosexual relationships are not equal to heterosexual ones. People reinforced this by citing the heated political and religious debates about same-sex marriage which were blasting out from radios, televisions and newspapers.

People talked about losing friends – as well as family – when they came out, and a few mentioned how this can have a greater impact for those coming out, or transitioning, in later life.

I have a short history, I transitioned in my 60s and most of my life isn't applicable now

Gay men are habitually less likely to have kept contact details of people – a result of historic fear of arrest; many also lost huge numbers of friends from AIDS.

A question posed: "Do heterosexual people assume we are out to our families?" If they do then there is a danger of being outed inadvertently if they do not understand what the issues might be – especially if they don't have a 'problem' themselves – 'I don't mind if you are gay' – it makes them brave in their confidence and possibly righteous on another's' behalf. This could create a situation which is potentially dangerous.

Some speculative concern arose around the potential of an LGBT person suffering with dementia whose family have never approved or felt comfortable with their identity as LGBT. It may be tempting for that family member to deny their relative's sexual/gender identity to others.

I want people to know about my life so that they know as best they can who I am inside when I am not in position to tell them

Many LGBT people have complex families and varied interpretations of 'family'. Relationships, trust and honesty about identity, daily lives and lived experiences may lie with created rather than blood family.

1.5 Uncertain environments

Hospitals and doctors

One group discussion touched on the experience of being in hospital and the impact this has had on expectations for the future

> *I am terrified of ageing as a gay man … being a gay man in hospital is a big enough issue – being on a ward, feeling vulnerable alongside majority heterosexuals – at visiting time their families descend in numbers and I don't have any visitors or maybe a few. You are either on your own or your friends come in and do not fit in with the groupings of other people's friends.*

Another gay man in the group was prompted to reflect on being visited by his partner in hospital on different occasions.

> *M comes in with flowers and kisses me. He then looks round for others' reactions – if it all seems easy we can both can relax – if not then it feels tense and when he goes – I'm still there.*

A few people mentioned GPs and, as with the general population had varied experiences. One respondent had always been out to his GP and in fact the first person he ever came out to was the family GP. Some participants thought it was intrinsically important to be out to their GP – others did not understand the need at all.

Trans people have no choice but to be open with their GP if they want to access the transition process. There was some concern that GPs do not understand the trans process and pathways and make a long process even longer which has both practical and emotional consequences.

Residential Care Homes

When we talked to people about 'housing' issues they tended to talk about their own home or a care home. There was very little consideration of options in-between. In some ways this stifles constructive conversation and perhaps innovatory thinking about what we could create as viable and appropriate alternative ways of living.

No-one really anticipates/wants to go into a care home and so there is a danger that it becomes about other people, although a few respondents said that this raised some fairly frightening – and distinctive - issues for them.

> *I'm never going to have the energy to challenge anti-gay stuff if I'm in a home – I don't challenge it now when older people are homophobic.*

Almost everyone commented on the notoriously high turnover of staff working in residential homes and the implications of this for constant 'coming out' at a micro level. This turnover also has implications for training as staff do not necessarily stay once trained. Lack of trained staff then has further implications for their ability to manage situations, where colleagues or other residents are homophobic or discriminatory.

When I am vulnerable I am already needy and needing reassurance – I don't want to fight – if I do I am labelled as trouble – being difficult. I am worried about being more vulnerable and the patronising way of people and I am having to come out again – especially as there are more agency staff – means we have to come out again

Some of the research participants have worked in care homes in various capacities, or visited relatives. They have witnessed homophobic incidents and been subject to prejudicial remarks.

I was discriminated against myself – as staff, being a lesbian …

These people familiar with care homes, also commented on the lack of LGBT celebratory events when other cultural events are celebrated like Black History Month and religious festivals. They also commented on the dearth of LGBT oriented books, music, visuals and films or television programmes selected for collective viewing leading to a total invisibility of LGBT lives.

They were concerned that Care Plans are unlikely to include questions about sexuality or gender identity and questioned the implications of this. Generally participants in the research were concerned about the lack of accountability in private sector care – and the possibility of more religious-oriented organisations picking up current Council provision, with potential bias against LGBT people.

There was some speculative concern that, if suffering with dementia family members may not reveal sexuality or may not know and yet they would be expected to respond to the questions asked by care home staff.

There are significant gaps in knowledge about residential care – levels of privacy and potential response to sensitive cultural difference. Some gay men asked

What would happen if I wanted someone to visit me for sex?

What are the rules around censorship of porn – have they even thought about it?

People told their own stories about visiting (straight) relatives in care homes and those relatives being subjected to homophobic teasing or being ostracised once their visit was over and they had left.

This prompted another recollection where, as a consequence of a similar incident the person asked the visitors to 'act more straight' on their next visit – they then stopped coming!

In our own homes

It's pot luck if they are OK with us or not

A few research participants touched on the subject of domiciliary care and wondered about the expectations of the carers who come into their homes to care for them and what they need to prepare in order for the carers to feel comfortable around them

It is the quality of care that is most important – once I need care I will lose some of my dignity anyway – unless a carer is overtly homophobic it wouldn't be easy to tell what they thought

What is in my house that might upset and offend someone who came into care for me? Which pictures and books should I put away?

LGBT people are deeply affected by pervasive stereotypes about them

I am worried they will make assumptions about me fancying them just because I am a lesbian

Perhaps they won't want to touch me – how horrible

Some people have particular ideas about the preferred gender of potential carers – this may not differ from the general population – except for the reasons behind this preference which may be a result of hurtful, painful pasts or of confidence and risk assessment.

Public environments are largely unknown, which can make them 'unsafe' for LGBT people who are uncertain about reactions to them. Personal home environments – original safe domains – can become unsafe when professionals visit.

1.6 Legal and financial issues

I wonder if gay marriage will make a difference to how heterosexual people feel about our relationships

It's interesting that as a natural spin off from conversations about health and social care, people have been talking about legal issues and money. There are clear connections but these areas of provision don't seem to be very closely related. There are aspects that people haven't considered and in some cases are not aware of and yet all of the issues raised in the research can have an impact on the arrangements we choose to make – for example.

People are concerned about Lasting Power of Attorney – and yet haven't made any arrangements. They are concerned about who is going to make decisions about their finances and health if they are unable to do so themselves – and what the assumptions are of others.

However supportive my family, my sister is …..she isn't central to my life…. ….

I have both blood family and friendship family – I prefer my friendship family to make decisions about me

I want the people who make decisions to know enough about me – I need to trust them to make decisions putting me first – you never know who may come out of the woodwork and how they'd be….

I separated from/lost my family. I never felt close to them or wanted to be part of them, so I haven't approached Lasting Power of Attorney. I stick with my societal group which is made up of gay or gay-friendly people. The idea of making a will is a traumatic process which I have been putting off for sometime – the base issue is confronting old age. I have now made a will – I used a gay-friendly solicitor which advertised in a gay magazine.

Some LGBT people recognise the importance of revisiting wills regularly as their priorities change.

The shape of lesbian & gay families change over the years – we have a less assumed bond with people – more people come and go in our lives.

Gay life is more episodic – different phases, different people. We pare down who is significant in later life – no point doing it before because it will all change.

Many LGBT people haven't thought about – or are actively avoiding – legal issues: wills, powers of attorney, housing arrangements – conversations which make it necessary to 'come out' and share the lives they have been keeping very personal – conversations which mean they have to explore the complexity of their relationships.

1.7 Tricky issues

Not everybody feels comfortable about discussing LGBT issues and this includes LGBT people themselves. The research has flagged up a number of 'tricky issues' – the things that are difficult to talk about and which may prove to be barriers to progressing this work into action. There are likely to be more.

1. Acknowledging that someone is a trans person: how do we talk about these issues, is it OK to talk about them? So little is known by the general population and there are a lot of historical oppositional issues in the LGBT world.
2. LGBT people know very little about each other's worlds and cultures and, in some cases, are actively opposed to them.
3. Some LGBT people want to be totally 'integrated' into the straight world whilst others want to maintain a distinct cultural identity.
4. Some LGBT people are challenging binary gender stereotypes and heteronormativity, and the LGBTQI[15] people the world is seeing are those who are 'out there' – and not the ones just getting on with their lives.
5. Researchers and researchees are talking about carers who may come from countries where 'homosexuality' is an issue/problem. These conversations, if handled badly can err on racism or be silenced by accusations of racism.
6. There is a vocalised expectation that the younger generation of carers will be much better than those around today, because the younger generation is more tolerant and less discriminatory. This assumption is contradicted by the high level of homophobic bullying in schools[16].

– on one level all that LGBT people have got in common is that they do not conform to 'heteronormative' expectations.

Heteronormativity is the belief that people fall into distinct and complementary genders (man and woman) with natural roles in life. It asserts that heterosexuality is the only sexual orientation or only norm, and states that sexual and marital relations are most (or only) fitting between people of opposite sexes. Consequently, a "heteronormative" view is one that involves alignment of biological sex, sexuality, gender identity and gender roles. Heteronormativity is often linked to heterosexism and homophobia.
(Wikipedia 10:21 26/03/15)

[15] Lesbian, Gay, Bisexual, Trans, Queer – or Questioning, Intersex – or Inquiring
[16] Over 90% of LGBT school children report homophobic verbal abuse
http://www.stonewall.org.uk/at_school/education_resources/7957.asp

7. There is also an expectation that the upcoming generation of older and old LGBT people will think differently, that attitudes are changing and 'our generation will feel no compunction about coming out'. This is not borne out in this, or other recent, research.
8. Can discrimination be a self-fulfilling prophesy? If we expect to be discriminated against do we behave in defensive, awkward ways based on past experience, which in turn provoke an adverse reaction?
9. There is an enduring conflation of 'sex' and sexual orientation/identity – where sexuality is only valid if one is sexually active. This gives permission for care staff and workers who view older and old people as 'not interested in that sort of thing anymore' to completely dismiss sexuality as a vital aspect of an individual's identity.
10. The terminology used to refer to LGBTQI people is colourful and varied[17]. It can challenge people's sensitivities – whether as an audience to it or a target for it and make people reluctant to ask questions or engage in discussion.

The heteronormative stuff matters. When doing this research we sometimes felt that we were talking a lot about what to some might appear to be the minutae of daily experience/s. First of all we realise that we, as a society, rarely talk about the issues that impact on LGBT people and, because 'heterosexuality' is considered 'normal' we don't even recognise that most of the time that's what we talk about – in the media, in service development, in all aspects of policy development.

[17] An example is the complex world of language around the T as borne out through this Glossary: Transgender: An umbrella term (adj.) for people whose gender identity and/or gender expression differs from the sex they were assigned at birth. The term may include but is not limited to; transsexual people, people who cross-dress and other gender-variant people. Transgender people may identify as female-to-male (FTM) or male-to-female (MTF). In the UK it is usual to shorten the term to 'Trans'. Trans people may or may not decide to alter their bodies hormonally and/or surgically. Trans man / Trans men: People born female bodied but who have a gender identity like that of a man. Trans woman / Trans women: People born male bodied but who have a gender identity like that of a woman. Trans people: Members of the Transgender Community. Transsexual Person: A term originating in medicine and psychology. While some transsexual people still prefer to use the term to describe themselves, many people now prefer the term trans to transsexual. Unlike transgender, transsexual is not an umbrella term, as many transgender people do not identify as transsexual. It is best to ask which term an individual prefers. Altering one's birth sex is not a one-step process; it is a complex process that occurs over a long period of time. Transvestite: Often used in a derogatory way. ref: Press for Change, Changing Names and Changing Gender; A Guide for Employers and Other Organisations 2012

Research findings - Section 2

We need to inform people but that's not enough – we need them to think about it, what the implications are and then we need them to change what they do!

Research participant

What needs to happen to ensure that LGBT 'issues' form part of mainstream thinking about the future of health and social care in Shropshire?

In addition to asking research participants about the issues they are facing as they get older, we also asked them to think about what needs to happen to make things better.

2.1 Training for care providers

Perhaps, not surprisingly the research revealed a need for training for those who design and those who deliver a whole range of care including domiciliary, nursing, day, respite, dementia and to be included in NVQ curriculums in social care.

What needs to happen? Participants said:

- Undertake research into training designed and delivered elsewhere
- Add suggested content from SAND research as appropriate, to include:
    - understanding identity – and the notion of complex identities
    - understanding the importance of gender and 'getting it right' for the individual
    - understanding human rights
    - understanding the 'minority experience' and its implications – when LGBT people may never have been in the majority in a space
    - understanding and practicing the advocacy role in care provision
    - picking up on the subtleties of signals to understand hidden identities e.g. the use, or non-use of pronouns in conversation when referring to the important people in our lives
    - how to ask the questions without being intrusive
    - 'I don't mind if you're gay' – how does this feel? What does this imply?
    - assumptions, implications and behaviours – understanding the implications of operating from a 'heteronormative' position
    - what are the fears that carers have?
    - managing homophobia and ignorance amongst residents (this was flagged as very important at the dissemination event)
    - specific health issues for the different groupings under the 'LGBT' banner
    - facing the awkward stuff – sensitivities around touching; myths about predatory lesbians; ignorance about dangers
- Identify statutory, legislative, moral levers to encourage care staff to access this training – including exploring how LGBT communities can influence the CQC and

other regulatory bodies to ensure that LGBT issues are recognised and addressed in health and social care
- Monitoring training and subsequent practice to ensure that this stays on the agenda and does not slip off or become a tick box exercise

It takes skill and knowledge to understand and challenge homophobia and prejudice, or to know how to work in ways which are empowering.

2.2 Supporting our own communities

What needs to happen? Participants said:

We need opportunities and support for LGBT people to talk about all of this

I am worried about being located away from friends as networks are hard to establish

We have got friends from years ago from the forces when it was illegal to be gay. You had to really trust people. It forces people to take care of themselves – they are all self-starters[18]

Why are networks important?

- People who share similar experiences and 'get it' can support each other
- Having access to, and sharing information
- Trans people need support to transition – 'where you learn how to be a woman/man'
- To learn more about each other and our own differences so that we can support each other better

Lots of people have never knowingly met a trans person – they see a drag queen or a pantomime dame – people who are entertaining.

From the dissemination event: it was so interesting to meet all the people who had taken part in the research. I had some fascinating conversations and learned a lot about aspects of life for people in the LGBT community that I don't normally – if ever – come into contact with

[18] self-starters is a term suggesting self-sufficiency outside the mainstream

The benefits of being part of a group to discuss and change current practice out-weigh the fear of facing the issues which may impact on us as we age. LGBT people are keen to build on existing networks to support each other to achieve change in a supported environment.

2.3 Improvements in care homes

I want to feel reassured that the care home manager would not discriminate – and that they would challenge homophobia

What needs to happen? Participants said:

- Care homes need to have well trained and informed care home managers
    - Have clear, informed policies which include and protect LGBT residents, visitors and staff
    - Know and understand equality laws – and why they are important
    - Monitor how these policies are put into practice
    - Have the option to adopt a 'mark' signifying awareness (see recommendations)
    - Develop personal care plans which include the additional threats that may face an LGBT person in care, the potential impacts on them and how to mitigate these
    - Have clear information to help people understand the do's and don'ts of sexual activity – and to understand the reasons for these
- Older and old LGBT people share knowledge, information and experiences of care homes and personnel
- Methods are adopted to follow national research and keep informed of good practice

How would I know that a care home and other residents would accept me – or not? That I wouldn't need to watch what I say – wouldn't need a barrier around me?

What needs to happen? Participants said:

- In addition to the points above, care home managers should recognise that this does not have to be difficult to achieve
    - have pictures, films, music, brochures, books which reflect LGBT lives
    - have clear statements in promotional materials which welcome LGBT people
    - include LGBT celebratory events in social programmes

- ask open questions in care planning which make LGBT feel safe to disclose if they choose to
- have accessible complaints / suggestions / whistle-blowing processes

Another idea was to create a flagship home that has a code of conduct which says that prejudice is not acceptable, that has training for staff and clear policies with procedures to ensure they are put into practice.

Health and social care providers need to actively engage in discussions and plans for improved service delivery which takes account of LGBT life experiences.

2.4 Housing

The research reveals that LGBT people over the age of 50 have little or no understanding of the range of housing options which may be available to them in later life.

They talked about staying in their own homes or about full-on residential care – and very little in between.

How can this happen?

- Look at other ways of organising, e.g. trusts like Sunlight/Rowntree
- Explore specific LGBT housing
- Consider other models – flats with communal spaces
- Work with the Chartered Institute of Housing

There are big gaps in research to underpin initiatives aiming to improve the experience of older and old LGBT people accessing health and social care. This study reveals particular gaps around issues impacting on trans people, and trans experiences; on the impact that dementia may have on people who have (had) hidden lives; barriers to accessing legal services and research into housing options.

Conclusions

There are known knowns. These are things we know that we know. There are known unknowns. That is to say, there are things that we know we don't know. But there are also unknown unknowns. There are things we don't know we don't know.

Donald Rumsfeld

C.1. Shropshire is ahead of the game in consideration of these issues and the journey to change. We have an interested and engaged community of older and old LGBT people who increasingly understand the issues facing their community and want to be a part of change. Where other areas of the country are at the forefront of academic research, SAND is building a community of interest on the ground, assisted by this research.

C.2. The findings in this Shropshire-based research resonate with those from larger national studies and reinforce our previous desk research both in terms of the hopes and fears of older and old LGBT people accessing health and social care, and also the lack of recognition of those issues by service providers. The research raises similar issues in Shropshire about family relationships and expectation of discrimination linked with past experiences which can make people mistrustful and cautious. This research also revealed the lack of information locally available about and to older trans people, as noted nationally.

C.3. LGBT people are perfectly able to see some ways forward to achieve improvement – and are willing to put their own efforts in. The responsibility for change needs to be shared and the challenge remains, to engage health and social care staff and policy makers in these discussions.

C.4. Our sexual orientation and gender identity are only a part of our identity. In an ideal world this wouldn't be an issue but, because it clearly is an issue for the rest of the world, LGBT people are put in the position of having to focus more attention than maybe is warranted – and then are accused of 'banging on about it!' A bit of a catch-22 no win situation! LGBT people are a varied and complex bunch who have got

- Different life experiences
- Different levels of confidence
- Different values
- Different cultures

C.5. "Just because you can't see us does not mean we are not there". LGBT people choose to stay hidden for all sorts of reasons and so no care provider can ever really be sure that they have no LGBT people in their care and should always behave as if they do. These are real issues which do not go away for people as individuals if care staff choose to ignore them. Besides, if care is a positive experience – as much as it can be – for older and old

LGBT people, then it is going to be good for everyone else and so it provides a good benchmark.

C.6. Levels of confidence make a significant difference to the experience and expectations of older and old LGBT people, whether about housing or about health and social care. LGBT people don't access information about housing options in later life and their understanding of the possibilities and alternatives is limited. This lack of knowledge feeds some of their fears about what to expect.

C.7. There is a danger of a regressive pathway as LGBT people get older. The confidence to manage and assess different situations can reduce as their identities are undermined and it may be possible to identify tipping points in the care pathway – points at which LGBT people reassess and make choices about whether to be 'out', whether to talk about gender identity, or whether to withdraw.

C.8. Many LGBT people have complex families and varied interpretations of 'family'. Relationships, trust and honesty about identity, daily lives and lived experiences may lie with created rather than blood family.

C.9. Public environments are largely unknown, which can make them 'unsafe' for LGBT people who are uncertain about reactions to them. Personal home environments – original safe domains – can become unsafe when professionals visit.

C.10. Many LGBT people haven't thought about – or are actively avoiding – legal issues: wills, powers of attorney, housing arrangements – conversations which make it necessary to 'come out' and share the lives they have been keeping very personal – conversations which mean they have to explore the complexity of their relationships.

C.11. The heteronormative stuff matters. When doing this research we sometimes felt that we were talking a lot about what to some might appear to be the minutae of daily experience/s. First of all we realise that we, as a society, rarely talk about the issues that impact on LGBT people and, because 'heterosexuality' is considered 'normal' we don't even recognise that most of the time that's what we talk about – in the media, in service development, in all aspects of policy development.

C.12. It takes skill and knowledge to understand and challenge homophobia and prejudice, or to know how to work in ways which are empowering.

C.13. The benefits of being part of a group to discuss and change current practice out-weigh the fear of facing the issues which may impact on us as we age. LGBT people are keen to build on existing networks to support each other to achieve change in a supported environment.

C.14. Health and social care providers need to actively engage in discussions and plans for improved service delivery which takes account of LGBT life experiences.

C.15. There are big gaps in research to underpin initiatives aiming to improve the experience of older and old LGBT people accessing health and social care. This study reveals particular gaps around issues impacting on trans people, and trans experiences; on the impact that dementia may have on people who have (had) hidden lives; barriers to accessing legal services and research into housing options.

Recommendations

It felt really good to be encouraged to think about these issues and be part of very necessary change.

Research participant

Doing this research has made us appreciate that it is absolutely critical that people in positions to make decisions and act in ways which impact on people's lives understand the reasons **why** it is important that they know about their lives.

R.1. Health and social care providers and commissioners build on the momentum created by this research and SAND's advances in the County – engage with SAND and commit to improved outcomes for older and old LGBT people. Shropshire CCG, Shropshire Partners in Care (SPIC), Shropshire Council (incl Public Health), Shropshire Voluntary & Community Sector Assembly (VCSA), Royal Shrewsbury Hospitals NHS Trust, Shropshire Community Health NHS Trust, South Staffordshire & Shropshire Healthcare NHS Foundation Trust, Staffordshire and Stoke-on-Trent Partnership Trust and the care home sector.

R.2. Health and social care providers and commissioners (see R.1.) work in partnership with SAND to increase confidence and capacity of older and old LGBT people in Shropshire to engage in a process of change.

R.3. Health and social care, legal services and housing providers invest in further research in Shropshire to explore care pathways of older and old LGBT people; trans experiences; barriers to accessing legal services and housing options. See R.1. and also Shropshire Solicitors for the Elderly Network, Severnside Housing, South Shropshire Housing Association, Stonham Housing Association, Bromford Housing, Sustain and the legal sector.

R.4. Health and social care providers, legal services and housing providers in Shropshire (see R.3.) equip their staff with the skills and knowledge and structure their organisations to create safe environments for older and old LGBT people.

R.5. Health and social care providers, legal services and housing providers in Shropshire (see R.3.) work with SAND to develop a kite-mark, Champions scheme, or similar way of publicising those services with raised levels of awareness about issues impacting on older and old LGBT people in Shropshire.