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Title: Collaboratively setting the priorities for health and social care research for older lesbian, gay, bisexual and trans* people

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Abstract

This paper reports on a novel approach to setting research priorities relevant to the needs of older LGBT people. Research is growing in this area and has recognised the negative impact of contemporary and historical discrimination towards non-normative genders and sexualities. The results of a symposium, survey and agreement analysis are presented to identify the levels of priority placed on sixty different research topics. Discussion focuses on the novelty and/or similarity to existing research patterns on LGBT ageing, as well as prioritising topics such as: how to include unheard voices; exploring trans* people's experiences and preferences around long-term hormone use; and, embedding research findings into policy and practice.

Keywords: ageing, LGBT, HIV, research priorities, survey, agreement analysis

Introduction

This paper reports on a priority setting exercise for LGBT research in four specific areas: trans* ageing; lesbians and bisexual women's ageing; gay men, ageing and HIV; and research methodologies. Importantly, older LGBT people are not treated as one homogenous group, and whilst commonalities can be identified in their life courses there are also important differences. Additionally, the authors were mindful of not developing knowledge 'for' minority groups as this risks exercising a paternalistic approach to research (King & Cronin, 2010). Hence, the this paper is suggested as being one way to engage in a broader based collaboration between academia and the various LGBT communities in the early stages of research.

Gender, sexuality and being older

Using just four letters, 'LGBT', is not meant to silence other gender and sexual identities, as one always reaches the point where 'etcetera' is deployed (Butler 1990). However, this does not mean that the social categories of LGBT are meaningless. On the contrary, the literature reviewed below suggests that people who identify and are identified as non-heterosexual and non-cisgendered frequently experience violence, prejudice and poorer health outcomes.

Defining 'older' in relation to the LGBT community is also problematic. Most literature tends to consider people older when they reach an age between 50 to 65. Whilst there is no clear consensus on what constitutes 'older' in terms of a fixed cut off age within the LGBT community, it can be argued that there is a cohort of LGBT people who share an immersion within a culture where societal attitudes and legislation around gender and sexuality have radically changed.

For gay men, many Western countries moved to decriminalise homosexuality between roughly 1945 and 1965 (Herzog, 2011) but despite liberalisation at a legislative level, pathologisation of homosexuality remained and many gay men were subjected to aversion therapies, the effects of which were often long term and harmful (Dickinson, 2015). Whilst such practices were challenged and reduced over the 1970s and 1980s, HIV/AIDS then became a global reality that hit the LGBT community particularly hard (Herzog, 2011). Many gay men lost large numbers of their social circle during their youth to HIV/AIDS decimating their social circles (Rosenfeld, Bartlam, & Smith, 2012). Survivors are now reaching their 50s, 60s and 70s, in societies where anti-retroviral therapy is accessible, though frustratingly homophobia often remains problematic and the legacy of stigmatisation takes its toll.

With regards to lesbianism a somewhat different narrative can be traced. Non-heterosexual women were still frequently subjected to psychiatric 'treatments' (Jivani, 1997; Minton, 1996; Terry, 1990). However, of all reported cases in the medical literature, only one published study discussed aversion therapy being administered to women (MacCulloch & Feldman, 1967). It is important to note that while female sexual deviation (predominantly prostitution) was inscribed within forms of investigation that mirrored the regulation of male sexualities, lesbianism generally remained invisible in the laws that had made male homosexuality illegal (Walkowitz, 1982). The more common narrative appears to be one outside of compelled psychiatric treatment where instead the pressures of a patriarchal and heteronormative culture were oppressive. Whilst some lesbians found a strong community in feminist networks to resist such pressures, many did not and entered into marriages that were ultimately problematic (Summerskill, 2012). Similarly HIV/AIDS impacted the lesbian community differently. While lesbians themselves did

not die in high numbers from HIV/AIDS many shared in the care of and grief at the height of the epidemic as well as engaging in activism (Schulman & Hubbard, 2014) uniting a somewhat divided lesbian and gay community (Summerskill, 2012). However, lesbianism still remained more invisible and as such the morbidity and mortality of lesbians frequently went unrecorded. Yet if one considers lesbianism to be somewhat hidden, the life courses of bisexual women seem to be even more so, to the point that almost all studies link the two together. Jones (2010) has begun to document this, and suggests that the silence on bisexual life-courses is due to the complexity that comes with defining bisexuality itself, as well as biphobia. Ultimately further work is needed to more rigorously explore the life courses of bisexual women and men.

Being trans* in the mid to late twentieth was equally fraught with problems, the US for example passed multiple laws requiring people wear clothes associated with their birth assigned gender making living one's day-to-day life particularly difficult as even though communities did exist they tended to be isolated and relatively secretive (Stryker, 2008). Films like '*Paris is Burning*' (Livingston, 1990) document the ways in which the trans* and drag communities supported one another but there are criticisms that the wider LGB community offered few spaces (literal or metaphorical) for trans* people to exist (Namaste, 1996) often excluding them on misogynistic and misandristic grounds (Stryker, 2008). Trans* people were also hugely impacted by the HIV/AIDS epidemic, and whilst the absolute number remained small in comparison to gay men, proportionally the rate was comparably higher than gay men and even more so for trans* people of ethnic minorities (Baral et al., 2013). Shame and stigma also impacted on many trans* people's ability to seek appropriate support health and social support. There is some optimism on the horizon with 2015

being hailed in multiple international publications as being "the year of trans visibility" (Capuzza, 2016). Yet murders, suicides and severe mental health problems remain disproportionately high among the trans* community (Blosnich et al., 2013; Tarynn M. Witten, 2004).

In summary the mid to late 20th Century brought both hardship and liberation for the LGBT community but the accumulations of hardship have impacted on and been responded to differentially across the LGBT community. In light of this, it is only right to separately review the contemporary and foundational research for each of the four specific themes addressed in the research priority setting exercise. It is not an exhaustive or systematic review of the literature on LGBT ageing does give the reader an overview of the research that has been conducted.

Trans ageing*

The earliest academic reference to older trans* people we could find dates back to Lothstein (1979) which exclusively addresses people wishing to transition later in life. Of particular note in this paper is its overall approach of pathologising individuals, this has several implications. For example, whilst Lothstein identifies that depression and anxiety are frequent difficulties associated with the aging transsexual patient and it is assumed that depression had to be treated before any further medical or surgical interventions could be undertaken. That medical and/or surgical interventions could have resolved the depression was simply not considered. Additionally the desire to move quickly with medical and surgical interventions, which contemporary research suggests improves quality of life (Simonsen, Giraldi, Kristensen, & Hald, 2015), was deemed to be "manipulative, controlling, coercive and paranoid" (Lothstein, 1979, p.9). Collaboration and co-operation between medical professionals and trans*

people was not considered, nor was there any understanding of trans* people as a distinct community.

More recent literature offers different understandings about the complexities, difficulties, solutions as well as the joys of ageing and being trans*, recognising the socially mediated nature of positive and negative ageing. For example, the formation of strong and meaningful community ties is a particularly important source of resilience for trans* people when ageing (McFadden et al., 2013), and whilst this is also true for all people who are ageing, trans* peoples' social networks have frequently been fractured by prejudice reducing this vital support mechanism (Finkenauer, Sherratt, Marlow, & Brodey, 2012). Additionally, dementia (Marshall, Cooper, & Rudnick, 2015) and end of life care (T. M. Witten, 2014) remain problematic. With regards to dementia the evidence is limited, but research suggests that families, carers (lay and professional), and peers struggle to understand and navigate trans* identities when they do not clearly remain within one of the binary understandings of gender (Marshall, Cooper, & Rudnick, 2015). With regards to end of life care, trans* people may harbour fears around their gender identity not being respected in terms such as clothing choices and gravestones. Of particular note in Witten's (2014) work was the clear and considered approach to suicide. Whilst suicide is a recurring theme in a large section of literature about end of life care, the reasons given tend to focus on people not wanting to be severely disabled or in excessive pain (Steck, Egger, Maessen, Reisch, & Zwahlen, 2013). The reasons for suicide amongst trans* people were not in keeping with this, instead centred on wanting to avoid prejudice when at their most vulnerable (Witten, 2014).

Evidence suggests many underlying needs are not significantly different for older trans* people: acceptance, supportive communities, freedom from discrimination,

financial stability; yet they are frequently denied them (Finkenauer et al., 2012). There are however some specific considerations raised in the medical literature about organ specific cancers (such as prostate, breast, cervical, ovarian etc) and how screening programmes may not identify trans* people as needing these investigations, as well as how individuals lack knowledge cancer risks (Sattari, 2015). There are also medical debates about the management of hormonal administration in later life (Gooren & Lips, 2014) and a lack of literature which engages trans* people's experiences and beliefs on this topic. Hence, key gaps in the literature relate to: the psychological and social aspects to trans* ageing; the positive aspects to ageing as a trans* person; the involvement of trans* people in healthcare; ageing and hormone use; dementia; and, end of life care.

Lesbians and bisexual women ageing

The older lesbians and bisexual women literature suggests higher rates of alcohol consumption and smoking, and higher rates of breast and ovarian cancer in comparison to heterosexual women (Averett & Jenkins, 2012; Meads & Moore, 2013; Zaritsky & Dibble, 2010). Westwood (2014) also highlights that dementia amongst older lesbians may make recognition of their identity problematic and that lesbians entering residential care for dementia risk isolation because their social networks are generally more intra-generational than heterosexual women. Additionally, care homes are considered to be heteronormative spaces which leave older lesbians less well supported. However, putting these disease specific issues to one side, two overarching themes in the literature appear to be the importance of community, and the problem of invisibility.

Community is a vital source of care frequently including ex-partners as well as other older lesbians, though it may also include other trusted heterosexual women (Hash & Netting, 2009) with rotas covering care needs from short term support, all the way through to personal and palliative care (Richard & Brown, 2006). The use of professional care support appears to be less prevelant (Averett, Yoon, & Jenkins, 2011) which is perhaps not suprising given the historical mistreatment of lesbians by healthcare professionals (Jones & Nystrom, 2002; Traies & Munt, 2014). Additionally, the literature suggests a heteronormative approach makes lesbians reticent about accessing care (Fullmer, Shenk, & Eastland, 1999). Self-supporting care networks therefore appear to ameliorate lesbians' uneasy relationship with healthcare professionals. However, this reduced propensity to engage with healthcare services coupled with increased risk factors makes the older lesbian population particularly vulnerable to life limiting diseases. To date there is little literature on how the caring communities described in the literature can work with healthcare professionals to increase screening for key illnesses in older age and how to help decrease physically harmful behaviours such as smoking.

In addition to fearing prejudice from health professionals, the invisibility of older lesbians is a concern (Kehoe, 1986). The needs and concerns of older lesbians are frequently erased due to: ageism, sexism, homophobia and heteronormative assumptions being made about women's sexuality, sometimes based on previous marriages and child-rearing (Traies & Munt, 2014; Fullmer et al., 1999). With regards to the causes and effects of invisibility, physical violence is occasionally cited, though most commonly it takes the form of micro-aggressions where someone is made to feel less worthy than others because of their gender, sexuality or age (Waite, 2015) and treated less favourably because of it (Traies & Munt, 2014). This compounds

older lesbians invisibility by making some reticent to challenge prevailing authorities when care is inadequate or inappropriate. Additionally, the triple invisibility has also been theorised as extending to a quadruple invisibility for non-white lesbians where racism can compound all the above problems (Averett & Jenkins, 2012). Whilst experiencing any of these prejudices from society at large is traumatic, it has been suggested that the lesbian community can itself be ageist and racist (Copper, 2015; Macdonald & Rich, 1983) thereby further isolating lesbians from black and minority ethnic (BME) backgrounds.

Further research is needed to ensure research covers diverse populations and addresses directly issues of ageism and racism (Averett & Jenkins, 2012), as well as exploring the health inequalities in relation to dementia, cancer, and appropriate support mechanisms for ageing lesbians and bisexual women.

Gay men, ageing and HIV

It is important to explore the key ways in which gay men with HIV age in reference to medical and social responses (see Nagington, 2015 for a more wide ranging review). Perhaps one of the most immediately striking changes are highly active anti-retroviral therapies (HAART). This treatment has resulted in long term suppression of HIV infection leading to near normal life expectancy. As such the AIDS epidemic has largely ended in countries where there is free and/or low cost access to HIV treatment and resulted in an ageing population of people living with HIV, for example a predicted 50% of people living with HIV in the US will be over 50 in 2015 (Centre for Disease Control, 2011). However, the medical literature highlights that the effects of HIV are not limited to the immune system, instead almost every bodily system and

organ can in some way be affected by HIV. As such, HIV is frequently conceptualised as accelerating ageing (Justice, 2010).

However, ageing is also a social and psychological process, which many gay men engage with differentially to their heterosexual counterparts. There have been suggestions that gay men age more successfully, as they have a history of developing peer support networks and developing resilience to the psychosocial difficulties (Harrison, 1996; Kimmel, 1978). However, evidence also suggests that gay men struggle to maintain their health and wellbeing as they age when compared to their heterosexual counterparts. In keeping with the medical literature this is also referred to as accelerated ageing (Martin & Volberding, 2010). The mechanisms by which this acceleration occurs are less well understood but may include: the gay male life course may lack certain legitimising social processes such as marriage, procreation and the raising of children; that the gay male community itself is ageist and prises youthful bodies and activities such as partying, drug and alcohol consumption over other forms of social interaction; fewer social spaces for older gay men to socialise in a safe environment; and finally, a generalised concern around homophobia from generic services, both statutory and voluntary; and shame and stigma related to HIV diagnoses (Nagington, 2015, Simpson 2015, Robinson 2008).

Further research is needed to explore the non-pathological sides of ageing with HIV, as well as exploring the affirming stories of ageing with HIV as a gay man that take account of the often different social structures in gay male lives. Additionally, a more nuanced understanding is needed in the literature with regards to people who have aged with HIV, and those who have become HIV positive at an older age. To date, the research literature has done little to explore the differences that this may present.

Research methods

This paper can't review and critically evaluate all the different methods that have or have not been used in relation to LGBT. However, there are some broad discussions and critiques of LGBT ageing research presented.

King and Cronin (2010) suggest of particular importance is the way in which researchers identify and recruit participants. They take their approach to social research with LGBT people from queer theorists such as Butler and suggest that research methods need to attend to the instability of LGBT categories by questioning not only what they mean but also how they are produced. Doing so brings critical insight into the variety of ways in which one can be older and LGBT. They also suggest a key part of this is allowing and encouraging research participants to explore how they categorise themselves and how this may differ from normative assumptions of age, gender and sexuality.

However, there remains a foundational difficulty in how to recruit people into research who identify as neither heterosexual, cisgendered or as LGBT. One possible way of addressing this is 'snowball sampling' where any participants who are recruited to studies are encouraged to invite other people into the study. Whilst this can result in a homogenous sample, Brown (2005) highlights that commencing snowball sampling across a wide demographic base can help to ameliorate homogeneity in a sample. Snowball sampling also has the advantage of accessing 'hidden' groups more easily, and whilst societal attitudes to LGBT people have significantly improved over the last few decades, homophobia and transphobia remain consistent features in why older people avoid identifying as LGBT beyond close family and friends therefore making them potentially difficult communities to

recruit within. This allows for more covert recruitment methods that do not rely on people being engaged with LGBT media or communities in order to hear about the study, and allows recruitment to occur via existing social networks.

Finally, the way in which intersectionality is dealt with can be problematic. As alluded to above, gender and sexuality do not stand in isolation to identities, instead people may identify and be identified in an array of different ways, including (but not limited to) age, levels of ability/disability, race and ethnicity, class, political affiliations etc, and whilst there has been mention of triple and quadruple invisibility and disadvantage it must be questioned if different identity categories can be added together in such simplistic ways (Bowleg, 2008). Finally, almost all research into LGBT people has been cross-sectional. More longitudinal research is needed to help policy makers understand how their decisions effect LGBT people in the long term (Averett & Jenkins, 2012).

Summary of background literature

Grouping LGBT people all into one category will ultimately fail to capture a meaningful understanding of the ways in which people with non-normative genders and sexualities experience ageing. The literature does point towards some important research priorities such as ensuring diversity in samples and avoiding making the mistake that LGBT identities are the source of any shortcomings in health and wellbeing. Instead the literature is clear that it is societal prejudice that lies at the root of almost all poor health outcomes for LGBT people. Yet the research priorities in the academic literature are not clearly drawn from community involvement, therefore one possible method of achieving this is described in the remainder of this paper.

Methods

The research priority setting exercise reported below was adapted from Preston et al's (2013) approach for setting research priorities in palliative and supportive care. In collaboration with healthcare professionals Preston et al developed a long-list of topics for input into a survey which was circulated to the original professionals. Participants were asked to rate the priority on each topic on a Linkert scale and an agreement analysis (see below for further details) was then performed on these ratings. In relation to palliative and supportive care research, limiting the consultations to professionals is somewhat more justified as engagement of people with severe and life-limiting illnesses could be problematic. However, this is clearly not the case for engaging older LGBT people. As such, the research priority setting exercise was adapted slightly to include the broader LGBT community at both the long-list development stage and the survey stage. At neither of the stages outlined below were contributions 'filtered' on the basis of someone's reported gender or sexuality. Instead, it is the authors' argument that it becomes increasingly complex and impractical to decide whether for example a "queer woman" can legitimately contribute to discussions on lesbians and bisexual women. Hence, the exercise relied on people's integrity to contribute where they considered they could make meaningful contributions.

Symposium stage

The symposium created an atmosphere where ideas for research priorities were stimulated, debated and captured. To this end, two key-note speakers spoke on each of the key themes of LGBT ageing in four workshops on the topics identified by the authors. Two parallel workshops took place in the morning (trans* ageing; and

gay men, ageing and HIV) and two parallel sessions in the afternoon (lesbians and bisexual women ageing, and research methodologies).

The symposium was primarily advertised via existing networks of the ageing research group at the host University which consists of a large database of academics, third sector organisations and older service users. Local and national organisations (such as HIV and LGBT charities) were also invited. Seventy three people signed up to attend and institutional affiliations were collected, of these: 41 were from academic institutions (of which 7 were students), 23 people from third sector organisations, 5 from various health and social care organisations, and 4 people did not identify any particular institutional link. Data on attendees' professional roles were also collected and were extremely varied however 6 stated that they were attending in a non-professional capacity. Yet the overlap between 'professional' and 'community member' is likely to blurred within work addressing the LGBT community (as opposed to Preston's work on palliative care where professionals are unlikely to be in receipt of palliative and supportive care), and those with a professional affiliation may also have been contributing in the capacity of being an older LGBT person themselves. As with Preston et al'ss work further demographic information was not collected at the symposium stage, this makes asserting the findings as definitively the views of older LGBT people somewhat limited. As this is a novel approach which other researchers may wish to utilise, it would be the authors' recommendation that future research priority setting work considers in greater detail what demographics need collecting and at which points in the initial consultation stage in order to assess the representativeness of the exercise.

During the workshops notes were taken by each of the authors about the different priorities that participants felt needed researching. Immediately after the symposium the authors met to formulate the research topics into succinct research topics, see boxes 1 to 5 for the full list. Where possible the original wording as spoken by attendees was preserved, though in some cases some truncation was necessary. These research topics where then put into a survey for distribution to the public. Overall 60 different items of research were identified.

With regards to workshop attendance there was an imbalance in the two afternoon workshops (lesbians and bisexual women, and research methods); only 10 people attended the lesbians' and bisexual women's workshop with the remainder attending the research methods workshop. The other two workshops were noted to include roughly half the participants in each. Therefore, some workshops identified more research topics than others. Whilst this again narrows the foundation of the exercise it was not felt conducive to 'force' people to attend a workshop on a topic where priorities for research would be identified if they did not prioritise attending it themselves. This creates a limitation in the older lesbians and bisexual women theme, but to exclude this theme from the findings would possibly do more disservice than including it. As such, it may be particularly beneficial to run a similar exercise focussed exclusively on lesbian and/or bisexual women.

Survey stage: design

Participants ranked each item on a Likert scale from 1 "very low priority" to 7 "very high priority". The survey was online only and distributed to all conference attendees, as well as a wide array of patient advocacy groups, third sector organisations, professional networks, and the authors' own personal networks. Full demographic

details were collected at this point. In keeping with the complexities of describing gender and sexuality participants were asked to state in their own words what best described their gender and the country they live in. All other categories were multiple choice.

Survey stage: analysis

Survey data were analysed for the level of agreement around the different research topics by calculating the median score and interquartile range (IQR). The intention was to present the data in line with Preston et al'ss work which highlighted six potential levels of agreement ranging from strong agreement with high consensus, through to no agreement with low consensus. This however was not possible, instead Figure 1 details the four types of classification which were developed to help differentiate the priority that researchers should place on taking forward and/or incorporating the topics into future research projects.

[insert figure 1 here]

Based on our 7-point Likert scale, it was apparent (see Graph 1) that all of the item's medians were medium to high (between 5-7) and the level of agreement was medium to high (i.e. 1-3).

[insert graph 1 here]

No research topics could be meaningfully classified as having a low priority. Therefore, the classification scheme used in this paper (see Figure 1) has been developed to differentiate between the observed results (i.e. relative scale) to aid interpretation, and as in Preston et al's paper (2013) cannot be considered an absolute scale. However, the classification does track the descriptors given on the

Likert scale and can be considered a logical categorisation of the data. All analyses were conducted using SPSS.

Results

Demographics

A total of 258 participants completed at least one section of the survey, one participant filled in the demographic data but then did not complete any section of the survey. Their demographics are therefore omitted from Table 1. The survey remained open for 12 weeks. Participants were permitted to 'skip' sections if they so wished, as not all sections could be assumed to be applicable to everyone. As can be seen in Table 1, there is a reasonable balance across the different demographic characteristics. However, in the first two weeks there was poor uptake within the BME community and as a result BME community leaders and third sector organisations were contacted to assist with distribution of the survey to the BME community. This resulted in 13% of the sample identifying as being from a BME background, which is approximately the same as the adult BME population in England and Wales (where the majority of the sample came from) as of the 2011 census (Office of National Statistics, 2011). There was however, no clear BME voice in the symposium stage of the priority setting exercise. With regard to older people completing the survey 44% (n=116) were aged 50 or above.

[insert table 1 here]

One participant entered their age as 14 but as the survey was not targeted at organisations dealing with anyone under 18, the authors assume this to be a typographical error and thus did not exclude their contributions. Even if this were not

a typographical error whilst consent would normally be sought from parents/guardians for people under 16 for involvement in research, this project can be more properly considered a stakeholder engagement exercise, not research. Therefore, issues regarding consent to research are not as pressing, especially considering responses were anonymous.

By allowing participants to self-identify their gender and sexuality a diverse range of responses were received, and apart from minor changes such as harmonising capitalisations, the results in Table 1 represent participant's self-identifications. With regards to gender 96.5% placed themselves within the male-female binary but 3.5% did not, instead identifying in multiple different ways with one participant conveying that their gender identity was fluid; additionally, 21.3% stated that their gender was different to the one assigned at birth. In relation to sexuality 85% identified as either lesbian, gay, bisexual or heterosexual, and 15% identified as a range of other sexualities. With regards to the relationship with healthcare services 54% identified themselves as service users.

Classification of recommendations

Three items were classified as very high priority and very high consensus (Box 1). Seven items were classified as having a high priority and high consensus (Box 2). Three items were rated as medium priority with high consensus (Box 3). Finally, nine items with different median values all had low levels of consensus (Box 4) rendering the median value less meaningful in assessing the priority of the research. The remainder of the thirty-eight research topics did not clearly fall into any one of the above categories (Box 5), this is largely because 54/60 (90%) rated items had a median response of 6, and 50/60 (83%) had an IQR≤2, therefore, a lot of the

questions resulted in similar priority ratings with a similar degree of consensus and there is no way to further differentiate them statistically. As some of the survey items were somewhat prolix all questions have been assigned a code 1 – 60 to easily link them to the graphical data.

Discussion

Because of the varying levels of priority and consensus the potential research topics are grouped into different categories (listed below) for discussion. On some occasions these link with ongoing research and/or priorities highlighted in the literature, in other cases they highlight under-researched areas to be addressed.

Very high priority/very high consensus
The results with the highest median values and level of agreement generally highlighted the need for embedding research findings into policy and practice (see Box 1).

[Insert box 1 here]

Something that Averett and Jenkins (2012) argue should be at the forefront of researchers' aims and objectives. However, a generation of queer/post-structural/feminist approaches to research drives us to question which voices make it into research and therefore into policy and practice; the survey results hint at the need for this critical requirement by also rating the inclusion of "unheard voices" as equally important. The available literature confirms that this is an issue and suggests some ideas of subgroups that may constitute 'unheard voices' in LGBT ageing

research, such as the bisexual community (Jones, 2010) and the BME community (Averett & Jenkins, 2012; Bowleg, 2008). In addition the now well established LGBT charitable sector may silence the of voices that fail to speak intelligibly within the constraints of the competitive funding models for research that charities and university researchers must satisfy by clearly and unambiguously defining the target and impact of their research. Therefore, such definitions and categorisation of identity whilst sometimes useful for political mobilisation also produce exclusions, no matter how hard we try otherwise (Brown 2008). Yet political mobilisation also serves as a starting point for highlighting what constitutes an 'unheard voice' by engaging with 'fringe' political groups that exist outside of the funding structures of medium to large scale charities and research programmes thereby broadening out the categories of 'LGBT' (Wiegman 2012). Finally, voices can also remain unheard when violence and prejudice silence them, and/or when people with diagnoses such as dementia fail to produce an intelligible voice (Marshall et al., 2015; Stein, Beckerman, & Sherman, 2010; Westwood, 2014). Overcoming these barriers requires a refusal to concede that violence and prejudice "don't exist anymore", as well as allowing it to be represented when it does.

In summary, whilst linking research, policy and practice is essential, critical approaches to research must question what voices produce policies as well as accounting for the forms and types of oppression(s) that shape the groups that produce the research. This will always require a multi-avenued dialogue which avoids creating a dichotomy between academic evidence or the lived experience of individuals.

High priority/high consensus

The research topics identified as high priority and high agreement (Box 2) help give further understanding about how including unheard voices may be achieved. King (2014) highlights one of the key ways to achieve this can be the utilisation of action research to recruit and engage older people with the research process and the implementation the findings of research. This general approach clearly links to several of the priorities in box 2 because action research intrinsically links academics and service users and relies on community engagement to disseminate and apply findings.

[insert box 2 here]

The geographical basis collaboration may also be suggested to be prioritised as nationally focussed, this largely makes logical sense in that one of the key influences in LGBT lives (despite encroaching globalisation) are national laws, policies and practices (Richardson 1998). Other broader influences such as religion and culture which are clearly implicated in the representation of gender and sexuality (Adamczyk 2009) did not come up as priorities at the qualitative stage of this priority setting exercise. A certain degree of reflexivity is relevant here in that the influences of religion may be different outside of the relatively secular UK nation state. Therefore, whilst identifying areas of good or bad practice within the same legal and policy frameworks may result in research that can be more quickly actionable without substantive political campaigning, the influence of broader culture cannot be forgotten.

In relation to specific research topics the long term use of hormones for trans* people was highlighted. Some authors have critiqued the focus on trans* identities as too slanted towards hormone use (Fredriksen-Goldsen et al., 2013), possibly reflecting the broader resistance against pathological models of trans* identities. However, the survey results suggest a third way could be achieved where trans* people's lived experiences of hormone use informs and challenges medical practice with regards to hormone prescribing.

In relation to older gay men with HIV two topics were highlighted: what works to reduce social isolation; and what preferences older HIV positive gay men have towards the end of life. The first of these again is broadly in line with the contemporary literature that suggests older HIV positive gay men can face significant social isolation (Lyons, Pitts, Grierson, Thorpe, & Power, 2010; Nagington, 2015; Owen & Catalan, 2012), however the wording of this question makes it clear that research now needs to start addressing ways to ameliorate social isolation rather than just documenting it; something which is only just beginning to be addressed in the UK at a grass roots level (Terrence Higgins Trust, 2016). In relation to end of life care, there was little in the contemporary background literature and as the population of HIV positive gay men ages there is a need to explore issues around the end of life. Currently the literature on palliative and end of life care in HIV/AIDS is heavily focussed towards the pre-HAART/AIDS era (Armes & Higginson, 1999; Newshan & Sherman, 1999) or the early post-HAART era which tends to focus on the issues associated with polypharmacy and complex HAART regimes (R Harding et al., 2005). Whilst research has begun to address the needs of sexual minorities in

palliative care (Richard Harding, Epiphaniou, & Chidgey-Clark, 2012), the complexities of being HIV positive in a post-HAART era are not yet explored.

Finally, while some longitudinal studies are beginning to incorporate questions on sexual identity (Semlyen, King, Varney, & Hagger-Johnson, 2016) many do not, and trans* status is rarely included. As such, it's no surprise that the survey highlighted issues around including question on existing longitudinal studies about gender identity and sexuality as a high priority with high consensus. Addition of gender identity and sexuality questions, whilst problematic because of the complex ways in which people identify, remains an important source of data to help establish a more detailed understanding of health inequalities and would help researchers analyse large scale data sets for health inequalities as well as inequity in access to treatment. However, when taken in combination with the broader literature calling for longitudinal work (Nagington 2015; Fredriksen-Goldsen et al., 2013; Meads & Moore, 2013; Rosenfeld et al., 2012) it may also be necessary to develop LGBT specific or adapted longitudinal studies that enable researchers to address LGBT relevant health and social issues in culturally appropriate ways and that continue to allow flexibility in the way that people identify their sexuality (King and Cronin 2010).

Medium priority/good consensus

Research into older bisexuals and the way in which more fluid sexual identities can produce advantages or disadvantages across the life course are only just beginning to be explored (Jones, 2010), bisexuality aside there remains within the public discourse the idea that sexuality is a fixed or natural entity (Evan 2013). Whilst queer theory has begun to challenge these assumptions there remains an essentialist

approach to sexuality which may explain why "exploring if and how sexual identity changes over time" is rated as a medium priority/good consensus item (see Box 3).

[insert box 3 here]

Similarly, the public discourse on ageing with HIV is not well progressed (Nagington 2015), nor is understanding about treatment as prevention (Persson 2013). Therefore, a lack of awareness may be deprioritising the topics of changing sexuality and the use of antiretroviral to prevent transmission in older gay men.

Low consensus

In relation to the items where there was low consensus (see Box 4) there are some items where the lack of agreement may by symptomatic of longer standing disagreements.

[insert box 4 here]

For example, the lack of agreement over "Developing strategies to include trans* women in research projects examining lesbians and bisexual women" may reflect (sometimes acrimonious) disagreements over if and how to include trans* women within women's groups and/or the lesbian and bisexual community (Heyes, 2002). Likewise, historic and complex disagreements in society about euthanasia (Hendry et al., 2013) may equally explain the lack of agreement for the item "Is assisted dying of more relevance to older HIV positive gay men?". Similarly, the low consensus for creating links between researchers, gender clinics, hospitals and statutory

organisations may reflect the complex and at times difficult relationships that trans* people have had with health and social care.

There are however some topics that clearly link to existing literature such as exploring the meaning of lesbian and bisexual identities, and critical examination of LGBT categories (Averett & Jenkins, 2012; Averett et al., 2011; R. Jones, 2010; Seidman, 2003) and, whilst it was noted above that there needs to be further work in establishing LGBT relevant questions in longitudinal research, with regards to trans* people this was rated with a low consensus. There was low consensus regarding the need to increase research into older bisexual people, which may to some extent explain why bisexuals are invisible within the literature. There was also low consensus regarding the need to examine cultural and national differences which could be reflective of ethnocentrism within the LGBT community.

In summary low consensus should not be read as there being a low priority placed on these research topics for some sections of the LGBT community, however it may in some cases remind researchers that some areas of LGBT research have complex histories to navigate when planning and undertaking research.

Other items outside of classification structure

Individual discussion of all the other items (see Box 5) that had a median response of 6 and reasonable levels of agreement (IQR ≤2) goes beyond the remit of this paper because the established analytical technique did not give any meaningful differentiation between these items.

[insert box 5 here]

The previous use of this analytical technique by Preston et al (2013) did not result in a high number of high medians with modest agreement. However, because research into older LGBT people remains a relatively under researched area, it may be possible to suggest that when reviewed collectively these items demonstrate that almost any research into older LGBT people is a modest priority.

Limitations

There are a number of limitations with this prioritisation exercise. Firstly, the overall direction of the priority setting exercise was set by the four key themes highlighted above which reflected the authors areas of expertise. Therefore, discussion was not directed towards specific demographics such as the BME community, who are often under-represented in research. Secondly, with regards to access to the survey because it was online-only it required people to have access to the internet as well as a modest level of IT literacy. The high level of engagement required to complete this task potentially side-lines people experiencing issues around dementia, and end of life care that are present in the contemporary research literature on LGBT ageing, potentially making them 'unheard voices'. The calls for a comprehensive literature review of LGBT ageing literature (Averett & Jenkins, 2012) followed by broad based stakeholder engagement may help to more clearly identify other unheard voices and engage in robust dialogue(s) about research priorities. Thirdly, whilst we have identified a number of topics that appear to be higher priorities than others, the reasons for these suggested above are tentative and not based on any stakeholder engagement. Future research could consider conducting follow up interviews, focus

groups, or collecting qualitative data within the survey so respondents can explain their scoring. Finally with regards to the statistical methods used, the high number of similarly rated items could be reduced by increasing the range of answers from a 7 point to a 9 or even 11 point scale. Ranking the priorities could also offer an alternative approach.

Conclusion

The literature has demonstrated that older LGBT people likely experience a range of inequalities yet establishing research priorities purely from the academic literature risks taking a paternalistic approach to a community. This exercise took a novel approach in relation to LGBT ageing by adapting Preston et al's (2013) work to engage not only 'professionals' in prioritising research, but also a wider section of the LGBT community. Notably a generally high priority is placed on researching older LGBT health and social needs and no items could be considered a low priority.

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References

Adamczyk, A., & Pitt, C. (2009). Shaping attitudes about homosexuality: The role of religion and cultural context. *Social Science Research*, 38(2), 338-351

Armes, P. J., & Higginson, I. J. (1999). What constitutes high-quality HIV/AIDS palliative care? *Journal of palliative care, 15*(4), 5-12.

Averett, P., & Jenkins, C. (2012). Review of the literature on older lesbians implications for education, practice, and research. *Journal of Applied Gerontology, 31*(4), 537-561.

Averett, P., Yoon, I., & Jenkins, C. L. (2011). Older lesbians: Experiences of aging, discrimination and resilience. *Journal of Women & Aging, 23*(3), 216-232.

Baral, S. D., Poteat, T., Strömdahl, S., Wirtz, A. L., Guadamuz, T. E., & Beyrer, C. (2013). Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *The Lancet infectious diseases, 13*(3), 214-222.

Blosnich, J. R., Brown, G. R., Shipherd, P., Jillian C, Kauth, M., Piegari, R. I., & Bossarte, R. M. (2013). Prevalence of gender identity disorder and suicide risk among transgender veterans utilizing veterans health administration care. *American Journal of Public Health, 103*(10), e27-e32.

Bowleg, L. (2008). When Black+ lesbian+ woman≠ Black lesbian woman: The methodological challenges of qualitative and quantitative intersectionality research. *Sex roles, 59*(5-6), 312-325.

Brown, W. (2008). *The Impossibility of Women's Studies*. In J. W. Scott (Ed.), Women's Studies on the Edge. London: Duke.

Browne, K. (2005). Snowball sampling: using social networks to research non-heterosexual women. *International Journal of Social Research Methodology, 8*(1), 47-60.

Butler, J. (1990). *Gender trouble: feminism and the subversion of identity*. London: Routledge.

Capuzza, J. C. (2016). Improvements still needed for transgender coverage. *Newspaper Research Journal*. doi: 0739532916634642

Centre for Disease Control. (2011). *HIV Surveillance Report*. Atlanta: U.S. Department of Health and Human Services.

Copper, B. (2015). Ageism in the Lesbian Community. *Journal of Lesbian Studies, 19*(1), 7-12.

Delva, W., Eaton, J. W., Meng, F., Fraser, C., White, R. G., Vickerman, P., . . . Hallett, T. B. (2012). HIV treatment as prevention: optimising the impact of expanded HIV treatment programmes. *PLoS Med, 9*(7) doi:10.1371/journal.pmed.1001258

Dickinson, T. (2015). *'Curing Queers': Mental Nurses and Their Patients, 1935-74*. Oxford: Oxford University Press.

Emlet, C. A. (2006). "You're awfully old to have this disease": Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. *The Gerontologist, 46*(6), 781-790.

Evans, D. (2013). Sexual citizenship: The material construction of sexualities London:Routledge

Finkenauer, S., Sherratt, J., Marlow, J., & Brodey, A. (2012). When injustice gets old: A systematic review of trans aging. *Journal of Gay & Lesbian Social Services, 24*(4), 311-330.

Fredriksen-Goldsen, K. I., Emlet, C. A., Kim, H.-J., Muraco, A., Erosheva, E. A., Goldsen, J., & Hoy-Ellis, C. P. (2013). The physical and mental health of lesbian, gay male, and

bisexual (LGB) older adults: The role of key health indicators and risk and protective factors. *The Gerontologist, 53*(4), 664-675.

Fullmer, E. M., Shenk, D., & Eastland, L. J. (1999). Negating identity: A feminist analysis of the social invisibility of older lesbians. *Journal of Women & Aging, 11*(2-3), 131-148.

Gooren, L., & Lips, P. (2014). Conjectures Concerning Cross-Sex Hormone Treatment of Aging Transsexual Persons. *The Journal of Sexual Medicine, 11*(8), 2012-2019.

Grinsztejn, B., Hosseinipour, M. C., Ribaudo, H. J., Swindells, S., Eron, J., Chen, Y. Q., . . . McCauley, M. (2014). Effects of early versus delayed initiation of antiretroviral treatment on clinical outcomes of HIV-1 infection: results from the phase 3 HPTN 052 randomised controlled trial. *The Lancet infectious diseases, 14*(4), 281-290.

Harding, R., Epiphaniou, E., & Chidgey-Clark, J. (2012). Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: A systematic review. *Journal of Palliative Medicine, 15*(5), 602-611.

Harding, R., Karus, D., Easterbrook, P., Raveis, V., Higginson, I., & Marconi, K. (2005). Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sexually Transmitted Infections, 81*(1), 5-14.

Harrison, A. (1996). Primary care of lesbian and gay patients: educating ourselves and our students. *Family Medicine, 28*(1), 10-23.

Hash, K. M., & Netting, F. E. (2009). It takes a community: Older lesbians meeting social and care needs. *Journal of Gay & Lesbian Social Services, 21*(4), 326-342.

Hendry, M., Pasterfield, D., Lewis, R., Carter, B., Hodgson, D., & Wilkinson, C. (2013). Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying. *Palliative Medicine, 27*(1), 13-26.

Herzog, D. (2011). *Sexuality in Europe: a twentieth-century history* Cambridge: Cambridge University Press.

Heyes, C. (2002). Identity politics. *Signs, 28*(4), 1093 - 1120.

Jivani, A. (1997). *It's not unusual: A history of lesbian and gay Britain in the twentieth century*. Indiana: Indiana University Press.

Jones, R. (2010). Troubles with bisexuality in health and social care. In R. Jones & R. Wards (Eds.), *LGBT Issues: Looking beyond categories. Policy and practice in health and social care.* Edinburgh: Dunedin Academic Press.

Jones, T. C., & Nystrom, N. M. (2002). Looking back… looking forward: Addressing the lives of lesbians 55 and older. *Journal of Women & Aging, 14*(3-4), 59-76.

Justice, A. (2010). HIV and aging: time for a new paradigm. *Current HIV/AIDS Reports, 7*(2), 69-76.

Kehoe, M. (1986). Lesbians over 65: A triply invisible minority. *Journal of Homosexuality, 12*(3-4), 139-152.

Kimmel, D. (1978). Adult development and aging: A gay perspective. *Journal of Social Issues, 34*(3), 113-130.

King, A. (2014). Knowledge Exchange Action Research: Creating Impact with Social Science Research. London: SAGE Publications, Ltd.

King, A., & Cronin, A. (2010). Queer methods and queer practices: Re-examining the identities of older lesbian, gay and bisexual adults. In K. Browne & C. J. Nash (Eds.), *Queer methods and methodologies: Intersecting queer theories and social science research*. Farnham: Ashgate

Livingston, J. (Produce/Director) (1990). *Paris Is Burning* [Motion Picture] United States fo America: Off White Productions.

Lothstein, L. (1979). The aging gender dysphoria (transsexual) patient. *Archives of sexual behavior, 8*(5), 431-444.

Lyons, A., Pitts, M., Grierson, J., Thorpe, R., & Power, J. (2010). Ageing with HIV: health and psychosocial well-being of older gay men. *AIDS care, 22*(10), 1236-1244.

MacCulloch, M., & Feldman, M. P. (1967). Aversion therapy in management of 43 homosexuals. *British Medical Journal, 2*(5552), 594-597

Macdonald, B., & Rich, C. (1983). *Look me in the eye: Old women, aging and ageism*. Tallahassee: Spinsters Ink.

Marshall, J., Cooper, M., & Rudnick, A. (2015). Gender dysphoria and dementia: A case report. *Journal of Gay & Lesbian Mental Health, 19*(1), 112-117.

Martin, J., & Volberding, P. (2010). HIV and premature aging: A field still in its infancy. *Annals of Internal Medicine, 153*(7), 477-479.

McFadden, S. H., Frankowski, S., Flick, H., & Witten, T. M. (2013). *Resilience and Multiple Stigmatized Identities: Lessons from Transgender Persons' Reflections on Aging*. In J. Sinnot (Ed.), Positive Psychology: Advances in Understanding Adult Motivation (pp. 247-267). New York: Springer.

Meads, C., & Moore, D. (2013). Breast cancer in lesbians and bisexual women: systematic review of incidence, prevalence and risk studies. *BMC public health, 13*(1), 1127 - 1138.

Minton, H. L. (1996). Community empowerment and the medicalization of homosexuality: constructing sexual identities in the 1930s. *Journal of the History of Sexuality, 6*, 435-458.

Nagington, M. (2015). The utility of queer theory in reconceptualising ageing in HIV-positive gay men. *Aporia, 7*(4), 6 - 17.

Namaste, K. (1996). "Tragic misreadings": Queer theory's Erasure of Transgender Subjectivity In B. Beemyn & M. Eliason (Eds.), *Queer Studies: A Lesbian, Gay, Bisexual, and Transgender Anthology* New York: New York University.

Newshan, G., & Sherman, D. W. (1999). Palliative care: pain and symptom management in persons with HIV/AIDS. *The Nursing clinics of North America, 34*(1), 131-145.

Office of National Statistics. (2011). Census 2011. London: HMSO.

Owen, G., & Catalan, J. (2012). 'We never expected this to happen': narratives of ageing with HIV among gay men living in London, UK. *Culture, health & sexuality, 14*(1), 59-72.

Persson, A. (2013). Non/infectious corporealities: tensions in the biomedical era of 'HIV normalisation'. Sociology of Health & Illness, 35(7), 1065-1079.

Preston, N. J., Fayers, P., Walters, S. J., Pilling, M., Grande, G. E., Short, V., . . . Higginson, I. J. (2013). Recommendations for managing missing data, attrition and response shift in palliative and end-of-life care research: part of the MORECare research method guidance on statistical issues. *Palliative Medicine, 27*(10), 899-907.

Richard, C. A., & Brown, A. H. (2006). Configurations of informal social support among older lesbians. *Journal of Women & Aging, 18*(4), 49-65.

Richardson, D. (1998). Sexuality and citizenship. *Sociology*, 32(1), 83-100.

Robinson, P. (2008) *The Changing World of Gay Men* Basingstoke: Palgrave Macmillan

Rosario, M., Schrimshaw, E. W., Hunter, J., & Braun, L. (2006). Sexual identity development among lesbian, gay, and bisexual youths: Consistency and change over time. *Journal of Sex Research, 43*(1), 46-58.

Rosenfeld, D., Bartlam, B., & Smith, R. D. (2012). Out of the Closet and Into the Trenches: Gay Male Baby Boomers, Aging, and HIV/AIDS. *The Gerontologist*. doi: 10.1093/geront/gnr138

Sattari, M. (2015). Breast cancer in male-to-female transgender patients: A case for caution. *Clinical breast cancer, 15*(1), e67-e69.

Schulman S. (Producer) & Hubbard J. (Producer/Director). (2014) *United in Anger* [Motion Picture]. United States of America: United in Anger, Inc.

Seidman, S. (2003). *The social construction of sexuality*: Norton New York.

Semlyen, J., King, M., Varney, J., & Hagger-Johnson, G. (2016). Sexual orientation and symptoms of common mental disorder or low wellbeing: combined meta-analysis of 12 UK population health surveys. *BMC psychiatry.* doi: 10.1186/s12888-016-0767-z

Simonsen, R. K., Giraldi, A., Kristensen, E., & Hald, G. M. (2015). Long-term follow-up of individuals undergoing sex reassignment surgery: Psychiatric morbidity and mortality. *Nordic Journal of Psychiatry*, doi: 10.3109/08039488.2015.1081405

Simpson, P. (2015) *Middle-Aged Gay Men, Ageing and Ageism: Over the Rainbow?* Basingstoke: Palgrave Macmillan

Steck, N., Egger, M., Maessen, M., Reisch, T., & Zwahlen, M. (2013). Euthanasia and assisted suicide in selected European countries and US states: systematic literature review. *Medical Care, 51*(10), 938-944.

Stein, G. L., Beckerman, N. L., & Sherman, P. A. (2010). Lesbian and gay elders and long-term care: Identifying the unique psychosocial perspectives and challenges. *Journal of Gerontological Social Work, 53*(5), 421-435.

Stryker, S. (2008). *Transgender history* Berkeley: Seal Press.

Summerskill, C. (2012). *Gateway to Heaven: 50 years of Lesbian and Gay oral history*. London: Tollington.

Terrence Higgins Trust. (2016). Health Wealth and Happiness.   Retrieved 16/05/16 from http://www.tht.org.uk/myhiv/Staying-healthy/Health-Wealth-and-Happiness

Terry, J. (1990). Lesbians under the Medical Gaze: Scientists Search for Remarkable Differences. *The Journal of Sex Research, 27*, 317-339.

Traies, J., & Munt, S. (2014). Life histories and health narratives of older British lesbians. In L. Zeeman, K. Aranda & A. Grant (Eds.), *Queering health: Critical challenges to normative health and healthcare* Ross-On-Wye: PCCS Books.

Waite, H. (2015). Old lesbians: Gendered histories and persistent challenges. *Australasian Journal on Ageing, 34*, 8-13. doi: 10.1111/ajag.12272

Walkowitz, J. R. (1982). *Prostitution and Victorian society: Women, class, and the state* Cambridge: Cambridge University Press.

Wiegman, R. (2012). Object lessons: Duke University Press.

Westwood, S. (2014). Dementia, women and sexuality: How the intersection of ageing, gender and sexuality magnify dementia concerns among lesbian and bisexual women. *Dementia*, doi: 10.1177/1471301214564446.

Witten, T. M. (2004). Life Course Analysis—The Courage to Search for Something More. *Journal of Human Behavior in the Social Environment, 8*(2-3), 189-224

Witten, T. M. (2014). End of life, chronic illness, and trans-identities. *Journal of Social Work in End-of-Life & Palliative Care, 10*(1), 34-58.

Zaritsky, E., & Dibble, S. L. (2010). Risk factors for reproductive and breast cancers among older lesbians. *Journal of Women's Health, 19*(1), 125-131.

Box 1: Very high priority / very high consensus

32. How do we include unheard voices?

38. Embed research findings into policy

39. Embed research findings into health and social care practice

Box 2: High priority / high consensus

15. What works to reduce social isolation of older HIV positive gay men?

16. What preferences do older HIV positive gay men have for end of life care?

43. How can we best communicate our recommendations?

49. Getting questions added to existing longitudinal studies about gender and sexuality

51. UK focussed research

58. Creating links between older LGBT community and academics

22. What are the long-term effects of hormone use?

54. Action research involving service users

Box 3: Moderate priority / good consensus

3 How does stigma influence the use of antiretroviral treatments (HIV

medications) to prevent transmission in older gay men?

26 Longitudinal studies to explore if and how sexual identity changes over time

52 Collaboration: Internationally focussed research,

Box 4: Low consensus

25. Creating links between researchers, gender clinics, teaching hospitals, and statutory organisations

31. Developing strategies to include trans* women in research projects examining lesbian and bisexual women

1. What works for tackling HIV stigma for older gay men?,

17. Is assisted dying of more relevance to older HIV positive gay men?

18. Establishing trans* related questions on longitudinal health studies

30. Exploring the meaning of lesbian and bisexual identities for older women

33. Critical examination of the categories Lesbian, Gay, Bisexual and Trans

44. Increase research into older bisexual people

53. Examining cultural and national differences

Box 5: Other items outside of classification structure

2. What works to change the perceptions of HIV to a manageable chronic condition?	24. How can we best secure funding for studies into trans* related health and social care?
4. How can it be best communicated to older gay men that HIV positive people on treatment are at a lower risk of transmitting HIV?	27. Longitudinal studies exploring breast cancer risk for lesbian and bisexual women
5. What is the impact of non-HIV related dementia on older HIV positive gay men?	28. Developing recruitment strategies to faciliate broad and representative samples
6. Is the experience of dementia different for older HIV positive gay men	29. Exploring the experience of home care for older lesbian and bisexual women
7. What are the long term effects of ageing with HIV?	34. Ensuring a broad sample in terms of race/ethnicity
8. What medical interventions help reduce the effects of ageing with HIV for older gay men?	35. Ensuring a broad sample in terms of disability
	36. Ensuring a broad sample in terms of class
9. What non-medical interventions help reduce the effects of ageing with HIV for older gay men?	37. How can we demonstrate impact of LGBT ageing research?
10. What do older HIV positive gay men want in later life with regards to long term health and social care?	40. How do we measure changes in attitudes and services?
	41. Narrative/case studies to engage learning and advice
11. What are older HIV positive gay men's preferences with regards to housing and long term care facilities?	42. How can we ensure our research has user-friendly outlets
	45. Increase research into older Trans*

12. How can local and national policies be developed to improve the support given to older HIV positive gay men?	people
	46. Increase research into older gay men
13. How best can we support carers of HIV positive older gay men?	47. Increase research into older lesbians
	48. Researching the strategies that people already have for managing their illnesses
14. Are peer support networks helpful for carers?	
	50. Locally focussed research (cities/regions)
19. Exploring how dementia impacts on older trans* people's identity	
	55. Equip practitioners (nurses, social workers, professionals) to do research
20. How does cancer screening work for older trans* people?	
	56. Equip service users/patients /carers to do research
21. What effects do hormones and other medications have on bone density, falls and subsequent fractures?	
	57. Recruit co-researchers (patients, practitioners etc)
22. What are the long-term effects of hormone use?	
	58. Peer support groups – to carry out research hand implement policies
23. How can services be shaped for older trans* people in line with the equality and diversity agenda?	
	60. Use of literature review as a research method

Graph 1: LGBT ageing: future research priorities, IQR, +=median

Table 1: Survey demographics

Age		Sexuality		Gender Same as Assigned at Birth		Ethnicity	
Max	76	Gay	115	Yes	204	White	234
Min	14	Lesbian	31	No	55	*Black/African/Carribian/Black British*	3
Average	49	Asexual	8			Asian/British Asian	4
		Bisexual	22			Mixed/Multiple	6
		Unsure	4			Chinese	2
		Panromantic	1			Latin American	4
		Pansexual	5			Blank	5
		Queer	16				
		Straight/Heterosexual	51				
		Blank	5				

Gender		Background		Country	
Male	109	Academic	36	UK	240
Female	140	Patient/Service user	140	Australia	2
Gender Queer	4	Activist/Campaigner	2	Canada	1
Intersex	2	Health and social care professional	36	Germany	1
FtM Transexual	2	Blank	2	Ireland	1
Femme gender queer; sometimes agender	1	Other/mixture	42	USA	6
				Blank	7

Figure 1: Classification of recommendations

Rating	Median	IQR	Code
Very high priority / Very high consensus	=7	≤1	⬛
High priority / high consensus	=6	≤2	⬛
Moderate priority / good consensus	=5	≤2.5	⬛
Low consensus		>2.5	⬜