Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations


ABSTRACT

Background Healthcare organisations have legal and ethical duties to reduce inequalities in access to healthcare services and related outcomes. However, lesbian, gay, bisexual and/or transgender (LGBT+) people continue to experience and anticipate discrimination in health and social care. Skilled communication is vital for quality person-centred care, but there is inconsistent provision of evidence-based clinician education on health needs and experiences of LGBT+ people to support this. This study aimed to identify key stakeholders’ experiences, preferences and best practices for communication regarding sexual orientation, gender identity and gender history in order to reduce inequalities in health care.

Methods Semi-structured qualitative interviews with LGBT+ patients with serious illness, significant others and clinicians, recruited via UK-wide LGBT+ groups, two hospitals and one hospice in England. We analysed the interview data using reflexive thematic analysis.

Results 74 stakeholders participated: 34 LGBT+ patients with serious illness, 13 significant others and 27 multiprofessional clinicians. Participants described key communication strategies to promote inclusive practice across three domains: (1) ‘Creating positive first impressions and building rapport’ were central to relationship building and enacted through routine use of inclusive language, avoiding potentially negative non-verbal signals and echoing terminology used by patients and caregivers; (2) ‘Enhancing care by actively exploring and explaining the relevance of sexual orientation and gender identity’, participants described the benefits of clinicians initiating these discussions, pursuing topics guided by the patient’s response or expressed preferences for disclosure. Active involvement of significant others was encouraged to demonstrate recognition of the relationship; these individual level actions are underpinned by a foundation of (3) ‘visible and consistent LGBT+ inclusiveness in care systems’. Although participants expressed hesitation talking about LGBT+ identities with individuals from some sociocultural and religious backgrounds, there was widespread support for institutions to adopt a standardised, LGBT+ inclusive, visibly supportive approach.

Conclusions Person-centred care can be enhanced by incorporating discussions about sexual orientation and gender identity into routine clinical practice. Inclusive language and sensitive exploration of relationships and identities are core activities. Institutions need to support clinicians through provision of adequate training, resources, inclusive monitoring systems, policies and
WHAT THIS STUDY ADDS
⇒ Clinicians want to provide LGBT+ inclusive care but report a lack of adequate training, inconsistent support at organisational level and anxiety around how to talk about sexual orientation and gender identity. This can be exacerbated when caring for seriously ill LGBT+ people. When seriously ill LGBT+ people feel unable to share experiences and opinions about identity, the impact can be devastating.6 26 27
⇒ LGBT+ people facing serious illness find it easier to be open when assumptions are avoided, non-verbal signals attended to, direct questions about identity are made relevant to care and organisations demonstrate LGBT+ inclusivity.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY
⇒ Our 10 evidence-based recommendations can support clinicians and healthcare organisations to deliver LGBT+ inclusive care in routine practice and may help to achieve national policy and monitoring standards. Full guide here: www.kcl.ac.uk/nmpc/assets/research/projects/abc-lgbt-inclusive-communication.pdf

INTRODUCTION
Data from 27 countries revealed that 8% of adults have a minority sexual orientation, and 1% identify as trans or non-binary.1 Despite legal advances to protect LGBT+ people from healthcare discrimination in many countries,2 experience and anticipation of discrimination within healthcare continue to be concerns, which can delay seeking health services.3–11 The acronym LGBT+ refers to lesbian, gay, bisexual and/or transgender people, and anyone who considers themselves to have a minority sexual orientation, gender identity or gender history (the relationship between gender identity and sex assigned at birth).

Experience of discrimination among LGBT+ people is linked to higher incidence of serious illness (eg, cancer, cardiovascular disease and respiratory disease),12 poorer health outcomes,13–16 more risky health behaviours (eg, alcohol and tobacco consumption) and difficulties accessing healthcare.15 17–25 When seriously ill LGBT+ people feel unable to share important aspects of identity, the impact can be devastating.6 26 27

Competent communication is vital for LGBT+ inclusive care,28–30 building trusting relationships, informed decision making and person-centred care.31 The WHO identifies person-centred care as one of its seven domains of quality, focusing on the individual so that care ‘responds to individual preferences, needs and values’ including social circumstances and lifestyle.32 33 Poor communication and assumptions made by clinicians about patients’ gender and sexual orientation undermine clinical relationships, leading to disenagement and loss of trust. Specifically, heteronormativity (the assumption that being heterosexual is the ‘normal’ sexual orientation) and cisnormativity (the assumption that having a gender identity that aligns with sex assigned at birth is the ‘normal’ gender identity) are pervasive and damaging.34 35

To improve LGBT+ inclusive communication and care, it is vital to understand challenges, preferences and potential benefits for all key stakeholders—patients, significant others and clinicians.3 6 36 Although clinicians are often overlooked in LGBT+ health research,36–38 their participation is essential to understand how prior clinical experiences shape communication behaviours and inform feasible and acceptable communication strategies. This study aimed to investigate experiences and preferences regarding communication about sexual orientation, gender identity and gender history in the context of serious illness (where involvement of significant others and person-centred communication and decision making are vital) and to identify best practice to inform evidence-based recommendations for clinicians and educators relevant to all clinical scenarios.

METHODS
Design
This national, qualitative interview study sampled three populations in England to optimise the feasibility and acceptability of recommendations: (1) LGBT+ people with serious illness (patients), (2) their informal caregivers (significant others) and (3) clinicians. The study is reported in accordance with the COREQ (COnsolidated criteria for REporting Qualitative research) checklist.39

Procedure
Team
Our team comprised: clinicians (medical consultant, social worker); five experienced qualitative researchers; a sociolinguist; a psychological scientist; a sociologist; three experts in healthcare intervention and improvement; and six researchers experienced in LGBT+ health research.

Patient and public involvement
Three LGBT+ patient and public involvement (PPI) team members were integral to the study. PC, ED and RR attended ethics committee meetings and steering group meetings, supported recruitment, contributed to analysis and recommendation development, wrote lay summaries and presented findings at dissemination events.
Inclusion criteria
LGBT+ patients with serious illness: ≥18 years old, self-identified as LGBT+, living with serious illness (a condition that carries a high risk of mortality, negatively impacts quality of life and daily function and/or is burdensome in symptoms, treatments or caregiver stress).  

Significant others: ≥18 years old, ‘unpaid, informal providers of one or more physical, social, practical and emotional tasks. In terms of their relationship to the patient, they may be a friend, partner, ex-partner, sibling, parent, child or other blood or non-blood relative’.  

Clinicians: doctors, nurses and social workers employed by the National Health Service (NHS) with experience caring for patients with serious illness.

Exclusion criteria
Patients and significant others were excluded if they lacked cognitive capacity to give informed consent or were too frail/unwell or distressed to participate.

Sampling and recruitment
Patients and significant others were recruited nationally through LGBT+ organisation mailing lists, newsletters and social media platforms and through clinical teams (hepatology, HIV, palliative care, pulmonology and renal) at two hospitals and one hospice in England. Those who self-referred were appraised against the inclusion and exclusion criteria by the researcher and discussed with the clinical site lead as required. Purposive sampling criteria were applied to patients: diagnosis, age, ethnicity, gender modality and sexual orientation. Significant others could participate without the patient entering the study. We sampled professions (doctors, nurses, social workers) anticipated to be consistently involved across serious illnesses. Recruitment, data collection and analysis were conducted iteratively to inform subsequent sampling. We continued to conduct interviews until we reached pragmatic saturation, as relevant to the study aims and objectives.

Data collection and analysis
Semistructured interviews were conducted using a topic guide informed by systematic reviews, empirical work and revised with steering group and PPI members. DB conducted the interviews to the study aims and objectives. Sampling and recruitment informed future interviews. Interviews were audio recorded, transcribed verbatim, pseudonymised and uploaded to NVivo V.12 for analysis.

Reflexive thematic analysis was conducted through data familiarisation and immersion, coding, developing initial themes, then reviewing developing and defining/naming themes. Initial coding was inductive and subsequent coding informed by theories of person-centred and holistic care. DB read and coded all transcripts. RH read five early transcripts and KB and RH met with DB to discuss coding and theme generation to inform ongoing analysis. The draft and final coding frame were reviewed by all authors for interpretation.

This work is positioned within a critical realist paradigm, where our interpretations of reality are shaped by our standpoint. Our research and PPI team includes individuals who identify as lesbian, gay, bisexual, queer, heterosexual, non-binary, women, men, trans and cisgender. Our previous work with LGBT+ people demonstrates exclusion and discrimination in care settings and has informed work of regulators of healthcare services and government inquiries to support improvements in care for LGBT+ people.

RESULTS
Sample characteristics
Seventy-four participants were interviewed (November 2018–November 2019): n=34 patients, n=13 significant others, n=27 clinicians (see table 1). All interviews with patients and significant others were conducted face to face (median duration 113 min, range 55–233 min) and one to one (except one patient and significant other who participated as a dyad). In two interviews, a significant other was present in the room but did not participate. Eighteen clinicians were recruited from hospitals and nine from hospices (median duration 104 min, range 50–190 min). Eight clinician interviews were conducted remotely. After receiving study information, 24 people chose not to participate: too unwell (four patients), uninterested (four patients), lack of time (two patients, three clinicians) and reason unknown (eight patients, three clinicians).

Findings
Overview
Three main themes were generated: (1) creating positive first impressions and building rapport; (2) enhancing care by actively exploring and explaining the relevance of sexual orientation...
Original research

Table 1 Sample characteristics

<table>
<thead>
<tr>
<th></th>
<th>LGBT+ patients n=34</th>
<th>Significant others n=13</th>
<th>Clinicians n=27</th>
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<tr>
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<tr>
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<td>Sexual orientation (self-described)</td>
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<tr>
<td>Doctor</td>
<td></td>
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</table>

Note that sometimes percentages do not total to 100 due to rounding to the nearest whole number

and gender identity; and (3) visible and consistent LGBT+ inclusiveness in care systems. Exemplary quotes are presented for each theme, with additional quotes from across the populations sampled in online supplemental 2.

Theme 1: creating positive first impressions and building rapport

Some routinely used terminology and practices can feel excluding to LGBT+ people. Using appropriate terminology was important for all stakeholder groups. For clinicians, this was underpinned by fear of offending. Although positive experiences were described, many service users shared negative experiences, often linked to incorrect assumptions, which caused distress and unnecessary emotional labour.

They’ve quite often asked if [my partner’s] my husband or just assume, err ‘Oh your husband let me in’ and I said ‘Oh I haven’t actually got a husband’ (laughter) and they said ‘Oh the man.’ I say ‘No that’s not a man, that’s a lady.’ Yeah, so I’ve had to explain that situation quite a few times. (Patient, lesbian female, cisgender, in her 50s)
Incorrect assumptions about LGBT+ identities negatively impact relationships with clinicians and force LGBT+ people to decide whether to correct the clinician or allow the assumption to stand. Either choice can provoke anxiety and undermine trust.

If I’d said, ‘And, is your partner working? Is he working?’ to a woman, […] I mean I’m very conscious not to, […] that would be one of those hiccups because the patient might just choose to answer, ‘No they’re not,’ and avoid giving gender but would take that mental note of [pause] you know, ‘She’s assumed I’m heterosexual’ you know and whatever emotion that stirs up for them. The ‘Do I— [pause] Is it safe to disclose or not?’ You know that, that constant ‘Do I have to come out? Do I want to come out?’ (Nurse, in her 50s)

In response to these challenges, participants across the stakeholder groups described simple ways to achieve inclusive communication.

Using neutral language
All three populations advocated avoiding heteronormative and cisnormative assumptions. An effective approach was to use neutral language until relationships and identities are established. For example, using neutral references to gender (eg, ‘they’) avoids assumptions about sexual orientation or gender identity.

... a lot of the time the hospital sends letters to the GP and it’ll be like ‘I met this lovely young lady’ and that just really annoys me […] that’s not who I am, and I feel like it springs up this image in people’s minds that isn’t me. So that kind of makes me uncomfortable. Those certain phrases whereas if they were just gender neutral I’d be a lot better with it. (Patient, queer non-binary person, assigned female at birth, in their 20s)

Listening and echoing terminology
Within a consultation, a clinician should use the words that patients and significant others have chosen to describe themselves and their relationships.

[Using the language that the patient uses, so not changing say pansexual into bisexual or, you know not making assumptions […] and if you’re gonna note it down, note it as that, if you’re gonna carry on a conversation then carry it on like that. (Patient, pansexual male, transgender, in his 20s)

Not paying attention to language can be distressing, as it implies the clinician either is not listening, or objects in some way.

[My partner] gets frustrated when people, when she says ‘partner’ and they say ‘boyfriend’ or ‘husband’ or— And I’m like ‘No it’s my girlfriend.’ Or sister, or— I’m everyone but ‘girlfriend’ when I’m there. (Significant other, lesbian female, cisgender, in her 30s)

Considering non-verbal signals
Awareness of non-verbal signals is vital to LGBT+ inclusiveness. Shifts in body positioning or facial expressions after a disclosure can be interpreted as discomfort or negativity.

[When I say, ‘lesbian,’ […] I’ll look for a little micro-expression behind the eyes, a twitch or—, to see how sensitive they are to it. […] I can almost read, okay, you’ve taken that on the chin, I respect that. […] you didn’t make me feel bad. (Patient, gender non-conforming lesbian, assigned female at birth, in her 60s)

Tone, pitch and volume of speech also warrant attention, as they can be suggestive of clinicians’ views surrounding a topic.

[I]t’s not necessarily what they say, but just their tone, […] they react as if they’ve heard it all before. It’s when they ask as if it’s nothing as well […] which makes me feel more relaxed about answering it honestly. (Patient, gay male, cisgender, in his 20s)

Theme 2: enhancing care by actively exploring and explaining the relevance of sexual orientation and gender identity
Participants gave divergent views on discussing LGBT+ identities. Sensitive exploration of preferences for disclosure is an important first step.

[If] someone’s in a relationship that they haven’t traditionally been able to be open about, then that may affect how they can communicate with healthcare, or had bad experiences with healthcare professionals in the past, or had assumptions or more old-fashioned societal rules. (Doctor, in her 40s)

While discussions about LGBT+ identities were viewed as appropriate for holistic, person-centred care, some participants saw these as sensitive topics, and clinicians sometimes avoided initiating discussions.

[You do ask sometimes like ‘How would you describe your sexual orientation?’ There are times maybe where I miss it out because I’m not sure how to ask. […] I know this is maybe not great, but where you kind of think someone might not be straight, you’re more likely to ask. But that’s not good practice. (Doctor, in his 30s)

Some clinicians considered broaching these topics a potential threat to relationships and rapport, particularly with limited time to build relationships.

[You do in hospice care but you don’t always outside of that, get that time to build a relationship where people will trust you. So, it can be very hidden and that means that people may not always get appropriate support because they haven’t talked to you about that. (Social worker, in her 50s)
While apprehension may cause avoidance of discussion, incorrect assumptions and absence of early candid discussions create subsequent difficulties for all stakeholder groups.

"The longer you leave it the harder it is to ask and the harder it is to tell definitely." (Significant other, gay female, cisgender, in her 40s)

**Communicating relevance of LGBT+ matters as part of high-quality, person-centred care**

There was widespread agreement that explaining the relevance of questions about LGBT+ identities can increase acceptability.

"It should come from the healthcare professionals because in a way that would inform their treatment of the person [...] but also it would inform any decisions that they might make on behalf of their patient [...] I think a lot of people probably in a similar way to me, probably wouldn’t necessarily know if it was safe to bring it up themselves, or whether they’re just gonna get dismissed or scoffed at." (Patient, queer non-binary person, assigned female at birth, in their 20s)

When asking patients questions about LGBT+ identities, providing a rationale for the questions, an opportunity not to respond if preferred and asking permission to record information enables informed disclosures.

"I would always make it clear why I’m asking [...] ‘If I’m going to look after you this is something I might need to know, to help me look after you’ [...] I don’t want anyone to think that sometimes we’re prying and asking things we don’t need to know about or I might you know give the person the option of actually not answering the questions." (Doctor, in his 50s)

**Respecting gender**

Use of incorrect pronouns is distressing for the individual and impacts on relationships with clinicians.

"It is better to ask me ‘What pronouns do you use?’ rather than call a woman a man, or address a woman with masculine pronouns [...] any sort of doubt at all, don’t be afraid to ask which pronouns you’re using." (Patient, bisexual female, transgender, in her 50s)

Being referred to as ‘trans’ immediately discloses a person’s gender history. As such, clinicians need to understand how to frame questions about gender history where relevant to the care they provide.

"People sort of ask ‘When did you transition?’ [...] it’s a common way to talk about it but it is essentially meaningless. Because, my transition started long before any form of medical intervention happened and its gonna carry on for the rest of my life [...] Do you need to know when I started on hormones? Do you need to know about any surgeries that I’ve had? Like these are the things that I think you are trying to ask but actually you need to ask them specifically, because they are scattered over a number of years." (Patient, queer non-binary woman, transgender, in their 30s)

Additional sensitivity and attention are required in discussions about anatomy in the context of treatment.

"If that person has said to you ‘No I identify, as female’ [...] and they’re talking about their genitals then there is nothing wrong with saying, you know ‘her penis’. (Patient, pansexual male, transgender, in his 20s)

**Including significant others and sexual orientation appropriately**

Participants across the samples noted the importance of identifying significant others.

"If I haven’t met them but I’ve met the patient [...] I’ll say ‘Who’s most important to you? Can I contact them to offer support?’ and most people are grateful for you to do that." (Social worker, in her 40s)

Understanding the depth and nature of a relationship helps clinicians to appropriately include significant others in decision-making and care.

"There are a lot of people who aren’t able to or don’t feel comfortable being open about their relationships [...] and that may affect their symptom management or their experience of end-of-life care or the ability of their loved one to be there and supportive to them." (Doctor, in her 40s)

Both language and behaviours are important in involving significant others appropriately.

"My partner’s like [pause] like the kitchen team on the ward would [...] try and get into conversation, ask how they are. Really include them, and so would, like the nurses and everyone [...] talking, directly to them. I’ve never really had that even with sort of family members, even if they sit with me in consultation, I’ll just be focused on. So, I’ve never had issues with partners or anything, ever." (Patient, lesbian female, cisgender, in her 20s)

**LGBT+ patients who commence new relationships during their care may also feel anxious about involving new partners if clinicians are unaware of their sexual orientation.**

"I don’t have a long-term partner. And when I was dating, and I was trying to take people with me, there always was that thing of like, this is something that I’m going to have to add to my appointment. You know, that extra level of stress. Yeah. Because we’ve never had that real, like, declarative conversation - 'This is me' - coming out to the whole department." (Patient, gender-fluid gay person, assigned male at birth, in their 30s)

Some participants felt it beneficial to explicitly include sexual orientation in care-related discussions at the outset.

"Sexual orientation, I feel like, yeah, they should know this about me. [...] If it’s recorded at that stage, at the beginning [...] and then they’ve got it on record,"
then it can be acknowledged because then you know you’ve given that information. (Patient, gay male, cisgender, in his 20s)

Considering the environment and who else is present

Many participants described the artificial nature of drawing curtains around patients in a ward and the potential threat to confidentiality and personal safety.

I think environment is really key, isn’t it? So, like, clinic room; you’re on your own. Curtains on a ward; not soundproof. [...] I might be very cool about it, and try and be very cool about it, but you don’t necessarily want to out someone to a ward of strangers that they are staying with. [pause] I think that puts them in a very vulnerable position [pause] really. Um, for any, kind of, orientation. And then, I think particularly for trans individuals. That’s a huge problem [pause] really. (Doctor, in his 40s)

Stakeholders also raised the importance of who is with a patient and recognising that patients may not have shared their sexual orientation or gender history with friends or family members present.

I wouldn’t say it outside of the hospital. I wouldn’t say it to my workmates, I wouldn’t say it to my family although I—, some of them may know already [...] but they’ve never approached me directly. [...] I would speak about it with health professionals yeah but not outside. (Patient, gay male, cisgender, in his 60s)

Theme 3: visible and consistent LGBT+ inclusiveness in care systems

Participants valued visible, clear and consistent LGBT+ inclusiveness within health systems and resources, while clinicians noted the lack of specific training within curricula.

[O]ne section of a one hour lecture at medical school in the genito-urinary medicine block probably where certain elements of sexual practice were touched upon. No. No more than that. [...] I haven’t sought out courses in that field, so I have no other formal training. (Doctor, in his 40s)

Standardising the approach to LGBT+ related discussions

Routine inclusion of sexual orientation and gender identity in care processes may provide a structure to support clinicians.

I think when you aren’t meeting lots of LGBT+ people then, it’s not normalised to ask it, and then it becomes scary and it becomes awkward, and quite a lot of that is you as a health professional, and actually, normalising it within the NHS processes as questions that everybody is going to ask takes away the fear of offending anybody. (Doctor, in her 40s)

The use of routinely applied questions may reassure service users that they are not being selected for, or omitted from, such discussions.

I think pronouns are quite often used as a, a sort of Trojan horse to ask someone about their gender history [...] ‘Ooh I think this person might be transgender [...] we’ll ask pronouns,’ and it is very noticeable when you walk into a room and nobody asks anybody’s pronouns and then they go up to the trans person and they want to be all woke and pretend they’re a good ally; ‘What are your pronouns?’ ‘My pronouns are this’ and it’s like, cool, I can see what you’re doing there but also you were just saying like, ‘Hi trans person’. (Patient, queer non-binary woman, transgender, in their 30s)

Assumptions regarding social, cultural and religious background were identified as barriers to LGBT+ inclusive practice. Clinicians and service users described hesitation when considering discussion of sexual orientation and gender identity with people from some demographic groups, including older people, people with religious beliefs and people from black, Asian and ethnic minority backgrounds.

I know that culturally, you know sort of black and ethnic minority people, it’s very difficult for them to be gay, and it can be very, very taboo. [...] we have a lot of African patients, and I would find that quite a difficult question. [...] I would do it and I would ask because [...] if they’ve got someone who appeared to be a same sex partner I’d want to know. [...] you can’t kind of just let that influence your practice and not do it, and be like ‘Oh okay, my belief is that African people find it very difficult to talk about being gay’, and actually they might not. They might be a person who’s really fine with it. (Nurse, in his 40s)

Establishing inclusive processes

For participants who were comfortable sharing such information, standardised recording was considered useful for avoiding repetition, assumptions and mistakes.

So it should be ‘Are you gay? Are you straight?’ ‘Yes’ that’s it. Just get it out in the open [...] you don’t want to have to go through the thing every time so just get it on the record. (Patient, homosexual male, cisgender, in his 60s)

Transgender participants described systems’ inability to accurately capture gender identity (titles, names and pronouns) without amending sex on their medical record.

I said ‘Can you please call me under the name Karen (surname)?’ ‘Okay fine’ and they put a note on the notes [...] and the receptionist comes to call me ‘birth name’ [...] I totally ignored her and they called three times and I ignored them every time and then after about 10 or 15 seconds, [...] I stood up, I walked over to her and said ‘I did ask’. (Patient, straight female, transgender, in her 60s)
However, service users and clinicians recognised that changing recorded sex may impact on the individual’s ability to receive appropriate healthcare resulting in a conflict between use of affirming communication and access to appropriate healthcare.

[T]he NHS has a huge, a blind spot in regards to those because those calls for scanning and screening are based on your gender in your documents. So, if you change your gender identity to female because you’re a trans woman, you won’t get called for prostate screening. (Doctor, in his 40s)

Several participants described concerns regarding information sharing within clinical teams, and the need to explain who can see that information.

[H]e was a gay man in a same-sex relationship and he didn’t want that disclosed. [...] He talked to me about that but he didn’t want anyone in the team to know because he’s worried about how they might view him and he was very worried about receiving services. (Social worker, in her 50s)

Markers of inclusiveness
Markers of inclusivity (eg, LGBT+ inclusive images, indicators of relevant training delivered, inclusive policies, lanyards or badges in relevant colours) were reassuring to patients, signifying that clinicians welcome discussion of these aspects of identity.

[M]aybe just having a little bit of visibility around hospital for patients. [...] you have all the pictures up of all the staff who’ve done really well, like, advertising the hospital. Like, one of them could have a rainbow lanyard on. I don’t know if they do. I haven’t actually seen. Like, just something small like that. You know. “Cause it only takes something small for people to think ‘Cool, that’s me [pause] That’s me there.’ And like, when I come next month, I know that there’s people here who are gonna understand me, on a level that I need you know, when you’re in care. (Patient, gay genderqueer person, assigned female at birth, in their 20s)

Recommendations for LGBT+ inclusiveness in clinical communication
The recommendations based on the data are presented in Box 1 in line with the three main themes from study findings.

DISCUSSION
Principal findings
Our data demonstrate that inclusive discussions about identities and relationships, in an appropriate environment with explanation of relevance to care, may assist clinicians to deliver appropriate person-centred care. Formal training, inclusive assessment and monitoring systems, appropriate policies and visible demonstrations of inclusivity are central to this. While social, cultural and religious background can influence willingness to initiate and engage in discussions about

Creating positive first impressions and building rapport
1. Use neutral language, such as neutral pronouns or neutral terms for significant others. Neutral pronouns such as they/them, and neutral terms like ‘partner’ or ‘person’.
2. Use the words your patients use to describe themselves and significant others. If your patient refers to a significant other as ‘they/them’ or as a ‘partner’ or ‘friend’ use the same words.
3. Consider the messages your non-verbal signals might send. When discussing sexual orientation and gender identity, be mindful of the impact of potential non-verbal signals of discomfort. For example, your facial expression or volume/tone of voice may be suggestive of surprise/disapproval, or physical expressions such as shifts in posture/eye contact may be suggestive of discomfort.

Enhancing care by actively exploring and explaining the relevance of sexual orientation and gender identity
4. Create a safe space by making your questions about sexual orientation and gender relevant to care. Explicitly state why you are asking these questions, and give an option not to answer, so that patients can make an informed choice. This will vary depending on clinical specialty, for example, you may be asking to ensure they are receiving required screening invitations, or because you want to ensure patients’ significant others are being included appropriately.
5. Respect gender. Routinely introduce questions about gender identity and pronouns into your practice so you provide opportunity for patients to share and ensure you refer to them correctly. You could try saying ‘I want to make sure we are using your names and pronouns correctly. My name is XXXX and my pronouns are YYYY, What about you?’ Only ask about gender history in private, using specific, justified questions.

6. Incorporate significant others and sexual orientation appropriately. Ask about significant others inclusively, with neutral language. You might say ‘So I can look after you the best I can, can you tell me who’s important to you?’. If asking about partners or spouse, avoid gendered terms (such as wife or boyfriend). Instead, you could ask ‘Do you have a partner?’.

7. Consider your surroundings and who else is there. Ensuring that patient preferences are known before discussing sexual orientation and gender identity where other people, including significant others, might overhear is vital.

Visible and consistent LGBT+ inclusiveness in care systems

Continued
sexual orientation and gender identity, avoidance of these discussions may risk compounding existing intersectional inequalities. Our 10 evidence-based recommendations offer a clear approach to realise the intention.

Strengths and limitations of the study
This is the largest published qualitative study to specifically explore the experiences and preferences for communication about sexual orientation, gender identity and gender history in healthcare. It is the first to incorporate perspectives of clinicians, LGBT+ patients with diverse identities and illnesses and their significant others. By targeting serious illness, we aimed to explore communication preferences for person-centred care (a central tenet of all quality healthcare) and when involving significant others. Our recommendations are intended to foster trust between service users and clinicians at every interaction, thus facilitating care that accounts for preferences, needs and values at times of heightened need and also during usual care provision.

Although the eight transgender and/or non-binary patients and three bisexual/pansexual service users provided diverse depth of insight, we acknowledge that our sample cannot fully describe the breadth of trans/non-binary and bisexual/pansexual experience. Also, despite efforts to recruit participants across England and the UK, the majority of service users (38/47) and clinicians (21/27) were based in Greater London, which has a comparatively large LGBT+ population. We anticipate different experiences in less urban areas. We recruited 7/47 service users having black, Asian or ethnic minority backgrounds, which is a good participation rate in LGBT+ health research. Our findings are drawn from patients in England, and although this is an ethnically diverse country, recommendations should be appraised for relevance by clinicians working in different settings.

Other related studies
Previous studies have described important tenets of inclusive clinical communication, many of which are confirmed by our study. Our study contributes to the evidence by identifying specific, practical routes to equity. Our findings and recommendations move beyond broad constructs into actions (what clinicians should say and do) to enable proactive inclusiveness.

Our study also extends prior findings to incorporate the perspectives of a broad age range of adult patients and their significant others living with varied serious illnesses and clinicians across multiple specialities. This increases the transferability and acceptability of our findings and recommendations beyond prior literature, which focused on specific illnesses or older people.

Implications
Inclusive, person-centred healthcare requires appropriate communication between service users and clinicians and organisational structures to support those interactions. Despite clinicians’ willingness to learn about LGBT+ inclusive care and evidence that doing so can improve knowledge and confidence, clinicians’ need for LGBT+ training persists.

We provide evidence-based recommendations for LGBT+ inclusive care in the context of serious illness through simple communication strategies. Assessment and discussion in line with our recommendations will relieve pressure on patients and their significant others to determine whether sharing their LGBT+ identities is relevant. It will also reassure them that doing so will be met with understanding, care and respect. The full LGBT+ inclusive communication guide can be accessed here: www.kcl.ac.uk/nmpc/assets/research/projects/abc-lgbt-inclusive-communication.pdf

Our study recommendations may help to achieve national policy and monitoring standards (eg, NHS Sexual Orientation Monitoring Standard). While person-centred care was central to our participants and the recommendations we have made, delivering such care provides opportunities for improved monitoring data to inform broader understandings of health needs, outcomes and inequalities.

Future research directions
Our findings contribute to the evidence on person-centred care, offering practical and structural ways to integrate discussion of sexual orientation, gender identity and gender history into inclusive care. Evaluation
of strategies to implement our recommendations are essential to understand effectiveness and broader challenges. Further research should focus on inclusive communication preferences of people who are bisexual and pansexual, transgender and non-binary, black, Asian and ethnic minorities, and those who live outside of urban centres.

Our evidence-based recommendations provide clear approaches for clinicians and organisations to reduce health inequality through proactive LGBT+ inclusive practice and systems.

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**Correction notice** This article has been updated since it was first published online. The IQ Joint study group has been added to the author list. In addition to this, blinded data in the methods section has been updated with the correct information.

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**Data availability statement** No data are available. To preserve the confidentiality of the interviewees, the transcribed interviews are not available for sharing.

**Supplemental material** This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

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Original research

51 ACCESSCare. Written submission from the Cicely Saunders Institute of palliative care, policy and rehabilitation on health and social care and LGBT communities (HSC0012). women and Equalities Committee, 2018.
Supplemental 1: ACCESSCare C Topic Guide – LGBT+ People (Patients)

Introductory Statement
Thank you for agreeing to participate in a research interview. I am one of a group of researchers from King’s College London, and we are working on a research project which is looking to improve the way that sexual orientation, gender identity and gender history are discussed, addressed and documented in healthcare settings. As I will be asking you about sexual orientation, gender identity and gender history, as well as relationships with significant others, there may be some questions that you find sensitive. If there are any questions you would rather not answer then we can move on, or if you want to stop the interview at any time, just let me know. You may take a break and continue again or stop altogether. Everything you say in this interview will be confidential. If we use quotes for our research, we will make sure that you cannot be identified from the quote, by replacing names, places and any other identifiable information. Do you have any questions before we start?

Demographic information
- Age
- Gender / Trans Status / Gender History
  - “How do you describe your gender?”
  - “Sometimes, the sex you’re assigned at birth, meaning on your original birth certificate, can be relevant in healthcare. Would you mind telling me what sex you were assigned at birth?”
  - “What are your pronouns?”
- Sexual Orientation
- Ethnicity (cultural ID)
- Relationship status (and duration)
- Living arrangement
- (If relevant: Gender of partner(s) / Trans status / Gender history)

Illness History
- Diagnosis/diagnoses
- Time since diagnosis: when did you first become unwell?
- Can you tell me where you’ve received care for your illness?
  - (Prompt: Primary: GP/pharmacy/dentist/optician; Secondary: Hospital/Community, planned or emergency; Tertiary: highly specialised, referred from Secondary)
- What are your main needs and problems?
  - (Prompt: physical, psychological, social spiritual)
- How have those changed over time?

- Are you living with any other serious illnesses or conditions? (PROMPT: explore as above)

- In what ways do you think your experience of your illness might be different because of your gender history?
- How about your experience of care, how might that have been different?
  - How did it make you feel?
  - Do you think that experience impacted on your feelings about healthcare afterwards?

- How about your sexual orientation, how has that impacted on your experience of illness and care?
  - How did it make you feel?
  - Do you think that experience impacted on your feelings about healthcare afterwards?
Preferred Approaches to Discussing Gender identity/gender history and Relationships

- When you are with your health care providers, so the doctors, nurses, and other members of the health care team, do any of them know your gender identity/gender history? What about the sex you were assigned at birth?
  - YES....how? OR NO....why?
- Is this how you prefer it to be?
- How do you feel about being asked directly about your gender identity/gender history?
- Should you be asked directly by the health care providers, or should it come from you first?
- Would you ever volunteer information about your gender identity/gender history without being asked?
  - When? Why? With whom?
  - How do you decide who to tell/not? Why?
  - What do you tell them?
- Have there been times when you have felt it was important to share your gender identity/gender history?
  - How do you decide when it’s relevant?
- What kinds of things make it easier/less easy to let health care providers know your gender identity/gender history? (Prompt: communicative, environmental, societal, institutional)
- When taking your personal history or talking to you during appointments, do health care providers ever refer to your gender identity/gender history?
  - How do they do it? Well? Badly?
- Do you feel they respect and understand your gender identity/gender history? How do they demonstrate this?
- Do healthcare providers always use your correct pronouns?
- How do they react when they get your pronouns wrong?
- Are there phrases or words that the health care providers have used that made you feel more able to talk about your gender identity/gender history?
- How about in terms of the way they talk to you – their manner, body language?
- Do you find the health care providers use the same words to describe gender identity/gender history as you?
- Can you tell me about when it hasn’t been handled well?
- Are there phrases or words used by the health care providers that made you feel uncomfortable about sharing your gender identity/gender history?
- Have there been times when their manner or body language have stopped you sharing your gender identity/gender history? How?
- How would you like your gender identity/gender history to be acknowledged and referred to by the health care providers?

Preferences and Concerns about Recording and Sharing Gender identity/gender history

- How do you feel about your gender identity/gender history being recorded in your health care records? How about the sex you were assigned at birth specifically? Or your pronouns?
- What do you see as the benefits of this information being documented?
  - Why?
- Would you have any concerns about this information being documented in health care records?
  - Why?
- How would you want that information to be shared with other healthcare professionals?
  - Why?
Preferred Approaches to Discussing Sexual Orientation and Relationships

- When you are with your health care providers, so the doctors, nurses, and other members of the health care team, do any of them know your sexual orientation? What about the gender or sex of your partner(s)?
  - YES....how? OR NO....why?
- Is this how you prefer it to be?
- How do you feel about being asked directly about these?
- Should you be asked directly by the health care providers, or should it come from you first?
- Would you ever volunteer information about your sexual orientation without being asked?
  - When? Why? With whom?
  - How do you decide who to tell/not? Why?
  - What do you tell them?
- Have there been times when you’ve felt it was important to share your sexual orientation?
  - How do you decide when it’s relevant?
- What kinds of things make it easier/less easy to let health care providers know your sexual orientation? (PROMPT: communicative, environmental, societal, institutional)
- When taking your personal history or talking to you during appointments, do health care providers ever refer to your sexual orientation?
  - How do they do it? Well? Badly?
- Do you feel they respect and understand your sexual orientation? How do they demonstrate this?

Are there phrases or words that the health care providers have used that made you feel more able to talk about your sexual orientation?

- How about in terms of the way they talk to you – their manner, body language?
- Do you find the health care providers use the same words to describe sexual orientation as you?
- Can you tell me about when it hasn’t been handled well?

Are there phrases or words used by the health care providers that made you feel uncomfortable about sharing your sexual orientation?

- Have there been times when their manner or body language have stopped you sharing your sexual orientation? How?
- How would you like your sexual orientation to be acknowledged and referred to by the health care providers?

Preferences and Concerns about Recording and Sharing Sexual Orientation and Relationships

- How do you feel about your sexual orientation being recorded in your health care records? How about the gender or sex of your partner(s)?
- What do you see as the benefits of this information being documented?
  - Why?
- Would you have any concerns about this information being documented in health care records?
  - Why?
- How would you want that information to be shared with other healthcare professionals?
  - Why?

Involvement of Partner/family/chosen family

- Do you ever take anyone with you to appointments?
  - Who do you take? How do you introduce them? Do healthcare professionals ask?
- Do you want them present?
- Have you felt they would be welcome?
• Why? Why not?
• Can you tell me how they are acknowledged by health care providers?
• Have they talked about what the experience was like for them?
• Would you like it to be any different? How?
• How involved is your partner in decisions about your care?
• How involved is your family in these decisions?
• Who is listed as your Next of Kin? Is your partner listed? (if applicable)
  o When did you make that decision? Why was that important to you? Why not?

Training Recommendations
From our previous work, many health care professionals would like more guidance on discussing gender identity/gender history and relationship. From your experience, how could healthcare professionals improve the way they discuss or raise the subject of gender identity/gender history?
• How could healthcare professionals improve the way they discuss or raise the subject of sexual orientation?
• What recommendations would you make to healthcare professionals caring for LGBT people facing serious illness?
• How would you recommend they ask about gender identity/gender history?
  o What words would you suggest?
• How would you recommend they ask about pronouns?
  o What words would you suggest?
  o How should they react when they get pronouns wrong?

• How would you recommend they ask about sexual orientation?
  o What words would you suggest?
• How would you recommend they ask about significant others and important relationships?
  o What words would you suggest?

• When would you recommend these discussions be carried out?

• Are there any particularly good experiences you can recall that we could share as examples of good practice?
• How about more negative experiences, is there anything we should encourage professionals to avoid?

• Is there anything else you would recommend?
• Is there anything else you would like to add?
• Is there anything you would like to ask me about the study?

Thank participant for their time
### Supplemental 2: Additional quotes from stakeholders

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Supporting quote</th>
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<tbody>
<tr>
<td><strong>Theme 1: Creating positive first impressions and building rapport</strong></td>
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<tr>
<td>Creating first impressions and building rapport</td>
<td>“I always have that feeling where I can’t decide how much I want to say […] when I was having this radiation test, the nurse kind of went through these questions and sort of asked when I had my last period and I just said that I don’t have periods and she kind of looked a bit confused, and was like, ‘Is that because of your contraception?’ And this is the point where it depends, if it is a thing that’s in passing that I can’t be bothered to deal with, like I will often say to someone ‘Oh it’s because I don’t have a womb.’” (Patient, queer non-binary woman, transgender, in their 30s)</td>
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<td>Using neutral language</td>
<td>“we have to have people—, get people experienced in approaching the word ‘partner.’ So, if somebody says, if you came to me as a patient and you said, ‘My partner,’ I would always say, ‘And what do they do?’ until it’s declared.” (Doctor, in his 40s)</td>
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<td>Listening and echoing terminology</td>
<td>“always referring to [my partner] as ‘she’ all the time, even though I’m just like ‘they.’ And they don’t get it. Because they don’t ask. But they keep doing it, and then it’s really hard for me” (Patient, gay genderqueer person, assigned female at birth, in their 20s, with a non-binary partner)</td>
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<td>Considering non-verbal signals</td>
<td>“It’s like a physical repulsion, they physically back away from you […] And maybe it’s subconscious, I’m sure people don’t intend to do it. But you know, you know it’s the thing that I’m gay but I don’t fancy every woman. […] Like I’ve had people washing me when I was in intensive care and they’re like—. I mean I can’t physically move, but you won’t wash me properly because you’re scared I’m gonna get turned on, and I’ve had that said to me and you just think— it’s just ridiculous, but again you just have to deal with it […] Because what can I do, in that situation.” (Patient, gay female, cisgender, in her 20s)</td>
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<td><strong>Theme 2: Enhancing care by actively exploring and explaining the relevance of sexual orientation and gender identity</strong></td>
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<td>Views on actively exploring and explaining the relevance of sexual orientation and gender identity</td>
<td>“Well as far as I’m concerned, issues of sexuality are completely irrelevant to the treatment you’re receiving, so it’s neither here nor there. If it comes up and they know that you’re…that’s your social environment as it were, then that’s fine, but really it should make no difference at all.” (Patient, gay male, cisgender, in his 50s)</td>
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<td>“when I was younger, I had to hide it quite a lot and it would really embarrass people […] not even that long ago, even when I go to GPs the amount of embarrassment that I’ve somehow managed to cause just by saying that I’m gay is, is quite surprising. So I would tend, unless I feel that I need to, I’ll probably just not answer or not go into it […] it might be me, my interpretation of things because of how it used to be rather than how it is now. I hope that’s true, but yeah. See I’m getting embarrassed talking about it now which is crazy.” (Significant other, bisexual female, cisgender, in her 50s)</td>
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<td>“what I would prefer is that people knew, […] it’s just another, another facet of this person that makes up the whole person. It’s not the be all and end all but it’s a bloody big part” (Patient, gay male, cisgender, in his 50s)</td>
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<td>“I would find that, a bit you know ‘Ooh what does that have to do with me, you know with my illness?’ I don’t think that would be the first question— If that was the first question that came out of their mouth and I would say, I’d be taken aback you know ‘Why you need to know that?’” (Patient, gay male, cisgender, in his 60s)</td>
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<td>“I think I kind of only feel comfortable bringing it up with someone if I do feel comfortable around them, and I have a consultant at the hospital but to be honest I rarely ever see him because he’s so busy and whenever I’ve got an appointment with him, normally it ends up being with somebody else and he doesn’t actually come to the appointment” (Patient, queer non-binary person, assigned female at birth, in their 20s)</td>
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<td>“we’re doing lots of work on sort of equal opportunities where you just treat everyone the same. Well you don’t, you treat everyone according to their needs don’t you. And you can’t acknowledge that people might have different needs if you don’t acknowledge difference can you. […] being blind to all these things doesn’t actually make it better does it, sweeping things under the carpet just means they are not addressed.” (Social worker, in her 40s)</td>
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|                                                                          | “you’re kind of locked into this longstanding lie because you’ve either not brought it up or you’ve just gone along with someone’s supposition that you have a different partner. It’s harder then to break because you might not only have to come out, also disprove their concepts about you. But also, defend that
and it’s—, yeah, it’s just so much harder to be like, ‘Actually, for the last year you thought this about me, but now I need to tell you that all that’s untrue and this is actually the way I live my life.’ And that can also become a barrier because, it goes on for so long.” (Patient, gender-fluid gay person, assigned male at birth, in their 30s)

Communicating relevance of LGBT+ matters as part of quality, person-centred care

| It’s not just me that reads their notes and it may be that although I’ve got the relationship with them that I may well know […] that other people don’t know and, it’s not fair to [pause] out them to everyone, if they don’t want them to know. […] if I had to write in notes for any reason about it, I would always ask them.” | (Nurse, in his 20s) |
| “I think the health professional has to point out that ‘It’s a safe space and everything that is discussed, is confidential and whilst I’d like to put it in the notes because it would be helpful, if you don’t want it putting it in the notes, I’ll keep it up here [in my head].’” | (Patient, gay male, cisgender, in his 70s) |
| “It should be somebody’s choice that it’s recorded. […] I think it’s a good idea, for me, and everybody else probably wouldn’t feel the same way, or they’d feel labelled, targeted, or get paranoid about it.” | (Significant other, gay male, cisgender, in his 50s) |

Including significant others and sexual orientation appropriately

| “So, if somebody says, ‘Are you married?’ ‘No. What is it to you? You know, why do you need to know? What does this have to do with my continuing healthcare? Why do you ask?’ So, I should be able to say, ‘Why do you ask?’ without it being a big deal. ‘Oh, we need to know because— you know. It’s all I want. I think that’s fair really. So, now, ‘Sure go ahead.’ But why? […] I need the safety. ‘What are you going to do with that information? How’s it going to affect me? And, you know, my future.’” | (Patient, gender non-conforming lesbian, assigned female at birth, in her 60s) |

Considering the environment and who else is present

| “I mean I started having counselling myself around that time because I’d be… I was supporting her. […] I talk to her every morning on the way to work on the bus, I call her from the bus, that’s when we have our chat, so that was like supporting her emotionally.” | (Significant other, female with fluid sexual orientation, cisgender, in her 40s) |
| “If they were a bisexual man and they were with a man I would put them as a gay man, if they were a man and they came with a woman I would call them a heterosexual man. Terrible isn’t it? I never even think about bisexual, and that is probably an issue. Well it is isn’t it? Bisexual invisibility, people get very [pause] frustrated about [ … ] I don’t think a bisexual person would ever come up in conversation, it would just be, b | | [in my head].” |
| “I’d always want to ask permission to talk in front of that person as well. And if they are your neighbour or someone you know from work it may not be a good thing to do. So I always sort of routinely ask, you know ‘I want to have an in-depth conversation. Is it alright if I do that with both of you or would you prefer me to come back another time?’ I think those things are quite important” | (Social worker, in her 40s) |
| “A lot of trans people don’t like— You know yes they are transgender from a medical point of view but as far as they’re concerned that’s not a part of their identity, like they’re not trans. And I mean for me I’m, apart from in a medical setting, with you know people who knew me before hand, people like my colleagues and my friends don’t know that I’m trans” | (Patient, pansexual male, transgender, in his 20s) |

Theme 3: Visible and consistent LGBT+ inclusiveness in care systems

<p>| I mean sometimes we’ve supported people in gay relationships but they’ve maybe not said if it’s been a little while ago, and we think they were in a same sex relationship but they spoke about the person as friend so we, we had to kind of go with that, that was the friend. I think there might be maybe something around generational, yeah, I’m not sure […] I mean, err the lady was older, and I think, I might be absolutely wrong here but I wondered if it was, you know she’d never come out as gay.” | (Social worker, in her 50s) |
| “I think that I’d probably be apprehensive if I knew there was quite a lot of religious vibe on the ward or something. D’you know what I mean. Or even just really religious staff because you don’t really know-, ‘cause obviously for a lot of people, you know, religion is like a huge, huge, you know |</p>
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<th>Establishing inclusive processes</th>
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<td>“I think there are a lot of problems that come about because my records say that I’m female which means that I’m not, later on in life, I’m not gonna come up for prostate cancer screenings, just like trans men like suddenly don’t come up for cervical cancer screening. And, actually like that is because medical records are full of assumptions which is just like I changed the gender marker from M to F and since that happened, it then gets immediately assumed that I have a womb, ovaries, cervix and don’t have a prostate and testicles and that is a problem.” (Patient, queer non-binary woman, transgender, in their 30s)</td>
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<td>“I know that (the hospital) have got the brilliant rainbow badges they— which are really really cool and I must confess I would very much like one but none the less it— So I think you know that type of thing is incredibly important because it just means you, you know for patients who may or may not have felt comfortable before, to turn around say ‘Well hold on a minute here. You know these people are wearing a rainbow badge’ or you know ‘This clinician’s wearing a rainbow badge. She’s clearly, not necessarily that she gets what I’m on about, but she’s clearly aware that this is something that can be talked about here’ so actually it just makes me more approachable” (Nurse, in her 40s)</td>
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