

Participant Information Sheet
Experiences of older LGB people using community based social care services, groups and activities



Who is undertaking the study?



My name is Liz Wands-Murray and I am a PhD student undertaking research at the University of York funded through the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). Approval to undertake the research has been provided by the University of York Social Policy & Social Work Ethics Committee.

What is the purpose of the study?

The purpose of the study is to understand the experiences of older (50+) lesbian, gay and bisexual (LGB) people who are accessing community based social care services, groups and activities. I will use this data to consider how these are, or can be more inclusive. This research is being undertaken as part of my PhD.

It is important to understand what factors influence these experiences and whether there are things that can be done by services/groups to be more inclusive for older LGB people. The research will include interviews with individual people who use or work in these types of services & groups. It will also include a focus group after the interviews to talk about the findings and how some positive changes might be made to the delivery of these services or groups in the future.

Why have I been invited to take part?

You have been invited to take part as you may be a person who is over the age of 50, who may identify as lesbian, gay or bisexual, and you may have formally assessed or self-identified social care needs (this might be loneliness/isolation, lack of community links or social support networks or other social care needs such as requiring support with day to day living).

What does taking part involve?

Taking part involves having a one to one interview with me. This will most likely be a single interview but could be two if you feel this is needed. If you agree to take part, I will ask you about:

- the type of services/group/activities you have accessed,
- how you found out about these opportunities,
- what you hoped for and why you attended these services or groups, what your experiences of accessing these opportunities was like including any positive or negative experiences
- and what impact (if any) you felt your sexual identity has had on these experiences.

We will also talk about the things you would consider in deciding whether to access a new service/group or continue accessing a service or group you already use.

If you agree, the interviews will be recorded and transcribed (typed up) and will usually take between 1 – 1.5 hours. The interviews will take place at a time that suits you and in an environment you choose, taking into consideration any COVID-19 restrictions that might be in place at the time. This could be your own home, at the University, in a neutral place such as a meeting room at a community centre, online using a tool such as Zoom or over the telephone. If you have any physical or sensory impairments that need to be considered to enable you to participate, these will be discussed with you before the interview. Any relevant COVID-19 restrictions and safety measures will be adhered to.

Do I have to take part?

Participation is voluntary and you can withdraw from the research at any time before the research is written up and concluded, without needing to provide a reason, and without detriment to any service you may be in receipt of. You will need to give consent before participating and will need to have the capacity to give this consent.

What are the benefits and risks of participating?

Benefits

The main benefits of taking part in the research are indirect and include adding to the body of knowledge about older LGB people accessing community based social care services and groups. It is possible that the results will improve the inclusivity of services and opportunities in the future.

Risks

The main risk in taking part is the emotional distress or discomfort that may arise from talking about your experiences. You will not be obliged to discuss anything personal or distressing if you do not wish to. The interview will be a safe space to talk about your experiences.

You will have the ability to end the interview or take a break at any time. I will provide you with details of helplines or organisations you can access for support if you feel distress as a result of talking about previous negative experiences.

You will also be able to indicate if you would like any part of the interview to be excluded from being analysed at the end of the interview and for two weeks after the interview has taken place. You will also be able to withdraw any part or all of your data from the research up to the 30th September 2021.

Will I be identified in any research outputs?

No. Although I will know your identity, I will ensure that you are not identified in anything that arises from the research. I may use direct quotes from your interview in any write up of the research but I will use a pseudonym (fake name) so you will not be identified.

The only reason I would reveal your identity to anyone would be if I learned that you, or someone else, may be at risk of coming to harm. Where possible, I would discuss this with you first.

How will you keep my data secure, for how long and will it be shared?

Please see the 'data information sheet' for details of how your data will be stored, managed, and shared.

How do I find out more information or make a complaint?

If you would like more information please email liz.wands-murray@york.ac.uk or call 07980971622. In the first instance any complaints should be directed to me. If you are not satisfied, you may discuss this with my supervisor, Professor Yvonne Birks (yvonne.birks@york.ac.uk). You may also approach the University of York Departmental Ethics Committee for Social Policy and Social Work at spsw-ethics@york.ac.uk.

Data Information Sheet

Experiences of older LGB people using community based social care services, groups and activities.

The purpose of this information sheet is to explain how your data will be used and protected, in line with GDPR (General Data Protection Regulations).

On what basis will you process my data?

Under the GDPR, the University must identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data.

In line with our charter which states that we advance learning and knowledge by teaching and research, the University processes for personal data for research purposes under Article 6 (1) (e) of the GDPR are:

Processing is necessary for the performance of a task carried out in the public interest

Special category data is processed under Article 9 (2) (j):

Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes

Research will only be undertaken where ethical approval has been obtained, where there is a clear public interest and where appropriate safeguards have been put in place to protect data. In line with ethical expectations and to comply with common law duty of confidentiality, we will seek your consent to participate where appropriate. This consent will not, however, be our legal basis for processing your data under the GDPR.

How will you use my data?

Data will be processed for the purposes outlined in this notice and in the main information sheet. All face to face or telephone interviews will be audio-recorded (with consent). The device used for audio-recording will be password protected; the audio file will be transferred to the secure University of York encrypted file server at the earliest opportunity and then deleted from the recording device. All online interviews will be recorded using the Zoom recording tool which will then be automatically uploaded to the University encrypted files server. You will be required to provide informed consent for participation. This will include your signature. These consent forms will be kept in a locked cabinet (if paper forms) or on an area of the University files server (if digital) that only the researcher has access to. The anonymised findings will be analysed, and a thesis will be submitted to the University. A research paper may also be produced and submitted to a journal with the aim of publication. A summary of the findings will also be shared with those who took part in the study and any services, networks or groups which have an interest in the findings.

How will you keep my data secure?

The University will put in place appropriate technical and organisational measures to protect your personal data and/or special category data. For the purposes of this project we will ensure that all audio files and interview transcripts are password protected and saved onto the secure University of York files server.

Information will be treated confidentiality and shared on a need-to-know basis only. The University is committed to the principle of data protection by design and default and will collect the minimum amount of data necessary for the project.

Will you share my data with 3rd parties?

Data will only be accessible to the lead researcher and academic staff involved in the assessment of my PhD, on a need-to-know basis. If I use a transcriber (a person who types up the notes) they will have a copy of the recording shared with them for transcribing and will then delete any recordings. If any risk of harm is identified during the interview there may be a need to share data with other relevant parties. This would usually be done with your consent. We will request that other researchers have access to the anonymised transcripts for future research, but you will have the opportunity to opt out of this at the consent stage.

If your participation is in person and the pandemic continues, there is a minimal chance that I would have to share your data for COVID-19 track and trace systems. However, this is highly unlikely and would be extremely limited data.

Will I be identified in any research outputs?

You will not be identified in any research output. Consent will be required for us to use direct quotes in publications, but these will be untraceable back to participants. Participants are not obliged to consent to this.

How long will you keep my data?

Data will be retained in line with legal requirements or where there is a business need. Retention timeframes will be determined in line with the University's Records Retention Schedule.

Anonymised transcripts will be kept for ten years from the end of the study; consent forms will be kept for three years from the end of the study; audio recordings will be deleted at the end of the study.

What rights do I have in relation to my data?

Under the GDPR, you have a general right of access to your data, a right to rectification, erasure, restriction, objection or portability. You also have a right to withdrawal. Please note, not all rights apply where data is processed purely for research purposes. For further information see, <https://www.york.ac.uk/records-management/general-dataprotection-regulation/individuals-rights/>.

For this particular study, you have the right to withdraw your data from being analysed for up to two weeks after your interview has taken place. You also have the right to withdraw all your data from the study completely at any time without giving a reason up until 30th September 2021.

Questions

If you have any questions about this participant information sheet or concerns about how your data is being processed, please contact liz.wands-murray@york.ac.uk. If you are still dissatisfied, please contact the University's Acting Data Protection Officer at dataprotection@york.ac.uk.

If you are unhappy with the way in which the University has handled your personal data, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.