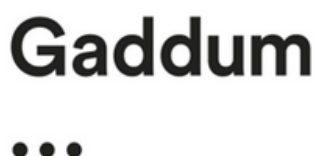




Patient and Public Involvement Toolkit

Involving LGBTQ+ Unpaid Carers



Contents

1. Introduction

1.1 What is Patient and Public Involvement?

1.2 Why involve LGBTQ+ carers?

1.3 How and why LGBTQ+ carers want to get involved

1.4 Barriers to LGBTQ+ carers being involved

2. Recruitment

2.1 Materials

2.2 Promotion

3. Training

3.1 For peer researchers

3.2 For research teams

3.3 Training considerations

4. Support

4.1 Emotional

4.2 Practical

4.3 Technical

4.4 Financial

4.5 Other

5. Activity

5.1 Flexible methods of involvement

5.2 Activity guidance

6. Further resources

6.1 Tips for researchers from LGBTQ+ carers

6.2 Tips for peer researchers from LGBTQ+ carers

6.3 Support

Glossary

LGBTQ+

LGBTQ+ is an acronym used as an umbrella term covering a variety of sexual and gender identities. It stands for lesbian, gay, bisexual, trans/transgender, and queer or questioning. Queer is a reclaimed term within the community and is considered an umbrella term for those who do not identify with any specific label. It is worth noting that not all people feel comfortable with the term queer given its historical use. Questioning describes someone who is questioning their sexual and/or gender identity. The '+' refers to a range of sexual or gender identities that are not covered by the letters.

For explanations on each of the terms Stonewall has a useful [glossary of definitions](#).

Unpaid carer

[NHS England](#) defines a carer as 'anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support'.

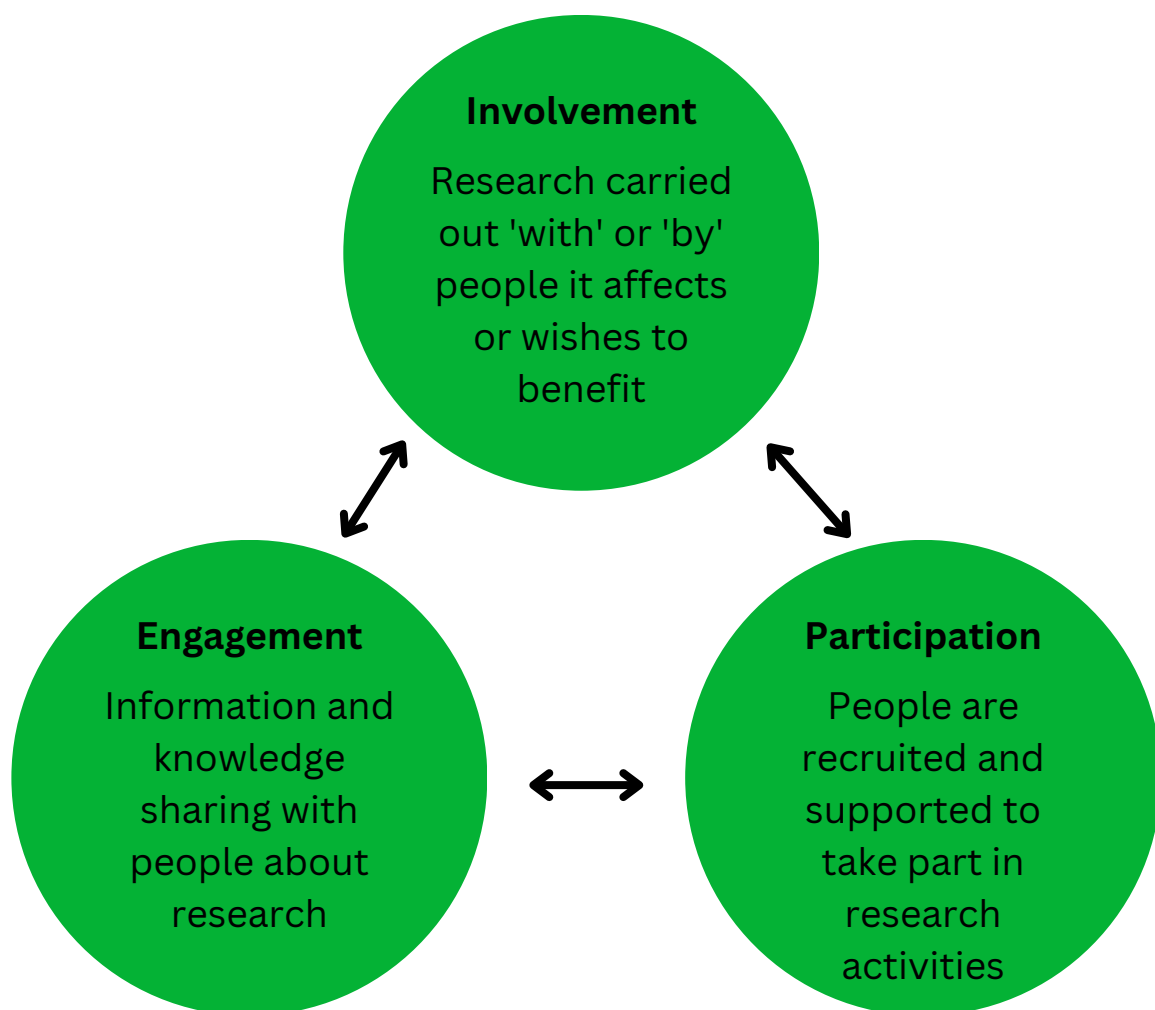
Often people do not see themselves as a carer. They see themselves as a partner looking after their partner, as a child caring for a parent, or a friend supporting their friend. People will often see caring as something they do for someone in their life that they care about, as a part of their relationship with that person as opposed to a separate responsibility. The terms 'unpaid', 'informal', 'unwaged', or 'family' carer are all used.

Introduction

1.1 What is Patient and Public Involvement?

INVOLVE define patient and public involvement (PPI) in research as research that is carried out **'with'** or **'by'** the groups it affects or wishes to benefit rather than **'to'**, **'about'** or **'for'** them. PPI can take place throughout all stages of the research cycle.

The diagram below highlights the difference between patient and public involvement, engagement and participant in research.



1.2 Why involve LGBTQ+ carers?

Gap in research

LGBTQ+ unpaid carers are an underrepresented group in research. As of August 2019, [Carers UK](#) estimates 390,000 people from the LGBTQ+ community are unpaid carers, but research on LGBTQ+ carers remains scarce and there are no clear figures on the number of unpaid carers within the LGBTQ+ community.

Specific needs

There are specific challenges that are unique to being an LGBTQ+ unpaid carer and specific support needs. This can include discrimination, invisibility, assumptions made by services, a lack of understanding around LGBTQ+ communities as well as caring in unsafe environments, to name a few. LGBTQ+ carers involvement in research can help address these needs.

1.3 How and why LGBTQ+ carers would like to be involved

How

The identify and design phase of the research cycle to ensure the right questions are being asked. This was the area carers felt they could bring their immediate expertise from their lived experience.

Consider the skills, knowledge and experience LGBTQ+ carers will bring outside of their lived experience of their caring role. Their professional backgrounds and previous involvement in research or PPI will impact interest in areas of possible involvement.

Why

Participants may feel more comfortable to discuss and disclose their experience or concerns to someone who they view as sharing identities in gender or sexual diversity and other identities as well as in their caring role, experience and understanding.

It provides the opportunity for LGBTQ+ carers to be involved in change for their community.

There can be a lot of trauma in what some LGBTQ+ people go through which only other LGBTQ+ people can recognise and understand.

The research project could benefit from the understanding and insights LGBTQ+ carers can bring.

It offers LGBTQ+ carers the opportunity to be involved in and access a larger network and support.

1.4 Barriers to LGBTQ+ carers being involved

Barriers	Solutions
<p>The LGBTQ+ carers community does not currently exist as one group with only a few dedicated support services and spaces for LGBTQ+ carers across the country.</p>	<ul style="list-style-type: none"> • Work needs to be done to create a community/national network. • LGBTQ+ carers from existing groups could be involved in recruitment by sharing PPI opportunities and research projects with their own personal/professional networks to reach new people.
<p>The perception of PPI contribution as time-consuming, complicated or akin to work that is not paid.</p>	<ul style="list-style-type: none"> • Payment or reimbursement. • Making the PPI opportunity more fun and engaging. • Showing how contribution can make a difference. • Provide the opportunity to acquire new knowledge and develop new skills. • Provide the opportunity to network and build connections and alliances with others.
<p>Time commitment as often carers do not know what is going to happen from day to day and carers can also have full time jobs or other responsibilities, so it is difficult to plan a commitment.</p>	<ul style="list-style-type: none"> • Research teams should be explicit about time requirements and provide a fixed timetable of actions (i.e. do not move activities about) so carers can try to organise themselves. • Offer levelled opportunities for those with varying time to offer.

Recruitment

2.1 Materials

Information

- It is important for carers to have all information before a decision to apply can be made. This is so carers can organise themselves around their caring responsibilities and other commitments such as work.
- This includes providing a detailed role description with a timeline of expected activity. Avoid changing the timeline as this will impact the carers ability to plan and be involved.
- Stating support that is available is beneficial as it gives LGBTQ+ carers the assurance that their well-being is important and being looked after. This is with particular reference to the possibility of LGBTQ+ carers having any negative experiences triggered for those who have faced discrimination and exclusion due to their sexual and gender diverse identities.
- The PPI opportunity could be framed to highlight benefits and make it more appealing. For example, the skills and experience gained could be highlighted as attractive for carers who are looking to return to work.
- Offer one pagers in plain English or informal discussions with the research team to aid understanding of the opportunity.

Inclusion

- When seeking to recruit LGBTQ+ individuals, organisational inclusivity is important. This could be with reference to the track record of the organisation in engaging and working with LGBTQ+ affirmation or unpaid caring policies.

- Organisational inclusivity highlights to LGBTQ+ carers that an organisation is serious about supporting the community and is not just a tick box for a research project. As a result, LGBTQ+ carers might feel more valued and be more likely to get involved.
- Visibility in recruitment materials should also be a consideration as visible inclusion can make people feel comfortable to access the opportunity.
- This can include LGBTQ+ symbols or equalities statements such as ‘this workshop seeks to be inclusive of people from diverse sexual and gender identities’. When using the rainbow flag ensure use of the progressive rainbow flag.
- Recruitment materials should be diverse. For example, LGBTQ+ people of colour or people with disabilities. To achieve this a one size fits all approach will not work and different materials and campaigns might be needed to reflect different intersecting factors such as age and race.
- Demographic information can be collected to support equality of access to the opportunity. Research staff might benefit from training on how to sensitively implement this.

Terminology

- Providing real examples of being a carer may be more beneficial than providing a definition of an unpaid carer. Often unpaid carers do not realise they are carers so making clear what this entails can help with this identification in people. For example, ‘do you do the shopping for someone on a regular basis?’, ‘do you provide crucial support for someone who is becoming more dependent on you?’, etc.
- Using neutral/non-gendered language in recruitment materials shows an awareness of the LGBTQ+ landscape by the recruiting organisation. For example, using the terms 'partner'/'spouse'/'friend'/'family' instead of 'husband'/'wife'.

2.2 Promotion

- When promoting the PPI opportunity, it is important to consider the multiple identities of being an LGBTQ+ carer i.e., identifying as LGBTQ+, being a unpaid carer, and people who might have other diverse characteristics.
- Channels/organisations that specialise in these separately could be used to recruit more people. For example, LGBTQ+ carers may be registered as a carer and attend general carers groups or may be accessing support that is LGBTQ+ specific and unrelated to caring.
- Targeting places LGBTQ+ carers already access because of their caring role such as hospital waiting rooms and GP surgeries can be beneficial.
- Also consider more generalised spaces such as night venues and social spaces for the LGBTQ+ community and/or carers as well targeting existing carers groups including ones with no current LGBTQ+ inclusion.
- Partnering with reputable and trusted organisations can be important as an 'endorsement' of safety to LGBTQ+ carers.



Social Media

Social media allows for a wide reach but there is a lack of control as to where the opportunity goes and subsequently who can apply. This could attract anti-LGBTQ+ trolls or spambots, especially if there is an incentive attached.

Solution: implement a screening process such as a 10 minute informal discussion to establish experience and motivations and safeguard others involved.

Training

Whilst those involved in PPI who are sharing their lived experience do not necessarily need formal training, there are instances where training would be beneficial, and other instances it might be required when considering the needs of LGBTQ+ carers.

3.1 For peer researchers

- Peer researchers could be offered specific training where there is a technical or specific ask such as conducting interviews and collecting data, or analysing and interpreting data.
- As well as providing the needed skills, training can also provide peer researchers the confidence to contribute meaningfully and could help address the power imbalance that can sometimes exist between research teams and PPI contributors.
- General training on research design and approaches as well as any technology used would be beneficial for peer researchers understanding and ability to engage.
- Training on data control/processing can be an important consideration. There may be instances in which carers taking part as participants are not 'out' yet and peer researchers must be trained on processes in place to maintain confidentiality and data protection.

- EDI training can be beneficial. It is important not to assume that because a peer researcher is a member of the LGBTQ+ community that they will have this understanding. The spectrum of LGBTQ+ identity and experience is broad and there are lots of intersectional factors, such as race, disability, faith, socioeconomic status, and age, that can impact experience and understanding.
- Training on emotional awareness for peer researchers in contact with participants as LGBTQ+ carers may not know the signs to look out for if a participant experiences distress.

3.2 For research teams

- The research team could benefit from LGBTQ+ awareness or unconscious bias training to show they can provide a safe space for LGBTQ+ carers. A well-informed research team can help LGBTQ+ carers feel comfortable and support the quality of the research.
- Training can aim to provide a good understanding of the community, the strengths they bring and challenges they face in caring roles. E.g., an understanding of LGBTQ+ identities and terminology, and issues that affect the lives of LGBTQ+ people.



3.3 Training considerations

- Any request for peer researchers to undertake training should consider the time demands and commitment required. This is especially important as carers can be short on time or struggle to find the time around caring responsibilities, and possibly work commitments.
- It is good practice to outline any additional commitment required such as attending or completing training in the recruitment phase so carers can assess if it is feasible and plan this into their schedule. In addition, such requirements should be designed flexibly to accommodate the various caring and work patterns of the different individuals involved.
- Taking into account the barrier of time different levels of involvement could require different training. It should be clear in recruitment that not all training is needed for all roles.



Quality

The research organisation could consider applying for a recognised quality assurance benchmark in LGBTQ+ standards such as Stonewall or EDI top 100 employers.

This could help to make the project more credible to LGBTQ+ carers.

Support

In line with the UK Public Involvement Standards, it is important to provide ongoing support to PPI contributors and there are particular considerations for supporting LGBTQ+ carers.

4.1 Emotional

- Emotional support for LGBTQ+ carers as peer researchers is important. Whilst involvement in research should not be traumatic, LGBTQ+ caring experiences can be negative therefore discussion of these experiences could be triggering for peer researchers.
- This could be external to the research team or a specific role within the team with appropriate training to provide this type of support.
- LGBTQ+ carers should be made aware of this support and the level and limits to the support from the beginning.
- Check in points throughout the research, and debriefing and review when the project has ended would also be beneficial.

4.2 Practical

- There should be a designated key contact for LGBTQ+ carers with a member of the research team taking on this role.
- LGBTQ+ carers should be aware of who their key contact is for updates and support should they need it.
- This practical support should relate to operational elements of involvement and development as opposed to an emotional support role.
- Support sessions should be regular to provide peer researchers to ask questions, address issues and give/receive feedback.
- This will also provide a person centred approach to involvement.

4.3 Technical

- Technical support should be provided for LGBTQ+ carers to get involved in research and to learn new skills.
- This should be easy to access in terms of content, time required away from caring schedule and practically in terms of in person or online.
- This could take the form of video modules or short audio clips.
- To make technical elements accessible consider using the simplest and easiest method instead of a more challenging and complicated skill.

4.4 Financial

- Support such as gift vouchers for LGBTQ+ carers giving their time and experience can make the opportunity more attractive and recognise contribution.
- It can also address any potential power imbalance between a paid research team and volunteer PPI contributors.
- Alternative rewards could be considered such as 'time credits' which could be used for a session with a careers advisor for example.
- Out of pocket expenses such as for travel should be reimbursed as standard.
- Financing replacement care for the cared for person should also be factored in.
- Consider costs for supplementing phone data, broadband or the lending of equipment.
- Consider costs for resources that enable inclusion by addressing other access issues such as disability/hearing/sight impairment, language interpretations and translations.

4.5 Other

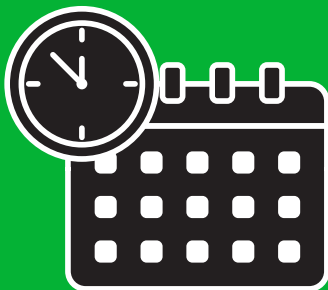
- Offer exit interviews to LGBTQ+ carers to formally end the opportunity.
- This can highlight the positives of the experience in terms of what the peer researcher has learnt and the contribution and impact they have made.
- It can also offer the research team the chance to develop and improve PPI opportunities for LGBTQ+ carers.
- Share findings and recommendations with LGBTQ+ carers from any evaluations and how these are going to be addressed.



Activity

5.1 Flexible methods of involvement

- LGBTQ+ carers may not have the capacity to be involved in a structured way but could be involved more flexibly by working on a task in their own time. This involves a person-centred approach by getting to know people and how they can contribute. This ensures the opportunity is inclusive and accessible and could remove the clinical and/or academic element of being involved in research.
- Due to intersecting identities as well as the nature of the caring responsibilities, different individuals may need or prefer different ways of getting involved. For example, while setting up and organising focus groups can be beneficial (individuals hear and learn about others' experiences and ideas can be cross fertilised), previous trauma, caring responsibilities, and the need for privacy (e.g., when the carer is not 'out' publicly), might require offering an opportunity for a one to one interview so that the above can be respected while the carer is not excluded.



Time

The barrier of time is a key consideration in involving LGBTQ+ carers in PPI activity.

Solution: a fixed schedule of activity so carers can plan to be involved when needed. Timings of these activities are also important. If it is stated that an activity will need 15 minutes of a carers time then make sure it does take 15 minutes.

- Considerations around unpaid caring that should be planned into any activity include the changeable nature of caring responsibilities. For example, this may mean running the same activity multiple times on varying days/times to account for last minute cancellations due to caring responsibilities. This could also require having a 'back up' peer researcher should this happen. Varying days/times should also be considered for working carers or parent carers who will have different schedules.
- Whether the activity is online or face to face will also affect carers involvement in their ability to be away from the cared for person. Regardless of whether activity is online or face to face and in line with accessibility and inclusion that some people may require different accommodations to access the same activity, some carers may require someone else to support the cared for whilst they are accessing the activity.
- Be explicit with LGBTQ+ carers as to whether the cared for person can be present whilst they carry out the PPI activity. If it is online activity be explicit as to whether a confidential space is needed.
- It is important to consider digital access and LGBTQ+ carers level of understanding and use of technology. Whilst technology can make an opportunity accessible for carers it would be beneficial to offer alternative or simpler mediums such as methods like phone calls and hard copies of materials and light technologies such as email. Technology might be easier and more user friendly for research teams and professionals but it is not always the case for user participation.
- Offer specific sessions as an option for LGBTQ+ carers of specific identities such as trans carers as it may help people feel more comfortable, particularly those less represented within the community.

5.2 Activity guidance

- It is important to create a safe for LGBTQ+ carers in any activity they are involved in. Ways to do this can include creating 'terms of engagement' outlining that any discrimination or bi/homo/transphobia etc. will be challenged and a course of action will be taken.
- Another way to support a safe space can be the invitation to share pronouns as standard in all activity.
- There should also be considerations for LGBTQ+ carers who are not 'out' yet. This can include a clear confidentiality policy and emphasis that they can participate without being named.
- There should also be clearly agreed contact methods. For example, not calling on a landline where anyone from their household could answer and using their personal mobile instead, and having an agreement on whether you can leave a message on their answerphone or not etc.
- It would also be beneficial to provide options for different venues to access in person activity. For example, not an LGBTQ+ centre/venue where they may be worried about being seen.

Further Resources

6.1 Tips for researchers from LGBTQ+ unpaid carers

Understand that the LGBTQ+ caring experience will be different from a heterosexual or cisnormative caring experience

Demographic collection forms to contain relevant sexual orientation, gender identity and trans status monitoring

Understand that people's identity can change so space must be allowed for this in the research

Be patient and understand circumstances change in the lives of carers

Do not do anything to break the trust between the carer and cared for person

Do not assume people's identity or relationships

Understand the different support systems and family structures within the LGBTQ+ community

Build relationships with carers and show empathy

Manage expectations over quantity of LGBTQ+ carers involved as peer researchers (and participants)

Be a vocal LGBTQ+ ally and keep yourself up to date with issues impacting LGBTQ+ carers

Specify how the research is funded so people can make informed decision on involvement based on EDI credentials of funder

Be explicit about how data is going to be managed particularly personal data to safeguard people who do not want to be 'outed'

Give peer researchers feedback on how their contribution has impacted

Understand the wider legal context around LGBTQ+ rights and legal protections

Accept the barriers people mention to you

Make allowances for people who need to come and go for caring reasons

Be committed to own learning on LGBTQ+ caring and be open to feedback

Respect people's choice to not share their identity or status as they not be fully 'out' yet

Understand the diversity of identity and language within the LGBTQ+ community

If people say they don't feel included then don't be threatened but thank them for coming forward and use the feedback to learn and change

6.2 Tips for peer researchers from LGBTQ+ unpaid carers

Do not feel you have to do everything - your first responsibility is to your loved one

Remember that PPI is not your main job and take a step back if you need to

Researchers are not mind readers so don't be afraid to ask question and speak up

Remember you can withdraw or decline at any time

Look after yourself as you take on the PPI role e.g. self care

Set your boundaries for what you feel comfortable disclosing or discussing

Find out what support is available for the PPI role

6.3 Support

Resource	Description
<u>Skills for Care LGBTQ+ Learning Framework</u>	Guidance for social care workforce to help work affirmatively, inclusively and effectively with individuals from gender and sexually diverse communities
<u>ABC of LGBT+ Inclusive Communication</u>	Guidance to support health and social care professionals to be more inclusive in communication with patients about sexual orientation, significant others, gender identity and gender history
<u>LGBTQ+ Caring Publications</u>	List of publications relevant to LGBTQ+ caring
<u>LGBTQ+/Carer Support</u>	List of organisations supporting the LGBTQ+ and/or unpaid caring community
<u>LGBT Foundation</u>	National charity based in Greater Manchester offering training and support



Acknowledgements

This toolkit was co-designed with LGBTQ+ unpaid carers who contributed to the content and design of this guidance through focus groups, interviews and feedback. We would like to give thanks to the LGBTQ+ unpaid carers who wish to remain anonymous.

The Project Co-creating a 'peer researchers toolkit' for LGBTQ+ unpaid carers received funding from the 2023 QR Policy Fund, Research England. It has been led by Dr. Efpraxia D. Zamani (Durham University Business School) and Dr. Laura Sbaffi (University of Sheffield). Prof. Trish Hafford-Letchfield (University of Strathclyde), Prof. Sharron Hinchliff (University of Sheffield), Lawrie Roberts (LGBT Foundation) and Jo Campbell (Gaddum) have also worked on this project. Keisha Tomlinson supported the project as a Research Associate.

Contact

Dr. Laura Sbaffi - l.sbaffi@sheffield.ac.uk
Project website found [here](#)

