



Consultation with Old/er Care Home Residents (by Interview) about Researching Sexuality & Intimacy.

OPuS Protocol for Reacting to Participant Distress or Reports of Abuse and Neglect (Residents)

Researchers should keep in view that this consultation is a first step. It is concerned with finding an appropriate and effective method with which to conduct research on care home residents and sexuality and is *not* an open-ended exploration of residents and sexuality. As far as possible, distress to any consultee should be prevented. However, the nature of the subject could cause residents/interviewees (or other participants) to think about issues that could lead to distress. Distress can also result from causes unconnected with the consultation. Whatever its causes, as researchers, we need to be prepared for interviewee distress in order to prevent or else minimize or alleviate its effects. This document sets out guidance that researchers should observe and could apply (according to circumstances) at various points during the consultation process.

Before interview

Consulting with care managers before a visit to conduct an interview could help identify participants who, for various reasons, feel comfortable talking on a topic related to sexuality. Above all, make sure that care managers are aware that we only have consent to interview those with uncompromised capacity to consent and this excludes those whose abilities to consent actually fluctuate. Care managers could help identify residents who can not only consent but are more likely to be comfortable talking about such issues. This would help avoid contacting anyone who might find the topic difficult to talk about for reasons connected with grief/loss or personal/community values etc.

The participant informed consent details will have already given individuals a chance to decide whether or not to take part in the consultation. These documents have asked participants to identify sources of support within (or outside) the care home that should be referred to in case of distress. **Don't forget** to take these details along to interviews with you. You must also take to any interview (as a precaution) details of generic support or counselling organizations such as the Samaritans – **08457 909090**. As the interview could broach sexual difference, make sure you take with you as part of your research pack details of local/regional LGBT helpline or support groups or services (which can be accessed by a Google search or the Principal Investigator). The Lesbian and Gay Foundation in Manchester - **0845 330 3030** - serves LGBT individuals in the Northwest but can refer on to more local services anywhere in the UK. (Yorkshire has no generic LGBT groups/advisory facilities). This

could be useful if a participant were to indicate struggle with gender and/or sexual difference.

The interview process

On meeting the interviewee

Even though a participant may have already consented to take part by telephone or letter, consent is not once-and-for-all and will need re-negotiating on the day (and possibly beyond). On the day, you must first check with a manager about whether the person is emotionally and physically ready (e.g. feels like talking with you and is not too tired to focus). If so, you should nonetheless check with the individual whether they are feeling ready for interview. When asking, be alert to what the person tells you and any mismatch between their words and facial expression and body language. If spoken and body language are consistent, this can be a good barometer of genuine consent rather than felt obligation but if in any doubt check again with a manager and the individual concerned. Be prepared if necessary to postpone the event of *any* signs of distress or even abandon the interview depending on the context and after discussion with the participant and any person they nominate or a manager.

At the start of interview process

It is crucial to emphasize several things at the start of the interview process.

- 1) Remind the interviewee that the consultation is about the importance of doing research on old/er care home residents and sexuality and how this could best be done. It is not an open-ended exploration of their experiences. This could help prevent conversations about personal sexual or erotic experiences. If an interviewee starts to talk about such experiences or desires - their own or anyone else's - you should acknowledge that they have a choice about how they express themselves but remind them evenly but politely of the focus of the consultation.
- 2) If the interviewee has not already provided details of a contact person in case of distress, ascertain with the interviewee if there is someone s/he would like to make you aware of who could fulfil this function.
- 3) Remind the interviewee that we will be referring to what interviewees tell us and will possibly cite some of their speech word-for-word in publications and at conferences. But, whilst confidentiality in this consultation cannot be absolute, remind interviewees of the various measures (as stated in the informed consent details) we will take to safeguard their **anonymity**. You should stress to the interviewee that our focus is on the privacy of what s/he says in the interview but bearing in mind any duty to report any issues to safeguarding and harm prevention.
- 4) The first issue on the interview schedule is designed to check whether the interviewee knows enough about the interview process. Do not skip this as it is important to ascertain if s/he would like more information before starting the

interview. You could reassure any individual that there is no obligation to continue (at any point) and that it would actually be unethical for you to do so.

During interview

Much of the advice in this section (and the one below on reports of danger, abuse and neglect) may not be needed in a consultation on how to do research on sexuality. Whilst it is important to adopt a friendly and open approach, this level or kind of familiarity should be avoided given our current focus. However, we need to be prepared in case distress occurs for unforeseen reasons whether connected or not with the theme of the consultation.

- 1) If any distress is or becomes obvious and significant e.g. crying then stop the interview and summon the help of a manager and/or the individual's nominated person immediately. If, judging by tension in facial/expression or body language (or mismatch between spoken and body language), the distress appears less pronounced, offer a comfort break and ask whether a particular member of staff or nominated person should be called to offer support. After an appropriate interval, check with the individual whether they want to continue with the interview but it must genuinely be their decision and could be informed also by a trusted member of staff/nominated person.
- 2) If you sense, again, through mismatch between spoken and body language, that any interviewee is uncomfortable about a particular question, you should check whether s/he would like to move onto the next question. You could offer the interviewee reassurance that they are free to refuse to answer any question and to stop the interview at any time without having to justify this. However, you could check diplomatically if there is anything you can do to address any underlying concerns the individual has. It might also be useful to remind the interviewee that they will remain anonymous and their views will be respected.
- 3) If an interviewee (or any other person you encounter when at the home) asks if you can keep a confidence, be honest and say that it depends on what they want to disclose. If anything of a serious nature such as physical, emotional or sexual abuse (see below for definitions) is communicated, you will be duty bound to inform a manager. Depending on the issue or what is divulged, you could encourage the interviewee to contact an appropriate member of staff such as a care manager and/or their nominated person.
- 4) If an interviewee communicates distress that could be linked to isolation, and provided that the individual consents to it, you could suggest that the care home be asked to make links with any appropriate support/voluntary organizations for information/literature and services such as social groups. As the consultation concerns how to research the spectrum of sexual citizenship, this could be particularly relevant for any interviewee who identifies as LGBT or who indicates struggle with their gender or sexual identity.

- 5) It is good practice to check how the person is feeling at the end of an interview. If you detect distress at the end of or immediately following an interview, again, observe and listen carefully, acknowledge the person's feelings and ask if they would like support from a member of staff or their nominated person. Do NOT attempt to 'counsel' an interviewee.

Danger and reports of abuse or neglect

Although witnessing or hearing about danger, abuse and neglect is highly unlikely, we have to be prepared in case we encounter them. The research team needs to act consistently in relation to any signs of them and the Principal Investigator (PI) is responsible for the management/oversight of a consistent approach. However, it is important that researchers familiarize themselves and are thus able to act in accordance with the safeguarding policies of the care home or any other appropriate authority (e.g. if run by a local Council). The PI will need to ascertain that researchers have done this.

As part of a consistent approach on matters of danger, abuse and neglect, working definitions of their various kinds are provided. Physical abuse or neglect could involve violence, denial of hydration or nutrition. Sexual abuse concerns unwanted sexual behaviour over time (or even a one-off sexual assault) and could include unwanted touching or interference with zones of the body considered most sexual such as breasts and the genital area but can involve unwanted attempts to kiss someone on the lips (or neck) or other private zones of the body. Emotional/psychological abuse or neglect could involve consistent and deliberate attempts at emotional cruelty, belittling someone or undermining their self-esteem. It could also involve denial of communication and attempts to ostracize.

Also, as part of a consistent approach, researchers will need to have regard to the following.

- 1) **If any individual is in immediate danger, contact the police immediately.** If you sense, or a resident (or anyone you encounter at a care home), hints at/reports physical, sexual or psychological abuse or neglect to you, you or the individual concerned could seek advice through the Care Quality Commission (CQC) helpline. This service also welcomes calls of a 'whistleblowing' nature and can be contacted via: **03000 6161 or enquiries@cqc.org.uk.**
- 2) Should you be told of (or even witness) any of the above, you must stop what you are doing immediately. You should register the seriousness and credibility of what the person is telling you. This applies to any disclosure of concern that could affect an individual's well-being such as past or even present experience of violence – physical, sexual or psychological/emotional. After registering the gravity of any disclosure, encourage the individual to disclose the information to the person to whom they would most feel comfortable divulging this information e.g. a manager and/or their nominated person.
- 3) If any allegation of abuse or neglect is made about a manager, ask the participant who else they think should be told (mentioning any nominated person), how and by whom. You should reassure any resident that care homes have a legal duty to protect

them and will have procedures to deal with abuse or neglect and that their concerns will be taken seriously.

- 4) If anyone you come across when at the care home asks you to keep something confidential, again, you should say that this will depend on what they intend to disclose. You should stress that if it is a matter that could impair somebody's well-being, you are duty bound to breach confidentiality and report this to an appropriate, responsible person or authority.

After interview:

If any interviewee contacts you and expresses distress some time after interview:

- 1) Listen carefully, empathize and note down the details.
- 2) Ask the person how they think the issue could be resolved and, if they are unsure, offer them some suggestions and the chance to come back to you to let you know what they would like you to do to resolve the issue. If what they request is impossible, explain why and suggest alternative resolutions.
- 3) If the individual is not happy with the above option, remind them of their right to take the matter up with Principle Investigator (PI) – and the University's Research Ethics or Governance Office (RGO) and/or other appropriate contact. Contact details of both PI and RGO are given in the informed consent details but you could supply these details again.
- 4) If any participant regrets sharing something or wants to withdraw their contribution in part or whole some time after the interview, remind and reassure them that any disclosure will be excised from any impending reports. You will also need to remind them that we would need to be informed of this by **XX of month and year** at the latest as, by then, we will be gearing up to publish or publicize findings in the media and journals.

Your emotional safety and need for support

If you witness or experience anything connected with the consultation before, during or after fieldwork that upsets **you** as researcher (or a research advisory group member), you can make use of support available from within the research team. All its members have developed active listening skills. As well as being able to share certain concerns at a team meeting, you could, depending on your needs, seek help from:

- The Principal Investigator (PI).
- A Co-Investigator (CI) of the same gender or sexuality.
- Your line manager.
- Another trusted colleague (of the same gender or sexuality).
- A family member, partner, friend/significant other or confidante.
- The University counselling/staff support service.

- Any other counselling service available through your volunteer work.

The above are not mutually exclusive and there are various permutations and pathways you could follow according to your needs. For example, you could begin with taking with the PI, CI or the wider team but if your distress persists or worsens, you could consult a counselling service.

Whilst you are free to share your feelings with a trusted person, it is important, however, that you don't breach anonymity and reveal actual identities of any interviewees or other study participants (e.g. care staff) or any others that you have encountered when researching at a care home.