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SAGE Research Methods: Doing Research Online

Online participatory research: lessons for good practice and inclusivity with marginalized young people.

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Abstract

This research project case focuses on the use of multiple participatory research platforms to explore the experience of multiplicity within young adult populations; multiplicity refers to the experience of having more than one person within a single body. The issues and approaches discussed are relevant across a range of participant populations who may find less frequently used participatory methods more accessible. The case study outlines the transferable learnings from one study, including the use of an online consultation model and social media platforms, as well as the researcher's reflections on the respective strengths and limitations. The importance of using appropriate methodologies when researching traditionally under-represented groups will also be examined, with specific examples used. The process of developing a positive, inclusive project that draws on the expertise of the participants will be outlined.

Learning Outcomes

By the end of this guide, students should be able to . . .

- Understand the process of conducting a sensitive participant-centred online consultation

- Critically consider how to engage marginalized people in online research

- Understand how to involve experts-by-experience in study design to develop recruitment strategies and positive engagement in research

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Case Study

Project Overview and Context

The pre-research consultation in this case was undertaken as part of the development phase of a PhD, focusing on personal experiences of multiplicity through utilizing a grounded theory informed approach. Online participatory methods were utilized to aid engagement with the consultation and gain feedback from the community. The term multiplicity refers to the experience of more than one self in the mind and body but is not a diagnostic term, nor do all experiences of multiplicity 'fit' within diagnostic criteria. Other terms that are used to describe multiplicity include plurality, endogenic, Dissociative Identity Disorder and Other Specified Dissociative Disorder (Brand et al., 2016; Hartmann & Benum, 2019). For this project, we adopted an accepting position, instead of focusing on diagnoses. We wanted to explore experiences of multiplicity through expert-by-experiences perceptions and reflection on experience; centering personal accounts from the outset as experts in their own experience. This approach could help us develop a novel person-centered understanding and develop authentic guidance and information for dissemination and staff training.

Traditionally, research into "dissociative disorders" believed that young people with these experiences lacked insight into their own daily lives and thus they did not understand what was happening to their sense of self. However, research and policy has stressed the importance of engaging experts-by-experience in all stages of the research process to ensure tailored and appropriate research is conducted *with* not *on* people who are experts in their

own experiences. In this case, we will discuss how we designed an inclusive recruitment approach to ensure the voices of the multiplicity community remained at the center of research throughout the process.

Section Summary:

- There is a lack of research focused on non-clinical experiences of multiplicity and how these experiences impact upon psychosocial functioning.

- Ensuring expert-by-experience involvement throughout the research process is key to developing an inclusive participatory research project.

- Conducting a consultation to inform future research plans allows the community to remain at the centre of the research throughout, ensuring all research can hear their needs and wants.

Research Design

Grounded Theory Methodology

Traditionally, grounded theory research focuses on psychosocial processes regarding behaviour and works to develop understanding regarding how and why people behave in certain ways, using an inductive approach (Charmaz, 2006). It is often the methodology of choice for research areas where there is little academic knowledge (Birks & Mills, 2015). For this project, a grounded theory approach was selected in order to develop a theory from the "ground up" (Strauss & Corbin, 1998), starting with a pre-research consultation, using a purposive sample of those with personal experiences of multiplicity, whether that being those with multiplicity or support networks and professionals. As a grounded theory approach begins with a broad area of study and allows the theory to develop through the data collected,

it was important to ensure that the questions developed as a result of the pre-research consultation were appropriate and focused on the areas of importance to the multiplicity community (Glaser & Holton, 2004). One core facet of grounded theory approaches is the exploration of experiences as described by participants (Charmaz, 2014). As such, it was vitally important to incorporate young peoples' voices from the outset, ensuring all phases of theory development are centered around their experiences. By utilizing a combination of a grounded theory informed approach and the use of a pre-research consultation, the project enabled a true participatory research process.

Pre-research consultations
Consultations are traditionally used to tailor and focus a project's ideas into a relevant and positive research plan through working with members of the required population group. Essentially, consultations should inform the research design process prior to a researcher deciding upon a particular course of action. Consultations can take place face-to-face or digitally, individually or in groups, formally or informally. The recommendations of expertsby-experience and stakeholders should be considered to promote accessible, meaningful and inclusive research. Often referred to as 'Patient and Public Involvement [PPI] within healthcare and biomedical research, consultations involve stakeholders, people with lived experiences, and researchers working to plan, design and conduct research *with* not *on* a group of people (Dudley et al., 2015). People with lived experiences bring an "expert" insight into the research and can identify both the areas of importance for the target group and eliminate potentially inappropriate or unnecessary studies being conducted (Biggane et al., 2019). Within our consultation, we chose to work with a group of people who had experiences of multiplicity, either personal, professional or through supporting someone to help design the subsequent research plan.

Various barriers have been found to prevent people engaging in PPI including equality, support, access and stigma which we took into account during the planning phase (Ocloo & Matthews, 2016). Often people have been stigmatized for their experiences, thus they are less likely to engage in openly sharing their personal accounts. As a result, online, anonymous methods were chosen as the most suitable methodology. While various methods are available, including interviews, focus groups and surveys, it is important to consider the target group and how they can both access the process and feel supported and valued throughout it. We used a short online survey which requested information about how participants would prefer research to be designed, what they would like the research to be focused on, and how to positively engage people in the process. Social media was used to recruit participants to the consultation as the research team identified a pre-established online support network for those who experience multiplicity who were open to sharing the information, which helped develop legitimacy of the process and resulted in a high level of involvement. As a result of the wording of our consultation questions, members of the multiplicity community were the authority and were able to share their opinions truthfully, which resulted in the focus of the subsequent research being tailored to the areas of importance for them.

Positionality: Perspective as a PhD researcher

Positionality is often used to describe a researcher's view of the world, the position they take within a research area and how they interact with participants (Holmes, 2020). As positionality is influenced by a variety of factors including values and beliefs, personal experiences, environment, and (dis)abilities, it is vital to assess one's own position before designing a research study. A researcher's positionality can influence how the research is designed, conducted, analyzed and presented (Rowe, 2014). With no personal experiences of multiplicity, I was an outsider in the area, thereby presented with a significant challenge in

designing a positive, inclusive study (Phelps, 2019). It was clear from the outset that I wanted to include personal experiences and voices in the study, ensuring that experts-by-experience were the main voice, with support networks and professionals being incorporated in a complementary role. It was important to ensure that any potential biases that myself as a researcher held did not influence the development of the study, or indeed the output from the research. Additionally, it was important for me to consider the wording of all information throughout the process, which resulted in reading grey literature around the topic and personal experiences via social media. As a result, a pre-research consultation was identified as the most appropriate means of ensuring young adults with multiplicity remained at the center of the research process from the outset.

Perspective as a PhD supervisor and practitioner

Supervising a project where one has a professional connection but no personal experience can be a challenging position to reconcile. Having worked as a clinical psychologist and researcher with adults with Dissociative Identity Disorder in clinical settings, I was aware of how valuable the diagnosis of Dissociative Identity Disorder can be for many people. During my own research and practice, I have heard all too frequently how people have been misdiagnosed, mistreated, unsupported, and how people have felt invalidated and even traumatized by their experiences of help-seeking (Parry et al., 2017, 2018). However, working with young people who conceptualize voice hearing as connected to experiences of being multiple has shed light upon the conceptual complexities of how we use language (Parry et al., 2021), who gets to decide what language we use and how we include young people in addressing these challenges. As a supervisor, my role emerged to be a bridge between various 'schools of thought' and to contain some of the uncertainties around a research project that has the potential to vastly expand our understanding of a misunderstood

and deeply personal phenomenon, if those uncertainties can be tolerated long enough to absorb new knowledge and voices of experience.

Section summary:

- Grounded theory informed methodology can be instrumental to the development of a successful, inclusive research project.

- Using a pre-research consultation to develop subsequent phases of research helped to ensure often marginalised voices remained at the centre.

- While consultations can be valuable and instrumental in a research project, it is important to consider the needs and preferences of the target community and utilise methods most suited to them.

Research Practicalities: Balancing Ethics and Engagement

Using a qualitative pre-research consultation to inform a grounded theory informed PhD project with an under researched group posed several challenges, including ethical considerations and how to engage young people in research, each of which will be discussed in depth.

Ethical considerations

A number of ethical concerns presented themselves regarding the consultation process:

- Participants were asked to provide pseudonyms for their responses, regardless of whether they gave explicit consent for their data to be utilised. Allowing participants to only be known as their chosen 'made up' name ensured anonymity throughout the process. Previous research has found this to be positive, particularly when focusing on young adults and potentially sensitive topics (Saunders et al., 2015).

- The survey that was developed for the consultation process and research was carefully designed based upon prior feedback with young people who identified as multiple and support from Voice Collective, a charity that provides support for young people with unusual sensory experiences.

- The survey provided an introductory paragraph at the start to state that people experience multiplicity in many different ways and that while some people may find it useful to have a diagnosis such as Dissociative Identity Disorder or Other Specified Dissociative Disorders, a diagnosis is not a requirement to experience multiplicity. Ensuring clarity in this information is important in validating and normalising underresearched areas and experiences, and worked to ensure participants understood the positive, curious approach the research was taking. Twitter feedback to the survey illustrated that the care taken around language and positionality had been appreciated by the young people who saw and shared it.

- When using online surveys such as Qualtrics in this project, I ensured that no personal information, IP addresses or location data was collected from participants.

- Consultation questions included in the survey were all open questions which ensured there was a lack of any potential researcher bias being employed in the survey. By ensuring young adults who experience multiplicity and their support networks remained at the centre of the process from the start enabled the unbalanced power dynamic between researcher and participant to be mitigated.

- Explicit consent was not requested during the consultation phase of the project. While it was a consideration that I had with my supervisory team, it was not deemed a requirement as a result of the wording of the questions. The consultation did not aim to explore the experiences themselves, as with the subsequent phases, instead focusing on the actual development of the project. While participants shared lots of valuable

and important information, allowing the community to engage with the planning phases without sharing their own experiences allowed a greater participatory and inclusive option.

Engaging young people in research

With a consultation, as with other forms of research, it is important to consider the most appropriate form of engagement and recruitment for your target population. In the early phases of planning, we considered recruiting through health services, however as a result of the complexity of multiplicity experiences, this was decided against. Many people do not consider their experiences 'fit' within or align to clinical descriptors, or do not access formal support for a myriad of reasons including having positive experiences and having other means of support (Luhrmann et al., 2019). As a result, it was determined that online methods were the most appropriate for a young adult population, particularly during the consultation phase. This was further supported via the responses, which highlighted the positive and inclusive online community which many with multiplicity engage with. As a result of this, it was decided to primarily use social media methods of recruitment throughout the PhD. Social media has been found to be effective in recruiting typically hard-to-reach groups (Gorman et al., 2014) and young populations.

Section summary:

- The ethical considerations for consultations are less structured, but no less important, than in "traditional research".
- It is essential to consider how to engage with target populations, which will often require alternative recruitment methods.
- Social media provides new platforms for research with communities who may have been excluded from research historically. Advertising opportunities for discussion

through social media provides a less intimidating 'neutral ground' that can help to remove power imbalances and can help share research opportunities through preexisting social networks.

Method in Action

When designing a grounded theory informed study everything is hypothetical, it is not known how successful any one chosen methodology may turn out to be. This is particularly true when conducting research with traditionally under researched or "hard-to-reach" groups (Chun Tie et al., 2019). Further exacerbating this uncertainty for my research was the COVID-19 pandemic which prevented the planning of any in person interviews as was initially proposed. As a result, the consultation process can be invaluable to the development of a successful, inclusive project. In a similar vein as pilot interviews, the consultation process can aid in question refinement and specificity (Cohen et al., 2007; Kim, 2011). I discussed the potential areas I wanted to work on with my PhD supervisory team prior to developing the project, however we decided it would be appropriate to speak to people in the multiplicity community themselves, in order to determine whether our plans fit with what they want from research.

The questions that were designed for use within the consultation were purposefully broad as to not bias any potential responses. We chose to use five questions which aimed to elicit clear conclusions regarding the subsequent plans for the research, including "what would you hope this research could achieve?" and "What would be your recommendation(s) for how to involve a range of participants in this research?". The wording of consultation questions posed a challenge to myself as a novice researcher. Initially, I found it difficult to differentiate between pre-research consultation and traditional research questions, developing

specific and targeted questions. After discussions with the supervisory team, it became clear that non-directional, broad questions were most appropriate at this early stage of the research. One fundamental lesson as a PhD researcher is to become comfortable admitting you are unsure and need guidance. I worried I would be judged for being unsure about how to word a consultation question, but it is necessary to understand that it takes time to develop skills in any area, and your supervisory team are there to support your development.

One main challenge I faced associated with the use of consultations was the inability to explain the meaning behind questions. I had spoken to peers and family and the questions were deemed to be clear. However, the general reading comprehension age is 13 years, and the UK Government suggest writing for a nine-year-old reading age (Government Digital Service, 2021), thus it is important to consider the wording used and whether the questions are truly clear to your target audience. Compared to interviews, online surveys lack the ability to elaborate or explain the purpose of the question. We found that while in the minority, there were some participants that mentioned they were not sure how to answer or answered in an unanticipated way to the question posed. For future research, I will ensure to ask young adolescents and members of the multiplicity community about the question wording before publishing the survey to ensure clarity in responses.

However, utilizing online methods during the consultation phase was extremely positive overall and resulted in a high response rate in a short period of time. I used social media as the main means of recruitment, which resulted in a snowball sampling effect occurring within members of the online multiplicity community. We found twitter to be extremely useful and saw the highest participation rates in the 24 hours following each post, which incorporated relevant hashtags to the community of focus. A search through relevant twitter users and posts to the topic identified three main hashtags that were used within the community; ensuring the use of wording that mirrored the community's own posts aided recruitment and

relevance. A point I had not considered when using visual posters during recruitment was how that could be inaccessible to certain groups (Chiarella et al., 2020). Following advice from commenters on my posts, I added "alt text" to the images which describes what the image is showing. Utilizing simple steps to ensure accessibility in research is vitally important to ensure the research is truly inclusive and positive.

Additionally, participant safety is of paramount concern within all research and consultation work and is particularly applicable when asking about potentially sensitive topics and with young adult populations. As a result of the online nature of the consultation, we chose to provide signposting and expository information at the top of the survey. This included information about multiplicity, our plans for the project, and an overview of the areas of interest. Additionally, at both the top and bottom of the survey there were links to more comprehensive information and support including the ChUSE network (www.mmu.ac.uk/health-psychology-and-communities/our-expertise/chuse-network/). In addition to the importance of providing appropriate and up to date support and information, the link to the ChUSE network website allowed participants to verify the authenticity of the research.

Section summary:

- Incorporate consultation work to aid the refinement of your survey/interview schedule and research focus.
- Consider word choices when developing online surveys and potential ambiguous phrasing.
- Using alternative recruitment methods including social media can be successful and more suitable to your target population.

Practical Lessons Learned

While this paper has provided an overview of my experience using a grounded theory informed consultation process, this section will focus on four of the practical lessons I learned along the way, which can be applied to other research.

Participants can help with recruitment

Recruiting participants is often seen as one of the most challenging parts of conducting research, particularly when conducting qualitative research. However, thanks to the somewhat recent adoption of social media as an appropriate means of recruitment, I was able to recruit above and beyond my ideal target within a relatively short space of time (Gorman et al., 2014; Martinez et al., 2014). Social media, including Twitter which I used, is a saving grace for many people in under researched areas such as the multiplicity community, lots of whom are open about their experiences online even if they do not feel comfortable in other settings. Before starting data collection, search relevant groups or hashtags which can help with snowball recruitment; if people have a positive experience, they are likely to share the information with their own networks.

Be mindful of accessibility

When developing your research, whether that is interview schedules, survey design or an alternative methodology, be aware of language and terms used by the community, the potential for misunderstandings and different ways of inferring information. Considering the language used at the start of the process will allow participants to understand the questions posed, thus the data collected will be of greater relevance to the research. Reading around critical disability theory is important for any researcher conducting research with potentially marginalized or disabled groups to develop the discourse used and mitigate power

imbalances, as these are often central to lived experiences (Goodley et al., 2019). Additionally, consider the overall readability of the information; if you are using online methods ensure the colour contrast ratio is high enough to differentiate text from the background as this will aid overall accessibility for participants with low vision (Huffington et al., 2020). Furthermore, allowing enough time to complete the consultation, particularly with online methods which have automatic time limits promotes inclusivity and positivity, not just for those with disabilities but for all participants.

Consider multiple participatory methods

Following the global pandemic of COVID-19, the use of various computer-based software became the norm within all forms of life, including research. Consider the utility of nonstandard methods, such as video conferencing software such as Microsoft Teams or online survey methods when designing research, particularly when considering traditionally "hardto-reach" groups and sensitive topics. The use of various online means can aid recruitment due to the reduction in time constraints, travel restrictions and locations (Heath et al., 2018), providing inclusive participatory opportunities.

Consider ethical issues

While consultations are becoming increasingly more ubiquitous with research development, it is important to consider the potential ethical considerations that accompany the approach. There is currently a lack of standard ethical goals that are used within consultation and PPI work which makes it difficult to differentiate the methods (Mitchell et al., 2019). Numerous ethical concerns have been raised regarding the use of consultations including a lack of consent, discussion of potentially sensitive subjects, potential power imbalances and unclear distinctions between consultation work and research (Pandya-Wood et al., 2017). As a result, it is important to critically consider the pre-research process and ensure you are working

within an ethically sound manner, as would be expected within traditional research. Ensure to use pre-research consultation as a means of project development rather than a "quicker option" to standard research, which is subjected to rigorous ethical procedures, for both researcher and participant safety. Pre-research consultation should focus on *how* to do research well, rather than to inform hypotheses and theories as to *what* may come about during the research process.

Top tips for using consultation methods

Be clear about your objectives – It is important to detail the overall objectives of the consultation and ensure the questions presented are specific to them. This will allow participants to understand the premise of the survey and will mitigate misinterpretation of questions and promote full completion of the consultation (Dixon et al., 2019). Additionally, it is important to make clear within the survey information how the responses will be used, and how you plan to work with the insights gained due to the expectation of consultations facilitating change within a project.

Be flexible – It is important when developing a consultation to consider the characteristics of the desired participants, and whether certain tools are most suitable (Dickert & Sugarman, 2005). While online survey methods can be instrumental in gaining a wide range of viewpoints, alternative methods may suit individuals more, or allow insights from "hard-toreach" populations. Depending on the nature of the consultation, the process may be better suited to focus groups or interviews, which may allow a more sensitive, nuanced discussion of the topic.

Ensure it is well planned – When considering any method of data collection, it is vital to remember participants are freely giving up their time to engage with your project. As such, it is important to carefully plan and test your chosen data collection method and questions prior

to publishing the consultation (Bowers et al., 2017). Furthermore, ensure you have planned how you will analyze and interpret the responses. While this may not feel as important with consultations as with other more traditional forms of research, it is an important step to developing a truly positive research process.

Consider peer research – Depending on the focus of a consultation, it may be useful, and even vital to utilize peer research as a means of developing a participatory research design. Peer research allows "inside" members of a group to take on the role of the researcher (Kilpatrick et al., 2007). This shift in power dynamics can aid understanding, allow greater levels of empowerment and produce clearer data at any stage of the research journey. Peer research is traditionally more suited to engaging "hard-to-reach" populations and is becoming more common within research with young people.

Section summary:
- Accessing appropriate online groups (which may need the addition of gatekeepers) can be a great recruitment tool, particularly when focusing on young adult or marginalised populations.
- Making changes to language and colouring of online research tools can aid accessibility of research.
- Ensure you are working in an ethically sound way, regardless of the approach being used, both for participant and researcher safety.

Conclusion

Working with young adult populations requires a unique set of skills to ensure a positive, inclusive study is developed. Several reflections and recommendations have been offered as a

result of this researcher's experiences. Firstly, consider the topic of interest and how best to develop an appropriate strategy. If working in an under researched area or working with traditionally "hard-to-reach" groups, it may be vital to conduct a consultation with the group of interest prior to the development of research questions, including surveys and interview structures. It is important to consider the potential ethical ramifications from utilizing a consultation approach, including how the responses can be used, how to maintain an ethically robust study, and how to ensure both participant and researcher safety and wellbeing. Within the design of the consultation, it is important to confirm the language used is appropriate and not able to be misconstrued. Additionally, consider modifying the standard methodologies to improve accessibility, including increasing colour contract ratios of survey backgrounds, and using "alt text" when using images on social media. Having a clear understanding of your study group and potential methodological approaches can ensure that a positive, participatory research project is designed, which is specific to your research aim.

Section summary:

- Pre-research consultations can be invaluable to the development of a research study, but they need to be carefully developed.
- When designing a study, consider the target population's preferences and the topic itself, to ensure the methodology chosen and associated language is the most appropriate to the research aims.

Discussion Questions

[Insert three to five discussion questions on the methods described in your case study]

Discussion questions should be suitable for eliciting debate and critical thinking. Avoid questions which require only a single-word answer such as "yes" or "no."

1. When are consultations an appropriate method for data collection?

2. What are some challenges associated with undertaking an online consultation with young adult populations?

3. How might you consider *ethically* researching a topic area which you have no personal experiences of?

Further Reading

[Insert list of up to six further readings here]

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Web Resources

[Insert links to up to six relevant web resources here]

- About our study: https://www.mmu.ac.uk/health-psychology-and-communities/ourexpertise/chuse-network/

- Choosing appropriate methodologies:

  https://www.thestudyspace.com/page/choosingappropriate-research-methodologies/

- Disseminating information: https://methods.sagepub.com/book/research-withchildren/i950.xml

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