

Please cite the Published Version

Parry, Sarah, Djabaeva, R and Varese, F (2018) Engaging Young People Who Hear Voices in Online Mixed-Methods Research. SAGE Research Methods Cases.

DOI: <https://doi.org/10.4135/9781526457783>

Publisher: SAGE

Version: Accepted Version

Downloaded from: <https://e-space.mmu.ac.uk/619561/>

Additional Information: This is an Author Accepted Manuscript provided by SAGE of a paper accepted for publication in SAGE Research Methods.

Enquiries:

If you have questions about this document, contact openresearch@mmu.ac.uk. Please include the URL of the record in e-space. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from <https://www.mmu.ac.uk/library/using-the-library/policies-and-guidelines>)

Engaging Young People Who Hear Voices in Online Mixed-Methods Research

Sarah Parry

Manchester Metropolitan University, UK

Rachel Djabaeva

Manchester Metropolitan University, UK

Filippo Varese

The University of Manchester, UK

Discipline

Psychology [D3]

Sub-discipline

Clinical and Abnormal Psychology [SD-Psych-3]

Academic Level

Postgraduate

Contributor Biographies

Sarah Parry, ClinPsyD, is a clinical psychologist within a trauma-informed looked-after children's service and senior lecturer. Her research interests include therapeutic uses of formulation, the utility of compassion-based approaches for clients and practitioners alike, and how interpersonal trauma can affect aspects of people's lives and their coping strategies.

Rachel Djabaeva is a Master's degree graduate at Manchester Metropolitan, studying psychological well-being in clinical practice. In addition to her studies, she is also the research

assistant for the Young Voices Study and has an interest in services that promote well-being among families.

Filippo Varese, PhD, ClinPsyD, is a clinical psychologist and clinical lecturer. He has been doing research on hearing voices, psychotic experiences, and trauma for more than 10 years. His primary interests are the impact of complex trauma on the risk of developing severe mental health difficulties and the efficacy of psychological interventions that could improve these difficulties.

Published Articles

Parry, S. L., & Varese, F. (2017, June 14). Parents, don't panic if your child hears voices, it's actually quite common. *The Conversation*. Retrieved from <https://theconversation.com/parents-dont-panic-if-your-child-hears-voices-its-actually-quite-common-78964>

Parry, S. L., Varese, F., & Djabaeva, R. (2017, July 13). Somewhere between “a great friend,” “scary” and “hard to explain.” *IamIn4*. Retrieved from <https://iamin4.com/2017/07/somewhere-between-a-great-friend-scary-and-hard-to-explain/>

Parry, S. L., & Varese, F. (2017). Ten tips for parents of children who hear voices. *Mad in America*. <https://www.madinamerica.com/wp-content/uploads/2017/02/Ten-Tips-for-Parents-of-Children-Who-Hear-Voices.pdf>

Abstract

This case study discusses the first online phase of a mixed-methods three-phase study with young people who hear voices and their parents/carers, populations that are particularly difficult to engage in research due to the widespread stigma surrounding the experience of hearing voices. The account has been developed by the primary researchers, which at this stage includes two early career academics and a postgraduate master's degree student. Throughout the case study, we discuss the innovative design of online recruitment and participation, and consider a number of challenges that arose throughout the development and early recruitment phases. In particular, we explore some of the challenges around recruitment with groups of people who may associate social stigma with their experiences and the type of participation platforms that can facilitate engagement. In addition, we discuss the processes in place for gaining informed consent with people aged below 16 years and the development of tailored research materials to suit the needs of research participants. Finally, we consider the important role of partnerships and field support in research projects and the complementary ways in which the research team can work together. The complexities of the case are discussed in relation to supporting literature and recommendations for students who may embark upon research that presents similar challenges.

Learning Outcomes

By the end of this case, students should be able to

- Develop broad recruitment strategies to reach people across settings
- Critically discuss helpful platforms for participation considering anonymity, convenience, and confidentiality
- Involve experts-by-experience and partner organizations in study design, development, and evaluation to develop effective recruitment strategies for research with young people.
- Critically consider how to develop inclusive informed consent processes for young people

Case Study

Project Overview and Context

Although hearing voices (in traditional psychiatric terms also called *auditory verbal hallucinations*) has been traditionally regarded as a symptom of severe mental health difficulties, growing evidence indicates that this experience is relatively common in the general population, and that hearing voices is often not a sign of mental health problems. Since the 1980s, the Hearing Voices Movement has campaigned to change the social views around voice-hearing, and a growing number of clinicians and researchers have ceased to consider hearing voices as a symptom of stigmatizing diagnoses, such as schizophrenia. Instead, we tend to adopt a more accepting and curious position that focuses on understanding why this commonly misunderstood experience can become distressing and problematic for some individuals, or comforting and supportive for others. To understand more about the experience of hearing voices with adults, previous researchers have found it invaluable to examine and systematically compare the experience of a range of voice-hearers, not only those that seek support from mental health services in relation to these experiences but also those who hear “benign” voices. Interestingly, some people have reported that their voices appear to them as a meaningful and positive aspect of their lives, and/or cope well with voices and other unusual experiences (e.g., visions). However, most of the research done to date has been conducted with adults who hear voices; very little research has been undertaken with young people directly and/or their parents/carers to gain a scientifically accurate understanding of these experiences amidst other developmental stages. Consequently, little direct empirical evidence exists to understand the experience of hearing voices in children and adolescents, and to inform services for young voice-hearers and their families.

Focusing on young voice-hearers is particularly significant in the light of longitudinal studies that suggest the distress and negative appraisals accompanying experiences of voices may predict the persistence of voices over time (Escher, Romme, Buiks, Delespaul, & Van Os, 2002a, 2002b). In turn, these “subclinical” experiences can develop to become more disruptive and distressing, which can culminate in mental health admissions and diagnoses for some, such as a diagnosis of psychosis. Understanding the factors that influence negative appraisals of voices at a

developmental stage, when these experiences are largely benign and unproblematic, may allow for the development of early interventions to prevent the subsequent exacerbation of emotional and psychological distress (Varese et al., 2016).

Research with adults who hear voices has indicated that changing the way in which voice-hearers relate to their voices can help people feel more in control, which enables a greater ability to cope and reduces distress (e.g., Hayward, Awenat, McCarthy Jones, Paulik, & Berry, 2015; Hayward, Berry, & Ashton, 2011). Although the way in which the individual responds to their voices is very important, in the case of young people, the family response and how significant others in the child's life react and make sense of these unusual experiences is highly likely to affect the way they themselves interpret the voices (Romme & Escher, 1993, 2000; Romme, Escher, Dillon, Corstens, & Morris, 2009). There is, as yet, a lack of empirical research into the influence of these systemic factors for young people who hear voices and *how* reactions of family members toward these experiences shape children's perceptions and ability to appraise, relate to, and cope with such experiences.

When we were developing the current study, our main aim was to contribute to the significant gap in the literature by developing a greater understanding of the individual and systemic psychosocial factors that exacerbate and maintain psychological distress for young people who hear voices. We also wanted to learn more about individual and systemic factors that support well-being and adjustment in relation to the voices. Finally, we hoped to understand the perceptions and attitudes of parents/carers toward the voices their child has reported and explore the impact of parental reactions to voices and, in time, develop a family-focused intervention for young people who hear voices.

Our work presented significant challenges in terms of the engagement and recruitment of young people with lived experiences of voices and their parents/guardians. Voice-hearing is in fact a highly stigmatized experience, which is often misportrayed in the media as a "symptom" associated with "madness," ridicule, and even acts of violence (Phalen, Warman, Martin, & Lysaker, 2016; Vilhauer, 2017). The associated stigma may present a critical barrier to the successful engagement of young voice-hearers in research. Individuals with lived experience of voices might avoid discussing their experiences with others, including their family members, for

fear of being judged. Similarly, parents may be reluctant to engage with clinical researchers and mental health services for fear that their child might be unduly “pathologised.” Here, we will discuss how we planned a varied and broad research strategy to deal with these potential barriers to engagement and recruitment to promote inclusive opportunities for research participation.

There is growing recognition that the perspectives of children and young people need to be heard within research connected to treatments and services developed for them (Huang, O’Connor, Ke, & Lee, 2016). The involvement of children in qualitative health research in particular has been linked to the empowerment of children and young people, ownership of difficulties, and invaluable insights in developing service provisions (Helseth & Slettebø, 2004; Kirk, 2007). Furthermore, the Children’s Rights agenda emphasizes that children “have a right to be consulted, heard and to appropriately influence the services and facilities that are provided for them” (Darbyshire, MacDougall & Schiller, 2005, p. 420). It is the duty of researchers to meaningfully include children in research, offering a suitably multimodal approach to enable children to select a method of engagement befitting for them personally (Hill, 2006; Lightfoot & Sloper, 2002). In the current study, the web-based survey added an alternative participatory option for young people who wish to contribute to the study but who may not wish to meet face-to-face or who are unable to travel to an interview.

The Young Voices Study: Research Design

Our Young Voices Study is a three-phase mixed-methods study (see Biber & Johnson, 2015; Hesse-Biber, 2010; Salmons, 2015a) consisting of (a) web-based surveys for young people and parents/carers, (b) face-to-face interviews with young people and parents/carers, and (c) focus groups with “experts-by-professions” (clinical practitioners working in psychosis and/or children and adolescents services) and “experts-by-experience” (young voice-hearers and adult voice-hearers who started hearing voices in childhood and could provide a perspective on the support they have received and/or would have liked to receive while growing up). These phases were chosen due to successful prior use of online recruitment strategies with young people (McGarry & McGrath, 2014; Salmons, 2016) and in the field of unusual experiences (Woods, Jones, Alderson-Day, Callard, & Fernyhough, 2015), the many benefits of explorative semi-structured interviews for gaining in-depth data in relatively under-researched fields (Midgley et al., 2017),

and the utility of focus groups for the triangulation of data (Lambert & Loisel, 2008; Stewart & Shamdasani, 2015). The study was planned as a pilot and feasibility study to inform a larger scale investigation on the experience of hearing voices for young people and the influence of family systems on the way voices are appraised and managed.

Essential through our design of the research was the input and consultation offered by relevant expert-by-experience groups and organizations that provided us with invaluable input to ensure our recruitment strategies were appealing and acceptable to our participants. More specifically, we have benefitted from the advice and input of the Voice Collective (<http://www.voicecollective.co.uk/>), currently the only service specifically tailored to support young voice-hearers in the United Kingdom. Although it is thought that around 8% of young people will hear a voice or voices during their childhood, which makes voice-hearing a relatively common experience, the barriers to research participation that we discuss in this section have meant that we needed to be particularly creative in terms of participation options. It is for this reason we have focused upon Phase 1 of our research for this case study—the online surveys for young people and their parents/carers.

Method in Action

Our study has been ongoing since March 2017, and the web-based surveys are administered via the software Qualtrics to collect data by means of two parallel surveys from young people who hear voices (aged 13-18 years), and their parents/carers. The use of qualitative web-based surveys offers a participatory alternative to face-to-face interviews to promote distance inclusion, completely anonymous participation, and diverse sampling, and the anecdotal evidence we received indicated young people prefer online options to talk about the voices. When we were designing the study, we considered previous investigations with adult voice-hearers (age range 16 to 84; Woods et al., 2015), which highlighted online surveys (Salmons, 2015b) as an acceptable and effective approach for collecting qualitative data in this area through carefully designed open-ended questions. In addition, the Voice Collective has extensively and successfully used web-based platforms in their ongoing work with young people who hear voices. Given the scarcity of research data on voices for young people, the option of a purely qualitative survey for parents/carers and a separate survey for young people, which includes both

qualitative and quantitative items, was viewed as a meaningful strategy to gather a varied and rich sample of perspectives on this under-researched topic.

Recent considerations around the number of participants required for a thorough thematic analysis, particularly in health and social care, have indicated that low numbers of participants are not necessarily a methodological weakness, due to the depth of insight and individuality that can be maintained within small data sets (Fugard & Potts, 2015). Despite this, we set an ambitious minimum recruitment target of 40 responses, which we have since surpassed. This high target was selected because, prior to conducting the study, it was still uncertain whether this data collection method would have allowed for a level of content and contextual detail that is similar to that which can be achieved with other qualitative data collection methods (e.g., interviews). Because a study of this nature and with this population had not previously been conducted, we also did not know how many responses to the survey we might achieve. Hence, rather than aiming to achieve data saturation or theoretical saturation, we considered a recent model of information power in relation to the personal accounts sought through the surveys would be more appropriate (see Malterud, Siersma, & Guassora, 2016). The information power model values narrative depth, novelty, and the relationship between the aims of the study and data collected, research specificity, and the use of established theory. Therefore, this model was fitting to our approach because our surveys are based on existing theoretical information with the specific aim of exploring unusual phenomena, although the range of experiences we would hear about was not known at the beginning of the study. The responses to the qualitative surveys of the *Young Voices Study* are being analyzed using an inductive thematic analysis (Braun & Clarke, 2006; Guest, MacQueen, & Namey, 2012) to develop a contextualized synthesis of the varied accounts.

Online participation options have many benefits and, in this study, have proved the most successful participation route so far. However, there are risks and challenges too, which we discuss here:

- Participant safety is always a paramount concern when designing any research project or intervention, perhaps especially when working with young people who may be particularly vulnerable. Due to the online nature of this phase of the study, we felt it was

important that we provided comprehensive signposting information on all study information material and at the beginning and end of the online survey so that young people and parents could easily find further support and information. Our partnership with the Voice Collective also enabled us to establish a system whereby all participants could email the Voice Collective's support team directly if they wanted to talk through their experiences and seek further advice.

- Online survey participation options often mean that both researchers and participants are relying on the questions and answers presented in the online survey entirely when engaging with the process as additional live and dynamic communication between parties is not usually possible, as it would be in an interview, either in person or using online platforms (e.g., Skype). Therefore, ensuring that information is kept up to date, that signposting links are working properly, the option for participants to not answer certain questions, and adding an option to hear an audio track of the participant information sheet at the beginning of the study can be helpful ways to ensure a positive experience for participants.
- In a live interview, it is possible to ask additional questions, to see whether participants can elaborate on interesting points they make, and explore the experiences they discuss in a conversational way. However, appreciating that anonymity and the option to complete the online survey in stages is important for this participatory option; we have not included an online chat or messenger option. Consequently, it was particularly important that we asked the right questions to elicit the fullest responses possible. In this study, we sought the advice of colleagues, young people who hear voices, and looked to the existing literature to see what worked well.
- We also developed a new measure (the Manchester Voices Inventory for Children; MAVIC) to gain some quantitative data from the young people's survey so that we could gather as much information about their experiences as possible. We looked at existing measures for adults who hear voices, measures that had been previously piloted and published ([Haddock et al., 2011](#); [Jenner, Rutten, Beuckens, Boonstra, & Sytema, 2008](#); [Van Lieshout & Goldberg, 2007](#)), and considered how best to methodologically design the stages of the measure ([Goodwin, 2010](#)). In line with the heterogeneous and often benign nature of voices in children, the items of the MAVIC were designed to assess both

positive and negative features of voices and have helped us collect data we probably wouldn't have heard through only qualitative questions.

- In terms of advertising the study through social media, we have mostly used Twitter and Facebook. Overall, we have found Twitter to be helpful in terms of making contact with support groups, practitioners, advocates, and fellow researchers internationally, although Facebook seems to have reached more young people. As such, we chose to use some of our small marketing budget to buy a Facebook advert that would appear to young people in their teens and saw a sharp increase in survey responses as a result. In addition to a designated advert, another approach that seems to have been particularly helpful in terms of advertising our study and recruiting participants, particularly parents/carers, has been to disseminate information online early in the study. As one of the aims of the study was to raise awareness of our findings among accessible platforms, rather than only academic journals, we took opportunities early on to discuss our results through media channels. We found that participation rose sharply across the 10-day period following the release of each article, perhaps because the articles provided some context to the study and our approach as a research team. Utilizing available media platforms such as online blogs, newspapers, radio, and TV also seems to be a helpful means through which to aid recruitment, while disseminating preliminary research findings.

Practical Recommendations

- **Measures.** Be creative. If you can't find something you are looking for, have a go at developing something new based on peer-reviewed information you can find elsewhere. Although it is always important to use psychometrically sound and valid measures in quantitative research, the largely qualitative focus of our work allowed for greater "degrees of freedom" in terms of developing new measures to quantify certain features of voices. The newly developed MAVIC measure also provides further contextual information to interpret the data we gathered through the qualitative open-ended items in our survey.
- **Study Design.** Think big! If you are designing a study that may well pose recruitment challenges, think through everything you can do early on to remove barriers. This may mean having multimodal participation options and using technology (e.g., survey

software, Skype, mobile apps) to facilitate a wider recruitment area. Importantly, when developing an ethics application, make it very clear whether you intend to use social media platforms and how this will be done. We address social media specifically in the “Research Practicalities” section of this case study.

- **Get connected.** Partner with organizations that work in the field so you can seek their advice and support, establish an effective recruitment and dissemination strategy with them, and explore how else the research could have practical benefits for the people you are trying to reach.
- **Risk.** Risks are an inevitable part of much research and often require a great deal of consideration throughout the study. However, there are often ways to address potential risks and ensure a safe and positive experience for participants and researchers. In our study, our partnerships with third-sector organizations and liaison with a variety of Research Ethics Committees have been a very important part of this process.

Research Practicalities

This study is novel for three main reasons. First, the study involves both young people who hear voices and their parents/carers, thus offering an individual and systemic present-day perspective on voice-hearing for young people and a systemic insight into the impact for a family supporting a young person who hears voices. Second, the study offers an option for people below the age of 16 to participate without parental consent. Third, the study involves broad recruitment methods to offer inclusive platforms to participation. In what follows, we shall focus on these last two logistical areas.

Informed Consent for Under-16s

Young people of this age group have not been directly included in research on hearing voices before ([Woods et al., 2015](#)), although they do engage with (as yet sparse) services for young voice-hearers (e.g., the Voice Collective). Therefore, it is essential that their perspectives and experiences guide service provisions specifically developed for young people ([Holt, 2004](#); [Huang et al., 2016](#); National Health Service [NHS] England, 2016). As such, it was seen as important to provide inclusive opportunities for participation, which means traditional

recruitment routes through statutory health services and charities were arranged, as well as social media and online advertising. In addition, due to the social stigma surrounding voice-hearing and anecdotal evidence that young people often don't tell their parents about their voices for some time, if at all, it was important to find an alternative to the usual child assent and parental consent process for people below the age of 16.

There is limited existing literature surrounding inclusive ethical recruitment practices with young people who may not be able to gain parental consent for their involvement in research (Finkelhor, Hamby, Turner, & Walsh, 2016). Due to the online nature of the web-based survey, the processes of parental consent and the assent of the young person were not possible for several reasons. First, it was not possible for the research team to guarantee that participants were the age stated on the consent form. Second, the research team could not guarantee that parental consent had been obtained by participants through an online tick-box system. Third, based on clinical experience and consultation with research partners, the team were concerned as to whether a minority of young people may put their psychological health at greater risk by informing parents/carers of their voices through seeking consent for their participation in this study. For example, a young person may have developed voice-hearing as a coping strategy for psychological distress they are exposed to at home (e.g., domestic violence or bullying), for which they are seeking support through a service such as the Voice Collective. Consequently, the research team explored how to employ a practice of demonstrating the children and young people who would take part to demonstrate their Gillick competence before completing the online survey (Fallon, 2003). Gillick competence was originally a medicolegal term that has come to encompass a process by which a young person below the age of consent (16 years old) can demonstrate their ability to make an informed decision with the information to hand about their participation in treatment and research.

It is important to state here that the processes involved in demonstrating Gillick competence are neither straightforward nor streamlined, especially for psychological research. Legal and governance frameworks also vary across countries and states, and it is always essential to discuss any such processes with the relevant governing body. As we developed our participation process using this method, we made use of our clinical expertise and contacts to ensure a thorough consultation process had been undertaken. We then discussed our proposed

methods with an academic ethics and governance committee, who were also liaising with the university legal team. Our amended plans were then discussed with the ethics representatives of national children's charities in the United Kingdom, as we were keen to seek their advice. Finally, we developed a system with suitable safeguards in place, in collaboration with our partner organizations, that was processed through academic and NHS ethics committees. Following the recommendations made by the NHS ethical committee, we made some final changes, which were then approved by both committees, and then proceeded with recruitment. This process took 5 months in total and a great deal of liaison and consultation with colleagues and specialists in the field.

During the design process, we reviewed general developmental milestones and considered how best to establish the age brackets for our research. By the age of 10 (our lower age limit for study participation), most children have developed sophisticated language skills, being able to understand and generate complex sentences, and are often able to apply logic and reason, cause-and-consequence thinking to tasks (Mercer, Wegerif, & Dawes, 1999; Perner & Wimmer, 1985). Furthermore, based on the principle of justice in the Belmont Report (2014), children with appropriate cognitive skills should be offered the option of inclusion to participate, so as to not exclude on account of age alone. In addition, the Belmont guidelines around informed consent addressing information, comprehension, and voluntariness imply an ethical dilemma in that if young people are not provided with an inclusive platform for participation, ethical practices may be overlooked for the sake of convenience. Therefore, a process of informed voluntary participation based upon accessible information and the demonstration of comprehension of information and participation was developed for the online survey for young people.

Although the literature cites a number of ethical and procedural strengths and limitations around using comprehension tasks to assess informed consent with young people (Buccini, Iverson, Caputi, Jones, & Gho, 2009; Hochhauser, 2007), there remains no validated alternative to this process. Following discussions with leading children's charities and research committees in the United Kingdom, the research team explored how to develop a process for delivering information about the study and ascertaining how much young people understood about their participation through the consent form. Consequently, the research team developed a multiple-

choice comprehension task for the online survey, which was to follow the participant information sheet, offered in written and audio form through the online survey. However, when the proposed plans were presented to a specialist pediatric research NHS ethics committee, they confirmed that a series of single-answer questions would be sufficient to demonstrate Gillick competence, promoting a more accessible means of safe inclusion for young people below the age of consent to safely demonstrate their informed voluntary participation.

Employing Social Media for Recruitment

Thankfully, it is now generally accepted that children and young people should be given equal access to participate in research studies, as it is recognized that children should have the right to express their opinion in matters that affect them (Twycross & Smith, 2017). One means through which to raise awareness of research with young people is through social media. Social media as a recruitment tool for research purposes is growing and showing signs of great effectiveness in recruiting typically *hard-to-reach* populations (Gorman et al., 2014; Martinez et al., 2014).

Recruitment through statutory health services is the traditional route for recruitment in the field of acute mental health. However, this singular route of recruitment can mean that people who are coping well, managing by themselves with support of family and friends, or people no longer in contact with statutory services are not included, which can naturally bias results. Recruitment through particular health services can also be extremely time-consuming and very much depends upon how much time clinicians can spare to discuss research with clients. Social media platforms can offer a novel alternative and often reach a very different group of participants. The use of social media for research purposes has grown exponentially over recent years, largely due to a recognition that young people turn to social media to support their healing across various health areas. For example, Seltzer, Stolley, Mensah, and Sharp (2014) found that social media use was high and regular among childhood cancer survivors, with positive attitudes toward using social networking platforms for recruitment of research.

In the current study, we developed social media accounts on Twitter and Facebook so that we could share information about our study and research, as well as the work of other researchers in the area and self-help information for anyone who hears voices. These accounts

have provided a great opportunity to reach more young people than would have been possible using traditional methods. This platform is particularly important for studies such as ours that hope to hear from people who may have internalized social stigma toward their experiences. For example, through our survey responses so far, we can see that a lot of young people do not talk about their experiences of hearing voices for a long time after onset, sometimes for years. The online survey provides an opportunity for young people to discuss their experience anonymously and safely in their own time, without the fear of identification. Therefore, an online presence through social media for an online survey has been extremely useful to disseminate information about the study. This online presence has been further supported through the publication of short articles in mainstream and mental health online magazines based on our early findings. These publications also help to normalize these experiences, raise awareness of how common voice-hearing is among young people, and hopefully reduce some of the stigma surrounding voice-hearing as well.

Although there are many positive aspects of using social media when recruiting young people for research, there are inevitably challenges as well. The main challenges of recruiting children through social media are that surveys may not always be completed. It is not possible to control for such circumstances so important information may sometimes be lost. We have tried to overcome this by creating an online survey with Qualtrics that enables participants to save their responses and complete their entries at a later date. Also, we don't know the circumstances of the young people, and do not have chance to ask further questions that may come to mind while reading their responses. For example, some children may answer only briefly and so you do not have the opportunity to probe further as you would in a face-to-face interview. It is for this reason we have multimodal participation options, so that we can conduct interviews in person as well, thus gathering a richer and varied data set.

Equally, it can be difficult to gauge how much a child has understood in terms of certain questions. Just like working with adults through online research, the researcher is unable to be attentive to cues and cannot enquire further to a particular answer. To address these issues, we developed our survey questions with the help of young people and monitor the data carefully to see whether particular questions present difficulties for participants. Another challenge faced while using social media to recruit children has been the social networking site guidelines

regarding protection of rights, account registration, and safety. Research recruitment could infringe upon these guidelines, if not carefully followed. For example, site users must agree not to send or post unauthorized commercial, intimidating, harassing, discriminatory, misleading, or unlawful communications. In keeping with these safety measures, there are strict limits as to how many posts can be shared at any time, which need to be adhered to. Similarly, site users must agree to provide an authentic profile and additional information. As such, we created a profile for the study with relevant links, information about where the study is based, and the designated email address for the study. Useful guidelines concerning the use of social media for research purposes have recently been published by [Gelinas et al. \(2017\)](#), following an explosion of studies highlighting the benefits of such platforms for research (e.g., [Gorman et al., 2014](#); [Martinez et al., 2014](#)).

A Student's Reflection About Working on Pre-Existing Studies With Supervisors

Among the benefits of working with someone a lot more experienced than yourself is that it enables you to learn new techniques and gain more advanced knowledge about the research topic. For example, working with my supervisor has provided me with access to key resources, organizations, researchers, and institutions around the subject of our research, which has been beneficial to me in researching the topic more thoroughly and obtaining the most up-to-date information. Exposure to different perspectives has enhanced the quality of my work by enabling me to form a more critical and balanced view, to the benefit of the research.

Of course, there is always room for improvement in everything we do. Sometimes you may feel concerned that your work may not be adequate to meet the standards of more experienced researchers, and of course nobody wants to disappoint their supervisor. Such concern, however, can be a positive force, pushing and challenging you to improve the quality of your work and to stretch your own thinking. Working with a supervisor can help you to achieve your goals much more quickly and effectively than you could do by working alone.

Top Tips for Students

1. Don't be afraid to ask your supervisor if you need help or don't understand something: they are called a "supervisor" for a reason! They are there to help and guide you and would prefer you to ask them rather than struggle alone.
2. Think "outside the box": Although you will have instructions to adhere to, supervisors will always welcome new ideas and be happy to hear different perspectives.
3. Academics in universities are busy, often juggling research and teaching workloads, so anything you can do to help will always be appreciated. If you see something that needs changing or could be improved, then offer to do this! It may be an edit to a survey, perhaps organizing data; anything that can improve the access or smooth running of the research will be a great help.

A Researcher's Reflections on Working With Postgraduate Students and Research Assistants

Academics are almost always juggling the many different aspects of their jobs, as well as personal lives, so we are busy! This is often the case especially for early career researchers and clinicians because we often have a particular set of competing demands around establishing research careers, in addition to teaching or training program development and perhaps clinical work as well. As such, we are always grateful for help and support with our research projects and very much see collaboration with students as a mutually beneficial process. As early career researchers, our own training is also pretty fresh in our minds and so can often relate to many of the challenges postgraduate students experience and are happy to discuss our experiences and perhaps what we or colleagues found helpful. Finally, researchers also worry about the "good enough" factor! In academic environments that tend to nurture perfectionism and competitiveness, few people are immune from these concerns. A conversation early on in the supervisory relationship around expectations, what counts as good enough and who is responsible for what jobs in the research process, can often be a really helpful starting point.

Researcher Self-Care in Emotive Research

Any qualitative research in a sensitive area entails the possibility that analyzing the data may cause a level of distress. This is in fact very common and something most researchers who work in sensitive fields have experience of. Although there are many helpful resources available, such as those listed among the readings below, talking through difficulties and having an agreed self-care and supervisory process in place is key.

Exercises and Discussion Questions

1. What may be some of the risks for research terms in developing methods to include young people below the age of 16 without parental consent?
2. What may be some of the risks to research and evidence-based practice of not offering an inclusion option for young people aged below 16 who cannot gain parental consent?
3. How might social stigma act as a barrier to participation in research?
4. How might singular recruitment streams (e.g., only social media or only statutory mental health services) lead to biases in mental health research?
5. What may be some of the benefits of considering mental health difficulties from a community psychology perspective?
6. What are some of the ways in which early data can be used to promote participant recruitment and awareness of a research topic?
7. How can social media be used as a safe recruitment method, protecting both participant and researcher?
8. What are some of the challenges and benefits for students who undertake course-based research with members of academic staff (e.g., supervision, boundaries, dual roles, responsibilities, etc.)?
9. How can researchers employ reflexive writing to enhance their learning and well-being throughout their research projects?

Further Reading

- Bahn, S., & Weatherill, P. (2013). Qualitative social research: A risky business when it comes to collecting “sensitive” data. *Qualitative Research, 13*, 19-35.
doi:10.1177/1468794112439016
- Choi, I., Milne, D. N., Glozier, N., Peters, D., Harvey, S. B., & Calvo, R. A. (2017). Using different Facebook advertisements to recruit men for an online mental health study: Engagement and selection bias. *Internet Interventions, 8*, 27-34.
doi:10.1016/j.invent.2017.02.002
- NHS Involve. (2016). *Involving children and young people in research: top tips and essential key issues for researchers*. Retrieved from <http://www.invo.org.uk/wp-content/uploads/2016/01/involvingcyp-tips-keyissues-January2016.pdf>
- Parry, S. L., & Varese, F. (2017, June 14). Parents, don't panic if your child hears voices, it's actually quite common. *The Conversation*. Retrieved from <https://theconversation.com/parents-dont-panic-if-your-child-hears-voices-its-actually-quite-common-78964>
- Parry, S. L., Varese, F., & Djabaeva, R. (2017, July 13). Somewhere between “a great friend,” “scary” and “hard to explain.” *Iam1in4*. Retrieved from <https://iam1in4.com/2017/07/somewhere-between-a-great-friend-scary-and-hard-to-explain/>
- Parry, S. L., & Varese, F. (2017). Ten tips for parents of children who hear voices. *Mad in America*. <https://www.madinamerica.com/wp-content/uploads/2017/02/Ten-Tips-for-Parents-of-Children-Who-Hear-Voices.pdf>
- Rager, K. B. (2005). Self-care and the qualitative researcher: When collecting data can break your heart. *Educational Researcher, 34*, 23-27. doi:10.3102/0013189X034004023

Thornton, L., Batterham, P. J., Fassnacht, D. B., Kay-Lambkin, F., Callear, A. L., & Hunt, S. (2016). Recruiting for health, medical or psychosocial research using Facebook: Systematic review. *Internet Interventions*, 4, 72-81. doi:10.1016/j.invent.2016.02.001

Tomkins, L., & Nicholds, A. (2017). Make me authentic, but not here: Reflexive struggles with academic identity and authentic leadership. *Management Learning*, 48, 253-270. doi:10.1177/1350507616684267

Web Resources

A Little Insight—Young People who Hear Voices—YouTube:

<https://www.youtube.com/watch?v=17iJvz2rtSE>

About our study: <http://www2.mmu.ac.uk/news-and-events/news/story/?id=5393>

Coding in qualitative data analysis—YouTube:

<https://www.youtube.com/playlist?list=PL14E49EDF20613008>

ESTEEM practitioner resources: <http://www.selfhelp.org.uk/practitioners/>

Tonic & Tea: Self-care when conducting qualitative research:

<http://tonictea.blogspot.co.uk/search/label/academia>

References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.
- Buccini, L. D., Iverson, D., Caputi, P., Jones, C., & Gho, S. (2009). Assessing clinical trial informed consent comprehension in non-cognitively impaired adults: A systematic review of instruments. *Research Ethics Review, 5*, 3-8. doi:10.1177/174701610900500102
- Darbyshire, P., MacDougall, C., & Schiller, W. (2005). Extending new paradigm childhood research: Meeting the challenges of including younger children. *Early Child Development and Care, 175*, 467-472. doi:10.1080/03004430500131247
- Escher, S., Romme, M., Buiks, A., Delespaul, P., & Van Os, J. (2002a). Formation of delusional ideation in adolescents hearing voices: A prospective study. *American Journal of Medical Genetics, 114*, 913-920.
- Escher, S., Romme, M., Buiks, A., Delespaul, P., & Van Os, J. (2002b). Independent course of childhood auditory hallucinations: A sequential 3-year follow up study. *British Journal of Psychiatry, 181*, s10-18.
- Finkelhor, D., Hamby, S., Turner, H., & Walsh, W. (2016). Ethical issues in surveys about children's exposure to violence and sexual abuse. In C. A. Cuevas & C. M. Rennison (Eds.), *The Wiley handbook on the psychology of violence* (pp. 24-48). Chichester, UK: John Wiley. doi:10.1002/9781118303092.ch2
- Fugard, A. J. B., & Potts, H. W. W. (2015). Supporting thinking on sample sizes for thematic analyses: A quantitative tool. *International Journal of Social Research Methodology, 18*, 669-684. doi:10.1080/13645579.2015.1005453
- Gelinas, L., Pierce, R., Winkler, S., Cohen, I. G., Lynch, H. F., & Bierer, B.E. (2017). Using social media as a research recruitment tool: Ethical issues and recommendations. *American Journal of Bioethics, 17*, 3-14. doi:10.1080/15265161.2016.1276644

- Goodwin, C. J. (2010). *Research in psychology methods and design* (6th ed.). Hoboken, NJ: John Wiley.
- Gorman, J. R., Roberts, S. C., Dominick, S. A., Malcarne, V. L., Dietz, A. C., & Su, H. I. (2014). A diversified recruitment approach incorporating social media leads to research participation among young adult-aged female cancer survivors. *Journal of Adolescent and Young Adult Oncology*, 3, 59-65. doi:10.1089/jayao.2013.0031
- Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. London, England: SAGE.
- Haddock, G., Wood, L., Watts, R., Dunn, G., Morrison, A. P., & Price, J. (2011). The Subjective Experiences of Psychosis Scale (SEPS): Psychometric evaluation of a scale to assess outcome in psychosis. *Schizophrenia Research*, 133, 244-249.
- Hayward, M., Awenat, Y., McCarthy Jones, S., Paulik, G., & Berry, K. (2015). Beyond beliefs: A qualitative study of people's opinions about their changing relations with their voices. *Psychosis*, 7, 97-107.
- Hayward, M., Berry, K., & Ashton, A. (2011). Applying interpersonal theories to the understanding of and therapy for auditory hallucinations: A review of the literature and directions for further research. *Clinical Psychology Review*, 31, 1313-1323.
- Helseth, S., & Slettebø, Å. (2004). Research involving children: Some ethical issues. *Nursing Ethics*, 11, 298-299.
- Hesse-Biber, S. (2010). *Mixed methods research: Merging theory with practice*. New York, NY: Guilford Press.
- Hesse-Biber, S., & Johnson, R. B. (Eds.). (2015). *Oxford handbook of multimethod and mixed methods research inquiry*. Oxford, UK: Oxford University Press.

- Hill, M. (2006). Children's voices on ways of having a voice: Children's and young people's perspectives on methods used in research and consultation. *Childhood, 13*, 69-89.
doi:10.1177/0907568206059972
- Hochhauser, M. (2007). *Why you shouldn't test for consent comprehension*. Retrieved from <https://www.socra.org/assets/SoCRA-Source/Articles-for-web/Hochhauser-Why-You-Shouldnt-Test-for-Consent-Comprehension.pdf>
- Holt, L. (2004). The "voices" of children: De-centring empowering research relations. *Children's Geographies, 2*, 13-27.
- Huang, X., O'Connor, M., Ke, L., & Lee, S. (2016). Ethical and methodological issues in qualitative health research involving children: A systematic review. *Nursing Ethics, 23*, 339-356.
- Jenner, J. A., Rutten, S., Beuckens, J., Boonstra, N., & Sytma, S. (2008). Positive and useful auditory vocal hallucinations: Prevalence, characteristics, attributions, and implications for treatment. *Acta Psychiatrica Scandinavica, 118*, 238-245.
- Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies, 44*, 1250-1260.
- Lambert, S. D., & Loisel, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing, 62*, 228-237. doi:10.1111/j.1365-2648.2007.04559.x
- Lightfoot, J., & Sloper, P. (2002). *Involving young people in health service development, research works*. York, UK: Social Policy Research Unit, University of York. Retrieved from <https://www.york.ac.uk/inst/spru/pubs/rworks/sept2002-1.pdf>
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research, 26*, 1753-1760.
doi:10.1177/1049732315617444

- Martinez, O., Wu, E., Shultz, A. Z., Capote, J., López Rios, J., Sandfort, T., & Rhodes, S. D. (2014). Still a hard-to-reach population? Using social media to recruit Latino gay couples for an HIV intervention adaptation study. *Journal of Medical Internet Research, 16*, e113.
- McGarry, O., & McGrath, B. (2014). "A virtual canvas": Designing a blog site to research young Muslims' friendships & identities. *Forum: Qualitative Social Research, 14*(1), Article 1.
- Mercer, N., Wegerif, R., & Dawes, L. (1999). Children's talk and the development of reasoning in the classroom. *British Educational Research Journal, 25*, 95-111.
- Midgley, N., Parkinson, S., Holmes, J., Stapley, E., Eatough, V., & Target, M. (2017). "Did I bring it on myself?" an exploratory study of the beliefs that adolescents referred to mental health services have about the causes of their depression. *European Child & Adolescent Psychiatry, 26*(1), 25-34. doi:10.1007/s00787-016-0868-8
- Perner, J., & Wimmer, H. (1985). "John thinks that Mary thinks that . . ." attribution of second-order beliefs by 5- to 10-year-old children. *Journal of Experimental Child Psychology, 39*, 437-471.
- Phalen, P. L., Warman, D. M., Martin, J. M., & Lysaker, P. H. (2016). The stigma of voice-hearing experiences: Religiousness and voice-hearing contents matter. *Stigma and Health*. Advance online publication. doi:10.1037/sah0000075
- Romme, M., & Escher, S. (1993). *Accepting voices*. London, England: Mind Publications.
- Romme, M., & Escher, S. (2000). *Making sense of voices*. London, England: Mind Publications.
- Romme, M., Escher, S., Dillon, J., Corstens, D., & Morris, M. (2009). *Living with voices: Fifty stories of recovery*. Ross-on-Wye, UK: PCCS Books.
- Salmons, J. (2015a). Chapter 29. Conducting mixed and multi-method research online. In S.-H. Biber & B. Johnson (Eds.), *Oxford handbook of mixed and multimethod research*. Oxford, UK: Oxford Press. ISBN: 9780199933624
- Salmons, J. (2015b). *Qualitative online interviews*. Thousand Oaks, CA: SAGE.

- Salmons, J. (2016). *Doing qualitative research online*. London, England: SAGE.
- Seltzer, E. D., Stolley, M. R., Mensah, E. K., & Sharp, L. K. (2014). Social networking site usage among childhood cancer survivors—A potential tool for research recruitment? *Journal of Cancer Survivorship*, *8*, 349-354. doi:10.1007/s11764-014-0348-4
- Stewart, D. W., & Shamdasani, P. N. (2015). *Focus groups: Theory and practice* (3rd ed.). Thousand Oaks, CA: SAGE.
- Twycross, A., & Smith, J. (2017). Undertaking research with children and young people. *Evidence Based Nursing*, *20*. doi:10.1136/eb-2017-102619
- Van Lieshout, R. J., & Goldberg, J. O. (2007). Quantifying self-reports of auditory verbal hallucinations in persons with psychosis. *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement*, *39*, 73-77.
- Varese, F., Morrison, A. P., Beck, R., Heffernan, S., Law, H., & Bentall, R. P. (2016). Experiential avoidance and appraisals of voices as predictors of voice-related distress. *British Journal of Clinical Psychology*, *55*, 320-331.
- Vilhauer, R. P. (2017). *Stigma and need for care in individuals who hear voices*. London, England: SAGE. doi:10.1177/0020764016675888
- Woods, A., Jones, N., Alderson-Day, B., Callard, F., & Fernyhough, C. (2015). Experiences of hearing voices: Analysis of a novel phenomenological survey. *The Lancet Psychiatry*, *2*, 323-331.