Raising Voices in Research: Local Plan for Research

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Introduction

The following Local Plan for Research was co-designed by voluntary, community and social enterprise (VCSE) organisations as part of their participation in ‘Raising Voices in Research’ from January – April 2023, with the purpose of outlining how these communities want to be engaged in research because they are experts in their own lived experience. Therefore, this plan should be used by local researchers as a guidance document to inform practice when seeking to engage with the represented communities.

The VCSE organisations involved provided invaluable insights that will reflect the experiences of many within their communities. However, it is important to recognise, they will not represent all the experiences and views of these communities. Therefore, as stated above, the following plan should be used as a starting point; all communities should be consulted with before beginning research, as each will have specific needs that could not all be captured within this project.

To produce the following plan Action Hampshire analysed all the data collected by the organisations involved, from which 7 themes were uncovered. These are considered main themes, as they were consistently discussed across many of the groups. Any nuances or important additional information has been noted later in the plan, where each organisations’ individual needs and considerations are provided in more detail.

Main Themes

1. Incentives

The community groups shared two main elements that either have or would encourage them to participate in research. The first is **financial compensation**, which participants felt highlights the value of their contributions and ensures they are receiving recognition for sharing their lived experiences. The second element is **making a positive difference.** Some shared that being able to see the impact of their contributions or knowing it would help other people and wider causes would motivate them to participate.

2. Feedback

Some groups felt research is often only one-way and their data was collected for the researcher's benefit, with no benefit or acknowledgement for participants. To address this issue, participants shared they would like to **receive feedback on the research outcomes**, so they are able to see how their participation has impacted the research or evidence how their insights have been listened to. These reasons link to communities' motivations for participating in research (i.e. knowing they have made a positive difference), further demonstrating the importance of keeping participants informed throughout the research process. One group suggested researchers should consider and answer the following questions:

- What will feedback look like?
- When will we give feedback?
- Who will report this back to participants?
- Where will the research be used?

Another group stated it was important for researchers to consider how participants can share feedback on the research process.

3. Effective Communication

It is important to many of the community groups that **messages and questions are clearly communicated**, **using simple language** and, when engaging with specific communities, **the correct language**.

In particular, **sharing the purpose of the research** with potential participants before they take part is very important to some groups, as they felt this would increase their understanding of why their participation is important. Furthermore, participants indicated they are wary about questions regarding their personal information, so **explaining the purpose of demographics questions** (i.e. how they are linked to the purpose of the research), can ensure participants are more comfortable sharing this data.

For some the **use of technology** in research was important but for others this was an excluding factor, evidencing the importance of selecting the most appropriate methods dependent on the target group (more detail is provided on this in the sections below).

4. Trust

Trust was highlighted as an important element of engaging community members in research. Firstly, some groups had a **lack of trust in research** due to previous negative experiences (such as no continuity of projects). Others worried about the potential for researchers to have an agenda, suggesting that **all views must be listened to and accounted for**, not just those that align with the researchers'. These views demonstrate the importance of embedding 'incentives', 'feedback', 'effective communication', 'data protection', 'respect', and 'transport', as actioning the communities' wishes will evidence communities' voices have been actively listened to, in turn building trust.

Engagement through an existing community group or community leaders associated with the group, will help encourage participation in research because community members have already built trust with these people. Some groups stated they feel more comfortable engaging with their community group in a **community setting** as it provides a familiar environment and is with a group of people they already know, including community group leaders who already understand their needs.

5. Data Protection

There are many layers to the concerns community members had around data protection in research. Firstly, some community groups were worried about potential scams and need **confirmation that research opportunities are genuine**. Such insight links to the theme of trust and further demonstrates the importance of engaging with potential participants through existing community groups/leaders as they are trusted sources of information. Moreover, participants want to ensure their personal data is kept safe, with **concerns about potential hacking and who has access to the data** (and in turn how those with access would use their data, such as impacting their access to benefits).

Also within this theme is the **need for confidentiality and anonymity**, as many indicated the importance of knowing whether they would be identified/identifiable within research. The reasons for this varied between groups (as discussed further below), but the main concerns were around being linked to the information they share and reducing anxiety about participating.

All of these concerns must be addressed before engaging with communities, and a **plan for data protection/storage should be shared** too.

6. Respect

Respect was identified by many of the groups as a value researchers must adhere to when undertaking research. To the community groups, showing respect is:

- Treating everyone as equals
- Being non-judgemental
- Acknowledging all/different views and lived experiences
- Avoiding stereotypes

7. Transport

Some community members shared they do not have the means to get to places where research is conducted. Therefore, either **providing transport, reimbursing travel expenses, or the option of being able to participate at home** (as some have caring responsibilities too) can ensure their participation is still possible.

As referenced throughout there were nuances within each theme, which is expected with such diverse groups of people. These are shown in more detail below, as a summary of the main points from each community group is presented.

Specific needs and considerations raised by Sight for Wight

Theme/Lived experience: Physical disability

Practicalities of accessibility

- Members are more likely to engage with face to face or telephone methods of data collection, as these methods are person centred. If possible, members would like to receive the interview guide/survey in advance so they can prepare their answers.
- Regarding surveys, scale questions are not appropriate due to being “too much” from a visually impaired perspective, and often people find them confusing. If using a survey, members should be provided with a nonvisual aid to judge the length of the survey and the font size used needs to be bigger/big enough. Particular colour combinations cannot be read by the visually impaired community, which needs to accounted for when delivering a survey and general research communications.
- Discussing particular experiences can be tiring and bring up negative feelings. Therefore, participants should be signposted to/given support after participating in research.
- Ensuring accessibility is extremely important and builds trust with members if done correctly.

When drafting research, Sight for Wight members suggested researchers should consider the following questions:

1. Has the number of questions been limited to those that are necessary?
2. Are the questions easy to understand and easy to answer?
3. Is there equality between electronic, accessible, and paper-based documentation?
4. Have an appropriate number of people been invited to participate?
5. Has the survey been evaluated for accessibility involving people who can make it accessible at the earliest possible stage?

Additional information regarding the main themes:

Incentives – members shared that a visually impaired person requires more time to participate in research and the incentives should reflect this.

Effective communication – using research methods as described above and ensuring the purpose of the research and demographics questions are stated.

Trust – Sight for Wight and the Isle of Wight Council were trusted sources of information for members, so they would be happy for these organisations to facilitate participation or engagement in research. Members also indicated that collaborative approaches to research reassure them researchers do not have a hidden agenda.

Transport – on the Isle of Wight this is a particular issue, members often have to rely on friends for lifts and some do not want to travel off the Island; a consideration for researchers when seeking members involvement in research.

Data protection – most members would prefer their participation in research not to be filmed/recorded.

Specific needs and considerations raised by St Denys Activity Group

Theme/Lived experience: Minoritized communities and mental health

Experiencing racism

- Some members shared particular experiences of racism within medical settings, such as a lack of understanding and awareness which has led to health inequalities. Researchers should be aware of and sensitive to these experiences when engaging with BAME communities.
- Additionally, members stated researchers should not use stereotypes to inform decisions or make assumptions about BAME communities.

Additional information regarding the main themes:

Incentives – taking part in research should be of benefit to the participants too, including the research outcomes which should benefit people of colour and not just one group. The research opportunities offered to members should be relevant to them. In particular, members of St Denys Activity Group would like to see more research undertaken on the side effects of mental health medication for BAME people.

Trust – transparency is important, meaning who is sponsoring or funding the research should be openly shared or stated before participation.

Data protection – members were concerned about their personal data being sold to third parties or being accessed by others, affecting their access to statutory services. Researchers should seek to alleviate these worries and address any concerns when engaging with BAME communities.

Specific needs and considerations raised by Basingstoke Hindu Society

Theme/Lived experience: Minoritized communities

Suitable timing

- Communicating with members to select suitable dates and times for participation and potentially connecting research into existing community events would support their involvement in research.

Additional information regarding the main themes:

Effective communication – the group suggested only relevant/key information needs to be shared in researchers' first contact with community members, as concise communication is preferred. It is felt that too many emails are sent these days and other methods of interaction are important to use too. Advance information about what their participation will require is important to this group's engagement.

Incentives – free refreshments are also appreciated by this group, in addition to a financial incentive.

Feedback – providing feedback on how their insights have been used within research is particularly important to members of Basingstoke Hindu Society.

Specific needs and considerations raised by Solent Mind

Theme/Lived experience: Mental health

Acknowledging different needs

- Members felt researchers should provide different ways to get involved in research, avoiding a ‘one size fits all approach’.
- Other considerations including allowing flexible timings and being understanding of the fact some community members may be too unwell to participate in research on the day it takes place.

There are many health and wellbeing issues that matter to members:

- Mental health and learning needs/disabilities – this must not affect benefit entitlements
- Investigating the boundaries in access support and why people are “falling between the cracks between services” – severe or borderline assessments and help
- Peer support for healthy activities (e.g., exercise, getting out and about, food shopping and meal preparation)
- Social isolation
- Support for carers
- Judgment, stigma and the impact this has on wellbeing
- Longer term treatments, continuity, and continuation of care
- Social prescribing

Additional information regarding the main themes:

Respect – being non-judgemental and showing respect are particularly important values for researchers to uphold, as members’ concerns regarding research are related to shame, judgement, and stigma around mental illness.

Incentives – Solent Mind members had other personal motivations for participating in research, such as feeling a sense of self-worth, having a voice and validation, and using the opportunity as a social activity. However, financial support and travel expenses were still important to members, particularly due to the cost of living crisis.

Specific needs and considerations raised by Drop the Mask

Theme/Lived experience: Neurodiversity and mental health

Online research participation

- Members suggested they would prefer to participate in research online because they would feel more comfortable, confident and less anxious participating in their own home, it would allow them to remain anonymous, and it would make the research more accessible for those unable to leave the house.

Specific topics members would like to see more research on included alcoholism and relapse triggers, mental health, and the impacts of VCSE sector workplace on neurodiverse people and those with mental health issues.

Additional information regarding the main themes:

Effective communication – The use of technology was important to this group, as it was suggested it could be used to communicate more effectively (particularly regarding the tone of messages). Additionally, members would prefer to approach researchers about topics they are interested in (such as an open day about research), rather than be asked to participate in something they are unsure about.

Incentives – there were concerns raised around gaining reliable and valid data when using financial incentives in research, although other members shared this type of incentive would be appreciated and could help them to feel valued. However, members of this group said they would be primarily driven by their personal link to the research and its impact on themselves or people they care about.

Feedback – one member of the group had previously participated in research, where they received a newsletter sharing feedback/outcomes and thanking them for their contribution. The group saw this as a great method of feedback, as it would reassure them their contributions had been noted.

Specific needs and considerations raised by Yellow Door

Theme/Lived experience: Young people and neurodiversity

Acknowledging different needs

- Members felt researchers should provide different options for people to choose how to participate in research, to acknowledge varying needs.
- A fixed time to complete research activities is unhelpful and does not accommodate different needs.
- In addition to physical needs, members highlighted the importance of being aware of emotional wellbeing too. Particular questions may raise difficult feelings, so it is important for researchers to signpost/provide access to support after participation.

Specific topics members would like to see more research on included support for children and young people with gender dysphoria, and autism and ADHD, as many members of the group have lived experience in these areas.

Additional information regarding the main themes:

Data protection – it would be necessary for members to know whether they were being filmed/recorded as part of the research process and where it would be shared/who it would be shared with. For some members, they would not want to be photographed or filmed at all and remain completely anonymous.

Trust – members of this group were concerned about whether research opportunities were genuine, with teachers, youth worker, therapist, and service facilitator all seen as trustworthy sources.

Effective communication – questions proposed should be kept simple as complex information can be overwhelming for members of the group.

Specific needs and considerations raised by Bantaba4change

Theme/Lived experience: Minoritized communities

Suitable timing and space

- Researchers must consult with community members about the timing of activities in order to reach as many people in the community as possible.
- Undertaking research activities during school hours should be avoided due to members caring responsibilities.
- Additionally, members often prefer participating in their local area.

Specific topics members would like to see more research on is mental health and domestic violence.

Additional information regarding the main themes:

Incentives – in addition to the findings in the main theme, members would also appreciate a certificate of participation if they have taken part in a community research project, as it evidences the skills they have used or gained.

Respect – researchers must respect cultural and religious differences, in addition to differences in lived experiences.

Trust – this group shared that continuity of projects is not common, which could perhaps lead to distrust in the community. Therefore, it is important to feedback the outcomes of research to the community (which links into the main theme of **feedback** too).

Effective communication – face to face is the preferable method of communication, however, members are increasingly using Whatsapp groups and Facebook. Not all members would like their participation to be filmed/recorded, so researchers should consult members when looking to do this. Using simple language and different languages, where appropriate, were highlighted as other important aspects of communication that should be considered by researchers. Moreover, it was shared that this community often gets approached to participate in duplicated activities, which can be frustrating. Therefore, members suggested researchers should collaborate with other researchers, to reduce duplication and requests to participate.

Specific needs and considerations raised by Age UK Portsmouth

Theme/Lived experience: Older people

Opportunities for engagement

- Community members have lots of engagement within medical settings, which they felt were potential opportunities to be informed or approached about research. However, members had not received requests to participate in research, despite their interest.
- Potential opportunities for research engagement included: daytime appointment visits to hospital; hospital letters before and after appointments; length of time in waiting room; visits to pharmacy; annual GP check-ups; NHS App for prescription renewal.

Additional information regarding the main themes:

Effective communication – one member had wanted to participate in research but could not as only digital methods were used. It is very important that research with this group is not solely digital, as this would make it completely inaccessible. Research opportunities should also be clearly signposted, as members could not find information on the NHS website.

Trust – previous negative experiences with the NHS meant members were worried about being ‘let down’, something which could deter them from participating in research.

Specific needs and considerations raised by Winchester Go LD

Theme/Lived experience: Learning disabilities

Practicalities of accessibility

- Multiple choice and using scales are types of questions some members find difficult to answer.
- Due to different levels of understanding, it was suggested that grouping people with a learning disability together may not always be the best method.
- Tailoring to suit individual needs.

- Family members play an important role in supporting to find and participate in research projects.

Masking

- The group facilitator reported some community members may give pre-conditioned answers, based on what they believe to be the right answer, termed ‘masking’.

Additional information regarding the main themes:

Effective Communication – face to face communication was preferred by most members as some had worries around not understanding computers or websites and others did not want lots of emails. One barrier to research was the interpretation and answering of questions.

Specific needs and considerations raised by Recapture Life

Theme/Lived experience: Carers

Capacity

- Members have little time for themselves and any time they do have it is important for them to use that time for themselves to maintain their mental health. Therefore, they do not have much time to participate in research and researchers should be aware of this when looking to engage carers in research.
- Research requires a lot of emotional and mental resource, which members do not always have as they use most of their emotional and mental capacity caring for someone else.
- Looking after the person the member cares for would give members time to participate and support them to concentrate on the research.

The group were keen to continue having a voice and want to see more research done on the diversity of needs and symptoms regarding dementia and the experiences of male carers.

Additional information regarding the main themes:

Effective communication – online platforms, such as Zoom, are not always accessible, so face to face participation was preferred by most members.

Respect – each member is different with different opinions and needs, so it is important to listen to everyone.

Trust – due to previous experiences, members were worried about researchers having a hidden agenda. It was highlighted that actively listening to members is very important and should perhaps be done by someone who shared their lived experience.

Transport – members would assess if research was near to their home and easy to get to and would want to ask if researchers could come to a location convenient for them.

Specific needs and considerations raised by Disabled People's Voice

Theme/Lived experience: Disabilities

Accessibility

- Information should be shared in accessible format and research venues should be accessible too, including wheelchair accessibility.
- Adequate support should be provided after the research is complete.

Wasting time

- Linked to the main theme of trust, members were worried research opportunities require a time commitment which may be a waste of their time.
- Some members worried research would not be taken seriously as it was just a superficial exercise to make it appear the researchers were consulting disabled people on their views, rather than actually listening to members.

A couple of members expressed worries about the side effects from medication in clinical trials.

Specific topics members would like to see more research on included (but were not limited to) disabled people's experiences of social isolation, visually impaired people’s experiences of sleep problems, and research on autism conducted by autistic researchers.

Additional information regarding the main themes:

Incentives – in addition to being motivated to participate in research that is relevant to their personal experiences, members also would need to be paid or given vouchers for their time. Some members highlighted that researchers should cover the cost for a Personal Assistant in Care’s time.

Effective communication – evidence that the research will benefit members and is not “just a tick box exercise” should be shared with members. As identified in the main theme, members need information to be communicated in a simple and clear way, to support their participation in research.

Trust – members raised concerns that their views could be misrepresented, or their stories not told properly. To address this, one member suggested researchers could take the views of disabled people into account by having an advisory group made up of people with the same lived experience as those being researched.

Respect – as well as those with lived experience being recognised as equals in research, members suggested researchers should have disability awareness training.

Data protection – many members were concerned about data protection, suggesting researchers should: make clear how data will be used; allow participants to review what has been written before publishing; and share clear guidance on the responsibilities of each party.