

Appendix A

What we already know about how people want to be involved

Over the last 18 months, work has taken place across a variety of partner organisations where there has been a theme or link to involvement in general terms. It is important that we acknowledge and use all available resources and assets where this is appropriate, and in this context, we acknowledge the work done by the following organisations.

- CYP voice – connected to the Health Equity Collaborative work which includes SY
- Octa – Call to action
- Engagement Charter for the engagement of Children and Young People in Barnsley’s Mental Health and Wellbeing Services.
- General YP
- The South Yorkshire Children and Young People's Alliance Key Vision and Aim, August 2023
- Feedback from the People and Communities Strategy
- Working Together in Research workshops: Themes relevant to engagement
- South Yorkshire and Bassetlaw Integrated Care System Insight into the experiences of all populations of services for Antenatal and Postnatal Maternity Services Evaluation report summary document
- BAME Women’s Health workshops

The key themes emerging from this are:-

- **Relationships and trust are important in all the work considered.**

Building trusted relationships is vital to solid involvement work. This needs to determine the nature of the work, where ongoing conversations with familiar trusted partners are seen as far more positive than one-off calls for involvement, and far more likely to elicit a response.

Communities and organisations want – and need – to work with familiar people who understand the community issues. We (statutory organisations must work with honesty and openness, and be able to build shared values, aims and priorities with the communities we work with.

- **Accessibility and process**

A lot of comments from different organisations centred around how we can ensure that we meet a variety of different, and sometimes conflicting accessibility needs. It is clear that there is no ‘one size to fit all’, no one format, venue or time that works for everyone. It is also important that we go to people where they are, and where they are comfortable, and safe, but without forcing or intruding on communities, people and organisations. Each community or organisation will have different preferences, and ideally organisers would work with the target community to plan sessions where, when and in the format preferred – or could potentially devolve that action to the relevant community lead.

Most bodies referred to language, the use and avoidance of jargon and large amounts of text; accessible language should be used whenever possible, and explained if necessary. We need to check with communities if translators are needed, and resource this.

People liked and valued interesting, interactive and creative ways to involve people, and using a variety of different methods, no one method is right for everyone.

We need to involve people and communities as early as possible in pieces of work, not bring things nearly complete to be ‘signed off’. As part of this, we need to offer appropriate support and training, and resource this where needed, building capacity, knowledge and skills as we develop this approach. Decision makers need to be part of the involvement process, ideally in the room, showing that they are really listening to people.

Importantly there needs to be enough time given to make sure that involvement is real and meaningful, both in terms of the time communities and organisations need to plan, build and

prepare and in enough time in any meetings or events, acknowledging that informal communities meetings and activities can take longer than formal 'business' meetings

- **Principals and Values**

There was a strong message that having your voice heard is a right, not a favour; this needs to be reflected generally in how we ask people for their time and involvement. This is a right that applies to all, we need to ensure an equal voice to all, not just the loudest, most resourced and confident voices. In addition, we need to avoid duplication, sharing outputs and insight where we can. Our activity should not be seen as taking out of communities, but putting in and adding value, building knowledge, skills and resources, as well as services that meet people's needs.

Equally important was the acknowledgement that people want to be involved in improving the services that impact their lives directly; people want to be a part in shaping the things that are important to them, however these may not be our priorities. Linking into this, it is important that we work with people and communities with clear and shared aims within involvement work and projects.

We need to demonstrate clearly how we value and use people's lived experience, and the value we place on involvement. This could be in a number of ways, though allocating resources to VCS bodies, through attractive events, through offering training, vouchers or payment. A key part is also demonstrating the importance of participation and involvement by having the decision makers in the room, or a clear pathway to the decision makers, and providing timely and solid feedback on decisions and actions.

Summary of key points from all the documents – colour code is at the end

Relationships and trust came through as important in all the work considered

- Trusted relationship
- Genuine
- Build relationships
- Open and friendly
- Treat people with honesty and respect
- Value meaningful connections, real conversations, show that people care
- Honesty
- Valued
- Trust
- Familiar people/people I feel comfortable with
- Knowing people care
- Shared values
- It needs to be transparent
- Relationships, trust were cited frequently
- No relationships/trust; feeling used.
- People won't get involved if they think they have heard it before, but nothing has been done
- Trust/collaboration/relationship important
- Most of the individuals consulted during this review were highly vulnerable for a variety of reasons. Many were not comfortable with an 'outsider' speaking to them. This was tackled by organising focus groups lead by a project manager familiar to those consulted to sit with them and talk them through everything we were doing. The project manager helped facilitate the questions and we took the notes and feedback.
- There was a lack of institutional trust - the groups often feel like their views are not truly valued and expressed concerns that they were only being asked to 'tick another box'. One support group said 'We only agreed to do this because it is yourself [SYCF] asking for help'.
- An open and honest approach, building relationships and trust was important
- Work towards a system of community researchers/activators/engagement champions?
- The women wanted to keep an open conversation, not meeting so often that it became onerous, but ongoing contact, voice and access was important

Accessibility

- Interpreters
- Avoid jargon
- Tone of communication
- Communication not written in a culturally sensitive way
- Written information not being available in different languages
- Interpretation
- Big words and jargon (mentioned several times)
- Putting clinical terminology into community languages; the number of languages
- Difficulties in translating one community language into another
- Interpreting concepts; simple translation doesn't work without context, also context changes possible meanings, for example not knowing how health system works
- No translation available – we tend to approach English speakers only
- Translation costs mentioned several times
- Focus and resources often target 'popular' languages- need to be specific for community
- Reliance on family members to translate/views impact on translation and privacy
- Making assumptions that someone speaks/writes xxx language
- Sign language is not written
- Literacy

- No spoken language/LD/Autism/non verbal
- People might not read the language they speak
- Resource for translation / Funding for resources in different languages
- Access to translators for some community languages, ie those less commonly spoken; and ensuring quality of translation
- Use everyday words/plain English/ Easy read
- Researchers who speak community languages/BAME researchers
- Don't use hierarchical language – ie top down, bottom up
- People used and liked diagrams to explain things, and felt they could be used more

Other Barriers

- Digital access for some people remains poor
- A discussion was preferred to a lot of written text
- One of the biggest barriers was found to be that Black, Asian and other minoritised ethnic communities don't share or talk about personal issues including their health even when informed that their thoughts would be invaluable.
- It was hard to ensure that ethnic minorities and people with disabilities were given a voice.

Principals and values

Validation

- Having your voice heard is a right not a favour
- Validate experiences
- Value lived experiences
- Deal with prejudice
- People want to be involved in designing and improving services that impact them.
- Not Tokenistic
- Don't just hear the positive comments
- Knowing the results of what we did and that something will happen as a result
- Feel that my voice has been heard
- Feeling that it made a difference

Inclusion

- Make sure people know there is an invitation to take part in consultation / engagement taking place
- All are involved and heard
- Included
- Equal voice
- Equality of thinking
- Equal authority
- People are believed
- No-one is excluded
- Clear representation
- Everybody is different
- (everyone is) Valued and listened to
- Go to where people affected are, including healthcare settings, community spaces and leisure and retail spaces.
- Lack of understanding, information, previous negative experiences hinders involvement
- It should involve the right people in the right way at the right time
- Involve the right people; acknowledge demographic bias – ie the more confident people, and those with skills and personal resources are most likely to come forward

Avoiding Duplication

- Community fatigue is real - address this by finding ways of better sharing insight and information and avoid duplicating work
- Having a “one stop shop” portal for NHS South Yorkshire to promote all involvement opportunities including the outcomes of previous involvement exercises

Other

- Neutral perspective
- Safe space
- Work is often ‘extractive’ – i.e. it takes out but doesn’t give back

Process- How to involvement; practical issues

Interesting & creative activity relevant to people

- Creative mechanisms -Use story telling and drama for example
- Engaging – interesting activities
- Interactive engaging process
- Accessible and diverse ways to engage
- Make it interesting
- Not boring and formal
- Interactive activities
- Not too formal (what people wear and the way the event works)
- Not dull, soulless and corporate
- There should be a mix of ways for people to have their say for any given involvement
- Work in ways preferred and valued by the community
- Technology, tablets
- Community champions
- The sessions that worked best were very interactive; for example, demonstrating breast examination on models, and using visual aids

Clear aims

- Clear goals
- Being clear about the aims and objectives of the involvement so that everyone would know what the value of their contribution was and how it would influence decisions
- Avoid over consulting
- Open discussions

Support to include

- Chat before meeting (briefing)
- Know what happening in advance
- Not understanding whats happening, no info beforehand
- Hard to join in
- Info before and afterwards
- Training so people understand participation and their roles
- Find the middle ground in competing ideas

Listening

- Active listening
- Really listen to people
- Listened to
- Assurance that you are listened to/info will be used
- Not being asked questions directly/put under pressure to share views or experiences
- People able to speak without interruption

- Active listening

Decision making

- Include people in decision making, not just consultation
- Top decision makers in the same room and actually listening, demonstrating interest
- Young person/service user led
- Involving people as early as possible in any decision-making process and offer them opportunities for continued involvement (so that there is potential involvement from planning stages through implementation and evaluation).
- Making sure that decision-makers were bought into the process of community and stakeholder engagement from the onset.
- It has to have a clear pathway to and from decision-makers so that people know who is responsible and accountable

Real partnerships

- Work as a team
- Working together
- Setting up more opportunities for there to be genuine co-production of solutions between patients and professionals
- Don't tick boxes
- Co-production – everyone has a different interpretation of what this is

Subjects for engagement

Topics should be those most important to the community; some topics may be taboo

The subjects were determined by the women, not dictated by services – they attended because the subjects were important to them

Value and appreciate people and their contribution,

- Show appreciation
- Give credit
- Reimburse travel
- Development opportunities
- Offer refreshments, rewards, credits, certificates
- Celebration events
- Demonstrate lasting and visible change
- Pride when able to contribute to change
- Paid for time
- Reimburse people
- No cost to me
- Make the experience positive; for example people felt they learnt something, they remembered the session afterwards, they met new people, or went away smiling
- Freebies, goody bags or food; gift card
- Activity must be cost neutral for individuals and VCS bodies
- Funding and resources allocated pre-involvement; ie to support development and capacity building
- We rely on participation through goodwill and people giving freely of their own time- and potentially resources; ie travel. VCS bodies or individuals might provide tea and coffee out their own budgets etc

- Funding and the VCS – acknowledgment that VCS bodies are in many cases struggling for funding, and don't have the resources and capacity, and flexibility, that they had previously
- Acknowledge constraints within VCS bodies ie timescales imposed by funding regimes and they may not have the flexibility to respond quickly to initiatives

Follow up and feed back

- Make sure the suggestions and ideas are heard
- Let people know when and where you will use their work
- Manage expectations
- Honesty about what can and cant be changed
- Follow up and feed back
- follow up and feedback
- Debrief or feed back
- Feedback
- Continuous feedback
- Keep updated
- Feeding back the outcome and impact of any involvement and engagement exercise both to those who had taken part and the wider public and stakeholder communities

Other issues

The impact of the significant rise in the cost of living and managing to keep accommodation, and felt that the general stress of managing day to day to be a huge pressure

Service issues

- the lack of gender and transgender services and support
- they felt eating disorders don't just need to be about being seriously ill and more should be done in this space
- access to health services in general is very difficult, they described access to GPs etc as particularly challenging

Access to dentistry services and impact on people

Engagement -Hard to define engagement; NHS use involvement; Overlap with participate etc. Context is important. Could define as a spectrum. Consultation has specific legal meeting for statutory bodies. Co-production often used to mean co-design or involvement.

'Being Involved in something'

Colour code – who said what

CYP voice – connected to the Health Equity Collaborative work which includes SY

Octa – Call to action

Engagement Charter for the engagement of Children and Young People in Barnsley's Mental Health and Wellbeing Services.

General YP

The South Yorkshire Children and Young People's Alliance Key Vision and Aim, August 2023

Feedback from the People and Communities Strategy

Working Together in Research workshops: Themes relevant to engagement

South Yorkshire and Bassetlaw Integrated Care System Insight into the experiences of all populations of services for Antenatal and Postnatal Maternity Services Evaluation report summary document

BAME Women's Health workshops