Community Voice in Action

INFORMATION BOOKLET

Delivered by

KINGSTON VOLUNTARY ACTION

Kingston University London

RVIR
Raising Voices in Research

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Contents

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Demystifying Health & Social Care Research

This part of the booklet summarises the key messages shared from the 'Demystifying Health & Social Care Research' section of the Introduction Call, led by Caroline Tiza Senior Engagement and Inclusion Manager, Research from University Hospital Southampton Foundation Trust. These key messages need to be shared with your community members in your first workshop, as indicated later in this booklet. You are more than welcome to use the presentation slides from the launch session to do this.

What is the purpose of health and social care research?

- To find people at risk of getting ill and help to prevent illness.
- To find new and better ways of preventing, diagnosing and treating diseases or conditions
- To provide the best advice and treatments for people
- To share knowledge and understanding about different conditions
- To prevent people from developing illnesses/conditions
- To improve health and care services
- To ensure everyone has a better quality of life – health and wellbeing

What are the different types of health and social care research?

- **Healthcare research** - to improve the nation's health
- **Clinical Research and trials** - study of health and illness in people. It is the way we learn how to prevent, diagnose and treat illness
- **Public health research** - helps researchers understand the environmental, genetic, and social health determinants that influence population health
- **Social care research** - It is the setting itself that is different, not the methods or analyses and is more about wellbeing than cure or successful treatment

What are the different ways people can get involved in health and social care research?

- **Engagement**
  - Science festivals open to the public with debates and discussions on research
  - Open day at a research centre where members of the public are invited to find out about research
  - Raising awareness of research through media such as television programmes, newspapers and social media
  - Dissemination to research participants, colleagues, or members of the public on the findings of a study.
- **Involvement**
  - As joint grant holders or co-applicants on a research project
  - Involvement in identifying research priorities
  - As members of a project advisory or steering group
  - Commenting and developing patient information leaflets or other research materials

- Undertaking interviews with research participants
- User and/or carer researchers carrying out the research.

- **Participation**

  - People being recruited to a clinical trial or other research study to take part in the research
  - Completing a questionnaire or participating in a focus group as part of a research study.

Why do people get involved in health and social care research?

- doing something positive and making a difference
- learn more about a condition - yours or someone you care about
- access new treatments or to take an active role in your own care
- to help shape research – what research gets done, how, and how it is shared
- meeting new people and share time, interests, and knowledge
- gain skills - training and other experiences that add to your CV
- offer of payment for your time and cover for reasonable expenses

How can people get involved in health and social care research?

Local links:

- Be Part of Research: Kingston and Richmond NHS Trust

Use the QR code to sign-up to Be Part of Research, a national directory of health and social care research opportunities:

The following links provide more information about research and opportunities to sign-up to:

https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-help-with-research/

Take part in a study | NIHR

UK Policy Framework for Health and Social Care Research - Health Research Authority (hra.nhs.uk)

https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435

Workshop 1: Demystifying Health & Social Care Research & Listening to Needs

Workshop 1 aims to:

1. Listen to and capture community members' needs and perceptions regarding health research. These insights must be captured in the Workshops Feedback Form (page 16) and returned to Kingston Voluntary Action. These insights will form the basis of a local plan for health research, which we are hoping local researchers will sign and use to inform their practice.

2. Share the knowledge you've learnt on health research with your community members (please refer to 'Demystifying Health & Social Care Research' for more details). The purpose of this is to 'demystify research' and increase your community members' interest in taking part in health research.

How to reach Aim 1:

To meet this first aim, we have a list of suggested topics and questions that you could discuss with your community members. You could use your own methods or some of the tools provided in the Workshop Tools Table below, to facilitate these discussions. The topics we've provided are split into core understanding and practicalities:

Core understanding

- SHARED VALUES – what values should researchers be committed to and why? Which of your values would you like to see researchers adhere to and why?
- UNDERSTANDING – what do you believe health research is about? What do you think participating in health research includes, and how did you form this perception/understanding?

Practicalities

- INCENTIVES – what would make you want to participate in health research and why? What would encourage you to participate in health research and why?
- WORRIES – do you have any worries about participating in health research, if so what are these and why do you think you have these worries?
- NEEDS – what do you need to be able to participate in health research? What needs to be put in place to ensure your participation in health research is supported and valued?

How to reach Aim 2:

Share the information provided in the 'Demystifying Health & Social Care Research' section in a way you feel your members will engage with best. For example, you could deliver the presentation that was shared with you at the training session.

Evaluation

We also need you to collect evaluation data during this workshop, to find out what your community members think of the project. Please refer to the Evaluation section of this booklet for more details.

Workshop 2: Understanding health research priorities

The aims of workshop 2 are to:

1. Increase understanding of communities' current health research priorities.

2. Increase understanding of whether current health research priorities align with communities' health research priorities.

How to reach these aims

We have a list of suggested topics and questions that you could discuss with your community members. You could use your own methods or some of the tools provided in the Workshop Tools Table below, to facilitate these discussions.

- LIVED EXPERIENCE – what health and social care issues matter to you and why? Which of these would you like to see more research done on and why?

- HOW TO TAKE PART – share the information provided in the 'Demystifying Health & Social Care Research' section about how to take part in research (see *How to take part in health and social care research involvement and participation opportunities* on page 4).

In addition to supporting your members to sign up to Be Part of Research, you can also share information about studies that are currently recruiting participants or public contributors. Please let us know if you need help identifying these.

Key things to remember for your workshops:

- Provide a safe space where everyone will feel comfortable sharing their lived experiences and opinions.
- Make sure you have gained verbal consent to participate from all your community members.
- Be an active listener and make sure to ask your community members follow-up questions such as 'please tell me more about that' or 'please can you tell me why you feel that way'.
- The insights shared by your community members must be collated in the Workshops Feedback Form (page 11) and shared with Kingston Voluntary Action (please send this completed form to Eneida via communityvoice@kva.org.uk).

Therefore, we suggest taking notes during your workshop to support you in providing feedback.

- This workshop and the insights from it must be completed and shared by Friday 11th December. Please contact communityvoice@kva.org.uk if you wish to discuss this deadline or if you would like support planning your workshops.

Workshop Tools Table

Below is a table of suggestions for how to facilitate your workshop discussions. However, you know how best to engage your community members, so please deliver your workshops in whichever way you would like to.

Groupwork tools	How to do it:	Great for...	May not be suitable for...
Graffiti wall	Pin a large sheet of paper to the wall (or lay out on a table) and provide lots of coloured pens. You could divide the paper into sections for different questions or leave it freeform. Ask participants to write their thoughts directly on the paper. A variation on this is the roadmap, where you create a "map" to your destination (engagement in mental health research) and ask people to add their barriers, enablers, key stops on the way, by drawing, writing or sticking on pictures.	Encourages multiple perspectives and thinking about the big picture Allows people to interact with others' comments Anonymous – may support participants in being open Provides a written record of thoughts Can use as a prompt for discussion afterwards	If your participants include people with low literacy levels, you could offer pictures to stick on as an alternative. Can be time-consuming. Be sure to think about how those with mobility issues will reach all sections of the wall.
Storyboard	Similar to the above, but here participants create a story about the barriers they face in participating in research and ways they might overcome them.	As above. Specifically asks people to think about the journey they need to go through to reach the desired outcome.	As above.
Drama or dance performance	Small groups are asked to create a short drama piece or dance performance that represents how they feel about the research topic. Performances should be time-limited (e.g. 5 minutes). Each performance can be used as a prompt for further discussion with the whole group – questions like "what did you feel as you watched this?" and "what three words spring to mind in response to this performance?" can help to prompt discussion.	Engages people in different ways, encourages thinking "outside the box". Collaborative encourages interaction during development of the performance. May tend to focus individuals on one or two aspects of the research topic rather than the bigger picture.	You'll need to think about how you can capture the "why" of the performance – e.g. by having an observer for each group as they develop their piece. Some people may not feel confident to engage in performance. Mobility issues could limit engagement.

			No written record of thoughts.
Roleplay	In pairs or small groups. People take it in turns to take on the role of a health researcher wanting to engage people in research. You might choose to have a prompt sheet for the "researcher" to help them think of questions to ask. A second person takes on the role of the individual who may or may not engage in research. You might also choose to have an observer for each pair. After the activity the trio can discuss what thoughts/feelings the role-play scenario brought up for them to better understand their perceptions of mental health research.	Encourages people to think about how they'd respond in a real situation, and why. May encourage an emotional response.	Some people may not feel confident to engage – the role of observer may feel more comfortable for those people. Individuals may find the "researcher" role challenging if they don't have any knowledge of health research. You'll need to think about how to capture the discussion and roleplay, e.g. observer takes notes.
Interviewing in turns	Create a predetermined set of questions that your participants will use. People then take turns to interview each other using the set questions and record the results. If you have several questions, you could ask people to swap partner after each question.	Helpful if you want to find answers to set questions. Participants are given the questions – may feel less anxiety about trying to think of questions themselves. Less emotionally challenging than role-play but may address similar issues.	Think about how your participants will record answers: do they need to take notes themselves, or could an observer take notes for each pair? This approach narrows down your insights – you'll only get answers to the questions you ask, and are less likely to explore unexpected topics
Digital tools	**How to do it and link**	**Great for...**	**May not be suitable for...**
Mentimeter	Easy to use software for creating polls that participants answer in real time. Commonly used to engage participants during presentations. https://mentimeter.com *Free version gives you 3 boards and 50 responses a month (with one exception per month).*	Quick questions with selection of answer types. Great to use as part of another activity, introductory presentation – everyone can see anonymous answers.	Participants need to be able to access via their phone, laptop or other device.

		Can be used at an in-person event or remotely as part of an online event.	
Online forms	Various tools for creating online surveys. These are longer than a Mentimeter poll and will need to be completed by participants individually. You'll need to think about what questions to ask and how best to ask them using a range of question types – e.g. multiple-choice, text-based answers, or rating a statement on a scale. • Google Forms: How to use Google Forms *Free and a good choice if your organisation uses Google workspace* • Microsoft Forms: How to use M365 Forms *Free and a good choice if your organisation uses Microsoft 365* • Survey Monkey: SurveyMonkey: The World's Most Popular Free Online Survey Tool *Free version includes up to 10 questions but you can't export to Excel for further analysis without upgrading to a paid for account.*	Asking a fixed set of questions, which can be sent to many participants. Does not require interaction between participants. People can complete at different times. Most software will automatically generate a summary of results.	Participants need to be able to access their phone, laptop, or other device to complete. Good survey design is essential to minimise bias.
Padlet	Padlet is an online noticeboard where participants can add ideas, comments, images, links or files in response to a question or activity. https://padlet.com *Free plan available, currently with up to 3 active Padlets and file upload limits.*	Collecting lots of ideas quickly in one shared online space. Participants who prefer to contribute anonymously or in their own time. Creating a visual written record that can be reviewed and grouped into themes afterwards.	Participants need to be able to access their phone, laptop, or other device to complete.

Shared documents and Whiteboards	Create a shared document or online whiteboard for use during your workshop. This is most appropriate when your workshop is being run remotely. For example, you might choose to create a whiteboard where people can share thoughts on one or more questions, or a slide deck where people write a problem at the top of a slide and others add their solutions underneath. • Google or M365 document • M365 Whiteboard *(free for M365 users)* • Canva whiteboard *(free with Canva account)* • Mural https://www.mural.co/ *(free with limitations e.g. numbers of boards and numbers of guests with edit rights)* • Miro https://miro.com *(free with limitations e.g. numbers of boards and numbers of guests with edit rights)*	Effective collaboration for participants in remote workshops – it's recommended to send out a link to the document(s) in advance. The document or whiteboard is also your written record of the event. Can be used for remote collaboration in a similar way to the graffiti wall or storyboard.	Participants need to be able to access their phone, laptop, or other device to complete. Participants who are less digitally savvy may struggle – clear instructions are needed. It can be confusing when many participants are using the same application simultaneously. There may be accessibility issues for those with screen readers or other accessibility software.

Workshops Feedback Form

Please complete the ONLINE END OF WORKSHOP FEEDBACK FORM

Copy of the online form:

Community Voice in Action

END OF WORKSHOPS FEEDBACK FORM

To be completed when you have undertaken both workshops

Please use this form to tell us how your workshops have gone, including a summary of the insights shared by your community members on their perceptions of mental health research.
If you have any questions, please email Eneida Capaldi: comunityvoice@kva.org.uk. You also are welcome to call Eneida on 020 8255 3335 with any queries or comments.

Name of your organisation: _____

Lead contact name: _____

How have you delivered your two workshops?

Please give a summary of what you delivered and the methods you have used to gain your community members insights. Please could you also provide your headcounts in each box (i.e. how many participants started and finished the workshops and dropout rates). If you have any materials from your workshops (such as pictures or videos), please send them to communityvoice@kva.org.uk.

Workshop 1:

Workshop 2:

What insights did your community members share in your workshops?

Use the themes in the table below to summarise your community members' insights. If any topics weren't discussed or aren't relevant, please leave blank.

Topic	**Summary of topic feedback**
SHARED VALUES	
UNDERSTANDING	
INCENTIVES	
WORRIES	
NEEDS	

LIVED EXPERIENCES	
RESEARCH PRIORITIES	
MENTAL HEALTH RESEARCH HUB THEMES	

What do you think went well with your workshops? What were the strengths of your workshops?

What didn't work so well? What were the barriers / difficulties?

How do you think Community Voice in Action could be improved?

Please tell us what you would change about the project delivery.

Any other comments

Is there anything else you would like to tell us about your workshops, or anything else you've learnt through this project?

Evaluation Toolkit

Aim: the aim of the evaluation is to capture learning from the 'Community Voice in Action' workshops, e.g., to understand more about what worked well, what could be improved, and how the workshops have affected people's willingness and confidence to participate in health and social care research in the future.

Who are we? The evaluation is being led by researchers from Kingston University: Prof. Debra Gray (Debra.Gray@kingston.ac.uk). If you have any questions about the evaluation, please do contact her directly. We are happy to support in whatever way we can.

What will your role be? Your role will be to collect the evaluation data that we need as part of the workshops that you will be running with your community members. Given the diverse organisations involved, and the diverse voices that we aim to capture through this evaluation, it is likely that the way data is collected might look slightly different in different organisations. We have designed a framework below which sets out the minimum data required from all organisations, as well as a set of resources you can use as a starting point. It may be that you choose to collect more data than we have suggested or need to adapt the way the data is collected.

It is important to get informed consent before data is collected with your participants. We have provided a sample information sheet and consent form you can use and adapt (RESOURCE 1). Following this, we need the following minimum data:

1. Pre-workshop questionnaire (RESOURCE 2): this is to help us understand who has taken part, and we suggest this is handed out at the start of Workshop 1.
2. Post-workshop questionnaire (RESOURCE 3): this is to help us capture change due to the workshop participation, and we suggest this is handed out at the end of Workshop 2.
3. We need to know how many people started the workshops (a simple count will do) and how many finished both workshops (i.e., how many went all the way through to the end of workshop 2; again, a simple count will do). This is to capture dropout rates.
4. Qualitative data (RESOURCE 4): this will help us to explore participants' experiences of the workshops. We suggest that the data is collected in either a short (30 minute) group discussion, or a short interview (30 minute) with one participant. We suggest that this happens during Workshop 2 to make it easiest for you and for participants, but you may decide to conduct it shortly afterwards. We would like these to be audio-recorded and can provide recorders to enable this. Please contact us to discuss alternatives where this is not possible.

All data should be returned to us. The process for this will be confirmed with each organisation. The evaluation team will analyse the data and collate findings across all organisations. Findings will be reported back to your organisation, to the collaborative, and to National Institute for Health and Care Research (NIHR) – Regional Research Delivery Network as funding body.

RESOURCE 1– INFORMATION AND CONSENT

We are from [INSERT ORGANISATION NAME]. The 'Community Voice in Action' workshops that you have been invited to attend have been funded by NIHR Regional Research Delivery Network, who are interested in finding out how we can support more people to take part in health research. To help with this, they have asked us – along with Kingston University – to collect some information from you that will help us to understand your experiences of taking part in these workshops.

You do not have to take part in this evaluation, and you do not have to answer any questions that you do not want to. If you decide not to take part, you can still attend the workshops and take part in all activities.

What will you be asked to do?
If you decide to take part, you will be asked to answer some questions about you, and your opinions about the workshops. You will be asked to do this twice – at the start of Workshop 1 and the end of Workshop 2. These should take no more than 5-10 minutes each time. We are also asking some people if they would be willing to take part in a group discussion or short interview about your experiences of the workshops. These should take no more than 30 minutes in total and will happen when and where you are most comfortable. With your permission, these will be audio-recorded.

Your rights
Your answers to the questions will be sent to Kingston University, but your name will be removed so no one will know which answers are yours. Research data will be kept for a period of 10 years. You can withdraw from this study up to a week after the data has been collected. If you wish to withdraw your data, please contact us at [INSERT CONTACT DETAILS], at which point your data will be destroyed.

Project Consent
I have read and understand the information presented in the Participant Information Sheet. I have had the opportunity to ask any questions. Based on this information, I agree to take part in the evaluation, and I give my permission for my data to be used for research purposes.

Signed:

Name:

Date:

RESOURCE 2: PRE-WORKSHOP QUESTIONNAIRE

What is your age?

_____

Which of the following best describes your gender?

- ○ Male
- ○ Female
- ○ Non-binary / third gender
- ○ Prefer not to say

Which of the following best describes your sexual orientation or identity?

- ○ Straight or Heterosexual
- ○ Gay or Lesbian
- ○ Bisexual
- ○ Prefer not to say
- ○ Other sexual orientation/identity (please describe)

_____

What is your ethnic group?

- ○ White
- ○ Black/African/Caribbean/Black British
- ○ Asian/Asian British
- ○ Mixed/Multiple Ethnic Groups
- ○ Prefer not to say
- ○ Other Ethnic Group (please describe)

_____

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last at least 12 months? Please choose one option.

- ○ Yes, limited a lot
- ○ Yes, limited a little
- ○ No
- ○ Prefer not to say

In the last two years, how many research studies have you taken part in? if none, put a 0 (zero) in the box

I feel confident that I could take part in a research study:

Strongly Agree	Agree	Disagree	Strongly Disagree

I would consider taking part in a research study in the future:

Strongly Agree	Agree	Disagree	Strongly Disagree

I think that it is important for people to take part in research so that everyone's voice is heard:

Strongly Agree	Agree	Disagree	Strongly Disagree

RESOURCE 3 – POST WORKSHOP QUESTIONNAIRE

The ‘Community Voice in Action’ workshops increased my knowledge and understanding of research.

Strongly Agree	Agree	Disagree	Strongly Disagree

I feel confident that I could take part in a research study.

Strongly Agree	Agree	Disagree	Strongly Disagree

I would consider taking part in a research study in the future.

Strongly Agree	Agree	Disagree	Strongly Disagree

I think that it is important for people to take part in research so that everyone’s voice is heard.

Strongly Agree	Agree	Disagree	Strongly Disagree

Can you tell us what you thought was the best or most useful thing that you learned from these workshops:

Can you tell us what, if anything, we should change about these workshops to make them better in the future:

RESOURCE 4 – QUALITATIVE QUESTIONS FOR FOCUS GROUP OR INTERVIEWS

- Can you tell us a bit about why you decided to come to the ‘Community Voice in Action’ workshops?

- One of the aims of the workshops is to try to get more diverse communities involved in research, as their voices are often not heard. Why do you think [members of your community] might not take part in research? What might some of the barriers be?

- Do you think that these workshops are a good way of overcoming these barriers – why or why not? What might be a better way if not?

- What do you feel have been the best or most useful things about the workshops?

- What do you feel could be done better or should be changed if we run these again?