How to co-facilitate a focus group



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Contents

Introduction	1
Recruit the right facilitators	
Know your co-facilitator	
Don't just show up	
What is the role of the facilitator?	
Do it differently	
Consider bias	
Training may help	7
Recognition and Reward	8
Case Studies	8

Introduction

This briefing paper has been drafted by Peter Bates¹. As readers provide feedback, further insights will be used to update it, so please contact peter.bates96@gmail.com with your contributions. As some of the issues involved in co-facilitating focus groups are similar to those involved in peer interviewing, readers of this guide should also review How to involve people as research co-interviewers.

One approach to gathering views from a group of people is to run a 'focus group' where people meet to discuss the topic with one another and with the host, who may be called a convenor, moderator or facilitator. Sometimes a focus group is facilitated by two people working together, and on some of these occasions, the pair comprise an academic researcher² and an expert by experience³. To date, it has been quite rare for some groups of experts by experience, such as people with lived experience of dementia⁴ or learning disabilities⁵ to be offered an opportunity to coproduce research, so this paper explores how to make this possible in relation to the collection of data via focus groups.

While focus groups are a particular approach to data collection, they are also a meeting between people, and so the extensive literature⁶ on group dynamics and meeting effectiveness will describe much of what happens. Indeed, there are similarities between our topic and some therapeutic

groups which are co-facilitated by a professional and an expert by experience⁷, so learning from these neighbouring practices may add value. Focus groups have a long history in social science research, being associated with pioneers such as Robert K. Merton and Ernest Dichter⁸. They sit within a broader emancipatory approach to qualitative research, often called 'participatory action research' and those affiliated to this set of values sometimes prefer to talk about group discussion methods, since the term focus group usually implies that the researcher remains in control of the focus of the discussion⁹. Typically, a focus group is made up of 6-12 members, meeting once for 60-90 minutes and discussing topics fed to them by the facilitators. Rather than the facilitators firing questions at individual members in turn, the distinctive focus group process occurs when the facilitators successfully trigger conversation between members and new insights emerge from these interactions¹⁰.

Some commentators label one particular version, in which two facilitators work side by side to lead the group as a 'dual moderator' focus group, and they might expect one moderator to attend to the agenda and another to attend to the group relationships and dynamics. Others have suggested that the more experienced moderator takes on the lead role and the other is designated an 'assistant moderator'. In contrast to these recommendations, at the outset of this paper, we are not making any assumption about the tasks taken by each facilitator. However, we are looking for more than asking one facilitator to act as scribe while the other leads¹¹ – this paper is written for those occasions when both the expert by training (i.e. the academic researcher) and the expert by experience share the task of leading the session.

In addition to their lived experience, some people also have substantial, relevant qualifications – perhaps as a clinician, health or social care manager, lecturer or researcher. Whilst we acknowledge the richness of this kind of 'dual qualification', this paper is focused on the situation where the expert by experience is bringing different skills to those held by the researcher, and indeed, their core skill is in being able to make constructive use of their personal experience to help the task of drawing out thoughts, feelings and responses from focus group members. Advice is available 12.

With all these alternatives and possible variations in the design of a focus group there is the risk of confusion. For example, researchers who struggle to understand the role of the Public Contributor to research may confuse their role with that of research participant, and the undisciplined use of the term 'focus group' (perhaps even applying it to a consultation meeting¹³) would increase the risk that the need for Public Contribution would be submerged. Internationally, it would be helpful if specialist focus group practitioners could develop a Fidelity Model, while in local planning, conflict will be reduced if Public Contributors and research staff clarify their expectations with one another before starting the work.

Before launching into this guide, it is important to note a potential critique of the whole approach. The tradition of Community-Led Participatory Research would hand over control of the whole research process to experts by experience, including the entire job of moderating the focus group. Academics might train the experts by experience, often rebadging them as community researchers, and a pair of community researchers might work together to cofacilitate a focus group, but in this approach the academic researcher remains in the background and does not even meet focus group members¹⁴. People within this tradition may well challenge us to justify our stance, accusing us of

tokenism, of retaining a kind of colonial control while offering no more than the illusion of power-sharing to only the most biddable members of the community. As Bellingham et al say:

the precarity of lived experience researcher roles, which are usually casual and reliant on the ongoing patronage of conventional researchers, while appearing inclusive can in fact reinscribe experiences of powerlessness, silencing and discrimination that mirror those experienced by people with lived experience in mental health services, labour markets, and the broader community.¹⁵

They may have a point and so we must proceed with humility, recognising that our chosen type of moderation, in which an academic and an expert by experience share the facilitation role in the focus group, is only one approach, and may not be the best. Indeed, it may turn out to be so fraught and loaded with complexities that the reader will be persuaded to move yet further forward and choose an alternative approach in which the moderation role in a focus group is carried out by trained experts by experience working either alone or in pairs, with the academics taking up no more than a training, coaching and support role, perhaps only attending the focus group to make coffee and be available for non-verbal support and then debriefing afterwards¹⁶.

Recruit the right facilitators

If you are advertising, shortlisting, interviewing and selecting facilitators for your focus group, it can be helpful to use the same process for both the academic and the lived experience facilitator. Advice is available on how to involve the public in recruitment and selection panels¹⁷. If more informal mechanisms are utilised, it still makes sense to set out a list of essential and desirable competencies of the person and record the process by which some people are offered the role and others not. In addition to the usual list of skills and attributes that are needed in all types of focus group facilitation, the expert by experience may need to be trusted and credible to the target community that is being invited to participate in the focus group.

Know your co-facilitator

In addressing the related question of Music therapists and Experts by Experience working together to co-facilitate a therapy group, Hillman, Pedlar & Bibb (2021)¹⁸ note that working together is easier when the values that underpin the practice of both the expert by training and the expert by experience are closely aligned. Spending time exploring each other's goals and discovering what motivates each co-facilitator can help to reveal whether there is sufficient common ground to enable collaboration to happen.

When working closely together, spontaneously responding to issues as they arise from the group, there is no real substitute for building a good working relationship so that you get on well together¹⁹. Each co-facilitator needs to know their co-facilitator well, be able to predict how they might respond to the unexpected and be ready to offer appropriate support when things do not go well. This starts before a specific piece of work has been identified, so that they work together on identifying the research questions, preparing the proposal, applying for funding and recruiting people to participate in the focus group. Indeed, the expert by experience may have access to many potential focus group members and know how they should be approached. However, if community members have been

treated badly by previous researchers, or indeed by any figure who is perceived to be in authority, then they are less likely to sign up to this focus group session and the expert by experience may be perceived in a negative light, rather than as a bridge to the community²⁰. It can also be helpful to collaborate on writing a prompt sheet that will guide you through the session, rather than starting to work together only after the parameters have all been set²¹.

Once you get to the stage of planning a particular focus group, you may need to meet up a few days before the event, travel there together, and you really must plan to spend time together afterwards reflecting on your successes and challenges²². If there is an opportunity to debrief with other pairs, that will speed up your learning too.

Don't just show up

The mere presence of identifiable impairment or history of service use in one of the facilitators adds very little to what makes any co-facilitation work. The usual accommodations that are needed in any setting apply: some people with cognitive impairments benefit from some extra time to plan and Easy-Read written materials for background and briefing; people who use augmentative communication devices or mobility aids need access to power to recharge.

After all your planning, it is particularly helpful to have a conversation on the day before the event, or even early on the same day, to ensure that there has not been a last-minute problem with your arrangements.

Once at the venue, you will need to create a welcoming space that might include someone at the door to shake hands with people and greet them personally, seating arrangements that trigger conversation, paper tablecloths and pens for graffiti work, sweets on the tables and music playing in the background. These simple gestures of hospitality can change the whole tone of the meeting, especially for professionals who are used to committees²³.

What is the role of the facilitator?

It is essential to develop a shared understanding of the purpose of the focus group and the role of the facilitator in this particular session, and then for each facilitator to support the other to be the best facilitator they can be. Real clarity about the desired outcomes will shape how the facilitators work and may help to divide up the labour. Some disability champions have learnt to tell their story and challenge others when a group member says something with which they disagree, but a different skillset is needed for facilitation. Indeed, the need for disciplined silence is so strongly set out that the assistant moderator is directed by Kreuger & King (1998 op cit) as follows: 'Do not participate in the discussion. Talk only if invited by the moderator. Control your nonverbal actions no matter how strongly you feel about an issue.' We note that in Krueger and King's version, both the moderator and the assistant moderator are community representatives (experts by experience), but this is just one way to run things.

In other focus groups, expert by experience facilitators may share some of their personal story, introduce the topic with a personal connection and add their ideas to the discussion. Fundamentally, their role is to help group members talk, rather than delivering a presentation or challenge. This

demands that they be skilled in listening without interjecting their own ideas, and then in communicating those ideas to others, again without bending them to suit their own opinion. A particular challenge can be to listen to distressing or critical accounts without needing to comfort or counter the negative story with a positive one. Advice is available on responding to distress²⁴.

There is sometimes a risk that the expert by experience becomes just another member of the group, and so holding on to their role as facilitator is important. Here are a few approaches that help:

- The person may frame their personal experience in the form of a question 'I've noticed this, what do others think?'
- If the facilitators know one another well, they can draw each other into the conversation by asking a direct question 'Didn't you once tell me that... Can you tell us a little more?'
- Some experts by experience speak slowly and use the vernacular rather than professional
 jargon. This can help group members to understand, smile and engage, so the academic may
 need to consciously slow down, relax and allow the pace to be set by the expert by
 experience.

Where there are two facilitators, one can take the lead for a section of the group session and the other can adopt a more supportive role in clarifying obscure comments or drawing in people who haven't contributed, before moving on to the next section and swapping over. Another way to divide up the work is for one to address the information-related issues and the other to attend to emotional factors, or for one to act as host and the other to chair the business part of the event. Hillman et al²⁵ explicitly avoided any sort of line management relationship between the two facilitators, worked together to define what they each called 'my space, your space and our space' and rebadged themselves as collaborators rather than co-facilitators.

Two facilitators will notice more than a solo facilitator and are also more likely to see different sides of a disagreement and so be able to draw out all perspectives, adding richness to the data. They may be identified with more than one characteristic, so could be of different ethnicities, genders, ages or drawn from diverse sections of the community, thus giving more focus group members a point of connection with the conveners.

Do it differently

Working together can release innovative presentation styles that add value to the meeting, perhaps by replacing the Powerpoint lecture with graphic recording²⁶ or an expert by experience bringing memorabilia from home to help with telling their story. Using a range of media in these ways can help people who don't read well or find it difficult to sustain concentration. Anyone who has attended more than one or two conferences or lectures will know how important it is to find out how equipment works before the start!

Consider the basics, such as the location of the meeting, the physical layout of the space and the number of people who attend. Sometimes the expert by experience will prefer a group which is smaller than usual.

Academic researchers sometimes have personal development work to do to overcome their traditional sense that their training and academic expertise gives them superiority. While they may

need to veto ideas, such as leading questions that would invalidate the research enterprise, they need to be open to innovative and creative ideas brought forward by experts by experience.

Traditional advice for focus group facilitators may encourage the involvement of experts by experience as co-facilitators but does not provide space for them to disclose their relevant life experience, although this may happen anyway, especially when the person's appearance, gait or other non-verbal signals reveal it²⁷. Imaginative approaches may be needed to provide space for this without distracting the group from the purpose of the focus group interview. Hillman et al note that the expert by experience can accelerate the development of trust in a group through skilled modelling of self-disclosure

Consider bias

Bergen and colleagues²⁸ conducted some focus groups that each had two facilitators and observed the presence of 'social desirability bias' in the data derived from the session. This occurs when focus group members mispresent their true opinions by changing them to appear socially acceptable. It is inevitable that this bias will exist in every interview or group discussion so researchers must do what they can to minimise it.

We might also ask how the presence of a second facilitator affects the range and strength of the bias. A larger audience may make any speaker less willing to admit nonconformist opinions; two facilitators representing two entirely separate fields may double the number of questions deemed sensitive and so bias more answers; a respondent identifying strongly with one facilitator rather than the other may trigger efforts to curry favour with that person, thus increasing bias; or two facilitators representing different norms in the same field may give the person more permission to say what they think, rather than be influenced by a single reading of what counts as socially desirable.

The 'availability heuristic', as described by social psychologists²⁹ occurs when experiences and information which are readily accessible to the mind increase the person's own assessment of risk. Put simply, a person who has recently fallen over will believe that trips and falls happen more often than the statistics show. The author has not found evidence to suggest that there is a significant difference in the power of the availability heuristic when the availability is driven by academic or second-hand knowledge versus experiential or firsthand knowledge. However, we might safely guess that there will be differences between the co-facilitators in their recognition of risk when one is a academic facilitator and the other is an expert by experience compared to a homogenous dyad.

These forces appear even before the focus group participants enter the room. The direction of the research inquiry is already subject to competing forces, as the senior academics may want it organised to further their own long term research endeavour while the novice researcher has much to learn and may want to keep things simple while they gain experience. The funder has a particular objective, and when the research is being hosted within a healthcare or social care setting, there will be ways to please the gatekeepers who grant access to potential participants. Admitting an expert by experience to the team that moderate the focus group could tug the work in a new direction.

Teams that choose to cofacilitate rest their work on a belief that this new direction is likely to add value as long as everyone thinks carefully about what they are doing. These forces are at work but

may be ignored or suppressed, weakening the rigour of the research, or they could be acknowledged and used to make sense of the findings and strengthen the quality of the focus group research.

Training may help

Some people will learn best by doing, so interactive training will be the best way to help people move into the role of a co-facilitator. Training in group facilitation may be useful and teachers can draw on the large literature on these topics³⁰ as well as their personal experience of facilitating focus groups coaching others. If that training could be co-facilitated by an academic and an expert by experience working together, then this would model the behaviour that is being taught. Training can take time³¹, and if a summative assessment is used to establish whether learners have acquired the required competencies rather than merely attending the training sessions, then it may slow down the process and create time pressures in relation to the project timeline (when the money runs out) and the 'tenure clock' which winds down as the fixed-term contracts held by paid staff expire.

The definitive text³² on facilitating focus groups is clear that academics are not born with the innate skill of facilitating focus groups and may indeed not match the set of competencies that the authors have defined unless they practice, receive coaching, review their success and aspire to improve. Citizens with lived experience may also lag in these skills – or they may have had informal or formal experience across a range of fields that mean they are well tuned in to group dynamics and the need for skilful facilitation. In addition, once a group have received training for one study, some of the people may be available for future studies, thus reducing both time and cost over the long term.

Training is not just about technical skills and learning how to deploy them but is about learning how to work together and practice reflexively. Both academics and experts by experience will have moments where they need to review their attitudes and behaviour and the best training provides a safe place for these moments of realisation and personal growth to occur in public. One area with potential for such development arises when experts by experience explore the limits to power and influence. It is easy to speak in the abstract of power sharing, equal status and valuing the perspective of experts by experience, but actually working together to run a focus group will reveal to everyone how this really works. Academics must learn how to present their offer of involvement to experts by experience, who will be on a parallel journey of discovery, finding out that individual freedom is bounded, and responsibility must be both held and shared.

One key skill that can be developed and used by a pair of facilitators working together is the ability to manage the talkers and draw out the listeners in the group. There are a variety of strategies can be deployed, as shown in the quote below, and the co-facilitators may wish to develop their own repertoire of management strategies so that they can help one another should the need arise.

"If one or two people are dominating the meeting, then call on others. Consider using a round-table approach, including going in one direction around the table, giving each person a minute to answer the question. If the domination persists, note it to the group and ask for ideas about how the participation can be increased."³³

Recognition and Reward

Careful thought needs to be given to the matter of payment. It has been argued³⁴ that research which engages volunteer facilitators is cheaper to run than that which utilises expensive trained researchers, although its slower pace of development and delivery may put the costs back up. Many organisations consider that this level of responsibility deserves a payment in line with that received by other casual or permanent employees. Where experts by experience receive welfare benefits, care must be taken to avoid destabilising the person's financial circumstances³⁵. Consideration needs to be given to welfare benefit and taxation rules, employment law, volunteering best practice and the arrangements that obtain in the host organisation.

Case Studies

Case Study 1: Evaluating the process of nurse recruitment

At Bournemouth University Service Users were recruited as co-researchers in a project which sought to evaluate the involvement of Service Users and Carers in a pre-registration adult values-based recruitment process. Service users were recruited as co-researchers as it was felt that they would offer insights into the lived worlds of their counterparts and provide a different discourse from the academic researchers who were all nurse academics. They were involved in the entirety of the project from its inception to conclusion.

Training was provided to all three co-researchers on qualitative research, leading and managing focus and thematic analysis. One of the arms of the evaluation involved service user focus groups and a co-researcher worked joined alongside a qualitative researcher. Each voice was equal in the research process (irrespective of the role) and decisions were made jointly.

Involvement of the service users in the research was mutually beneficial for the service users who really enjoyed the process, being part of the team and presenting the work, and for the research as the service users provided a very different lens for which to analyse the data.

Case Study 2: Evaluating a Widening Participation initiative

Bournemouth University Fair Access Research project is a university-wide research project which is committed to exploring the total student journey (pre-access, admission, student experience, attainment and progression) of 'widening participation' students. In order to align with the core philosophy of the research programme, the project recruited and worked with students as co – researchers. They have worked with students with disabilities, students from Black, Asian and Minority Ethnic communities and students who are the first generation of their family to access university.

Recruiting from this pool of what are sometimes referred to as 'vulnerable' students is important. Firstly, it challenges perceptions of vulnerability which typically have negative manifestations and instead focuses on resilience and assets. Secondly it enables the students to develop expertise in running research projects which enhances their CV. By being involved throughout the research and co-facilitating focus groups alongside an experienced researcher this student developed skills and confidence in research. They also co-authored a publication³⁶.

The student concerned reported that this experience contributed to her obtaining a first class honour mark for her dissertation, as well as giving her the confidence to present her work at both a local and national student conference. Having an emancipatory aspect of the work is fundamental when working with marginalised communities and groups.

Case Study #3: Focus Groups on Current Hydration Practices

A Public Contributor and Academic Researcher co-facilitated five focus groups on the topic of hydration and de-hydration in care home residents. This came about because the Public Contributor's mother became dehydrated when in hospital and this prompted her to think about creating a device which could be used to monitor the fluid intake of an older person in care.

The two collaborators did not have the ethical approval to conduct focus groups with care home residents, so chose to interview care home staff. Groups consisted of between 6 and 10 participants, and focus groups were held in the participants' place of work. Before embarking on the Focus groups, the collaborators got together and produced a prompt sheet that included saying who they were, why they were present and an introduction to the focus group session itself.

The primary role in the focus group sessions was taken by the expert by experience and the academic researcher provided support by helping the group to stick to the agreed upon process rather than wavering too much and managing the many occasions when people went off on a tangent.

This exercise was initiated by the East Midlands Research into Ageing Network (EMRAN) and so it was written up for publication on the EMRAN <u>website</u>. It took quite a long time for the collaborators to finalise the joint-authored report³⁷. The academic did most of the writing and because the original idea came from the expert by experience, and because of her contributions to the publication, she was named as first author. Often there are no explicit outcomes from focus groups as they simply inform the next stage of research, but it was important for the expert by experience to achieve a short-term outcome. The publication gave formal recognition of the contribution that she had made in cofacilitating the focus groups, as well as creating a long-term plan for the using the information that arose from the focus group sessions.

¹ Duncan Barron, Sammy Butcher, Chris Craig, John O'Brien, David Towell and Sally Warren have commented for this paper. The remaining weaknesses are the responsibility of the author. This is an early draft of notes written to prompt contributions from others and should not be considered as a definitive or authoritative statement.

² For simplicity, this paper sticks to the idea that the academic member of the pair of co-facilitators is a researcher. They may, of course, hold a variety of other roles, such as clinician, service development consultant or trainer. It also treats these as distinct rather than overlapping categories for the sake of clarity – but we know that professionals often have lived experience and people called 'experts by experience' often have a wide range of other expertise too.

³ Some would use the terms patient, client, disabled person or service user here.

http://www.academia.edu/746649/Methods of data collection in qualitative research interviews and foc us groups. also

https://www.researchgate.net/file.PostFileLoader.html?id=5854cc1a96b7e4fe641ef361&assetKey=AS%3A440 153928933378%401481952282518. Many similar but alternative formats for gatherings are available, one of which is a deliberative forum – see https://www.kettering.org/wp-content/uploads/Developing-Materials-guide.pdf. Some research organisations assume that anyone conducting a focus group must be involved in data collection and so should engage the full panoply of research processes, such as approval by ethics committee and so on. For others, the term is used much more fluidly, as a title for a group conversation.

⁴ See Di Lorito C, Birt L, Poland F, Csipke E, Gove D, Diaz-Ponce A, & Orrell M. (2017) A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia. *Int J Geriatr Psychiatry*, 32: 58–67. doi: 10.1002/gps.4577.

⁵ See Di Lorito, C., Bosco, A., Birt, L., Hassiotis, A. (2017) Co-research with adults with intellectual disability: a systematic review, in *Journal of Applied Research in Intellectual Disabilities* pp. 1-18 (in press).

⁶ See, for example, Weisbord MR & Janoff S (2007) *Don't just do something, stand there!: ten principles for leading meetings that matter*. Berrett-Koehler Publishers. Also Baldwin C & Linnea A (2010) *The circle way: A leader in every chair*. Berrett-Koehler Publishers.

⁷ See Hillman K, Pedlar D & Bibb J (2021) My Space, Your Space: Exploring the Potential of Collaborative Group Facilitation Between Therapists and Peer Workers in Mental Health Settings. *Community Mental Health Journal* https://doi.org/10.1007/s10597-021-00859-w.

⁸ Focus groups were used as a research tool to explore propaganda in American troops who were returning from the battlefield after World War Two, and then in research projects that investigated marketing. For an introduction to the use of focus groups in health research, see

⁹ Schubotz D (2020) Participatory Research: Why and How to Involve people in research. London: Sage

¹⁰ Morgan DL (1997, 2nd Edition) Focus groups as qualitative research. London: Sage.

¹¹ This view contrasts with that taken by Gibbs A (1997) (1997) *Focus Groups.* Social Research unit Update 19. Downloaded from http://sru.soc.surrey.ac.uk/SRU19.html 9 January 2020.

¹² See Krueger RA and King JA (1998) *Involving Community Members in Focus Groups*. Sage Publishing, ISBN 0-7619-0820-X

¹³ We were told of panels that reject funding applications if they read that meetings with Public Contributors have been constructed as focus groups. This is because they assume that the term 'focus group' means a data collection tool and so the academic members of the research team have treated their Public as research participants rather than Public Contributors, and so have not actually done any coproduction. (D Barron, personal correspondence, July 2020)

¹⁴ Kaufman JS, Abraczinskas M and Salusky IS (2019) Tell it to Me Straight: The Benefits (and Struggles) of a Consumer driven Assessment Process *American Journal of Community Psychology* 0:1–11 DOI 10.1002/ajcp.12373.

¹⁵ Bellingham B, Kemp H, Boydell K, Isobel S, Gill K & River J (2021) Towards epistemic justice doing: Examining the experiences and shifts in knowledge of lived experience researchers over the course of a mental health research training programme *International Journal of Mental Health Nursing* DOI: 10.1111/inm.12910.

¹⁶ Case AD, Byrd R, Claggett E, DeVeaux S, Perkins R, Huang C, Sernyak MJ, Steiner JL, Cole R, LaPaglia DM, Bailey M, Buchanan C, Johnson A & Kaufman JS (2014) Stakeholders' Perspectives on Community-Based

Participatory Research to Enhance Mental Health Services. *American Journal of Community Psychology*, 54: 397-408. doi:10.1007/s10464-014-9677-8

- ¹⁷ See Bates P *How to involve the public on recruitment and selection panels* at http://peterbates.org.uk/wpcontent/uploads/2017/05/how to involve the public on staff appointment panels.pdf.
- ¹⁸ See Hillman K, Pedlar D & Bibb J (2021) My Space, Your Space, Our Space: Exploring the Potential of Collaborative Group Facilitation Between Therapists and Peer Workers in Mental Health Settings. *Community Mental Health Journal* https://doi.org/10.1007/s10597-021-00859-w.
- ¹⁹ Chinery M, Barnes L & Towell D (2004) *Helping the work of learning disability partnership boards get better through good joint chairing* VPST, NHS Modernisation Agency and Department of Health.
- ²⁰ If community members whom one hopes will participate in the focus group have a strong sense of insiders and outsiders, then they may perceive the lived experience researcher as a traitor, poacher turned gamekeeper, turncoat or collaborator with the enemy. These are perhaps immoderate terms to use, but they highlight the point that the lived experience researcher may not always be perceived as an ally of the community that is being researched or that the collaboration will always demolish differences and bring trust and warmth in place of division.
- ²¹ Elspeth Mathie and colleagues have worked with people with dementia as co-facilitators of focus groups in the DEMCOM study. Their collaboration began well before the focus groups and involved working together on a number of aspects of the study. See http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/demcom-national-evaluation-dementia-friendly-communities-2/
- ²² Kaufman et al (2019) op cit found that working with consumer researchers took twice or three times as much time as the academics would spend on the work, while Krueger and King (1998) op cit. estimated that it was three times as long. However, these teams were training consumer researchers to facilitate focus groups with no academics present.
- ²³ See materials on Host Leadership at http://hostleadership.com/.
- ²⁴ Bates P (2021) How to respond to distress.
- ²⁵ Hillman et al (2021) op cit.
- ²⁶ See work by David Sibbet on this technique at http://www.grove.com/index.php.
- ²⁷ Jorgensen CR, Eskildsen NB, Thomsen TG, Nielsen ID, Johnsen AT. The impact of using peer interviewers in a study of patient empowerment amongst people in cancer follow-up. *Health Expect*. 2018;21:620–7.
- ²⁸ Bergen N & Labonté R (2019) "Everything Is Perfect, and We Have No Problems": Detecting and Limiting Social Desirability Bias in Qualitative Research *Qualitative Health Research* 1–10. DOI:10.1177/1049732319889354.
- ²⁹ Kahenman D (2013) *Thinking fast and slow.* Toronto: Anchor.
- 30 https://www.amazon.co.uk/Dont-Just-Something-Stand-There/dp/1576754251 also https://www.amazon.co.uk/Circle-Way-Leader-Every-Chair/dp/1605092568
- ³¹ The Kaufmann et al (2019) study cited above provided 14 training sessions to consumer researchers who conducted Community-based Participatory Research that included focus groups, each facilitated by a pair of consumer researchers. Academic staff were not present during the focus group itself, which makes this different from the scenario discussed in the present paper.
- 32 Krueger & King (1998) op cit.

³³ Basics for conducting focus groups Downloaded on 9 January 2020 from http://managementhelp.org/businessresearch/focusgroups.htm

³⁴ Krueger & King, op cit, chapter 1.

³⁵ For an example of a short statement that attempts to navigate the payments issue, see http://peterbates.org.uk/wp-content/uploads/2017/04/how to make sense of our payments offer.pdf

³⁶ Heaslip V, Hewitt-Taylor J, Alexander P, Ellis-Hill C & Seibert-Santos C (2015) What factors influence Fair Access students to consider university and what do they look for? *Journal of Widening Participation and Lifelong Learning*. 17(4); 67-88.

³⁷ See How to involve the public as co-authors <u>here</u>.