

## Supplementary Materials 2

Expert Stakeholder Group

Materials for ESG meeting 1

### Theory development – a crisis story

Two police officers are dispatched following a 999 call to a disturbance one evening. The woman who called 999 told the officers that her distraught neighbour called “Rob” has asked her for help because he’s hearing voices telling him to harm himself.

Rob tells the officers that he is tormented by the voices, which are very threatening. The voices have got worse since he has been served an eviction notice. Rob explains that he usually sees a mental health nurse once a month and goes to a weekly drop-in session at the local branch of MIND. Rob can’t remember the name of the nurse and has lost the paperwork the nurse gave him. Rob tells the police officers that the voices are becoming more threatening, and that they are telling him if he does not keep harming himself, he will have to harm someone else.

### Questions

1. Is this crisis story realistic?
2. Who needs to be involved? – Which people? Which organisations or agencies?
3. How should the people and organisations work together?
4. What would be needed to enable people and agencies to work together
5. What is it about multiagency approaches that work to resolve mental health crises?
6. There is a sense that the people in our crisis story need more information - What is it about having information that would make a difference?
7. If you think skills, knowledge or training would help, what is it about these three things that would make a difference?
8. What would a good outcome be?
9. What else needs to happen to make sure the best outcome is achieved?

Stakeholder Group Member Blog

### Co-creating knowledge on mental health crisis services

In February 2020, I, along with 12 other people, arrived in Leeds to join the kick-off meeting for the MH-CREST project. It’s not first time I’ve taken part in a study advisory group, or indeed contributed to research on mental health crisis care, but as the project draws to a close, I’m keen to reflect on what I have learnt as a participant, and why co-creating knowledge is fundamental to humane and effective mental health care.

MH-CREST is an NIHR funded study which seeks to understand how community crisis care services for people with mental health problems work, who they work for, and in what circumstances. It is led by a team based in The School of Healthcare at the University of Leeds and sponsored by Sheffield Health and Social Care NHS Foundation Trust.

So back to that initial meeting, and the first thing I'm struck by is the presence of people with lived experience. By the time we've gone round the room, and excluding the research team, over half of those present are people who are using, have used mental health crisis services, or are carers for people who use mental health services, with the rest of the group made up of mental health professionals, commissioners, policy makers, and researchers. It isn't just the balance of lived experience; it's also having a diversity of experience. This includes people from different cultural backgrounds, people currently using crisis services, people involved in service provision from a position of lived experience, and people who have had long-term experience of mental health services including crisis care. In part this has been achieved by reaching out and collaborating with local crisis services, so that people in their early stages of recovery are able to contribute with support from staff and keyworkers. But is also a marker of the commitment to lived experience and the approach the research team have taken including making the research accessible in terms of what we are doing and ensuring that people feel supported as part of this.

MH-CREST combines evidence synthesis with realist methodology. What that means in practice is that the team are effectively seeking to address their research questions using published research on mental health crisis care. But the areas they focus on, and their understanding and interpretation of the literature and findings is informed by an independent advisory group (that's us, outlined above). Co-design by nature is collaborative, but balancing different voices, diverse experiences and lived experience with notions of established knowledge can be tricky. One way they achieved this was by engaging us in common tasks – such as the diamond ranking task in the initial session. As my group huddled round the notion of 'access', seeking to understand its parameters and priority against other factors, we each shared our own individual experiences and knowledge - of accessing care in a crisis, being that member of staff at the end of the line, of commissioning services. I noticed how the process of knowledge creation became generative rather than cumulative, accepting and knitting together our common and different realities, rather than presenting them in isolation and opposition.

The meetings of the advisory group and our work together is perhaps the first time I've heard these different perspectives on crisis services voiced in the same room. However, of these it is the commonality of traumatic experiences that has stuck in my mind. Anyone who has been involved in mental health will have at some point listened to an individual recount their traumatic experiences of care. Fraught with emotion, they can be difficult to hear, and lead those in the room to question how unique or timely those experiences were. What I heard in the room, were how common traumatic experiences of seeking help are both in the past and present. This included what can only be described as systematic failings of care, to responses which were experienced as unhelpful or invalidating at a point when an individual felt at their most vulnerable and distressed. The consequence we heard is a growing mistrust of mental health services and a reluctance to seek help on future occasions.

And yet so many of us need and at times are dependent on that care. When I joined the first MS-CREST meeting, I did so largely as a policy researcher who has followed and written about provision of mental health care. But as the country was plunged into a series of lockdowns in response to the spread of Covid-19, my life became increasingly dominated by my own mental illness and I too had to consider whether to seek help in a crisis and the response that I would receive.

Over many years there has been an increasing focus and investment in services for people experiencing a mental health crisis. On the ground there has been a proliferation of services, from

crisis intervention and home treatment teams to street triage, crisis café's and most recently NHS crisis lines. And yet, we know that providing a means to access services in a crisis isn't enough - staff and services are often constrained in the response they are required or able to give, and not everyone who experiences a mental health crisis will access care. Our work as part of MH-CREST has shown that no one service is likely to work for everyone, but where prioritisation of a few common features of services identified through the collaborative work of the group and supported by the evidence have the potential to improve the acceptability and effectiveness of the crisis response provided to people in distress.

Helen Gilbert

Fellow in Health Policy, The King's Fund

Accessible at: <https://mentalhealthresearchleeds.co.uk/2021/09/06/co-creating-knowledge-on-mental-health-crisis-services/>



This study is funded by the National Institute for Health Research (NIHR) HS&DR programme (project reference NIHR127709). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

## Stakeholder Evaluation Questionnaire

### MH-CREST Expert Stakeholder Group Evaluation Questionnaire

Your views about your involvement in the MH-CREST Expert Stakeholder Group are very important and form a key part of our evaluation of the project. We would be grateful if you could answer the 7 questions below. The questionnaire is anonymous so your identity will not be linked to any of your responses.

For Questions 1 to 4 please put an X in the numbered box that matches your experience best. For Questions 5 to 7 please write about your experiences in response to each question. Please return the completed questionnaire to Michael Ashman at [xxx](#).

If you have any questions or need more information about this questionnaire please get in touch, and thanks for taking the time to do this.

<b>Question 1</b>	<b>Not at all</b> <b>High</b>				
<b>To what extent did you feel able to...</b>	0	1	2	3	4
a) Achieve your own goals through the research					
b) Make a contribution to the research					
c) Make decisions about how to do the research					
d) Express your views about the research topic					
e) Discuss research issues					
<b>Question 2</b>	<b>Not at all</b> <b>High</b>				
<b>To what extent did you feel there is potential for you to...</b>	0	1	2	3	4
a) Choose the role you play in the research					
b) Bring your own ideas and values to the research					
c) Work in ways that suit you					
d) Gain status, credibility or expertise because of your involvement					
e) Identify and organise your research ideas and priorities					
<b>Question 3</b>	<b>Not at all</b> <b>High</b>				
<b>To what extent did you feel...</b>	0	1	2	3	4

a) Valued as a partner					
b) Enabled rather than constrained					
c) Empowered rather than exploited					
d) Consenting (happy to be involved) not coerced (unhappy about it)					
e) It is acceptable that different people have different roles in the research and different opinions					
<b>Question 4</b>	<b>Not at all</b> <b>—————&gt;</b> <b>High</b>				
<b>To what extent do you think....</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
a) The researchers have the right reasons for wanting to work with you					
b) The way the researchers work with you is supportive					
c) The way the researchers communicate with you is supportive					
d) There was a clear role for you in the research					

**Question 5. What are the things that you felt were good about your involvement in the project?**

**Question 6. What are the things that you think that we could improve?**

**Question 7. Is there anything else you would like to tell us about your involvement in the MH-CREST project?**

## **Expert Stakeholder Group evaluation v2.0 27 08 2021**

### **Introduction**

In order to explore participants' experiences of taking part in the Expert Stakeholder Group (ESG) and so that the team could take forward learning for future work, an online evaluation was conducted. We used an adapted version of the Morrow et al (2010) questionnaire, which consists of a number of statements that participants are asked to mark how far they agree with using a Likert scale of 0 (not at all) to 4 (high). Three free text questions were also asked to ensure that participants were able to add additional comments. The three questions were:

- What are the things that you felt were good about your involvement in the project?
- What are the things that you think that we could improve?
- Is there anything else you would like to tell us about your involvement in the MH-CREST project?

Nine questionnaires were returned and the results are presented in the following sections.

### **Findings: scored questions**





Responses to scored questions can be seen in Table 1 below. All nine participants agreed or strongly agreed that they had contributed to the research, with 8 of the 9 participants strongly agreeing that there was a clear role for them to play.

Eight out of the 9 participants felt valued as a partner in the research, were happy to be involved in the research, felt empowered through their involvement and felt able to express their views about the research.

All nine of the participants agreed or strongly agreed that the researchers had the right reasons for wanting to work with the ESG and that the way the researchers worked with the ESG was supportive.

There was less consensus amongst the participants regarding the opportunity to make decisions about the research, with three participants agreeing or strongly agreeing, with 3 participants unsure and 3 participants feeling they had no opportunity to make decisions. Similarly, when asked if participants felt that they could choose the role that they played in the research, 3 agreed or strongly agreed, 2 disagreed and the remaining 4 were unsure. This perhaps reflects the methodology of the research project and the roles prescribed to the ESG, however despite perhaps feeling constrained by their role, it was clear that participants felt respected and listened to.

**Table 1. Question scores\***

<b>Question 1</b>	<b>Not at all</b>  <b>High</b>				
<b>To what extent did you feel able to...</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
f) Achieve your own goals through the research		1	1	3	4
g) Make a contribution to the research				2	7
h) Make decisions about how to do the research	2	1	3	1	2
i) Express your views about the research topic			1	2	6
j) Discuss research issues	1	1	1	2	4
<b>Question 2</b>	<b>Not at all</b>  <b>High</b>				
<b>To what extent did you feel there is potential for you to...</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
f) Choose the role you play in the research	2		4	1	2
g) Bring your own ideas and values to the research		1		4	4
h) Work in ways that suit you			4	2	3
i) Gain status, credibility or expertise because of your involvement	1		3	4	1
j) Identify and organise your research ideas and priorities	1		4	3	1
<b>Question 3</b>	<b>Not at all</b>  <b>High</b>				
<b>To what extent did you feel...</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
f) Valued as a partner	1				8
g) Enabled rather than constrained			1	2	6
h) Empowered rather than exploited		1		1	7
i) Consenting (happy to be involved) not coerced (unhappy about it)			1		8
j) It is acceptable that different people have different roles in the research and different opinions		1			8
<b>Question 4</b>	<b>Not at all</b>  <b>High</b>				
<b>To what extent do you think....</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
e) The researchers have the right reasons for wanting to work with you				2	7
f) The way the researchers work with you is supportive				1	8
g) The way the researchers communicate with you is supportive		1		1	7
h) There was a clear role for you in the research	1			1	7

Note: \*Numbers in the response cells indicate the total number of responses for that category, blank cells indicate that no participants responded in that category.

### **Findings: free text questions**

All free text response are shown in Table 2 below. Comments were positive about many aspects of the ESG including inclusivity, broad range of participants and opportunities to have one's say on what was clearly perceived as an important research topic. There were both positive and negative comments about the impact of Covid 19 and the move to online working. Some participants felt that some of the sessions were too long or lacked focus, others felt that the team adapted to online working well.

**Table 2. Free text responses**

<b>Question 5. What are the things that you felt were good about your involvement in the project?</b>	
<b>Respondent 1</b>	<ul style="list-style-type: none"> <li>• Opportunity to connect with other crisis providers.</li> <li>• Listening to service users experiences</li> <li>• Increase awareness of what's important to service users when accessing crisis services.</li> <li>• Being involved in research process.</li> <li>• Project updates</li> </ul>
<b>Respondent 2</b>	<ul style="list-style-type: none"> <li>• Got them to move to break out rooms allowing more openness</li> <li>• Shared my experience as a carer – initially not seen as someone significant</li> <li>• Moved to some realization that psychological safety is the key issue</li> </ul>
<b>Respondent 3</b>	<p>Good to meet a broad number of professionals and service users and hear their experiences and opinions</p> <p>Enjoyed contributing positively to research which could lead to improvements in mental health care in future.</p>
<b>Respondent 5</b>	<p>Was good for our organization to be approached – felt like our expertise was seen, acknowledged and taken seriously. My own input, while limited due to a change of role, felt very positive – I felt able to bring my learning and to contribute in a meaningful way.</p>
<b>Respondent 6</b>	<p>All the above</p>
<b>Respondent 7</b>	<p>I felt the topic was very worthy of being the subject of a research project as in my experience, it has often been a point of conversation amongst people who use mental health services and those that care for them. And so I felt that specific research in this area, hoping to effect positive change was long overdue, so I was very pleased to be asked to be involved in the project. I think it was very well organised and managed and the researchers adapted brilliantly to the pandemic and the problems caused by covid 19 virus, allowing the project to continue. I am very much looking forward to seeing the results of the research and would like to be involved in any useful way at further stages if required.</p>
<b>Respondent 8</b>	<p>An excellent experience, it was a great opportunity to put forward my opinions regarding crisis and crisis services, express my views, the good, the bad and the ugly and overall give a thorough snapshot of these services and how they're delivered.</p>
<b>Respondent 9</b>	<p>It felt like the team were really committed to working with the wider involvement group and listened to what they had to say. I also thought the group had good representation – at least half of the group in the first session identified as having used crisis services, or was a carer for someone who used crisis services; and amongst those, there was not only a diversity of people, but also people who were currently or recently used services (and with support where required). This felt unique – added a depth, but also help to identify issues and experiences which are consistent across time and organisations. I thought the exercises in the first group were particularly impactful, as they enabled people to use their different experiences to inform a common task. It helped develop knowledge which inherently incorporated difference and built on it do create meaning and shared understanding – rather than just hearing</p>

	<p>experiences in isolation.</p> <p>From my own experience – it felt like the team were open for collaboration on an ongoing basis. When I came across relevant literature, I sent it across and it was welcomed. Very personally, I really valued being able to bring both my policy knowledge and own personal experience (and not be confined by professional role). I also saw this among some of the group who came from professional backgrounds but were also carers. I think it’s powerful when people can bring the sum of their experience and identity rather than acting as representative. In terms of the work – it was impactful that the group effectively gave the steer or identified the core areas that the research team then focused their activities around.</p> <p>Thought was given to giving people suitable breaks and an opportunity to step back from the work during online meetings – and the team reached out when people experienced distress.</p>
<b>Question 6. What are the things that you think that we could improve?</b>	
<b>Respondent 1</b>	<ul style="list-style-type: none"> <li>• Having to move to online ERG did inhibit opportunity to have informal connections/communications with other members of the group. Recognise this couldn’t be helped.</li> <li>• Some of the sessions could have done with being longer as felt a bit rushed re timing.</li> <li>• Some of the sessions seemed to do off the point and needed better “managing” by facilitator.</li> </ul>
<b>Respondent 2</b>	<ul style="list-style-type: none"> <li>• Softer start with jokes and less formality</li> <li>• Better road map of what is going to happen</li> <li>• Think psychological safety – this is the better issue for people with mh problem</li> </ul>
<b>Respondent 3</b>	It would have been better if the meetings could have all bene face to face but due to covid this was not possible.
<b>Respondent 5</b>	Not much that I can see. It’s not easy to bring professionals and ‘experts by experience’ together in a way that feels like everyone’s being treated as an equal – but it really felt that this was the case here.
<b>Respondent 6</b>	None
<b>Respondent 7</b>	<p>I think it would be hard to improve on areas of consultation and involvement. Obviously, it would have been an improvement I think if Corona virus had not occurred! And we could have met face to face, as we did in the first meeting, maybe at least one more time. But having said that, I think working online worked really well! And in future using this method may be a great money/time saver as opposed to the costings involved in booking a venue, providing food and covering travel and finding a date when everyone is able to attend. I think it important to meet in person so people feel at ease with each other. And I think the opportunity for the first meeting was adequate to introduce the participants to each other and the researchers, for barriers to be broken and the start of rapport to be established, enabling frank and honest discussion. Ideally, I think if the pandemic hadn’t halted meeting in person, I think one further face to face meeting might have been useful. But I think the subsequent online meetings were managed well. And that they improved with each session, allowing everyone to speak. I think in one of the early meetings online, I felt it was a little difficult for everyone to have air time speaking, as some people were quite rightly passionate about what they wanted to say, and it was hard for everyone to contribute equally, but this was improved in other meetings as the groups were made smaller and therefor easier to manage,</p>



	giving more opportunity for everyone to contribute. I think each online meeting improved as people got used to the format and the meetings were managed extremely well and were really productive. Conversely, conducting meetings online, perhaps turned out to be an easier to arrange and cheaper option than continuing to meet face to face.
<b>Respondent 8</b>	The payment process is a hassle, it should have been a straightforward procedure to get paid on time. Having to repetitively fill in forms was a hassle, having to screenshot signatures, emailing back and forth, chasing up payments, it was all a nuisance. Things were discussed that branched off from crisis care, other things need exploring like preventative care so you don't reach a point of crisis, and aftercare. I think that drop-in services for prevention and aftercare are important, I don't like the current emphasis on groups or fixed appointments. It's important that the data are used and taken on board to improve services.
<b>Respondent 9</b>	The methods were quite technical – at the start, it was clear how the group were involved to identify the focus of the methods and the search. However, as it went on it was less clear how this interaction worked and the feedback from the group was adopted and informed the work. It could feel more traditional – the research team sharing findings and ideas and getting thoughts. It was clear during the process that amongst the group, there were many who had had poor experiences of crisis care. It felt at times individuals' experiences were privileged at the expense of understanding different perspectives, including those of staff providing and commissioning services (as was achieved in the first meeting). This is a difficult one – and that arises in many contexts - but there may have needed to be ways of capturing these experiences so that they could be learnt from within the context of the research, while defining and holding to the focus of meetings when the whole group were convened. Where I have seen this managed well has been through having a clear purpose and strong facilitation skills which are able to validate experiences and create productive dialogue.
<b>Question 7. Question 7. Is there anything else you would like to tell us about your involvement in the MH-CREST project?</b>	
<b>Respondent 1</b>	<ul style="list-style-type: none"> <li>• I really enjoyed being a member of this ERG and meeting all the people who were part of it as participants.</li> <li>• The facilitators did a really good job of creating discussions and being supportive. .</li> <li>• I would like to request a copy of final paper on the research.</li> </ul>
<b>Respondent 2</b>	<ul style="list-style-type: none"> <li>• I will you every success</li> <li>• I cannot use the payment card because i have tremors and dextorious movements on a mobile phone are not possible</li> </ul>
<b>Respondent 3</b>	n/a
<b>Respondent 6</b>	Very approachable Co ordinators
<b>Respondent 7</b>	I really enjoyed the experience as it felt relevant and real, down to earth and focused on practical issues. I think contact with other groups asking their views, may add more of a range of experiences, but the group overall, seemed to have a wide range of experiences from people that both used and worked in mental health services. That seemed a big plus, as often it can seem like research and consultation projects attract a similar type of person using services that is active in representation projects. I think the participants in the project were particularly well represented across a wide regional area and from people from BME backgrounds. It was interesting to hear about regional

	variances and different takes from other service users in different areas as to what was available. I thought all the researchers were very friendly and approachable and all the participants respectful of each other and interested and committed. I would definitely like to be involved in any further participation and research in the future if required.
<b>Respondent 8</b>	I'm really grateful for the opportunity to get involved, to be able to share what works, what doesn't work, and how things need to change, and also express how crucial these services are. I feel that further research needs to be done so that more crisis care can be available for people.
<b>Respondent 9</b>	I recognise the real challenges that COVID brought – the change of format and ability to work as a collective group in the same way – but also the vast amount of work that the team did which was ultimately the basis of the work, and the content for each meeting. I hope the team recognise the importance of this piece of work – we've been talking about crisis care for decades, and yet the conversations still seem to be about some of the basics – and there remain common experiences that suggest care is perceived to be not available or helpful, and with staff recognising that they are not able to provide the care they would like to, or what would be most helpful in alleviating crises. There is a tension in pieces of work like this – the knowledge base from which you are working is inherently based on the things that people have previously focused on – and need to create and present rationalised pictures of what services and care should look like. And yet what I experienced and heard in the groups sessions was the need for humane care (for both patients and staff). I wonder and challenge you as what you can do to ensure this doesn't just become yet another piece of work on factors to consider when designing and delivering crisis care.

### Reflections

Overall, the evaluation findings report very positively. COVID-19 necessitated that we move to online consultation and networking with the ESG group. This was a challenge for all for all. Online working is less dynamic and interactive than face to face involvement work so it is perhaps unsurprising that some respondents report that sessions could appear at times to lack focus or direction. However, it would appear that the ESG experience was still very positive.

### Opportunities for learning

The necessity for online working created some challenges but also made the logistics of the meetings somewhat less taxing. Online working has been shown to work in spite of the challenges, and though there is no substitute for face-to-face meetings, researchers may wish to consider using a mixture of online and in person meetings for future stakeholder involvement work.

### Reference

Morrow, E., Ross, F., Grocott, P. and Bennett, J., 2010. A model and measure for quality service user involvement in health research. *International Journal of Consumer Studies*, 34(5), pp.532-539.