**MHJ Impact log forms as of July 2021**



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| **Work Stream / Researcher** |
| **WS1** |
| **Date of SUAG input** |
| **31st March 2020 (by Zoom)**  |
| **Research question brought to SUAG** |
| **Contraceptive decision-making and people with learning disabilities: Plans for stakeholder involvement.** |
| **SUAG input (please be as specific as possible)** |
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| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
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| **You said…** | **We did / will do…** |
| How are you going to make sure you get representation from a range of people with learning disabilities? | * Will seek advice from Mencap contact on involving people with more severe learning disabilities in the research
 |
| It is important to define contraception – not just for people with learning disabilities – but for everyone. Be aware that some people with learning disabilities in the group may not be aware that what they are taking is contraception, or appreciate how conception works. | * A definition of contraception is being incorporated into the survey
* Time will be dedicated in the sessions with people with learning disabilities to define contraception and talk about what it means
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| Consider the language that people with learning disabilities may be most familiar with around sex and contraception. | * Be careful not to make assumptions when working with people with learning disabilities that they know what certain terms mean
* Speak to the organiser of the group to check in about members’ familiarity with and experience discussing this sensitive topic
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| Have you considered who you may be missing by conducting a survey online? | * Discussed with supervisors
* Will contact two organisations who work a lot with family members of people with learning disabilities to learn about how they keep in touch with their members
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| How will you capture the sessions and ensure that you don’t miss anything? | * Seek permission from the attendees to audio record the session
* Think about how pictures or interactive cards could be used to capture group members’ input – these will serve as a visual record
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| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| **Working with the SUAG was a positive experience. Well organised and the meeting ran smoothly. Helpful for not just thinking about my service-user plans, but other parts of the project too (e.g. highlighted the importance of the terminology used in the survey being clear). Aware that as my project is focussed on people with learning disabilities rather than those with mental health conditions, that SUAG members may have found it difficult to comment on the project and service-user involvement plans based on personal experience.** |

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| **Work Stream / Researcher** |
| **WS2** |
| **Date of SUAG input** |
| **4th September 2018** |
| **Research question brought to SUAG** |
| (1) Does anyone have experience convening or participating in PAR (or similar engagement groups)? If so, what have been some of the positive experiences? What was challenging and why? What could have been done differently and why?(2) What needs to be taken into consideration when establishing PAR groups? What are common mistakes?(3) How could we keep participants motivated and engaged over the 10-12 weeks? What does it take to minimize drop-out?(4) What practical issues need to be taken into consideration when working in groups like this? What resources are needed? What challenges could arise? What are common mistakes and frustrations?(5) What are some of the ethical and moral issues that we need to be mindful of? Group ethics, but also researcher – participant relations/respect?(6) What kind of tensions could arise? How are these best resolved? What do we need to be mindful of?(7) What other issues come to mind? |
| **SUAG input (please be as specific as possible)** |
| *Please note: My notes are in my office which I can’t access due to the pandemic; the below is based on memory. I would be happy to update once I am able to go back to my office*.X and I received incredibly helpful input by SUAG members. We received input on the following aspects of participatory action research:- The importance of recognising each persons’ expertise- Having concrete agendas and actions for the meetings in order for participants to remain motivated- Allowing participants to determine the agenda based on their experiences and needs- Having a clear and structured agenda while making sure that participation is at every stage voluntary. Participants need to feel that they can walk out, take a break, or do other things if they wish to.- Putting clear communication rules in place: giving everyone the space to speak, ensuring that people are not talking over one another, using respectful language, avoiding jargon, not talking down on anyone- Importance of paying participants a decent salary for their time as they are producing and interpreting knowledge just like the professional researchers |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| The advice provided was incredibly useful. The notes that I had taken during the meeting were used as guidelines for our PAR group preparation. First of all, we negotiated a salary for all PAR group members. This is something unusual in the Palestinian context. While Palestinian academics were at first sceptical, we were heartened to see that the organisation providing rehabilitation support to the PAR group members negotiated a higher salary for the members than we had initially offered. So, we went with the higher salary.Our group sessions were co-designed with the PAR group members. PAR members usually determined the topic for the next session and thought together with us about the best way in which to research it. They spoke up if they did not like suggestions we (professional researchers) brought to the table which was helpful as it allowed us to jointly think of alternatives.During PAR meetings, we were mindful of communication etiquette. Since such etiquette was not new to the members, they mostly reminded themselves of certain rules that they had previously agreed on together. Consequently, communication was mostly respectful and it was ensured that everyone could speak. Sometimes, I made a bit of extra room for the women to be heard considering that they were a minority in the group (3 out of 12).Our sessions were all creative and purpose oriented. Nevertheless, we ensured that everyone knew that they could take breaks or refuse to participate at any point. Fortunately, members were enthusiastic about the project and enjoyed working together with us, especially as they knew that the end product would result in an illustrated storybook. |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
| The advice from this session stayed with us and we reviewed it again in the following year when we carried out the second round of PAR work. |
| **Can you give a brief indication of your general experience working with the SUAG?** |
| Working with the SUAG was incredibly helpful. It felt reassuring to receive members’ advice based on their own expertise and experience.  |



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| **Work Stream / Researcher** |
| **WS2** |
| **Date of SUAG input** |
| **18th June 2019** |
| **Research question brought to SUAG** |
| We asked members of the SUAG to help us with the following questions:* What ways are there to disseminate research results beyond academia?
* What ways of disseminating research do you have experience with?
* What do you think about using film for dissemination/engagement?
* How can dissemination reach non-literate audiences effectively?
* What training needs might there be to involve service users in dissemination e.g. media training, writing skills?
* With regards to the illustrated story book: what should be taken into consideration when producing it?
* What issues come up around disclosure of identity? What are the potential risks and benefits?
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| **SUAG input (please be as specific as possible)** |
| * Members of our SUAG suggested that we could think with our Participatory Action Research group members to create information and awareness raising material. An interesting idea was to partner with companies. For example, one could create canned food labels that include a bit of information about mental health.
* We talked about various comic books that exist in English in order to help me think about how to best disseminate our illustrated storybook. All SUAG members seemed positive about conveying information about the lived experience of mental illness through illustrations. Concrete examples were given for us to explore including:

Mahew Johnstone’s I had a black dog – his name was depression.Kay Redfield Jamison’s An Unquiet Mind (an account of bipolar by an American psychiatrist who has the condion)William Styron’s Darkness Visible (about depression);Patrick and Henry Cockburn’s Henry’s Demons (on schizophrenia by father and son, who has condion). A story book for children about alzheimer's disease: hps://www.alzheimers.org.uk/get- support/publicaons-factsheets/its-me-grandma-its-me * SUAG members shared also other resources about how to talk publicly about mental illness (from a British perspective) which we thought was inspirational for us: hps://www.me-to-change.org.uk/get-involved/me-talk- day More importantly, also to think about how safe spaces can be created in which people would feel comfortable to share experiences.
* Using audio recordings which could be listened to as podcasts, on websites or over the radio about what it means for someone with a mental illness to live and parcipate in the community. SUAG members also thought that anitmation videos could work nicely.
* Regarding portraying persons with mental illness on film and in books we were advised to make sure that they don't look 'stupid' (even if not intentional); make sure that mental illness is not portrayed as a homogenous experience, but as one that is experienced differently by different people even when they share the same diagnosis; avoid linear heroic narratives (I was ill, then I received treatment, and now I am able to achieve all these brilliant things - mental illness fluctuates and is not linear)
* Members of the SUAG also thought about ways in which messages about mental health could be spread more effectively and, at the same time safely
* We also talked about de-anonymising especially as it relates to film. This can be a big step for people to take and the queson is how to keep them safe. This also means to have convesations about personal boundaries and how to maintain them while sharing personal experiences publicly. Somewhat related to this, we also contemplated about the importance of talking to people about what they don't want to share publicly, how they don't want to be presented, and what kinds of headlines they don't want to see about themselves in the media, film or books.
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| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| I shared these insights with my team in Palestine in preparation of our next round of intensive research. The advice was invaluable. This is how it impacted on our work:- We created information and advocacy material inform of cards which each included a key message on the front and information about the CRPD on the back. The cards were beautifully made with photos which we jointly selected. The cards were distributed in public spaces such as libraries, pharmacies, bakeries, restaurants, schools, universities, hair salons etc.- We organised an awareness raising event at the Open University in Qalqilya where members of the Participatory Action Research (PAR) talked about their rights and experiences in front of students and answered questions. We did a similar event at the public library. Both were incredible considering that members of the group had never spoken about their illness in public, were welcomed warmly (against their expectations), and felt that they were heard. The university and library wrote about the event on their websites.- The input into how to improve our illustrated storybook was taken up. We reviewed every story carefully with the Participatory Action Research group members paying particular attention to how people were portrayed, diversity of experiences, and the problematic ‘heroic narratives’. Indeed, we picked some of these issues up and revised them together with PAR members. - We talked about de-anonymizing the book regularly. After much contemplation and debate, PAR group members wanted to remain anonymous. They selected a group name for themselves which will be their pen-name. Persons portrayed inside the book receive pseudonyms. However, they wanted to have one image in the book where they could recognise themselves – such a group portrait felt safe to them.- We continue to struggle with finding a publisher. |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| This was such an extraordinarily fruitful session with lots of rich advise based on the expertise of SUAG members. |

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| **Work Stream / Researcher** |
| **WS2** |
| **Date of SUAG input** |
| **18th June 2019** |
| **Research question brought to SUAG** |
| **Portrayal of mental illness in participatory films****Risks and benefits of disclosing identity and mental health issues** |
| **SUAG input (please be as specific as possible)** |
| 1. Advice given on avoiding stereotypes, avoiding portraying people with mental illness as 'stupid' or ‘slow’; show variety of experience, make sure that mental illness is not portrayed as a homogenous experience, but as one that is experienced differently by different people even when they share the same diagnosis; avoid linear heroic narratives (I was ill, then I received treatment, and now I am able to achieve all these brilliant things - mental illness fluctuates and is not linear). Importance of showing people not as isolated ‘sufferers’ but interacting with others.
2. Advice on public disclosure of identity and diagnosis - can be a big step, how to keep people safe. Different options for disclosure e.g. just using first name. Consider personal boundaries and how to maintain them. Be prepared e.g. ask journalists what questions they are going to ask you beforehand. Importance of talking to people about what they don't want to share publicly, how they don't want to be presented. Important to discuss with their friends and family - revealing one's condition publicly has implications for them too, and they can help the person to think through the consequences e.g. in relation to looking for work. Important to consider how information is shared on social media. Media training can be helpful.
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| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| 1. **Advice discussed with members of the participatory groups in planning for participatory films.**
2. **Informed discussions with research participants on issues to consider in disclosing identity and diagnosis.**
 |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| **Has been extremely helpful in thinking through implications of introducing a participatory approach in Ghana with people who are involved in research as service users in the UK and can draw on their experience to provide advice** |

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| **Work Stream / Researcher** |
| **WS2** |
| **Date of SUAG input** |
| **30st March 2020 (by Zoom)**  |
| **Research question brought to SUAG** |
| **Support and independence within the community** |
| **SUAG input (please be as specific as possible)** |
| I did not attend the meeting, but received notes from my postdoc X about important insights provided by the SUAG. Topics discussed were supporting participatory group members through crisis and terminology referring to persons with mental ill health in journal articles. |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| With permission from SUAG members we shared the insights as well as zoom recording with our research teams in Ghana and Palestine. The Palestine team that I am co-leading felt that the insights were extraordinarily helpful. The discussion on “supporting participatory group members through crisis” led to a reflection on a difficult situation we had encountered in the previous year. At the time, we had felt quite helpless and were just hoping that we acted in an appropriate and supportive way. The advice by the SUAG members gave us a good sense of what we did right and what we could have handled differently. Since we continue to work with the participatory group, we will return to the reflections. With regards to “terminology”, the team in Palestine revised terminology used in a draft publication on the right to live in the community for persons with mental illness in war-affected settings. SUAG members helped us to decide on terminology that is respectful while also highlighting the serious implications mental ill health can have. |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| My experience working with the SUAG has always been insightful and eye opening. The expertise of the group is clearly shaping the way I am going about research. Thank you. |

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| **Work Stream / Researcher** |
| **WS2** |
| **Date of SUAG input** |
| **30st March 2020 (by Zoom)**  |
| **Research question brought to SUAG** |
| 1. **How to support participatory group members through crisis**
2. **Terminology for publications**
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| **SUAG input (please be as specific as possible)** |
| 1. **Advice on managing crisis – discuss with the group and individuals, identify triggers, advance planning with the person, wellness action plans, ground rules and protocols, acknowledge honestly when you make mistakes and learn from them, give the person space to recover and plan how to reintegrate them into the group.**
2. **Provided advice on acceptable terms e.g. service user, survivor, persons with lived experience, person with psychosocial disabilities – these vary depending on individual preference and context. Use of ‘severe mental illness’ is helpful to distinguish from broad notion of ‘mental health’. Some terms which have been reclaimed for self-identification such as ‘mad’ may not work across cultures. General preference to emphasise ‘experience’. Reintegration preferred to ‘rehabilitation’ as implying more active participation.**
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| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| 1. **Helped to guide the way we addressed the relapse of a group member and reintegrate him into the group. Informed the development of guidelines to manage crises with the group which will be followed in planning future activities e.g. advance planning to plan support in case of relapse**
2. **Informed the choice of terms employed in publications which was explained in a footnote**
 |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| **I have found the discussions very helpful in guiding the research and thinking through issues around representation. The practical experience-based advice on responding to the distressing events around the relapse of a participant during research was especially valuable for the researchers and participants and will guide our approach going forward.** |

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| **Work Stream / Researcher** |
| **WS2** |
| **Date of SUAG input** |
| **30th March 2020** |
| **Research question brought to SUAG** |
| **Participatory action research questions** |
| **SUAG input (please be as specific as possible)** |
| 1. **It was suggested that researchers should consider what it means to be excluded from the community more generally, alongside what this means specifically for people with mental illness**
2. **Discussion around representation and managing expectations. Suggestions: Being clear and honest; being aware of own knowledge gaps; allow for different communication styles; consider non-verbal ways of collecting data; acknowledge differences; allow for different levels of involvement**
3. **Discussion around involving people with severe mental illness. Suggestions: treat with respect/dignity; respecting boundaries; giving participants time out; check in with group; following up with people who don't attend**
4. **Remuneration - should be provided and reflect contributions of PAR participants**
 |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| 1. **Ethnography in Ghana included observations on the intersectionality of social exclusion for people with mental illness in relation to poverty, gender, physical disability, rural location, education level etc. This informs the approach to analysis**
2. **Using participatory film to communicate experiences of people with lived experience of severe mental illness in Ghana**
3. **Used suggested approaches to successfully include people who were experiencing symptoms such as hallucinations and mania in group activities and provide time out where needed**
4. **Remuneration agreed in discussion with group members and all participants were paid for their involvement**
 |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| **Very positive, friendly and experience-driven advice which helped to shape the way we developed and facilitated the participatory group in Ghana** |

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| **Work Stream / Researcher** |
| **WS2**  |
| **Date of SUAG input** |
| **4th March 2021** |
| **Research question brought to SUAG** |
| Support and independence within the community presentations – The capability to live in the community with equal standing |
| **SUAG input (please be as specific as possible)** |
| I presented the main arguments I am making in my PhD thesis on living in the community with equal standing. I requested general first impressions and general feedback as well as specific feedback on issues identified that emerge from my work. I received valuable contributions about the role stigmatisation and discrimination play in shaping the experience of people with mental illness or disabilities within the community. Additionally, I received feedback and comments surrounding the concepts of autonomy and equality, as well as their variability across cultures, religions, different contexts, and across different groups of persons with disabilities. Finally, the fact that some people might not want to live in the community was flagged, as was the fact that some people do not want to increase their social relationships.  |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| The conversation and feedback I received from the SUAG was both very insightful and led me to rethink how I frame some of my arguments. Additionally, the discussion around the idea that some people might not want to live in the community or form social relationships to support their community life, led me to include a section in my work discussing this point. I included the points made by the group so as to take into account the perspective some service users might have. Furthermore, the discussion reinforced how important it is for support in the community to be service user led so as to be meaningful for the persons who might rely on the support.  |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| It was a very valuable experience to present my work to this group. This was my first close interaction with the SUAG, beyond the interactions at the colloquiums, and I wished I’d come to the group sooner with some of my questions as the feedback provided both filled some gaps I had in my work and helped me further my thinking on some issues I had identified in my arguments. Beyond this, the possibility to discuss with service users is not common for many theoretical theses, however, I found that having the opportunity to meet with the SUAG helped me understand some of the value of my work as well as its pitfalls.  |

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| **Work Stream / Researcher** |
| **WS2**  |
| **Date of SUAG input** |
| **4th March 2021** |
| **Research question brought to SUAG** |
| Support and independence within the community presentations |
| **SUAG input (please be as specific as possible)** |
| We presented our application for an Impact Acceleration Award. As a team we struggled with the overall conceptual framework and SUAG members introduced us to the method called “deliberative dialogue”. We later received a key article outlining the method and decided that this would be the core that holds our application together. It has allowed us to write a well-rounded application where we experiment, through different creative approaches with deliberative dialogue in order to advance our project’s impact. We are extremely thankful for the intellectual input – without it, the application would have been a different one and, possibly, not as successful.SUAG members advised us also on practical aspects which we have integrated into the application. Particularly helpful was the discussion about our planned radio programme in Ghana which will feature call ins from the general public to inquire about mental health and react to the stories of lived experience that they have heard on the programme. SUAG members suggested important ways to protect service users from callers with discriminatory attitudes. Following SUAG feedback, calls will be ‘planted’ that is, spontaneous callers won’t be accepted. This will also allow for ensuring a more diverse pool of callers from groups who might otherwise be less inclined to call as we would be able to approach people directly (another helpful point raised by the SUAG). At the moment, we are working on another point that was raised related to the anonymity of the callers who might themselves feel stigmatised for just talking about mental health in a public forum. These suggestions will also be implemented in the context of Palestine where the general public will be invited to participate in an online discussion forum. |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| The SUAG’s contribution was crucial. It allowed us to develop a well-rounded and thought through application both on theoretical and practical levels. The application was successful and we are in the process of implementing the proposed activities. |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
| A thought that has come to mind after this very productive session was about ‘extraction’. We had the privilege to pitch our grant application to members of the SUAG and received crucial advice on intellectual and practical levels that helped to make the application significantly better. While I am glad that we are logging the impact here, I struggle with the feeling that we extracted insight and experience without proper recognition (e.g. including a couple of representatives of the SUAG in the application as paid advisors). In other words, the input has become invisible in the application itself which is a shame. We might want to have a conversation as part of the wider MHJ group of how to credit insight from members of the SUAG in publications and other outputs. |
| **Can you give a brief indication of your general experience working with the SUAG?** |
| Working with the SUAG has been extremely productive. The SUAG helped us with difficult practical issues around participatory action research, led us to rethink our approaches, and allowed us to engage with theoretical frameworks and methods that were new to us. We are grateful for everyone’s critical, constructive and empathetical engagement with our work in contexts that are far removed from the UK. |





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| **Work Stream / Researcher** |
| **WS3**  |
| **Date of SUAG input** |
| **4th March 2021** |
| **Research question brought to SUAG** |
| Advance directives presentation |
| **SUAG input (please be as specific as possible)** |
| **I presented current progress on the Crisis PACk to the SUAG, I asked for specific feedback on the language around alerts, who should be involved in making a Crisis PACk and language around third party supporters** |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| **As a result of the SUAG meeting I confirmed how I will flag up that service users have Crisis PACks on their clinical records. The group were very aligned with the term ‘supporter’ I was surprised by this because I had been wondering more about using the term ‘coach’. However, the SUAG explained that the idea of a Crisis PACk ‘supporter’ is more aligned to other similar scenarios in health care e.g. peer supporter/advocate and reflects the desired power differential – coming alongside the person better than the term ‘coach’ which suggests the coacher holds the expertise. I am using the term Crisis PACk supporter and ACD supporters in all the writing I am doing about the importance of this role.**  |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| **It has been extremely positive. I came with some practical questions that needed resolving and only the SUAG had the expertise to advise on these sensitive issues. Service user participants in the project really like to hear that the SUAG has been involved throughout the design and delivery of this research. It gives it more credibility with them and sends a message about how seriously we take service user expertise – vital for building trust and rapport in this project.**  |

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| **Work Stream / Researcher** |
| **WS4** |
| **Date of SUAG input** |
| **15th June 2017** |
| **Research question brought to SUAG** |
| **What standard of objectivity is relevant where mental health and justice interact?** |
| **SUAG input (please be as specific as possible)** |
| **Several members of the SUAG expressed skepticism about the framing of the research question, which seemed to presuppose that there was any objectivity, or any aspiration to objectivity, in the way that service users dealing with mental health issues are treated. Other members of the group emphasised the importance of objectivity and objective evidence in this arena.** |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| **This SUAG meeting was one of a series of events in which it became increasingly clear that divergent reactions to the research question itself was an important part of the phenomenon to be studied. This in turn informed our approach to the later public policy lab in which we approached these issues/themes. It also informed the approach that we have taken in developing a training module for professionals on ideals of objectivity in mental health and mental capacity law. In that training we thematise at the outset this divergence of initial responses, and then try to understand it.** |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| **The SUAG contributions have been consistently useful and insightful. There were times when I worried that we were trying the patience of SUAG members when pursuing points of law or philosophy, but even that experience provided an important point of reference.** |

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| **Work Stream / Researcher** |
| **WS4** |
| **Date of SUAG input** |
| **30th Nov 2017** |
| **Research question brought to SUAG** |
| **Review of Draft Materials for Ethics Review Process** |
| **SUAG input (please be as specific as possible)** |
| **Members of the SUAG reviewed draft materials that our team was preparing for our application for ethics approval for our study of insight and clinical decision making in ward rounds.** |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| **The following changes to the study were the result of the consultation:****• we have added observation of associated meetings to the ward rounds, as SUAG felt that some insight-related decisions about the service users treatment are often decided in care meetings and similar;****• SUAG members have pointed out that often insight is assessed informally and without explicit reference to the term, but rather with related questions, arrangements, behaviours and discussions such as “do you know why you are here”, “how do you think you will cope”, “do you understand why your therapist is concerned”, etc. We have included this in our study design areas of focus.****• SUAG have proposed both acute ward and eating disorders ward as good points of study of insight and we have followed their suggestions.****• they agreed that the chosen 'fly-on-the-wall' methodology with note-taking is a good comportment for observation of ward rounds.****• they advised us to emphasise in our information sheets and consent forms for the service users that there is no connection to their treatment or outcome.**  |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| **This meeting was incredibly useful in our preparation for the ethics approval process and in refining the protocol for the study itself.** |

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| **Work Stream / Researcher** |
| **WS5** |
| **Date of SUAG input** |
| **29th Nov 2018** |
| **Research question brought to SUAG** |
| **Using and weighing information and metacognition** |
| **SUAG input (please be as specific as possible)** |
| **The SUAG gave feedback on the overall design of the project which I presented. Additionally, I showed our novel measure of metacognition (“Metacogmission”) and we received feedback on that. After the meeting , several SUAG members piloted the task for us at home and gave detailed feedback.** |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| **Metacogmission was updated using the specific feedback given, including how the task could be navigated on a personal computer/device, the artistic design and the experience of undertaking the individual psychological tasks.** |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
| **The SUAG feedback has allowed successful rolling out of Metacogmission to over 300 participants, across the adult lifespan and including older adults.** |
| **Can you give a brief indication of your general experience working with the SUAG?** |
| **It has always been a positive experience and an asset to our project.** |

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| **Work Stream / Researcher** |
| **WS5** |
| **Date of SUAG input** |
| **12th Nov 2019**  |
| **Research question brought to SUAG** |
| Do situational factors like stress influence decision-making? |
| **SUAG input (please be as specific as possible)** |
| Main EngagementI engaged with the SUAG and the McPin foundation regarding preliminary planning of an experimental study, which would have involved recruiting older adults with and without mild dementia. This was my first study that would require NHS ethical approval and it carried a number of potential risks. I was therefore really keen to learn from the SUAG, many of whom have useful experience on ethics committees. I began by sending the Co-Chairs a two-page early draft of my protocol via email, which they circulated to the SUAG/McPin foundation. There were some aspects of my study that were not concrete at that stage and it had not yet been sent out for NHS ethics. I received extensive feedback two weeks later, focusing particularly on recruitment, the use of deception, carer involvement and reimbursement. One of the SUAG Chairs and I discussed some points via email and others were left to the meeting. During the meeting, I briefly presented the basis of my experimental project and what we hoped to find. I then had a discussion with the SUAG, which primarily included thinking about participant eligibility criteria, accessibility and safety. This was particularly challenging to assess considering that we were open to recruiting dementia participants outside of the NHS. There was some debate around whether we would require an upper age limit or whether this was potentially exclusionary. I also clarified issues around the hypotheses, data protection procedures and settings. The feedback I received made me feel much more confident in pursuing my complex and somewhat sensitive study. My discussions with the SUAG underlined the importance of making research inclusive, which can easily be forgotten when trying to mitigate risks. The only downside was that, if memory serves, the SUAG did not have stated representation of people who had dementia or their carers, who were the target population for my experimental study. The SUAG advised other organisations that could provide a review mechanism focussed specifically on dementia research. At the end of the meeting, one of the SUAG Chairs suggested that I could send through specific aspects of the NHS ethics application with specific questions if I needed further help. I agreed that I would update the SUAG with progress and further questions via. The SUAG Chairs. Other EngagementsIn the experimental study, I had planned to use a metacognitive task designed by a workstream 5 researcher, which was trialled with the SUAG for acceptability. Some members of the SUAG also contributed feedback for the workstream 5 public engagement ‘café sessions’ during the MHJ colloquium, focusing on ‘metacognition and decision making’ and also during informal discussions. This was a very useful exercise to practice communicating our findings outside of our silos and to reflect on the real-world impact of our research. We wrote down the anonymous feedback and constructive criticism and discussed them in our follow up workstream meeting.  |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| I discussed the email and in-person feedback from the SUAG with my supervisor in a follow up meeting. Partly on the basis of the feedback, we decided that: 1. We will tell participants the length of time in the task, to avoid unnecessary deception
2. We will adapt the legal decision-making task from qualitative to mixed methods, to provide further insight into our research questions
3. We will ask for participant feedback on the experiment during the debriefing
4. We will proactively offer breaks to participants throughout the study
5. We will not include participants who had already taken out a lasting power of attorney (to avoid potentially confusing them)
6. We will not have a formal upper age limit; instead we will use the screening questions and clinician judgements upon first approach
7. We will ask for a statement from the creator of the task that it should be feasible for participants with mild dementia
8. We will apply to Camberwell and St Giles NHS Research Ethics Committee for approval

For the NHS ethics application, I acknowledged the SUAG contributions and included anonymised minutes from the meeting as evidence. We had also planned to work with the Risograph studio at the Bethlem Gallery, in order to produce accessible recruitment materials. This derived in part from SUAG feedback. Unfortunately, the IOPPN required that all recruitment materials should be confirmed before submitting ethics, so we were unable to proceed with this plan due to time constraints.  |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
| Unfortunately, due to IOPPN restrictions on clinical research during the COVID-19 pandemic, I had to discontinue the experimental study. The protocol for the study will be included in my PhD thesis. I will acknowledge the contributions of the SUAG towards the design of the study and circulate the relevant section to them via. The SUAG chairs. The full thesis would be available if requested! I am very keen to resume the experimental study at a later stage in my career. In the current climate, it is difficult to know what the nature of any future engagement with the SUAG would be on this project. However, we still envisage that the project will result in a publication and then dissemination.We are also planning other potentially service user-facing research and if these ideas progress, we would be open to further coproduction.  |
| **Can you give a brief indication of your general experience working with the SUAG?** |
| Overall, I found the SUAG feedback very useful in terms of navigating the complex ethics process. The level of scrutiny was challenging but useful and entirely constructive. After the meeting, I felt far more confident that the project was feasible and useful. I have not had much engagement outside of this project, because my other projects were non-clinical, but I hope to engage more in the future.  |

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| **Work Stream / Researcher** |
| **WS6** |
| **Date of SUAG input** |
| **21st June 2018** |
| **Research question brought to SUAG:**  |
| **How should we think about the cause of a lack of capacity?** |
| **SUAG input (please be as specific as possible)** |
| **Nuala Kane and I presented a key question to the SUAG that arises in the context of capacity determination in England & Wales, namely how we should think about the ‘causative nexus’. In E&W, the MCA 2005 requires that an inability to make a decision be caused by an impairment or disturbance in the functioning of the mind or brain of the person in order for it be considered a decision made without capacity for purposes of the Act. Legislation in other countries, including New Zealand (which forms part of the WS6 research) does not have such a requirement. In the context of research interviews being conducted with lawyers and psychiatrists we were encountering the following situations/questions** * **Person with mild learning disability or dementia and powerful forces around them**
* **Where to draw the line between a person with a mental health disorder with strong views and a person who is unable to make a decision**

 **We wanted to test with the SUAG how they saw (1) the ‘work’ that is being done by the causative nexus; and (2) the validity of the causative nexus as a concept.**  |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| **The SUAG contribution was extremely helpful – we had a very detailed, and lively, discussion about the role of the causative nexus, with strong and opposing views being expressed by members of the SUAG. One point that particularly resonated with me which came from a SUAG member was an angle which we had not previously considered in quite this way: namely whether thinking about the impairment/disturbance was important so as to be able to identify what support the person might need in order to be able to make the decision in question. This framing of the question – which I should say may not have represented the majority view of the SUAG members – has been helpful in terms of developing further guidance relating to capacity assessment for purposes of the MCA.**  |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| **I have thoroughly enjoyed presenting both updates and specific questions to the SUAG. They have cross-examined with skill and polite passion, and have helped substantially both in terms of honing explanations of sometimes complex ideas, and also in thinking through the underpinning assumptions of those ideas.**  |

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| **Work Stream / Researcher** |
| **WS6** |
| **Date of SUAG input** |
| **25th March 2019** |
| **Research question brought to SUAG** |
| Workstream 6Typology of justifications from the court of protection judgements.  Questions:  a) does the typology of Court of Protection justifications of capacities have face validity to service users? What might be the areas of concern? Does the typology look comprehensive to service users? Are areas being missed?b) how should these justifications be taught to health and social care professionals and communicated to service users. How should we trial this at our mental capacity masterclass?Some materials and questions were circulated before the meeting and I made a brief presentation.  |
| **SUAG input (please be as specific as possible)** |
| In terms of the questions, there was some discussion and some useful comments about some of the categories which might be more controversial and the importance of presenting the categories in terms of decision specificity and starting with support. We didn’t cover whether some areas might be missed. There was input about the typology being taught critically and avoiding reverse engineering.  |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| I think it allowed us to feel more confident that the typology had face validity from a SU perspective, and it was good to hear the critical voice about reverse engineering – a concern that had been exercising us in the workstream too. There was some useful feedback about the controversy of some of the categories – e.g. consistency of choice and coherence of reasons. Both these points had impact on how WS6 wrote up a research paper on the typology – highlighting the more controversial categories and emphasising that the categories were targets for support as well as for understanding inabilities. |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
| We didn’t manage to get to b) for much time though the point about teaching to be critical was useful. It would be good to revisit as the masterclass is ongoing. |
| **Can you give a brief indication of your general experience working with the SUAG?** |
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| **Work Stream / Researcher** |
| WS6  |
| **Date of SUAG input** |
| 10Nov20 |
| **Research question brought to SUAG** |
| How should we think about the presumption of capacity  |
| **SUAG input (please be as specific as possible)** |
| I took the SUAG through a number of slides looking at different perspectives on the presumption of capacity, seeking to tease out their response to them; I was particularly concerned to which is the least dangerous assumption (especially in ‘high stakes’ situations) – that a person does or does not have capacity. The SUAG members challenged each of the perspectives, and brought their own experiences and concerns to bear, making the challenge more than simply theoretical.  |
| **How did the SUAG contribution impact on your research (please be as specific as possible)?** |
| I trust that it is a fair reflection of the SUAG meeting that I considered to be validated the approach that we want to set out in a guidance document as to the presumption of capacity (i.e. that it is not a licence not to investigate in the presence of proper reason to consider capacity).  |
| **Optional – any other details about research development/outputs relevant to SUAG contribution.** |
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| **Can you give a brief indication of your general experience working with the SUAG?** |
| As always, I was just sad I did not have longer for the discussion with them, as it was so productive and stimulating.  |