

# Broadening Diversity Through Creative Engagement in Research Prioritisation

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## Methodology

**Keywords:** art, Black, Asian and Minority Ethnic Groups, creative approaches, dementia, diversity, mental health, research prioritisation

**Posted Date:** October 19th, 2020

**DOI:** <https://doi.org/10.21203/rs.3.rs-92279/v1>

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**Version of Record:** A version of this preprint was published on January 6th, 2021. See the published version at <https://doi.org/10.1186/s40900-020-00244-z>.

# Abstract

**Background:** Patient and public involvement (PPI) can help with steering and shaping research prioritisation and execution. However, some groups of people may not be encouraged to take part and their voices may be seldom listened to in the production of research. This is important to consider because they may have poorer healthcare experiences. We wanted to try out using art as a vehicle for including individuals not necessarily invited to be part of research priority setting.

**Methods:** We contacted existing groups and organisations to reach people who are not routinely supported to be part of PPI. We targeted individuals: a) with dementia, b) with mental health conditions, and c) from Black, Asian and Minority Ethnic backgrounds. We ran a workshop with each group at which individuals shared their experiences of healthcare. A young amateur artist also attended, who produced a piece of artwork afterwards that reflected the research priorities raised. We held a Twitter chat to discuss the final pieces of art that were created, and the processes involved in their generation.

**Results:** From each workshop, we produced a list of research priorities. These included: a) improving coordination of care for people with dementia, b) supporting discussion of women's health issues in South Asian communities, c) information needs, anxiety/guilt around accessing care and costs associated with this for people with a mixture of physical and mental health conditions. These priorities were reflected in three pieces of art, which can be [viewed online](#). Feedback from those at workshops suggested that the artwork has helped them to feel their voice has been heard and triggered their interest in how research is developed. Those involved in the Twitter chat commented that art was one means through which researchers could connect with a range of groups in a PPI context when preparing and then producing a study.

**Conclusions:** We found the medium of art to be an effective way of including a range of people in research prioritisation setting. This approach could be useful for future public involvement and engagement, building on what we have learnt from the project described in this paper.

## Plain English Summary

Patient and public involvement (PPI) in research has become more prominent in recent years. Drivers for incorporating the voices of lay people into the planning and conduct of research include: a) to ensure that research addresses issues of importance to patients, b) informing how public funding is spent, and c) helping to design a study in a way that is acceptable to potential participants. There are specific groups that may be defined as 'seldom listened to' when it comes to PPI activities. We were interested in how to engage such populations in setting priorities for research. In particular, we sought to work with people: a) living with dementia, b) from a BAME background (Black, Asian and Minority Ethnic), and c) affected by co-occurring physical and mental health conditions. We used the creation of artwork as a vehicle for broadening diversity in the setting of priorities for research. We held separate workshops with representatives from each of the groups listed above. They were invited to talk about their health/care

needs, experiences of services, and to identify topics where future research should focus. An artist attended each group. They produced some artwork based on discussions around research priorities. We have shared this artwork with workshop attendees, and more widely through a blog, a narrated video and a Twitter chat. In this paper, we present our reflections on undertaking this project, lessons learnt and how this art-based approach could be used by others going forward.

## Background

Debates are ongoing about how to incorporate a diverse range of voices in the design and delivery of research as part of patient and public involvement (PPI) [1–4]. They include the lack of representation from Black, Asian and Minority Ethnic (BAME) groups, those living in deprived areas, care home residents and individuals with mental health conditions in PPI activities [5–6]. Their voices are often absent when research is being planned and conducted. This is unfortunate as these populations can have poor health outcomes (e.g. morbidity, mortality) and encounter negative experiences of services [7–8]. Their involvement may bring a range of benefits, such as ensuring that research addresses issues of interest to key stakeholders and improves the relevance of research questions to practice and policy [9]. Reaching beyond the ‘usual suspects’ who take part in PPI activities (often defined as older, White, middle class) [10] is important for realising these benefits.

Although traditional approaches to PPI (e.g. formal meetings) are useful, they may structurally limit who takes part. Hence, exploring innovative ways to facilitate PPI is required to allow for dialogue and engagement with a broader range of people. This includes producing novel approaches to co-producing ideas for research prioritisation (i.e. topics that warrant developing into proposals to be submitted for research funding). Art can stimulate discussion in an accessible manner [11], as it is used across cultures and settings as a form of communication that can foster responses such as awareness, contemplation and a drive to react [12]. We wanted to explore whether an arts-based approach could be a vehicle to support the inclusion of individuals who are not usually invited to identifying priorities for research.

## Aim

The project aimed to explore the use of art as part of PPI research priority setting with groups who are seldom listened to in this process. We outline a series of involvement activities that we undertook to provide a voice to people with dementia, people with mental health conditions, and people from BAME backgrounds. A PPI contributor (GR) was part of the project team; she helped with developing the idea for this project. We offer reflections on our experiences, lessons learnt and how this approach could be used by others going forward to identify and work with seldom listened to groups.

## Methods

### Groups involved and settings:

As the intention was to broaden the reach of PPI, this project involved a multisite collaboration that consisted of workshops with three different populations:

- In Oxford - people with young onset dementia;
- In Keele - people with musculoskeletal (MSK) and mental health problems;
- In Bristol - women of South Asian origin.

### **Artists and art involvement:**

At the outset, we planned to explore the involvement of amateur artists in health research. The team thought it would be a good opportunity for young people with an artistic flair to develop their portfolio and to engage in a project that was likely to have national coverage. In addition, it was an opportunity for them to learn about health services research and the notion of PPI. We recruited young people through broad local advertisements and invitations via schoolteachers to students (at secondary school or college) to be part of the project. Two young amateur artists (E. Prior aged 17 and M.Viljoen aged 19) responded and worked with the team on this project. MV attended workshops in Bristol and Keele, whilst EP was at the Oxford workshop.

### **PPI workshops:**

At each workshop, those attending were invited to share experiences of their health/care needs, services, and to identify priorities for research. We also highlighted what is meant by PPI in research, and how people might participate in this activity. Furthermore, we asked for suggestions about how best to share findings from this project to a diverse audience. All workshops took place in person during February 2020. Notes were made by researchers to record key points that were raised.

In Oxford, ST attended a young onset dementia group that meets once a month in a local pub. She had 50 minutes to talk to the group, which on the day consisted of 8 people (5 with young onset dementia, 2 relatives and the group coordinator).

In Bristol, SD contacted a community group with whom she had established links through previous research. She attended a meeting that this group was holding, facilitating a 70 minutes discussion with 11 women from South Asian backgrounds. SD communicated in Hindi as women who were present understood this language. An interpreter was also present to support discussions in Punjabi and to ensure that information was not lost or misinterpreted because of language differences.

In Keele, OB approached the College of the Third Age as a vehicle for recruiting older people with MSK and mental health problems. A date was arranged for those who were interested to attend a meeting at the University. Six older adults with various MSK and mental health conditions were present. 150 minutes were spent discussing lived experiences of their conditions, care and priorities for research.

At each workshop, those attending were invited to prioritise ideas for research that they had produced. In Bristol, topics that might be of interest were discussed in advance with the community group organiser. At

the workshop, these topics were presented to the group to arrive at a consensus on one that they wanted to discuss (and this became the focus of the artwork produced from this group). In Oxford, topics were written by the researcher on a post-it note as they arose during the workshop. Participants were then given three sticky dots and asked to place them on topics that were of most importance to them. In Keele, a tree of key concerns was created by the group to identify and represent their research priorities (see Figure 1).

An artist was present at each workshop to listen and asked questions of the group. They made rough sketches and noted topics of interest to be captured in the final artwork. Afterwards, researchers had a debrief with each artist, to explore initial ideas and reflections. Subsequently, they produced pieces of art based on identified research issues as prioritised by each group.

## Results

**Research priorities:** Research priorities to transpire from each PPI workshop are listed in Table 1. Engagement with the young onset dementia group at Oxford brought to light the need for evidence on co-ordinated support post diagnosis, so that people given this diagnosis can be helped to live as full a life as possible. At Bristol, South Asian women highlighted the hidden nature, myths and rumours associated with women's' health issues, specifically menstruation. Their conversations indicated there was a need for research into the lack of informed knowledge, and the difficulty of discussing women's health issues openly, and in the presence of male members of the community. At Keele, concerns and key challenges of older people with MSK and mental health problems that were raised included the burden of feeling isolated, the sometimes unhelpful treatment given for multiple conditions, finding the right information from the internet or other sources, and the "guilt/fear" of being judged as wasting health professionals' time. Hence, the three research priorities for this group centred on information needs, quality of life/anxiety, and cost of care.

Table 1  
Research priorities identified during group discussions

Young onset dementia	BAME community	MSK and mental health
How to ensure everyone has access to a range of support after being diagnosed with dementia?	What are the barriers and enablers to communication around menstruation and menopause?	How to address lack of information related to accessing health care (lack of navigation, inadequate signposting, and lack of feedback for example following test results)?  How to address the risk of misinformation from the internet or other sources (social networks, self-diagnosis)?
How to improve the co-ordination of services/support for people with dementia (and their family)?	How can we educate and support women from South Asian communities to engage in discussions around menstruation and menopause?	Due to limited consultation time with healthcare professionals, how do we reduce the burden of finding the right information for self-management as and when needed?
How to support people with dementia to engage in positive health behaviours (e.g. a good diet, getting vaccinated for flu, keeping physically active)?		How to combat loneliness, and isolation when living with multiple physical and mental health conditions?
How to best educate people about the condition (the general public, healthcare professionals, people living with dementia)?		How to manage anxieties, "guilt/fear" of being judged as wasting health professionals' time at consultations?
How to address the employment challenges and potential discrimination in the workplace that people with young onset dementia can encounter?		How to minimise cost and address the burden of uncoordinated care and treatments for multiple physical and mental health conditions?

**What we have learnt from undertaking the project:** Involving groups with the end goal of producing some artwork was effective in the following ways. Firstly, it encouraged people not ordinarily asked about research priorities to voice their opinions, which then shaped a piece of artwork. This allowed us to explore concerns based on their experiential expertise that could inform and underpin future research. Secondly, the end products – the artwork – offered an eye-catching and accessible way to disseminate these potential ideas for future research.

People involved were motivated by the prospect of helping to produce some artwork; they liked the idea of contributing to this through sharing their views and experiences. We sent them a photograph of the finished artwork produced from their group discussion. We asked for their thoughts on this and on the research priority it reflected. Their feedback stressed the power of images created by the artists, which

distilled their experiences. They noted how they welcomed the opportunity to share their views, and to have these turned into ideas for potential research projects. Hence, the use of art was an effective channel for eliciting the views of groups not ordinarily invited to develop ideas for research. It also allowed the research team to present and disseminate these research priorities in a visual format.

**What we feel went well with the project:** Working with the young artists was a positive experience. They were reliable in terms of attending meetings, providing us with updates, and asking for feedback. They produced powerful pieces of art, which are displayed below (see Figs. 2–4) and can be viewed online [13]. We have also created a narrated video of the final artwork, with a description of what each piece reflects ([www.spcr.nihr.ac.uk/news/blog/using-art-to-engage-with-people](http://www.spcr.nihr.ac.uk/news/blog/using-art-to-engage-with-people)).

In conversations with these young artists about their role in the project, they expressed some initial concerns about being able to produce the type of artwork that we, as researchers, were expecting. They also said they had some apprehension about being able to reflect group discussions adequately or about offending people because they did not share the same culture. However, they commented that any concerns were allayed through regular communication with the researchers; we supported the artists via regular emails and telephone calls, to ensure that they were happy with what they were doing (see Box 2 – learning point 2). This is reflected in the following feedback from one of them:

*“I feel that the organisation of the project went well...communication was good...My artwork hopefully conveys the key priorities... I have also been able to weave some of this project into my A Level, which adds another dimension to my coursework.” (E.Prior)*

Both artists said they would work on a similar project if asked again:

*“Yes, I have thought about issues that I wouldn’t in my everyday life and I have gained empathy for different walks of life.” (M.Viljoen).*

*Box 1: Learning point 1 – regular communication*

The importance of regular communication with the artists was highlighted. Set up an initial meeting to discuss what being part of a project involves. Give them time to ask questions. Be open and accessible as researchers. Encourage the artist to express any concerns or queries. Offer feedback and constructive suggestions as artists sometimes questioned whether what they were producing was what the research team required or expected. We would extend this importance of regular communication to the groups involved in workshops, so they understand what the project entails, how they can contribute and are provided with access to the final artwork. We also, as a team, met once a month to ensure that the work being carried out in different settings was in line with the project’s aim, budget and deadlines.

**What we feel could have gone better:** Initially, we struggled to find young artists to work with us. Over the first months of the project, we contacted several colleges and schools but were unable to get past gatekeepers to invite students to be artists. We sent several emails and, in some cases, made telephone calls, without success. We eventually used work contacts, sending out a request to colleagues, asking if they knew of any young people (family members or friends) who might wish to be involved. We invited

potential artists to share their work with us. If we were happy with their artistic skills, we met them in person or by phone to talk about the project and what it would involve, so they had a good understanding before committing to work with us.

*Box 2: Learning point 2 – locating artists*

Factor in sufficient time for locating an artist. Think about using existing contacts (e.g. colleagues, school governors). Consider alternative recruitment routes to schools/colleges (e.g. youth parliament, young people's involvement group at a local hospital, youth groups, church groups, outreach workers).

PPI workshops took place just before the COVID-19 pandemic hit the UK and lockdown ensued. At the workshops, we discussed how we might best disseminate the artwork to targeted groups. Those present suggested this might include sending short summaries to existing groups (e.g. Young Dementia Network, College of the 3rd Age) for them to publicise (e.g. in newsletters). Attending meetings in person to talk about research was also proposed, so that people could ask questions. This was stalled to an extent by social distancing rules.

**Thoughts about what we would have done differently:** The groups in Oxford and Bristol were pre-existing; hence, researchers attended one of their regular meetings. Attending a venue and time when groups usually meet was beneficial in terms of not having to arrange a separate meeting and ensuring that there was good attendance. In addition, because individuals knew each other, they were comfortable discussing their experiences together. However, it meant that the researcher had less control over how long they had to talk to the group; if there were other items on an agenda this reduced the time available to discuss research priorities. In addition, the setting may not necessarily be conducive to groupwork; for example, the young onset dementia group met in a local pub, which although quiet, made group activities more difficult.

*Box 3: Learning point 3 – using existing groups*

Attaching the workshop to an existing group meeting facilitated set up and meant that those attending were happy to talk as they already knew each other. It did limit the control a researcher had in terms of time devoted to discussing research concerns or in setting up activities. Nevertheless, it is important to consider whether meeting in a venue arranged by researchers may mean that the needs of the team overshadow those whose views are seldom listened to, if individuals feel more comfortable talking in a familiar setting at a familiar time. This may have been the case especially for those with young onset dementia. This highlights the issue of power relations in PPI. There is sometimes an expectation that PPI contributors will 'come to researchers', whereby we expect individuals to fit with the setting, communication, approaches with which we, as researchers, are familiar. This is likely to exclude certain people. Democratising and distributing spaces in which we interact as part of PPI is, therefore, important. This may be encountered as inconvenient to researchers' norms. However, overall, it can be productive and positive, enabling new and diverse groups to participate.

**Sharing what we have done and learnt:** Alongside the production of a blog [14], our narrated video (see above), and this paper, we are sharing the finished artwork with each group that was involved. An online meeting of the young onset dementia group was attended by ST, at which she showed those present (n = 8) the final picture. This led to a frank discussion about what it meant to them and how it reflected their

own story in terms of the emotions and struggles encountered post diagnosis (including losing a job, social contacts reducing and poor coordination of support).

Further face-to-face communication of findings is planned later in the year in Keele and Bristol – depending on social distancing rules due to COVID-19. This is particularly important for the Bristol group, given that those present were not fluent in speaking or reading English. The community group organisers were contacted, and findings were shared with them. Their input was sought to ensure that the artwork and accompanying text was depicted in a culturally sensitive manner, and that information was not lost in translation. The organisers for this group at Bristol, and older people at the Keele workshop, expressed the desire for and gave researchers an open invitation to engage in further discussion and dissemination of findings to wider networks in the future.

To support dissemination, we held a Twitter chat to share our work and to learn from others' experiences of using similar arts-based approaches. We advertised the Twitter chat a month in advance and sent an email about it to researchers, PPI contributors and co-ordinators, and other relevant organisations that might be interested. The Twitter chat involved an hour dedicated to discussing online the following questions: a) using artwork as a way to engage with groups about research priorities; b) creative approaches people had tried/been involved in as a part of public involvement or engagement; and c) lessons learnt from this, including anything that worked well or did not work. Ten individuals, including patients/the public, researchers and a PPI co-ordinator joined the discussion, along with five members of the research team. A snapshot of their discussions can be found in Fig. 5.

Participants (who were all researchers/PPI co-ordinators) on the Twitter chat felt that using arts-based approaches facilitated connections with audiences that might otherwise be difficult to engage in research. A few also felt that arts could be used to engage with diverse audiences on sensitive topics, as it can ease people into discussions and reduce awkwardness. It was suggested that arts can help develop 'metaphors' to describe complex scenarios or processes. Furthermore, arts were seen as a means to capture, unpick and identify areas of concern which may otherwise be unexplored through use of other approaches. Overall, there was agreement amongst participants that arts in involvement and engagement-based activities enhanced discussions, addressed power imbalances and facilitated further reflections. Participants noted other interactive approaches to involvement and engagement including storytelling, collage making (wherein participants can choose the materials used) and drama.

**How we intend to use what we learnt from this project:** We are members of the Evidence Synthesis Working Group (ESWG) ([www.spcr.nihr.ac.uk/eswg](http://www.spcr.nihr.ac.uk/eswg)), a collaboration of health services researchers and clinical academics from several universities in England, with an interest in a range of ways to synthesise evidence. We will use the artwork to propose topics for reviews. We plan to return to the three groups for PPI feedback on any review proposal that is taken forward based on priorities they identified. Those in these groups may also wish to be involved in the conduct and dissemination of findings from a related review (as PPI contributors). Other reviews we have conducted have involved patients/the public [15–16];

it was successful in helping us to think about data emerging from a review and in providing us with feedback on the presentation and interpretation of its findings.

## Discussion

We have shown the feasibility of using art to engage with potential PPI contributors who might not ordinarily be part of the planning or execution of research. Drivers for incorporating the voices of lay people in this way include those that could be classed as moral (e.g. ensuring that research addresses issues of importance to patients, informing how public funding is spent) and practical or methodological, ensuring that quality research is produced (e.g. helping with recruitment through connections with specific communities, designing a study in a way that is acceptable to those who might take part, disseminating beyond the academic community so that findings have broader impact) [17–18]. As noted by Gove and colleagues [1]:

Researchers have a legal and moral obligation to protect not only participants but everyone involved in the research process from harm whilst striving to ensure that the process and outputs of PPI are successful, meaningful and mutually beneficial.

However, research does not always involve PPI contributors in a manner that embraces these moral and practical aspects, and there may be certain groups of people whose voices are seldom listened to. Art may be one means of accessing what matters to them in terms of research prioritisation.

We now need to assess whether packaging research priorities as a piece of art means that researchers draw on this knowledge when planning a project. More broadly, it is important to consider whether it informs their thinking about incorporating PPI into the design and delivery of a study. Our arts-based project presents a novel approach to how PPI can be carried out. It also highlights the potential for new outputs (i.e. artwork). This may encourage a wider range of individuals to get involved in PPI activities. However, there may still be the challenge of researchers seeing the value and feasibility of PPI [19–20]. Furthermore, researchers may be disinclined to try a novel approach if they feel daunted by the prospect of embedding PPI into their work, especially when resources to undertake this activity in a meaningful manner are lacking [21].

On a more positive note, having role models and hearing from colleagues experienced in PPI may be beneficial [21]. We hope that the reflections we present in this paper will prompt further attempts by researchers to try novel approaches to engaging patients and the public in their work. Others have tried different art forms as part of the research process, as reflected in the Twitter chat mentioned above. For example, colleagues from ESWG used drama and actors to share their findings from a review on delegated home visits in primary care with an audience [22]. This highlights that creative approaches to support engagement and dissemination are possible. They need to be described in the way outlined above to encourage other researchers to think beyond traditional approaches to PPI and see that using alternatives is possible and can be successful.

## Conclusion

We worked with groups who are seldom listened to when it comes to PPI activities. We anticipated that a focus on artwork would make involvement and the information we produced accessible to a wider group of individuals. The approach we used proved successful in encouraging people to share their views and see these represented visually. For the research team, it enabled us to understand concerns and research priorities from the perspective of those whose voices may have been overlooked previously when planning a study. We would use this approach again; lessons learnt would make it easier next time around. We have provided recommendations for others who might try a similar approach in the future. Furthermore, we hope the paper will stimulate further discussions around novel approaches to PPI.

## Abbreviations

PPI – Patient and Public Involvement

BAME- Black, Asian and Minority Ethnic Groups

## Declarations

**Ethics approval and consent to participate:** Research ethics approval to undertake this work was not required as it is a public engagement activity.

**Consent for publication:** Not applicable.

**Availability of data and material:** Not applicable as this was not a research study. We have shared the artwork developed from the workshops.

**Competing interests:** None.

**Funding:** This project was funded by the National Institute for Health Research (NIHR) School for Primary Care Research (project reference 451). The views expressed are those of the authors and not necessarily those of their host institutions, the NIHR or the Department of Health and Social Care.

**Authors' contributions:** The original idea for the project was developed by ST, SD, OB, AMB, GR, AT and SP. Equal contributions to the project were made by ST, SD and OB; they ran workshops and liaised with groups involved. They also drafted the initial manuscript. All other authors contributed to refining the final manuscript. All authors read and approved the final manuscript.

**Acknowledgements:** Thank you to the groups involved in the workshops and to the two artists for their commitment to this work.

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## Figures

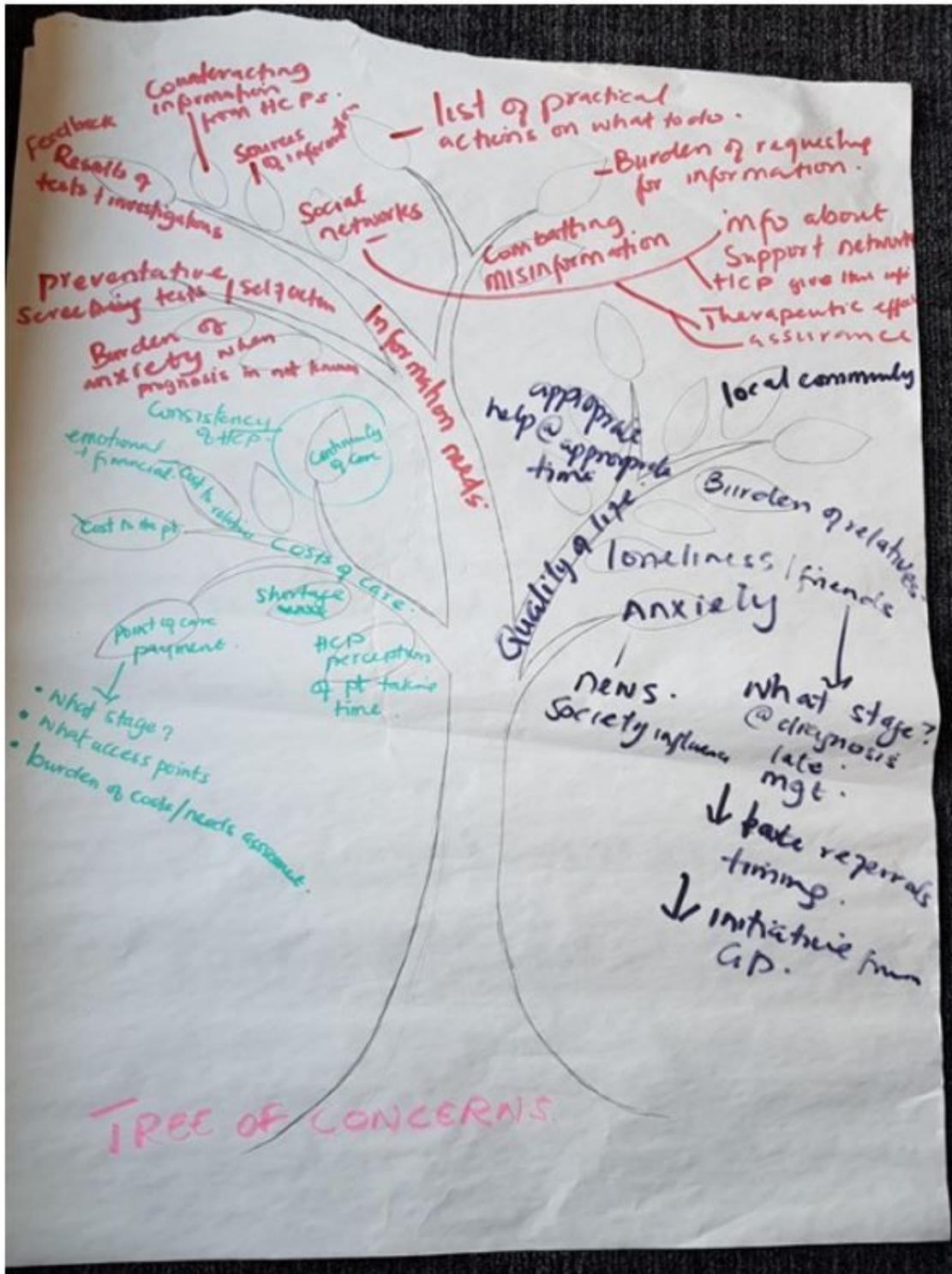


Figure 1

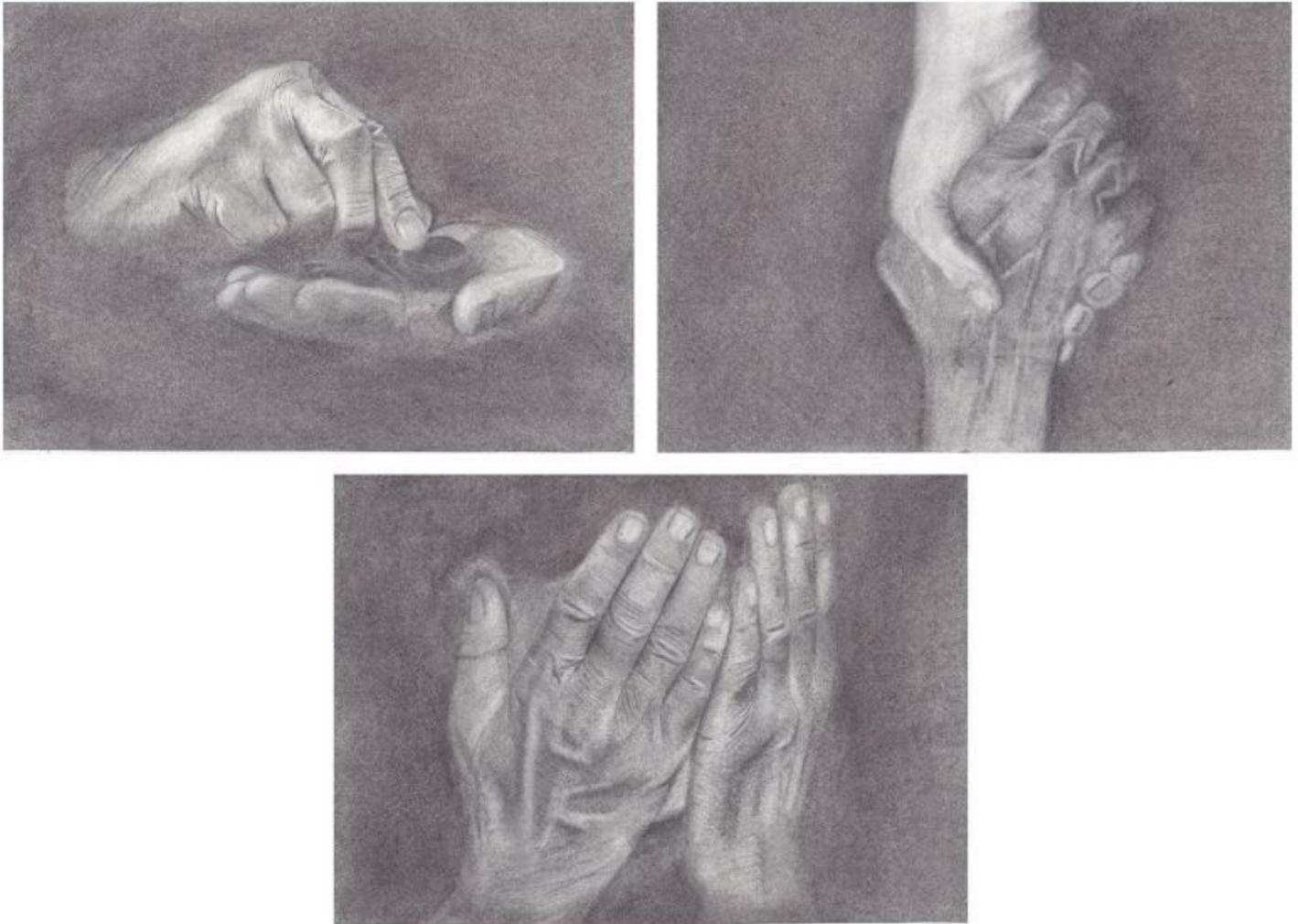
Tree of concerns created in the workshop at Keele





**Figure 3**

Meanings of menstruation and menopause: Cultural influences on management and experiences



**Figure 4**

The trilogy of hands: Healthcare priorities for older adults with physical and mental health conditions



Figure 5

A snapshot of discussions on the Twitter chat