## 'Have Your Say' on Mental Health Research
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### Introduction
This report presents findings of a stakeholder consultation. The consultation gathered views on what should be the priorities for mental health related research sponsored by the Economic and Social Research Council (ESRC). The stakeholders were people with lived experience of mental health challenges and/or experience of supporting others with such challenges (either in a paid or voluntary working role, or as a friend/family member). The report was commissioned by the ESRC to complement an expert reference group report (December 2015) and other consultations.  The not-for-profit Boingboing conducted the 'Have Your Say' consultation in collaboration with the University of Brighton. We drew on our experience of co-production in research and practice development with diverse and often marginalised groups, including people with lived experiences of mental health challenges. The events were organised and run by people with lived experience of mental health challenges and of supporting people with mental health issues. A copy of this report will be sent to each participant who either attended a consultation event or who filled in an online survey and chose not be anonymous.

### Process
Two half day consultation events were held in Brighton and Hastings. A total of over 100 people attended the events. Travel, accommodation, childcare and individual support (both on the day and afterwards) were provided to participants where necessary, and two British Sign Language interpreters were present on the day.  A further 13 people responded to an online survey which we developed as a result of 23 of the people we had invited saying they were too anxious or upset to attend the actual events. Fears of being labelled as having mental health problems,  extreme anxiety over travelling, or simply feeling in too much emotional pain to be in a sharing environment, were all raised by people who didn't feel able to attend.  Whilst the majority lived locally to the venues, efforts were made to ensure people attended from across the UK, with over a third of participants having travelled over 20 miles to attend. Likewise, invitations were sent with the aim of ensuring a diverse representation of different groups (notably re: age, learning disability, gender, sexuality, physical disability, ethnicity, employment status). It is not claimed that this provides a direct representation of the wider UK population. However, the summary of participant characteristics in Appendix 1 demonstrates that our aims of diverse participation representation were met. We also attended a meeting at Autism Sussex  to promote the event, explain clearly how the event would work on the day, and outline expectations and available support for participants. Eight people living with autism were present at this meeting. They shared their views on the challenges they faced negotiating and working with mental health services, often feeling under-represented and marginalised within consultations. They were unable to attend the event in Brighton and details of how to share their views after the event via the online survey were highlighted.

At the events a brief introduction explained the ESRC remit – notably in relation to ensuring that the research it commissions does not duplicate mental health research which might be more

appropriately funded by other bodies (e.g., the National Institute for Health Research). Participants were also explicitly told that eveybody's experiences were valued in the consultation and that they did not need to have an understanding of the formal mental health research base to be involved. The ESRC's intention to focus more specifically on issues related to depression and anxiety as commonly experienced mental health problems across society was also explained. At the same time we explained that this was not an exclusive focus and that these and other mental health and illness terminology are rightly open to challenge. Discussions then took place in groups of 5-10 people. These were initially prompted by the question, 'What do you think should be the priorities for mental health research commissioned by the ESRC?' Discussion groups were facilitated and notes were taken of the issues raised. After the events these notes, along with other individual written feedback provided by individuals during and after the event, were analysed.

**Findings**

Six broad categories of priority areas for research were identified from the consultation events. These relate to: *Mental health issues across the lifespan; Experiences of mental health challenges, social influences and consequences; Ways of helping people respond to mental distress; Organisational influences on mental health support and recovery; Inequalities and diversity;* and, *Policy.* Additionally, people raised issues relating to: *How mental health research should be done*.

1) *Mental health issues across the lifespan*.
Participants suggested research could help increase our understanding of how people can be supported through significant life course transitions (e.g., school to employment; adolescence to adult life; moving from receiving support from children and young people's services to adult services; working to partial or full retirement). Related to this, there were calls for knowledge about ages and life stages when people are most affected by depression and anxiety, partly in order to help target support. Such research could also help identity why some people appear to have more successful recoveries than others.

Many emphasised the importance of research into mental health issues related to children and young people, and whether life is getting 'harder' for them. This included understanding more about how, and in what circumstances, childhood experiences can influence mental health in later life. Schools were identified as an actual and potential arena for research into the design and effectiveness of initiatives to promote mental health awareness, resilience and well-being. Similarly, a need for greater understanding of how schools respond to children who experience mental distress was highlighted. Research could consider how other demands on the curriculum and limitations in opportunities for physical activity may impact on young people's mental health. In and beyond school there were calls for research into: the impact of bullying on mental health; learning more about the coping strategies used by young people; and the potential for mentoring to promote mental well-being and recovery. People also thought more knowledge was needed about how best to ensure children's mental health needs are identified and responded to at an early stage, and the factors that may influence whether parents and children ask for help.

Many research priorities related to young, middle and older stages of adult life are reported in other categories, but concerns were raised about whether there were gaps in support for people aged between 25 and 35. Discussion about people's working lives and mental health involved suggestions for more research into how best to help people facing mental health problems to keep their jobs. Research could consider whether the workplace is a place where mental health problems could be made worse, or improved through education, awareness and adjustments. In older life issues of isolation were raised and calls were made for research to explore how older people do, or could, make use of digital communication to overcome this.

2) *Experiences of mental health challenges, social influences and consequences*.
Questions related to how people experience anxiety, depression and other mental health problems were proposed. These were raised alongside a need to understand more about the social and economic factors that contribute to people becoming unwell. The role of old and new forms of media in challenging or reinforcing stigma was proposed. It was suggested that this would involve research into how mental health awareness campaigns actually impact locally and in diverse communities. Some considered there was a need to understand more about when and for whom diagnostic labels and other medical language were helpful or unhelpful. Related to this were calls for research into different cultural and community understandings and responses to mental health issues. Underpinning these, some suggested research into how cultures of consumerism and materialism may impact on mental well-being. Poverty – in terms of income and access to resources and infrastructure such as transport – was also highlighted. Domestic violence, isolation and boredom were proposed as topics which could be studied as either causes or consequences of mental health distress. Others asked what the economic and social impacts were that arise from the lack of purpose and focus that some people with mental health problems have.

3) *Ways of helping people respond to mental distress.*
Many proposed research into how people (including friends and family who care for them) can be helped best to cope and/or recover from mental health problems. This included understanding how people can be helped to recognise their needs at an early stage. For those who then seek help, some suggested studies into how different people access support (including whether this involves pressures to play a 'patient role'), their pathways through services, and what happens to people when they are 'discharged', or 'moved on'. The way in which formal support is provided was proposed as an important topic for study. This included: considering the impacts of long term use of mental health services; the potential of 'one stop shops' and GP surgeries as well-being hubs; whether social media offers an alternative to face to face support.

For many, just as important was a need for research into the nature of relationships between providers and recipients of mental health support. This included issues of trust, collaboration, attitudes, power relations and whether services sufficiently value 'people skills'. The growing use of 'lived experience' expertise, notably in various peer support approaches, was positively mentioned alongside an acknowledgement of a need to study how this expertise is developed and its

effectiveness. This was balanced with critical questions such as whether peer support services were becoming over used and risked being an 'excuse' for reducing other valued services.

Greater understanding of the coping strategies people use was prioritised along with influences upon this (such as support mechanisms and the media). The possible well-being impacts of 'getting involved' in communities and social activism was also proposed. Many suggested research into alternative approaches to mental health recovery that did not fall into more dominant medical or talking therapy strategies. These included creative activities, nutrition, exercise, leisure and entertainment (including laughter). How these worked alongside more formal approaches to mental health support in a wider system was also raised as an important research focus. Finally in this category were calls for research into the underpinning values and philosophies of different forms of mental health support. This included: holistic approaches; co-production in service design; the impact of competition in a context of decreasing resources; and, understanding how concerns to manage risks influences support.

4) *Organisational influences on mental health support and recovery.*
Suggestions were made for research into the influences of various organisations that are directly or indirectly involved in providing mental health support, and indeed the wider system within which these organisations operate. This included understanding: how resilient and sustainable services are; and, how they communicate and interact with each other. These issues were related to learning more about differences between voluntary sector and community supports on the one hand, and statutory health and social care services on the other. For both statutory and particularly voluntary sector services, people considered there was a need to know more about resourcing. Specifically, staffing challenges, how money is allocated, consequences of short-term funding models and whether smaller community/voluntary sector organisations were being superseded by larger, possibly less person-centred, ones. Many called for research into the impact of austerity and reduced funding for services. This included suggestions to follow up what happens to individuals and communities when funding for a mental health project ceases. Finally, proposals were made for research into how providers of mental health support are best supported. Such studies could investigate comparison of formal processes and informal practices within and between organisations. In this topic area the role of training, monitoring staff stress, communication, and 'cultures' of support and/or blame were highlighted.

5) *Inequalities and diversity.*
As well as a consistent concern with discrimination and stigma towards people with mental health problems, there were calls for research into how certain groups of people might experience mental distress differently and experience inequalities in accessing support. This included a need to understand more about interactions between mental health problems and physical disabilities, including how society and services respond to people living with both mental health problems and physical disability. Related to this there was a desire for research into the reasons for and responses to the comparatively poor physical health of many people with mental health problems. Specific

mention was made of the mental health needs of Deaf children and adults (seen by the Deaf consultation participants as a cultural group as well as living with a disability).

For Black and Minority Ethnic (BME) people it was suggested that research could help understand whether there is discrimination in service provision. Proposals were also made for research into the influence of cultural beliefs in some BME communities that might enable or inhibit people with mental health challenges in expressing their concerns and seeking support. Young working class men were also flagged as a group for whom research could usefully help understand how they could be better supported to respond to mental health problems. Suggestions were advanced for developing more understanding of the mental health experiences of Lesbian, Gay, Bisexual and Transgender (LGBT) people specifically in relation to how mainstream support services included or excluded them. Poverty was highlighted as factor that needed research to understand its links with poor mental health. Social attitudes to supporting the mental health needs of people from groups perceived as 'deserving' or 'undeserving' (such as prisoners and their families) was also proposed as an important topic. Finally, it was pointed out that research projects need to acknowledge intersectionality, that some people can be identified as falling into more than one specific marginalised group and that consequently they may have specific and distinct needs, and compounded disadvantage.

6) *Policy.*
Suggestions were made for research into how policy and policy statements influence mental health awareness and people's experience of mental health problems. People were also concerned with factors that influenced whether policy makers (at national or local levels) took note of mental health research and this was suggested as an important topic for research in itself.

7) *How mental health research should be done*.
Overarching suggestions were made for how people thought mental health research should be conducted. In terms of methods the value of a broad range of approaches was acknowledged including: longitudinal studies; surveys; interviews; quantitative data; comparative studies; and the use of creative methods – not just talking – to gather people's views and experiences. Co-production and user led research were emphasised, with a need to consider how best to support people with lived experience of mental health challenges to become researchers. This was seen not only as a valuable knowledge base to include in research teams, but also provided opportunities for people with mental health challenges to build skills and capacities that are transferable. Community-university partnership approaches were suggested as one way of achieving this. People also emphasised a need for consistent efforts to reach out to and engage those people least likely to engage in mental health research. This may be because of the nature of their mental health problems, or because they are from a marginalised group, or because they are not engaged with mental health or other support services yet are living in mental distress.

**Conclusion (relating themes to those in the ESRC December 2015 Reference Group Report).**

Many of the 'Have Your Say' themes are consistent with suggestions for a future ESRC research agenda presented in their December 2015 report. Notably, both call for research to consider how mental health problems are differentially distributed across society, with inequalities in how some groups are affected and provided with support. The importance of understanding experiences and development of mental health problems across the lifespan is also a shared concern, along with understanding economic, social and cultural factors that influence distress, resilience and recovery. This includes an emphasis on considering the role of communities, services and institutions as both sites of support and generators of common mental health problems. How the informal and formal mental health support sectors interrelated across a wider local system was also highlighted in both contexts.

No contradictions were identified between the two reports but the 'Have Your Say' discussions report gave more emphasis to the need for research to explore the increasing role of 'peer' or 'lived experience' support in helping people experiencing mental health distress. A desire for mental health research to 'make a difference' also led to suggestions that the way in which research influences policy and policy makers could be an important topic. Finally, both reports recognise the value of a range of research methods, including the value of co-produced mental health research that draws on the 'lived experience' expertise of people facing mental health challenges, and which also aims to develop the research skills and capacity of 'lived experience' and community-based researchers.

**Postscript**

The ESRC have now received this report. They are still waiting for their allocation of research funding so they are not able to make any commitments as yet in terms of funding calls. However, they will announce any funding opportunities on their website. Keep an eye out if you are planning to apply!

**Appendix 1.**

# Have Your Say Today Collated Demographics

## Monday 22 February & Tuesday 1 March 2016

99 people completed demographic information on postcards or online; 20 people from the Hastings event and 66 from the Brighton event (13 people completed the survey).

Are you a:

| Person with lived experience of mental health issues | Mental health worker | Friend or family member of someone with mental health issues |
|---|---|---|
| N=71 (71.7%) | N=44 (44.4%) | N=49 (49.5%) |

What is your gender identity:

| Male | Female | Other | Rather not say |
|---|---|---|---|
| N=31 (31.3%) | N=63 (63.6%) | N=3 (3.0%) | N=2 (2.0%) |

How old are you:

| 18-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65-74 | 75+ | Rather not say |
|---|---|---|---|---|---|---|---|
| N=9 (9.1%) | N=12 (12.1%) | N=24 (24.2%) | N=23 (23.2%) | N=18 (18.2%) | N=9 (9.1%) | N=1 (1.0%) | N=3 (3.0%) |

How would you describe your ethnic origin:

|  | N= | % |
|---|---|---|
| White | 7 | 7.1 |
| English/Welsh/Scottish/Northern Irish/British | 60 | 60.6 |
| Irish | 1 | 1.0 |
| Gypsy or Irish Traveller | 0 | - |
| Any other White background | 6 | 6.1 |
|  |  |  |
| Mixed/multiple ethnic groups | 3 | 3.0 |
| White and Black Caribbean | 1 | 1.0 |
| White and Black African | 0 | - |
| White and Asian | 1 | 1.0 |
| Any other Mixed/multiple ethnic background | 1 | 1.0 |
|  |  |  |
| Asian/Asian British | 1 | 1.0 |
| Indian | 1 | 1.0 |

| | | |
|---|---|---|
| Pakistani | 0 | - |
| Bangladeshi | 0 | - |
| Chinese | 0 | - |
| Any other Asian background | 1 | 1.0 |
| | | |
| Black/African/Caribbean/Black British | 3 | 3.0 |
| African | 0 | - |
| Caribbean | 1 | 1.0 |
| Any other Black/African/Caribbean background | 0 | - |
| | | |
| Other ethnic group | 1 | 1.0 |
| Arab | 0 | - |
| Any other ethnic group | 0 | - |
| | | |
| Rather not say | 11 | 11.1 |

Do you consider yourself to have a disability:

| Yes | No | Rather not say |
|---|---|---|
| N=37 (37.4%) | N=60 (60.6%) | N=2 (2.0%) |

How would you describe your sexual orientation:

| Heterosexual | Gay or Lesbian | Bisexual | Other | Don't know | Rather not say |
|---|---|---|---|---|---|
| N=64 (64.6%) | N=10 (10.1%) | N=14 (14.1%) | N=5 (5.1%) | N=4 (4.0%) | N=2 (2.0%) |

Are you currently in paid employment:

| Yes | No | Rather not say |
|---|---|---|
| N=70 (70.7%) | N=26 (26.3%) | N=3 (3.0%) |

How far did you travel to get here today (Information gathered from separate form hence different totals):

| Less than 5 miles | 5-10 miles | 10-20 miles | More than 20 miles | Rather not say |
|---|---|---|---|---|
| 30 (46.9%) | 9 (14.1%) | 4 (6.3%) | 20 (31.3%) | 1 (1.6%) |

31.3% of respondents had travelled over 20 miles to take part.