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COLLABORATIVE CENTRE

- ETHNIC INEQUALITIES
- SEVERE MENTAL ILLNESS
- MULTIPLE DISADVANTAGE

BRIEFING PAPER

Synergi national consultation on priorities to address ethnic inequalities in severe mental illness

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Synergi national consultation on priorities to address ethnic inequalities in severe mental illness
The Synergi Collaborative Centre

www.synergicollaborativecentre.co.uk

Email all correspondence to Professor Kamaldeep Bhui:
k.s.bhui@qmul.ac.uk

The Synergi Collaborative Centre is a national initiative focused on eradicating ethnic inequalities in severe mental illness through championing systems change, new science, creative inclusion, collaborative leadership and co-production/co-creation, while forging solutions with those experiencing mental distress, carers, commissioners, policymakers and politicians. Launched in 2017, the centre is funded by Lankelly Chase.

SYNERGI PROJECT TEAM

Professor Kamaldeep Bhui
Project Director, Queen Mary University of London

Professor James Nazroo
Project Co-Director, The University of Manchester

Ms Joy Francis
Project Co-Director, Words of Colour Productions

Dr Kristoffer Halvorsrud
Research Fellow

Dr Maria Haarmans
Research Associate

Dr Dharmi Kapadia
Lecturer

Roisin Mooney
Project Manager/Researcher

Dr Shamea Mia
Research Assistant

EXECUTIVE SUMMARY

Although there has been much discussion of how to address ethnic inequalities in the risk of severe mental illness and in pathways through care, this has rarely emphasised the views and experiences of ethnic minority people with lived experience.

The Synergi approach is to engage relevant stakeholders using co-creation and co-production approaches that enable the intended beneficiaries to influence and design the actions that seek to reduce inequalities.

To this end, we conducted a national priority setting consultation where we asked: "What are the most important issues that we should understand when trying to reduce ethnic inequalities in severe mental illness?"

221 people took part, with representation from a diversity of stakeholder groups (including service users and those with lived experience), a diverse range of ethnic groups, both women and men, and a relatively equal distribution of age groups..

Three underlying priorities were identified from responses to the consultation:
- The impact of racism and adverse care pathways;
- Facilitating social support, coping strategies and measures of positivity (e.g. optimism and hope); and
- Stigma and societal disadvantages (without reference to racism).

So, the most pressing issue identified by participants was multiple forms of racism, including in encounters with key societal institutions, such as health services and the criminal justice system, resulting in more adverse care pathways for ethnic minority people.

Also prioritised was the need to make therapeutic approaches more accessible for ethnic minority people experiencing severe mental illness.

Overall, there were few differences in the emphasis placed on these priorities across ethnic groups, age groups, men and women, and stakeholder groups.

THE CONTEXT

The Synergi Collaborative Centre tackles ethnic inequalities in severe mental illness. These are longstanding and disadvantage ethnic minority people in the UK – particularly those from the Black Caribbean, Black African and Black British ethnic groups. Ethnic minority people have a higher risk for experiencing symptoms of psychoses, a diagnosis of psychoses and more adverse pathways to and through care. These include more coercive care, for example, by contact with police and criminal justice systems, compulsory admissions and treatments, and comparatively less general practitioner care.[1]

Although there has been much discussion of these inequalities and how to address them, this has been driven mostly by clinical or academic mental health professionals, government, policymakers and charitable and non-governmental (NGO) providers, as well as specialist think-tanks like the King's Fund. Despite this attention, few actions have followed, explained (we believe) by divergent priorities about what is causing inequalities, and whether these are disparities to be remedied or variations that are to be accepted as inevitable and that they will always persist.

One way to advance the field is to see disagreement as an indication of insufficient experience-based evidence. The voices of service users, the public, and carers are less often known or sought. Furthermore, even when these voices are gathered, they are often not heard. There are always groups who still are not included and the voices of more dominant representatives are presented as comprehensive.

The Synergi approach is to engage relevant stakeholders using co-creation and co-production approaches that enable the intended beneficiaries to influence and design the actions that seek to reduce inequalities.

To this end, we conducted an open consultation to set priorities for Synergi's and our partners' future knowledge agenda to tackle ethnic inequalities in severe mental illness.

This briefing paper summarises the process used for this consultation exercise and its findings.

THE PRIORITY SETTING CONSULTATION

We undertook an online national priority setting consultation that was open to the public in the UK. This was advertised through many avenues including Synergi's website, email distribution lists, social media and other interested groups identified through partners and collaborators, and those signing up at our events and meetings to become involved. The priority setting consultation was open from 1st July 2018 to the 31st December 2018. It was advertised and circulated as a link on several occasions, and we distributed hard copies for completion and collection to relevant community organisations that had members who wanted to participate, but were not confident or able to go online to complete the priority setting consultation.

In relation to the question: "What are the most important issues that we should understand when trying to reduce ethnic inequalities in severe mental illness?", participants were presented with 42 subject areas that Synergi had identified from research and consultations with stakeholders. For example, the items were identified through telephone consultations and individual meetings at the beginning of the project, including the major NGOs within mental health, and networks that were already engaged with the work of the commissioner - Lankelly Chase Foundation; additional items emerged through Photovoice workshops and exhibitions.

For each item, participants rated their importance on a 5-point scale ranging from 'not important' (a score of 1) to of 'vital importance' (a score of 5). The order of questions was randomised. Participants were able to enter free text to share other ideas on priorities for ethnic inequalities in severe mental illness.

Demographic information was collected on participants' ethnicity, gender, age, and their role (professional, service user, carer, etc.), if they wished to share this. Participants were informed that their answers were confidential and would be aggregated to show overall opinions. Participants were also reassured that no personal or identifiable data would be disclosed to any third parties and that all data would be securely stored on a password-restricted computer. Importantly, this was not intended to be a research study, but a public consultation to help establish priorities for future knowledge generation.

WHO TOOK PART?

Table 1 illustrates the key demographic details of the participants. Based on 221 participants, there was representation from a diversity of stakeholder groups (including service users and those with lived experience), and ethnic groups, with a relatively equal distribution of age groups, and more women than men.

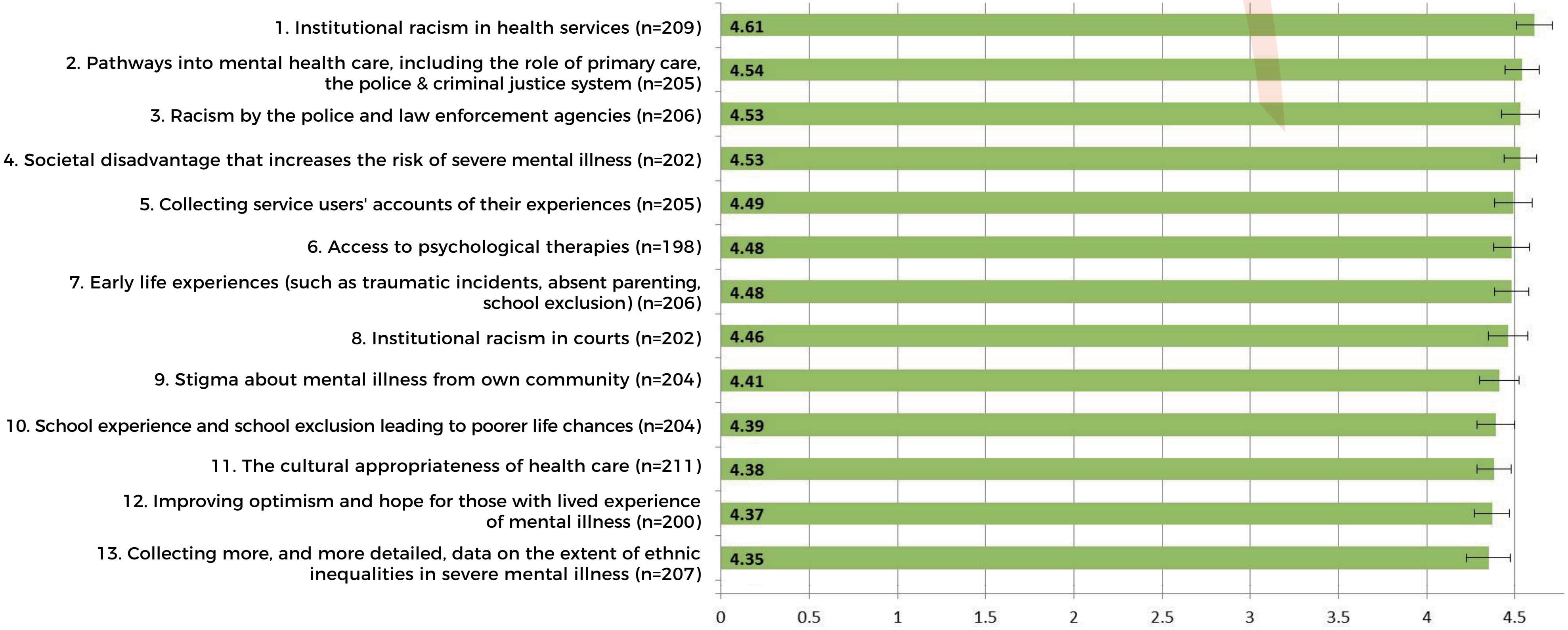
Table 1: Key demographic characteristics of participants (total n=221)

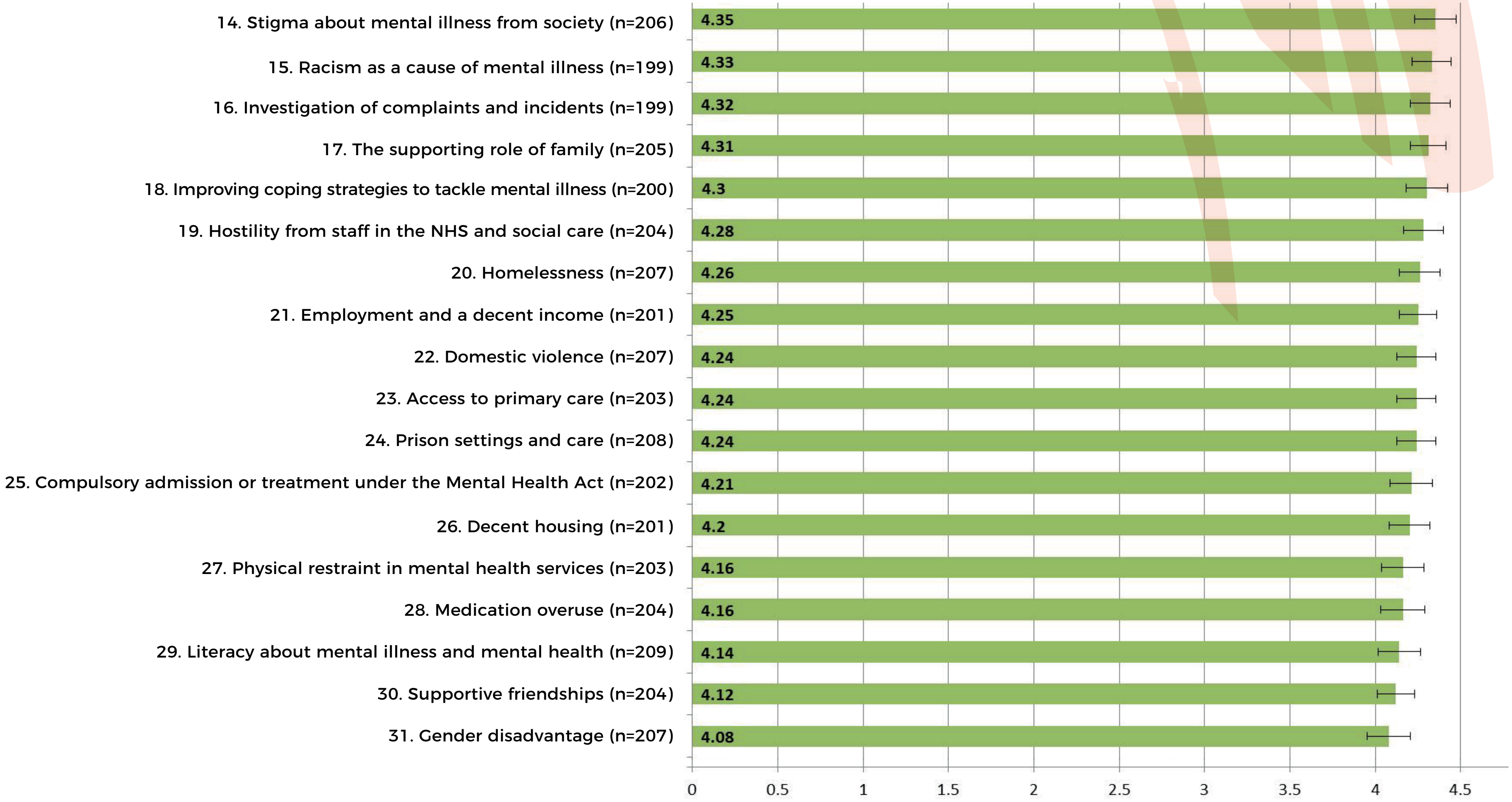
CHARACTERISTIC	N	≈ % OF TOTAL SAMPLE
Stakeholder group		
Service users/lived experience	42	19.0
Carers	26	11.8
Community/charity sectors	34	15.4
Healthcare professionals	31	14.0
Policy/managerial positions	4	1.8
Education sector	10	4.5
Other stakeholders	15	6.8
Multiple identities	7	3.2
Prefer not to say/unspecified	52	23.5
Ethnicity		
Black African	11	5.0
Black Caribbean	29	13.1
Black British	22	9.9
South Asian	21	9.5
Other Asian	8	3.6
White British	41	18.5
White Other	20	9.0
Mixed ethnic background	18	8.1
Other ethnic groups	4	1.8
Prefer not to say/unspecified	47	21.3
Gender		
Male	33	14.9
Female	141	63.8
Non-binary	2	0.9
Transgender	1	0.4
Prefer not to say/unspecified	44	19.9
Age		
19-29 years	31	14.0
30-39 years	29	13.1
40-49 years	35	15.8
50-59 years	56	25.3
60+ years	23	10.4
Prefer not to say/unspecified	47	21.3

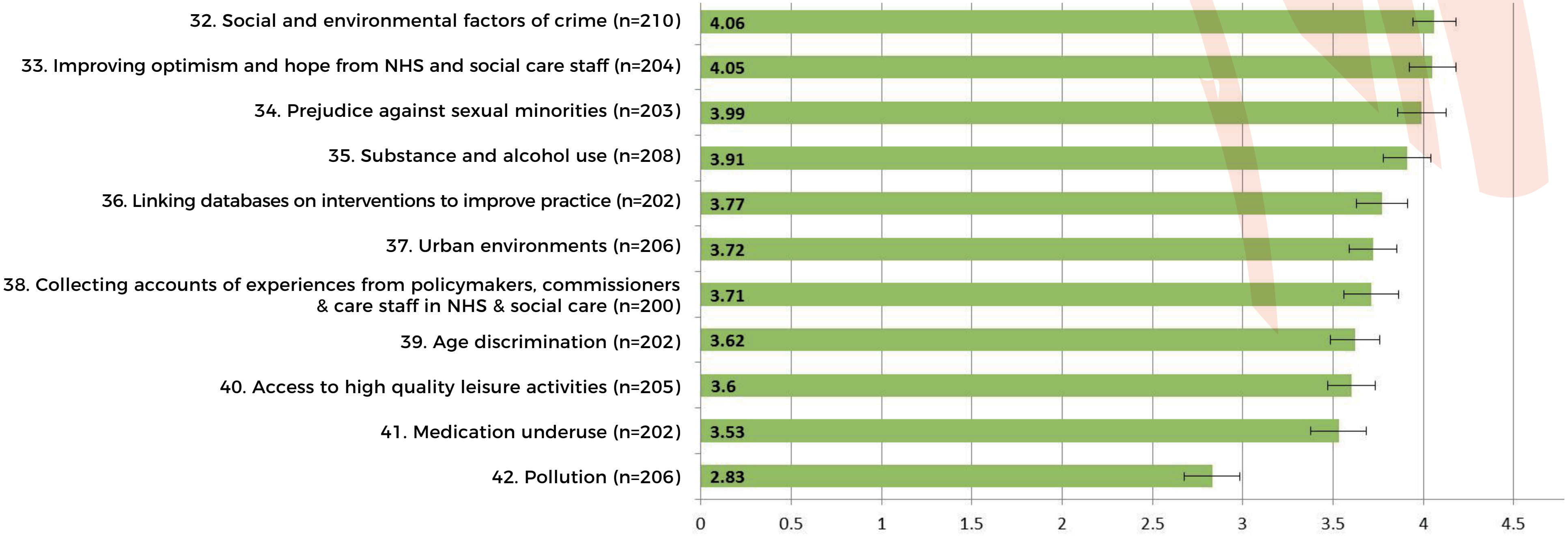
HOW WERE ITEMS PRIORITISED?

Figure 1 shows the number of observations (n), mean scores and confidence intervals for the 42 priority consultation items ranked by average scores. The percentage of people who gave a score of 'vital importance' (the highest score, a 5) was used to rank those who had the same mean score.

Figure 1: Ranked order of priorities by average scores, overall sample (n=221)




14. Stigma about mental illness from society (n=206)
4.35
15. Racism as a cause of mental illness (n=199)
4.33
16. Investigation of complaints and incidents (n=199)
4.32
17. The supporting role of family (n=205)
4.31
18. Improving coping strategies to tackle mental illness (n=200)
4.3
19. Hostility from staff in the NHS and social care (n=204)
4.28
20. Homelessness (n=207)
4.26
21. Employment and a decent income (n=201)
4.25
22. Domestic violence (n=207)
4.24
23. Access to primary care (n=203)
4.24
24. Prison settings and care (n=208)
4.24
25. Compulsory admission or treatment under the Mental Health Act (n=202)
4.21
26. Decent housing (n=201)
4.2
27. Physical restraint in mental health services (n=203)
4.16
28. Medication overuse (n=204)
4.16
29. Literacy about mental illness and mental health (n=209)
4.14
30. Supportive friendships (n=204)
4.12
31. Gender disadvantage (n=207)
4.08
0
0.5
1
1.5
2
2.5
3
3.5
4
4.5



As shown in Figure 1, the five highest ranked items were:
1) Institutional racism in health services;
2) Pathways into mental health care, including the role of primary care, the police and the criminal justice system;
3) Racism by the police and law enforcement agencies;
4) Societal disadvantage that increases the risk of severe mental illness; and
5) Collecting service users' accounts of their experiences.

As also shown in Figure 1, the five lowest ranked items, but still receiving scores around or greater than 3 ('medium importance'), were:
38) Collecting accounts of experiences from policymakers, commissioners and care staff in the NHS and social care;
39) Age discrimination;
40) Access to high quality leisure activities;
41) Medication underuse; and
42) Pollution.

In relation to the request to write in priorities not covered by the list of options that were already included, many participants in fact suggested issues that overlapped with these options, including structural inequalities and institutional racism within the mental health system and other institutions (criminal justice system, social care, education, voluntary sector, etc.). Participants also highlighted the interplay of multiple layers of disadvantage and marginalisation across, for example, migration and the immigration system, religion, gender, sexuality and disability.

A subsample of participants (n=9) agreed to a brief phone interview to explain how they found out about the priority setting consultation and their motivations for completing it. This covered a cross-section of stakeholders: service users, mental health professionals, carers and charity representatives, with some identifying dual statuses (e.g. service user and carer; carer and mental health professional). A range of ethnic groups were represented. Ages ranged from 26 to 61. The majority of participants were women (n=7).

Participants reported accessing the priority setting consultation through social media, service user organisations such as the National Survivor User Network (NSUN), mental health charities and the Synergi website. A major critique expressed by almost all participants was the lack of knowledge and understanding among formal mental health services regarding the impact of racism on mental health and how this lack of understanding manifests in the way services are delivered.

Also reiterating written concerns, several participants pointed to the need for mental health services to gain insight into experiences of oppression from the intersection of racialised and other marginalised identities impacting mental health (for example, gay, Black and male; older, South Asian, disabled and female).

And consistent with the free text comments, a few people (service users, mental health professionals, carers) voiced complaints about the lack of collaboration and information on medication use and side effects, and insufficient access to talking therapy. Indeed, many favoured a social model for preventing, understanding and treating mental health problems.

VARIATIONS IN PRIORITY SETTING ACROSS PARTICIPANTS

There was little variation in overall scores for the 42 priority setting items by demographic subgroups. However, given that many of these items related to each other, we set about aggregating them into groups of related items in order to explore differences across demographic subgroups further. To do this, we performed a factor analysis, which helped to reduce the original number of items into the most important underlying priority dimensions (or factors). The full details are provided in an online annex. Briefly, our original items were reduced into three factors:

- *The impact of racism and adverse care pathways;*
- *Facilitating social support, coping strategies and measures of positivity (e.g. optimism and hope);* and
- *Stigma and societal disadvantages (without reference to racism).*

Having identified these three dimensions to the priority setting exercise, we conducted a multiple linear regression analysis to see how priority setting scores varied across subgroups of the participants in the exercise (see Figures 2-4).

In the Figures 2, 3 and 4, we show variations of the three factors by demographic characteristics using one of the categories as the reference group against which others were compared. The reference groups were community workers/representatives for stakeholders, White British people for ethnicity, female participants for gender, and those aged 19-39 years for age. Due to the relatively low number of participants in specific categories, we combined respective subgroups into more aggregated groups.

For ethnicity, we combined Black African, Black Caribbean, Black British and Mixed Black/White participants into a ‘Black’ group; South Asian, Other Asian and Mixed Asian/White into an ‘Asian’ group; while White Other, Other ethnic groups and Other with mixed ethnic backgrounds into an ‘Other Ethnicity’ group. This is acknowledged as a limitation and Synergi will continue to work proactively to address potential barriers to participation in order to engage larger numbers of people from specific ethnic groups in the future. However, given the concerns about racism, this classification seems to be relevant and important despite not representing specific ethnic groups.

The results are presented using bar charts, with the height of the bars indicating the direction and magnitude of the relationship: above 0 indicates that the particular factor is of greater priority for the comparison than the reference group; below 0 indicates it is of lower priority for the comparison than the reference group. The bar charts contain 95% confidence intervals, which permit judgements about whether the differences are meaningful at the most common level used to assess statistical significance if the probability of getting that result by chance is less than 5% (often stated as $p<0.05$). Those confidence intervals that cross the zero line indicate no meaningful (statistically significant) differences.

Figure 2: Factor 1 *'The impact of racism and adverse care pathways'* by demographic subgroups

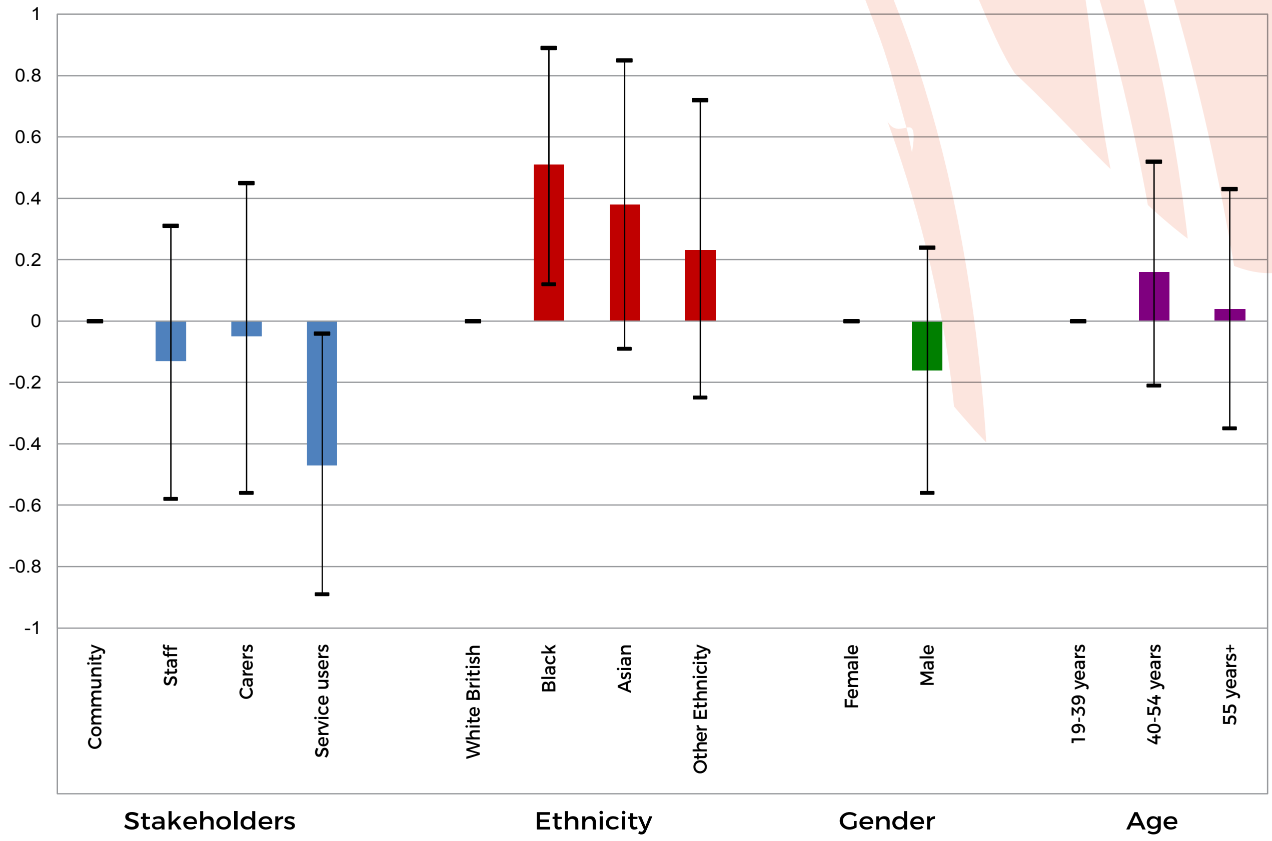


Figure 3: Factor 2 '*Facilitating social support, coping strategies and measures of positivity*' by demographic subgroups

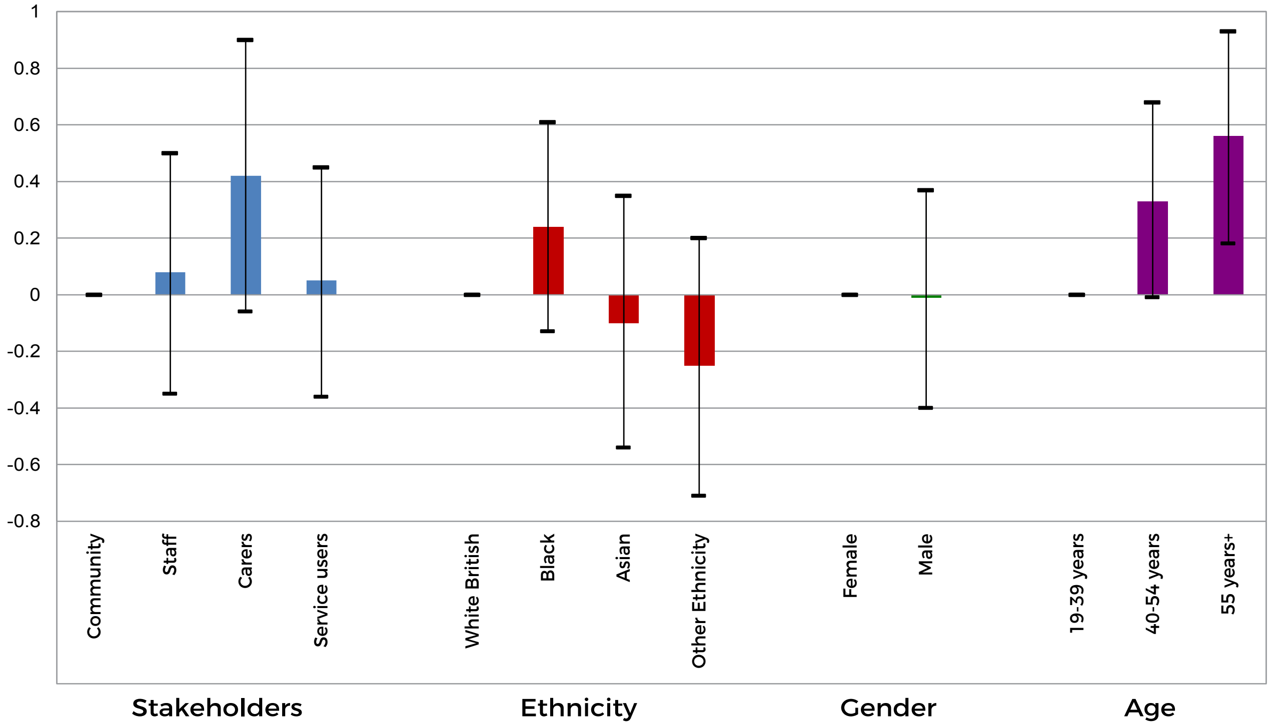
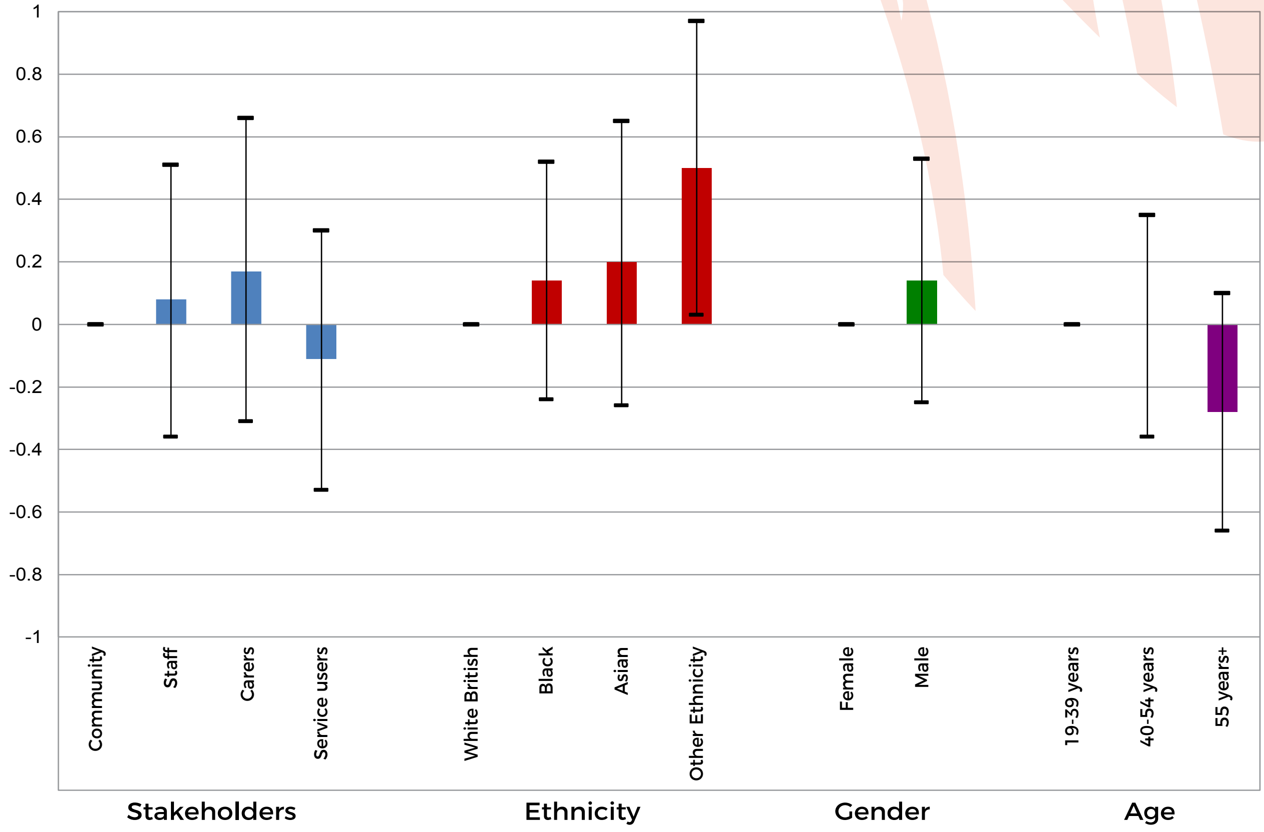


Figure 4: Factor 3 *'Stigma and societal disadvantages without reference to racism'* by demographic subgroups



The figures show:

- Overall there were few statistically significant differences.
- Factor 1: *The impact of racism and adverse care pathways* was significantly more important for Black than White British participants, and significantly less important for service users than those in the community category.
- Factor 2: *Facilitating social support, coping strategies and measures of positivity* was significantly more important to those aged 55+ years than those aged 19-39 years.
- Factor 3: *Stigma and societal disadvantages* was significantly more important for people of 'Other Ethnicities' than those of White British ethnicity.

IMPLICATIONS

The responses provided by participants in our national consultation on priorities to address ethnic inequalities in severe mental illness provide valuable insights on ethnic inequalities in severe mental illness that can be used in campaigning to transform health systems and that will shape Synergi's future programme of work.

The most pressing issues identified by participants were multiple forms of racism and adverse experiences, including in encounters with key societal institutions in Britain such as health services and police and criminal justice systems, resulting in more adverse care pathways for ethnic minority people.[1] This implies that there is a need to collect more knowledge on this from all stakeholders, particularly service users.

A related issue was the multiple layers of disadvantage and marginalisation faced by some ethnic minority people, as indicated by the high priority placed on items relating to social disadvantage and stigma in addition to written comments and concerns expressed in the phone interviews. These social-structural issues should receive careful attention in order to understand and address ethnic inequalities in severe mental illness. A need to make therapeutic approaches more accessible for ethnic minority people experiencing severe mental illness was also expressed. This should be addressed alongside measures of social support to assist with the development of efficient coping strategies. In all cases it seems evident that there is value in and a need for close partnership working with people with lived experience.

We acknowledge that the generalisations that can be drawn from this priority setting exercise are somewhat limited by the relatively small number of participants who took part, both overall and within subgroups. Yet, this is the first and only time such an exercise has been undertaken, with a specific focus on ethnicity and severe mental illness. We took proactive measures to improve access and participation, including targeted circulation of the priority setting consultation amongst a range of community groups.

Synergi will continue its work to engage the full range of stakeholders in our work, including those who are most marginalised.

REFERENCES

1. The Synergi Collaborative Centre. Ethnic inequalities in UK mental health systems. *Synergi Collaborative Centre Briefing 2017*; November:1-8

ANNEX DOCUMENT

An annex document on this briefing paper has been created. You can download it here.

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ABOUT SYNERGI BRIEFINGS

Synergi Briefings provide evidence summaries, and reflect Synergi's position, approach and values, to build a fairer health care system, and to improve population health. Although embedded in the published evidence, there is much evidence in practice and in unpublished sources, or on websites, or in the memories of organisations that work with ethnic inequalities. We welcome these other sources of evidence and will place them in co-production spaces to develop shared narratives of evidence, and actions which can be taken, to prevent and reduce ethnic inequalities in the experiences and outcome of severe mental illness, and which take account of multiple disadvantage.

We welcome use of the content and discussions about progressive approaches to enhance health and social systems.

Our briefings are free to use, but please do provide the citation as suggested inside the front cover.

Website
synergicollaborativecentre.co.uk

Contact
For more information, contact Dr Kristoffer Halvorsrud, Postdoctoral Research Fellow:
kristoffer@synergicollaborativecentre.co.uk

PROJECT PARTNERS

Queen Mary University of London

MANCHESTER 1824 The University of Manchester

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Lankelly Chase