

REPORT

Centre for  
Mental Health



## Fit for purpose?

Addressing inequities in mental health  
research exacerbated by Covid-19

A report by the Mental Health Research Group

Supported by  
Maudsley  
Charity

Backing  
Better  
Mental  
Health.



# Contents

---

	Acknowledgements	3
	Executive summary	4
1	Introduction	6
2	The landscape for UK mental health research	7
3	Research inequities and gaps	13
4	Doing things differently	22
5	Looking forward – ambitions for the future	28
	Glossary of terms	30
	References	31

## Acknowledgements

On behalf of the Mental Health Research Group, Centre for Mental Health would like to thank the Maudsley Charity for their support. Maudsley Charity is an independent NHS mental health charity which works in partnership with patients and families, clinical care teams and researchers at South London and Maudsley NHS Foundation Trust, the Institute of Psychiatry, Psychology and Neuroscience, King's College London, and community organisations, with a common goal of improving mental health, to support innovation, research and service improvement.

### Authors

- Dr Neha Shah, City University London
- Sarah Hughes, Centre for Mental Health
- Professor Sir Simon Wessely, King's College London
- Akiko Hart, National Survivor User Network
- Professor Stephani Hatch, King's College London
- Professor Eamon McCrory, University College London
- Andy Bell, Centre for Mental Health.

### Contributors as members of the Mental Health Research Group

- Professor Louise Arseneault, KCL / ESRC
- Dr Jacqueline Dyer, NHSE / Global Black Thrive
- Mark Rowland, Mental Health Foundation
- Kathy Roberts, Association of Mental Health Providers
- Professor Kamaldeep Bhui, Oxford University

- Sean Duggan, NHS Confederation
- Professor Martin Knapp, London School of Economics and Political Science
- Professor Elaine Fox, Oxford University/UKRI
- Paul Farmer, Mind
- Dr Graham Durcan, Centre for Mental Health
- Sir Norman Lamb, The Children and Young People's Mental Health Coalition
- Professor Louis Appleby, University of Manchester
- Lea Milligan, MQ Mental Health Research.

### Additional contributors

- Vanessa Pinfold, McPin Foundation
- Savitri Hensman, King's College London, Service User Research Enterprise
- Dr Chanelle Myrie, King's College London
- Steph Keeble, Birmingham LGBT
- Amanda Allard, National Children's Bureau
- Dr Nick Waggett, Association of Child Psychotherapists
- Shuranjeet Singh, Taraki
- Dr Grace Lucas, City University London
- Emeritus Professor Peter Beresford, University of Essex
- Dania Hanif, Association of Mental Health Providers
- Rupa Bhundia, King's College London
- Dr Angela Woods, Durham University
- Dr Sarah Carr, University of Birmingham.

## Executive summary

The Covid-19 pandemic has exacerbated the already existing inequity in population mental health in the UK (1). Inequity exists in levels of diagnosable mental illness, in experiences of mental distress, and in our chances of mental wellbeing. Recent intelligence suggests those most likely to experience worse mental health impacts in relation to the pandemic include those with pre-existing mental illness, young people, women and some racialised communities (2-4).

Despite this, longstanding limitations in mental health research mean that we do not have the necessary evidence to inform responses to the population's increasing and starkly unequal mental health needs.

Major gaps in mental health research relevant to Covid-19 include:

- Mental health research investment is not prioritised compared to physical health
- The funding we do have is skewed towards scientific and clinical research, with less funding for research on prevention or social interventions (5)
- There is inadequate routine data on mental health to measure inequalities in wellbeing or distress, or their social and economic determinants. A variety of new studies have emerged in the wake of Covid-19 but these do not allow measurement of change since before the pandemic, and may have sacrificed aspects of quality for speed (6) (7)
- There are not enough collaborative partnerships in place for research with groups of people facing the greatest risks, including racialised communities, children and young people, and people with pre-existing mental health conditions or with learning disabilities. These groups are too often overlooked in surveys and research (5).

The evidence base for public health and community interventions that promote mental wellbeing, resilience and social connectedness is underdeveloped. This limits the potential for policymakers to effectively deploy whole

population mental health promotion and prevention approaches. We lack existing infrastructure for national leadership and cross-sector collaboration to ensure a rapid and comprehensive response. There have been recent steps to address some of these shortcomings, including development of a better-balanced national mental health research strategy (8). It is essential that leadership and infrastructure for collaboration is in place to ensure that the strategy is implemented. The system needs to be fit for purpose.

**Our ambition is to improve mental health research for all, now and in years to come, with no one left behind.**

If we do not address current weaknesses in the mental health research system, these could worsen the existing inequity in mental health outcomes in the UK today. This requires action from those who fund, carry out, influence or use research, across several sectors and disciplines, working together (9, 10). We cannot achieve meaningful and inclusive cross-sector change without recognising the added power that those who set the agenda and fund research have in influencing this system.

We must acknowledge the subtle sources of power held by those who are in the majority or with professional status. Barriers such as structural racism, differences in professional perspectives and competition for resources can prevent research from reflecting the needs of the people and parts of the system that are currently underrepresented.

This paper is a starting point from which we hope true change can happen: to create a research system better aligned to addressing the greatest need; one where different ways of looking at a problem are valued and integrated, where no one's perspectives are forgotten, silenced or dismissed. We acknowledge that this change cannot happen overnight. But we can all take action now to influence the direction of travel and improve mental health research for all.

We propose the following actions to help us to achieve our shared ambitions for the future:

**1. Better representation:** Research funders and producers must ensure wider representation of groups and communities that have been silenced or overlooked. This can be achieved through:

- a. Measuring and enhancing ethnic representation in datasets and research funding, and increasing the expectation for high quality work in this area
- b. Enhancing representation of other key dimensions of ‘invisibility’ in datasets, including gender, sexuality, neurodiversity and digital exclusion
- c. Improving the quality, quantity and value of contribution that service users and those with diverse lived experience can make, from agenda setting, providing peer review, making or influencing decisions on publication, and communicating findings and recommendations.

**2. Equalise opportunities to create, share and use knowledge:** Research funders and producers must invest in widening the range of people and organisations that can get research funding and build their research capacity. This can be achieved through:

- a. Investing in research infrastructure and skills development in academia, statutory services and the voluntary and community sector that allows meaningful two-way engagement with communities and, where possible, coproduced and participatory research
- b. Developing values-based research funding that identifies equity, accountability, trust and partnership as core considerations of good mental health research
- c. Creating opportunities for non-traditional organisations, especially those that are user- or survivor-led, and those bringing alternative and complementary research models, to access research funding

- d. Providing gateway educational opportunities to help people with diverse identities and backgrounds become involved in and, where possible, lead research
- e. Increasing training opportunities to support clinical academics across the whole mental health workforce
- f. Widening the target audiences for research communication activities outside academic journals and conferences: to engage with people, communities, policymakers and practitioners to create ‘on the ground’ change.

**3. Developing research in key areas:** Research funders and policymakers must ensure resources are targeted towards key areas that will help to build the evidence base for tackling mental health inequalities. These include:

- a. Early years, children and young people
- b. Prevention and promotion
- c. Using complex systems approaches to improve population mental health.

**4. Integrating different types of knowledge:** Research funders and producers must find ways to bring together different types of knowledge in the production of evidence to inform policy and practice. This can be achieved through:

- a. A cross-sector programme of work to develop a best practice framework for policymakers and practitioners which addresses the value of different forms of mental health evidence
- b. Investing in collaborative and joint datasets that engage with social determinants of mental health alongside other factors, and which include data from varied sources
- c. Piloting a new funding model to build a more integrated approach to research which values a wider range of evidence and research. This could be tested within one topic area to identify what works, what hinders progress, and what helps to overcome any barriers.

## Introduction

---

Following the onset of the Covid-19 pandemic, The Royal Foundation of The Duke and Duchess of Cambridge brought together experts and representatives from the mental health sector to form the Mental Health Research Group. Its aim was to identify gaps in knowledge, experience and understanding in order to solve the complex challenges we face in addressing mental health needs in the UK. The independent group was chaired by Sarah Hughes, Chief Executive of Centre for Mental Health and Professor Sir Simon Wessely, Professor of Psychological Medicine at King's College London and Psychiatrist at King's College Hospital. The group identified a number of systemic issues that underlie the challenges that exist and that stand in the way of addressing those challenges.

This paper identifies and reflects on where the system fails to respond to those who need it most. We bring together opinions from experts across the sector to explore how inequities and gaps in mental health research limit our ability to understand what works, for whom, and how, and to address inequities in mental health. This is not a systematic review of the literature and so we cannot claim to cover every gap, but the insights demonstrate how the system of mental health research is working in practice and how this could be improved.

In the development of the paper we have consciously sought to consult with representatives of community groups and those with lived experience to explore these issues and to highlight research led from community and user-led perspectives. However, a thorough consultation or true coproduction was not possible within the time and resources available. Therefore, despite our conscious attempts to address this issue, we acknowledge there are limitations in how those with lived experience and from diverse community groups (in particular those without additional professional training) have been able to shape this report. A list of the contributors to this work can be found in the acknowledgements.

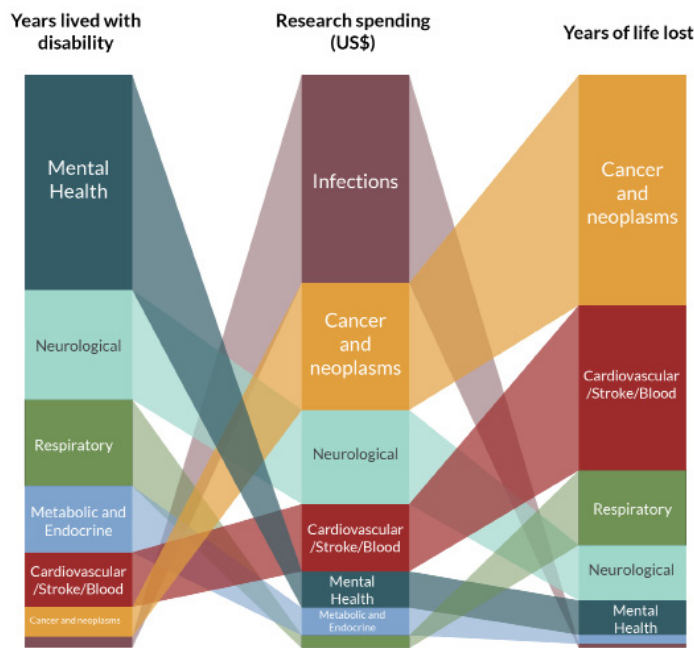
This report seeks to provide an overview and recommendations based upon the expertise and resources available. Addressing the inequities in mental health research will require collaborative efforts from across the system: including funders, producers and users of research working together. We want this paper to mark the beginning of a step change in this process. We hope it will create a new space for a more equitable mental health research economy to open up.

## The landscape for UK mental health research

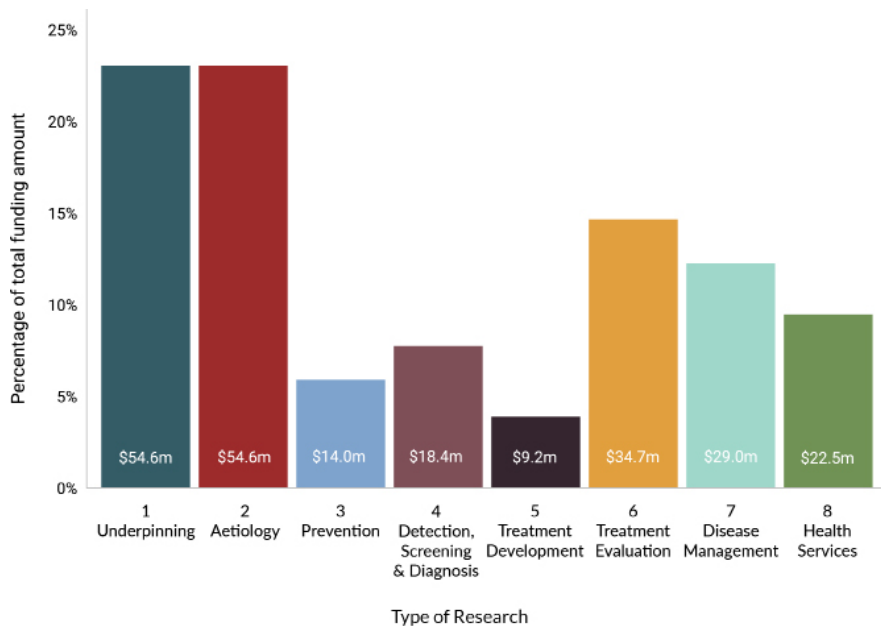
Mental health research internationally is underfunded compared to physical health: globally, 7.4% of health research investment has been found to be for mental health, compared to 19.8% for cancer and neoplasms, and 8.9% for cardiovascular/stroke/blood diseases (Figure 1). When compared to burden of disease, only

\$15 (US) was invested in mental health research per Year of Life Lived with Disability compared to \$755 for cancer and \$77 for cardiovascular disease and stroke (5). Overall the UK pattern of mental health research funding is similar to that of the global picture, with significant underinvestment in mental health research.

**Figure 1: Analysis of UK research spending per burden of disease**



**Figure 2: Spread of research investment in the UK by type**



Figures 1 and 2 from (5): Woelbert, E., White, R., Lundell-Smith, K., Grant, J., & Kemmer, D. (2020). Reproduced with permission from the International Alliance of Mental Health Research Funders



Funding for mental health research in the UK comes mainly from public sources (74%), but 26% of UK research is funded by charities or philanthropic organisations (largely the Wellcome Trust), a uniquely larger share than in other countries where less than 5% came from these sources, and the majority from government or public funding sources (5). Sixteen different public funders of research and 52 different charities and philanthropic organisations were noted as sources in the UK (12). Across the overall analysis, scarcely any research was funded by private/for profit organisations. However, a previous analysis of UK-based health research funding found that public donations account for 2.7% of mental health research funding – which, compared to other conditions, is very low. In cancer research, spending by fundraising charities makes up 68% of funding. In cardiovascular disease it is 41% and in dementia it is 28% (13).

Several imbalances exist within research funding:

- Reduced investment into clinical or applied research compared to that linked with understanding underlying mechanisms
- Underfunding of prevention compared to research related to treating mental health conditions
- A greater investment in adult over child or youth mental health (5).

There are also certain topics such as self-harm, suicide and personality disorder that attract less funding despite significant associated morbidity and mortality in the UK. Available analysis does not highlight the geographical spread of research within the UK, but contributors to this report have highlighted underfunding of mental health research in rural areas and those not aligned with larger centres of research.

While each funder has their own focus, there is a move to work together towards developing mental health research in key areas. A collaborative set of Mental Health Research

Goals 2020-2030 has recently been announced by five key UK mental health research funders: NIHR, UKRI, Mental Health Research UK, MQ Mental Health Research, and the Wellcome Trust (see Figure 3) (8). Key goals set out include research to:

- Halve the number of children and young people experiencing persistent mental health problems
- Improve understanding of the links between physical and mental health, and eliminate the mortality gap
- Develop new and improved treatments, interventions and support for mental health problems
- Improve choice of, and access to, mental health care, treatment and support in hospital and community settings.

These goals acknowledge current inequities including a need for focus on valuing preferences and lived experience, addressing mental health in non-clinical settings, and addressing needs of diverse communities and of children and young people.

**The question remains as to whether the system and landscape around mental health research is ‘fit for purpose’ to achieve these priorities over the next decade.**

## How is mental health conceptualised?

Researchers and practitioners interested in mental health span the clinical disciplines of psychiatry, psychology, nursing, social care and public health. They also include wider disciplines such as the humanities, arts and philosophy. Knowledge and attitudes about mental health, causes and appropriate ways to address these, and whether diagnostic categories of mental illness are appropriate or not, may vary between and within disciplines. This means there are challenges in establishing a cohesive understanding across the system.



**Figure 3: UK Mental Health Research Goals**

**Research goal 1:**  
Research to halve  
the number of  
children and young  
people experiencing  
persistent mental  
health problems.

- Target 1A: Increase knowledge of the aetiology, development (including risk and protective factors) and progression of mental health problems at key transition points across the life-course.
- Target 1B: Increase research on effective mental health promotion, prevention, treatment and support for children and young people in education, community and health, including specialist mental health, settings.
- Target 1C: Increase research on implementation of effective interventions in a range of settings to optimise outcomes. This includes research on service delivery and organisational factors influencing outcomes.

**Research goal 2:**  
Research to improve  
understanding of  
the links between  
physical and mental  
health, and eliminate  
the mortality gap.

- Target 2A: Research to strengthen our understanding of the comorbidity of both mental and physical health problems. This research should address clusters of health problems, underlying mechanisms and progression, and societal and individual risk and protective factors and in addition the implications for treatment and support.
- Target 2B: Research to improve the efficacy and effectiveness of interventions for prevention and increase maintenance of good physical health for people with mental health problems, or at risk of developing mental health problems. The aim is to reduce morbidity and excess mortality.

**Research goal 3:**  
Research to develop  
new and improved  
treatments,  
interventions and  
support for mental  
health problems.

- Target 3A: Research to investigate the mechanisms underlying mental wellbeing, mental health problems and related behaviours through use of markers from basic biological, psychological and social science to understand how to improve treatments, interventions and support.
- Target 3B: Develop and implement new and improved treatments, interventions and support, including medical, social and psychological approaches to increase patient choice and greater personalisation.
- Target 3C: Develop and evaluate effectiveness of digital interventions that complement and supplement face to face interventions for prevention, support and recovery.

**Research goal 4:**  
Research to improve  
choice of, and access  
to, mental health  
care, treatment and  
support in hospital  
and community  
settings.

- Target 4A: Research to understand the barriers to help-seeking and service access, and to delivery of mental health services and other support in diverse settings and across different communities.
- Target 4B: Research to accelerate the implementation of existing best evidence at the population and individual level. In addition, implement evidence on how patient choice and joint decision-making make a difference to outcomes in routine care.
- Target 4C: Increase research to inform strategies for tackling social and health inequalities to improve public mental health.

Many argue that a biomedical and scientific rationalist perspective (where evidence of structurally identifiable change in the body or statistically confirmed findings are valued as ‘true’) is the dominant model that influences health sciences. Mental health research does not always fit well into a biomedical or rationalist approach and this may be reflected in the underfunding of mental health research compared to physical health (14). The tension between different ways of understanding mental health is perhaps also reflected in the fact that the majority of international funding (56%) is towards research attempting to understand underlying mechanisms of mental health rather than that directly associated with improving it (5).

**This group understands mental health research to cover not only diagnosable mental illness, but experiences of mental distress, and more positive aspects of mental wellbeing.**

## Who influences mental health research in the UK?

Funders are not the only influencers of how research is ‘done’. Universities are the main producers of research. Alongside them, structures have been put in place to encourage broader collaboration across academia, policy and practice and make use of local knowledge and organisations. These include the National Institute for Health Research (NIHR) led Academic Health Science Networks and Applied Research Collaborations. The UK Research Institute (UKRI) Mental Health Research Networks initiative is aimed at forming meaningful academic and community research partnerships and also increasing the disciplinary diversity of input to mental health research. There are also initiatives that form community research partnerships such as the Synergi Collaborative, Black Thrive Global and Thrive London; and service user led research such as work carried out by the McPin Foundation.

### World Health Organisation definition

“Mental health is more than just the absence of mental disorders or disabilities.

Mental health is a state of wellbeing in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community.

Mental health is fundamental to our collective and individual ability as humans to think, emote, interact with each other, earn a living and enjoy life. On this basis, the promotion, protection and restoration of mental health can be regarded as a vital concern of individuals, communities and societies throughout the world.”

## Academic Health Science Networks

There are 15 Academic Health Science Networks (AHSNs) across England, established by NHS England in 2013 to spread innovation at pace and scale and to integrate research into improving health and generating economic growth. Each AHSN works across a distinct geography serving a different population in each region. The AHSNs connect NHS and academic organisations, local authorities, the third sector and industry.

## NIHR Applied Research Collaborations

NIHR Applied Research Collaborations (ARCs) support applied health and care research that responds to, and meets, the needs of local populations and local health and care systems. These 15 local partnerships between NHS providers, universities, charities, local authorities, Academic Health Science Networks and other organisations also undertake implementation research to increase the rate at which research findings are implemented into practice.

## UK Research & Innovation Networks

In 2018, UK Research & Innovation (UKRI) funded 8 mental health research networks. These networks are formed of academics, clinicians, third sector representatives and those with lived experience, amongst others. They tackle a variety of mental health research subjects, ranging from youth mental health to violence and abuse, to loneliness and social isolation.

Contributors noted that organisational rules and regulations, including those set by research funders, could at times limit the success of these initiatives and reduce their ability to be truly collaborative spaces.

This can be exacerbated by the hierarchical and competitive environment within academia and difficulties in career progression. This can hold back research areas or methodologies that do not neatly fit into established programmes of work, leading to replication rather than expansion into new areas. These examples highlight the interplay between how funders set the research agenda and how universities and academics may fulfil it and, in so doing, limit the diversity and originality of grant applications.

Users of mental health research are a broad mix of communities, clinicians/practitioners and policymakers. Some will be actively involved in research themselves and are well placed to influence and conduct research, being close

to points of decision-making, care and lived experience. In reality, most actors will take up multiple roles in influencing, developing and using (or not using) research, and the public, including media organisations and social media users, can also shape agendas and priorities in the system.

Another powerful influencer in health research is academic journals. One contributor to this report noted that results which were seen as 'objective' or 'precise' were valued by journals and so more likely to get published than those which may be important to communities. This is an important reminder that the ways research gets communicated and translated into policy and practice are as important as the research itself. Addressing inequalities in mental health research will mean looking at alternative routes to publishing and communicating the results.



## Reflection

A clinician noted that whilst many recognised the limitations of medical categories of mental illness, stepping away from these in the field of research left a lack of structure which they found too anxiety-provoking to work with. This raises the question of whether those working in the field and funding projects need to foster a greater capacity to work with the uncertainty that exists within mental health research. This could allow new ways of understanding to develop, including outside of clinical disciplines. Further work may be needed to strengthen alternative concepts and measures of illness to challenge use of diagnoses where they are not appropriate. For example, the ‘trauma-informed’ conceptualisation of mental health became more acceptable and integrated into research following quantitative research on the longer-term impacts of childhood adversity.

This also links to a wider existing debate of whether fewer standardised measures or a wider array of specified measures should be used as outcomes for mental health. A variety of measures is less coherent for comparing and integrating the evidence around mental health, but does allow for a more diverse understanding and critique of dominant ways of thinking.

## Research inequities and gaps

We asked contributors to identify the key inequities and gaps in mental health research. These have been grouped according to who is left out, what is left out and how this can be addressed.

### Who?

#### Racialised communities

Racism and its impact on mental health has been increasingly high profile in relation to the promise of Mental Health Act reform, the murder of George Floyd in the summer of 2020, the Black Lives Matter movement and the clear racial disparity in impacts of Covid-19 (9, 10). The importance of exploring the differential impacts of Covid for socially marginalised or disadvantaged groups, in particular racialised communities, has been raised by voices across academic mental health (10). Early exploration of mental health inequities in relation to race and ethnicity in the UK during the pandemic suggests disproportionate impacts on women of all ethnicities, and of men from some racialised communities, in particular those of Bangladeshi or Pakistani origin (11). Much of this disparity is explained by structural inequity such as people from racialised communities being more likely to be from socioeconomically disadvantaged backgrounds or working in keyworker roles than those identifying as White British.

The International Alliance of Mental Health Research Funders were not able to develop a metric for measuring representation of race or ethnicity in mental health research studies, and noted the majority of funding for research was for high income countries, and that racialised communities within them were largely overlooked or invisible (7).

Researching mental health by reference to race is limited by the lack of funding to support necessary 'ethnicity boosts' in national surveys. This leaves researchers with limited data collected on race or ethnicity. There are also gaps in routine service data (for example, in the use of the Mental Health Act) which are compounded by the widespread use of homogenising terms and categories

such as 'BAME' ('Black, Asian and minority ethnic') or 'non-white'. Communities may identify themselves through a range of factors (for example geography, religion, language or nationality) that may be filtered through common experiences of migration, discrimination, oppression, education and housing. Some researchers have sought to regard these multiple layers of experience as 'confounding factors' that need to be removed from the picture. This unhelpfully shifts the narrative away from addressing structural racism as a driver of differences in mental health outcomes between groups (15, 16). Diverse methodological approaches, including mixed quantitative and qualitative approaches, are needed to capture the complex interplay of these related factors.

Contributors to this paper raised that few mental health interventions, from population mental health campaigns to psychological therapies, were developed bespoke to different minority community needs and frames of reference, either through cultural adaptation (14) or through coproduction (12). Of those that existed, few also had evaluations which were published or recognised to be of good quality (17). Many well established scales for mental health may also not be validated to check they are understood and capture mental health states robustly in diverse populations, although there are some good examples of this (15).

Others spoke to subtle influences of racism in the spread of research. For example, by emphasising the greater risk of severe mental illness among Black men, research may passively reinforce stereotypical and stigmatising portrayals of dangerousness. By contrast, an increased framing of mental health in terms of traumatic experience was seen as helpful for shifting the narrative away from a racial 'othering' of certain populations.

#### LGBTQ+

Mental health inequities in LGBTQ+ individuals have been documented widely, yet few high quality research studies exist in relation to

addressing the mental health needs of this population (18). Routine data collection for LGBTQ+ communities is also traditionally poor, and this limits the ability for it to be addressed in research. Contributors highlighted the need for training so that mental health practitioners are more comfortable with asking questions which would enable data to be captured more accurately. The inclusion of sexuality and gender identity within the 2021 Census was seen as a positive step.

Cultural adaptation of intervention was also seen as important for this group – with traditional IAPT models of treatment seen as inappropriate for people who are struggling with internalised trans/homophobia and who may need a more bespoke approach. A contributor reflected that academic research on LGBTQ+ mental health needs was driven by personal interests rather than a feature of core programmes of work or agendas, and thus there was little to draw upon. Research initiated by the voluntary sector could fill this gap but may not be valued by policymakers, and therefore cannot influence practice in the way that academic research can.

### **People with long-term mental illness**

People living with a long-term mental illness continue to be a marginalised group in society, despite many years of anti-stigma and discrimination campaigning from charities, user-led organisations and professional bodies. Many have experienced a significant deterioration in their mental health during the pandemic (19). There is also compelling evidence of increased infection and far higher mortality rates amongst people living with mental illness during Covid-19. This highlights the clear need to address physical health inequalities and develop research projects that reflect people's lived experience and that can improve support (20).

Inherent to the pandemic, digital equity has become a much more pressing concern as more services have moved online or to other forms of remote working. Emerging research is capturing how the changing landscape of mental health service delivery is working for service users.

But there is a need to better understand what works for whom and how safety can best be taken into account (21). We also know little as yet about who is excluded from research which is primarily conducted online and what bias this may build into future research (22).

### **Children and young people**

Despite the known impact of childhood adversity on later mental health outcomes, there is remarkably little focus on prevention in the current landscape. Only a third of funding goes towards research for children and young people's mental health, limiting the ability of research to inform intervention at an earlier age (5, 11). Contributors also raised the importance of pregnancy and the first two years of life – the 'first 1,001 days' – on a child's mental health and development, and how appropriate interventions at this stage were relatively under-researched.

Population studies have highlighted how children and young people are particularly vulnerable to the impacts of the pandemic (23). Those who are disadvantaged economically, girls and young women, and those with pre-existing special educational or mental health needs are at greater risk of worsening mental health outcomes since the onset of the pandemic. Emerging data will also help us understand the ongoing impacts of experiences of trauma and disruption to education (24). Given the current context where sensitive developmental stages have been changed and disrupted for all children and young people, preventive work, access to appropriate additional support and monitoring are important, and will need to be addressed by research.

Contributors raised concerns about the absence of research on specific interventions for children and young people, and a tendency for research conducted with adults to be applied to children. This includes medications that have not been tested on children and are often used 'off label'. There is also little known about effective support for young people transitioning from child to adult mental health services (which in many cases means losing any support), and



there is a need to better understand what works in relation to social interventions for young people, for whom clinical services can feel less relevant or welcoming (12). Current research into implementing social prescribing for young people in a partnership between King's College London and the National Children's Bureau was highlighted as positive progress.

### **Older people**

Older people's mental health, in particular related to isolation, social exclusion, bereavement and cognitive/physical decline, is another area to consider in relation to equity of mental health research. Surveys during the pandemic have suggested that older people have fared better in relation to mental health outcomes than younger people, despite facing an increased risk of more severe disease and bereavement (23). There remain concerns that digitally implemented surveys may exclude some older people and may not be wholly representative. Some research suggests those with multiple health conditions and who have been asked to shield have fared worse than older people who haven't (25), and that health/health care related anxiety, stress of shielding and uncertainty about the future were key drivers of worsening mental health. Having a routine, a slower pace of life, maintaining social contacts and use of past experience to cope were protective amongst this age group (26). Understanding these risk and protective factors better in these unusual circumstances will allow better understanding of how to support older people's mental health more effectively in the future.

### **Carers and families**

Recent analysis has suggested carers have been at increased risk of depression during the pandemic (27, 28). A contributor to this project highlighted the way society devalues the work of carers, with caring responsibilities seen as 'women's work' and given little attention in research. Another contributor highlighted the need to research at the level of family systems rather than individuals alone.

### **Neurodiversity and learning disability**

Rates of mental ill health are much higher than average among people with neurodiverse conditions and learning disabilities. Yet there is little research available pointing to the most effective interventions, or ways of adapting them to the needs of these groups of people.

### **Rural communities**

Available analysis does not highlight the geographical spread of research, but contributors highlighted underfunding of mental health research that addresses the needs of people living in rural areas who may experience different risk and protective factors for mental health.

### **Intersectionality**

Research that only focuses on one attribute of a person cannot capture the full range of factors influencing their health outcomes. We need to raise our capability and capacity to research intersectional characteristics. This means being able to deploy a range of methods to dig deeply into the experiences of specific groups of people, with an awareness of the multiple layers of discrimination, oppression and disadvantage that some may be facing. Addressing these intersections allows a deeper understanding of mental health need and should enable the development of interventions and approaches that more effectively help individuals, families and communities.

### **What?**

#### **Prevention and public mental health**

The pandemic, related measures and economic pressures are drivers of worsening mental health which may be adding pressure to already stretched mental health services (2, 15). While most people will experience distress following disasters, not all will need clinical treatment (16, 17). Research into community-based approaches which could boost the protective factors for good mental health will be important to guide recovery at a population level. Clinical services will not be able to serve the mental health needs of the entire population, and

neither would it be right to see this as the optimal intervention for everyone (6).

There is a limited evidence base in relation to public mental health interventions, which often need complex systems approaches, making them difficult to evaluate (18-20). In some areas (such as parenting and school based approaches) a good evidence base using traditional methods of research exists, but there is difficulty in translating this into sustainable and widespread practice. For these areas, we need research about how to deliver effective interventions at a bigger scale, and it needs to be communicated well to encourage wider adoption.

But there are other topics that are poorly researched. These include looking at mental health impacts of policies relating to areas such as gender equity and violence, climate change, built and natural environment, and social security. Public health approaches involve working with schools, workplaces, community hubs and broader public services, all of which are well placed to address the social determinants of mental health (29) (30). This should lead to a greater focus on the inequities that drive poor mental health which should make it easier to make the case for policies and strategies that will make a difference (31).

Voluntary and community sector organisations who deliver many of these public mental health interventions face particularly high barriers to proving their worth across the mental health system. Clinical services and professions have an in-built advantage in the ways research is organised, communicated and accepted. This leads to a 'vicious circle' where a narrative around a 'lack of evidence' for approaches and services that challenge mainstream provision prevents their further development and scale-up.

### **Alternatives to traditional models of mental health and research**

Framing and understanding of mental health varies between cultures, which may understand mental health as a spiritual, moral or physical phenomenon rather than a medically explained or mind-based one (12, 13). It is difficult both to capture this granularity and to value it equally within research, especially if those that design and fund research value a more biomedical or 'Eurocentric' perspective and are more likely

to award grants to applications that align with this. Some contributors noted a historical link between Western science and European colonialism whose legacy may still be with us today.

Some research suggests a preference from service users for greater use of social models of mental health, and for mental health to be seen as an asset or a personal characteristic, not a disability or deficit (32). Additionally, service users were found to prefer use of wellbeing measures aligned to their experiences over professionally-determined scales (33).

### **Those with lived experience or who had experience with service user-led research felt that research too often happened 'on the outside looking in.'**

Researchers may not share similar characteristics to the people they are researching, especially if the people are from socioeconomically disadvantaged or racialised communities, or identify as having disabilities. This can mean that those conducting research may prioritise and interpret findings differently to those being researched. The quantitative interpretation of results was challenged as often not being 'informed by the lifeworlds' or experiences of those who are being researched.

An example of potential 'blind spots' was given by a contributor, where research into ethnic disparities in success of clozapine treatment did not take into account increased diabetes risk and medication stigma in African and Caribbean communities.

Research participants may also be more comfortable and willing to engage with research when the researchers themselves embody their lived characteristics, highlighting the value of representation.

One contributor pointed out that while most mental health clinical professionals in the UK had established routes to becoming clinical academics, counselling and psychotherapy professionals (apart from those with psychological training) were excluded from this due to non-statutory regulation, which acted as a barrier to professionals in this area contributing to the mental health research agenda and developing the evidence base for the field.

## Reflection

One contributor highlighted how our understanding of mental health focused on it being linked to the brain, but that increasingly the role of other parts of the body, especially the gut, were being recognised as potential sources and areas of manifestation of mental illness. The comorbidity of mental and physical illness is also well documented and areas of study such as psychoneuroimmunology attempt to explore this relationship. The social world and in particular discrimination is also implicated here, with pathways hypothesised where chronic stress is associated with increased ‘allostatic load’. This concept denotes biological dysregulation or ‘weathering’, a concept related to increased inflammation which can lead to the development of chronic physical illness and ageing. Research in this area suggests mental and emotional health is directly linked to physical health, and not just through ‘behaviours’.

While most therapies available focus primarily on working with brain-based cognitive and emotional processes via drugs or psychological therapies, a broader understanding may allow further exploration of the interrelatedness of our body as a whole with our mental health. This could lead to therapies that address the two better and perhaps even offer further solutions that use ‘bodily situated’ manifestations of mental illness as a starting point. This type of research is likely only to be possible with interdisciplinary engagement.

A question was also raised as to whether questionnaires that were framed in a cognitive way, linked to brain-based understandings, could also constrain people’s understanding of their own mental health, and whether this may distance them from a ‘complete’ experience of their (mental) health.

Others noted that the skillsets and knowledge gained by community organisations were particularly well-placed to explore how best to implement interventions and change. They might offer experience-driven analysis of what limits progress in real-world settings. Locality-based participatory research can evolve better tailored interventions and policies for mental health. This could, for example, be led by a housing association or a community collaborative who make or have a strong say in the funding decision.

Contributors were keen to highlight the importance not only of shifting funding to alternative settings, but investigating complementary ways of understanding mental health, of recognising unmet needs, and of testing out new approaches in the real world.

### Data collection

A gap exists in relation to timely collection of data. This has been increasingly apparent in relation to the need for rapid knowledge generation and mobilisation as a result of the pandemic. Recent literature suggests that the quality of many rapidly developed population surveys and intervention trials is poor, including with regards to:

- Ensuring adequate representation of the population
- Valid and appropriate measurements
- Appropriate analyses in regards to causal and confounding factors
- Transparent methodological reporting
- Use of qualitative methods
- Inclusion of those with lived experience or real coproduction (6) (15).

A lack of adequate infrastructure to rapidly coordinate research efforts, avoid duplication and encourage collaboration was also raised (6). Much of this research may not represent a valuable use of time and resource, or importantly benefit those being researched without reflection and learning going forward. There is also significant delay in obtaining accurate data on trends in suicide, due to the lack of adequate infrastructure to identify, classify and report potential suicides in a timely manner. (However, there is currently a programme of work taking place to address this important gap.)

The need to acknowledge the ‘biopsychosocial’ context of what creates or harms our mental



health is becoming more widely recognised. However, many health service records are not readily linked to data on wider social factors such as housing and employment that would allow an integrated analysis of these factors, as well as an assessment of the impact of interventions. Similarly, national surveys and cohort studies do not always collect data across all the biopsychosocial domains alongside granular detail on mental health and wellbeing. For example, it is difficult to find datasets that capture both a child’s mental wellbeing and their household circumstances – quality of relationships, financial status, or parental mental health.

Getting access to data is costly and difficult, particularly where organisations need to develop data-sharing agreements that assure confidentiality. There are signs that this is beginning to improve as a result of national guidelines from NHS Digital (35).

## How?

### Building trust, collaboration and coproduction

One contributor, speaking from a community perspective, discussed how they had no faith that the research they wanted to do would be kept intact if they partnered with an academic organisation to get funding. It was difficult for them to obtain funding directly from the bigger research funding organisations without university or NHS credentials. They were able in the end to source skills for free from willing individuals

to carry out research with their community. But they recognised that this was not a viable or sustainable choice for many communities.

Contributors were keen to also showcase good practice with reciprocity or ethical dissemination where communities would gain transferable skills in return for participating in research. They also emphasised the need for building sustainable relationships and redressing power imbalances in the course of the research (12).

Trust and reciprocity were also raised as being especially important for young people – with an example of work placement apprenticeships offered as a way a young person could also gain from participating in research.

Contributors emphasised the importance of sensitive research with parents and children: whilst the interrelatedness of parental and child mental health in families is well recognised, excessive determinism can lead to blaming of parents or negative attitudes and beliefs about the future.

The American Organisation, Chicago Beyond, has developed a guidebook for research organisations and funders looking to redress the power relationship in research (36). Key aspects to address are outlined in Figure 4. Adopting ‘value based’ or ‘compassionate’ research can ensure that issues such as equity, unintended and adverse consequences, and trust and reciprocity are consciously addressed as part of the research process.

**Figure 4: Chicago Beyond: Key areas to rebalance and establish trust with communities in research**

<b>Access</b>	Could we be missing out on community wisdom because conversations about research are happening without the community meaningfully present at the table?
<b>Information</b>	Can we effectively partner to get to the full truth if information about research options, methods, inputs, costs, benefits, and risks are not shared?
<b>Validity</b>	Could we be accepting partial truths as the full picture, because we are not valuing community organisations and community members as valid experts?
<b>Ownership</b>	Are we getting incomplete answers by valuing research processes that take from, rather than build up, community ownership?
<b>Value</b>	What value is generated, for whom, and at what cost?
<b>Accountability</b>	Are we holding funders and researchers accountable if research designs create harm or do not work?
<b>Authorship</b>	Whose voice is shaping the narrative and is the community fully represented?

## Lived experience and survivor leadership

Contributors were clear that ‘peer research’ approaches, where research is carried out by those with lived experience or common characteristics to those being researched, leads to deeper and more authentic findings (37). This approach challenges assumptions that only certain ‘qualified’ individuals and institutions are able to generate knowledge about the world (38). This may be important when addressing gaps in knowledge which impact on marginalised groups of people, especially where those gaps reflect existing imbalances of power.

Contributors highlighted the importance of addressing equity and diversity throughout the research pathway: in prioritising and designing research, choosing funding, and implementing and disseminating findings. While research generally now includes ‘patient and public involvement’ as a necessary element, the extent to which its potential has yet been realised is open to question. Contributors spoke to the importance of constructing advisory panels with diverse perspectives and attendance to who is and isn’t in the room. Inclusion is therefore important as an intrinsic practice within research, and not a marginal exercise.

Whilst many funders require demonstration of meaningful engagement with patients and the public in research development and implementation, in reality it is often tokenistic. Those with lived experience often have little opportunity to influence what happens. A recent review of Patient and Public Involvement in realist reviews found that ‘contributor involvement refers to stakeholders, experts, or advisory groups (i.e professionals, clinicians, or academics)... Patients and the public are occasionally subsumed into these groups and in doing so, the nature and impact of their involvement becomes challenging to identify and at times, is lost completely’ (39).

Some contributors felt that the funding of research infrastructure often did not allow for a significant budget to meaningfully or creatively engage with those with lived experience. The structure of research pathways, where funding and priorities may be set prior to engagement, and difficulties in obtaining the right education and training, acted as barriers for those with diverse experiences in actively engaging with or even leading research. Some people from service user led organisations found it much harder to gain funding due to a questioning of the reliability and credibility of their skills. Smaller organisations are also often excluded from larger projects because they cannot meet criteria for financial assurance that they could manage larger budgets.

## Reflection

Contributors raised the importance of identifying differences between lived experience leadership, peer research and consultancy. Some people with lived experience may not feel comfortable engaging with more technical aspects of research and would want a more limited role. Others may want to take up opportunities for leadership. There are examples of research leaders who have effectively used their own subjectivity and lived experience to inform and guide their research. This presents a challenge to the supposed ‘need’ to seek scientific neutrality in all aspects of research.

It points to the conclusion that researchers need to be aware that, like anyone, their view of the world is subject to their own identity and life experience. Recognising this can be valuable to understanding and taking into account the inherent assumptions, for example whiteness (or not), maleness (or not), ableness (or not), professional training (or not), that may be guiding the research.

## Bridging between parts of the system

Research that reflects and responds to inequity in mental health requires a wide range of skill sets across different sectors and disciplines, combining clinical, academic and lived experience expertise. Critical humanities approaches to mental health were not often funded by the same bodies as clinical research, for example. They are also rarely conducted collaboratively or published in the same journals.

There is therefore a need for interdisciplinary and collaborative skills and spaces to combine these skill sets and knowledge. This should extend to valuing the research conducted through the voluntary and community sector, where complementary skills and knowledge can bring further new perspectives to this collective effort. Acknowledging the inherent hierarchies held within the system, and exploring ways of working that encourage reflection and balance the power of different actors, are key to effective cross-sector collaboration.

The undervaluing of mental health research compared to physical health in health sciences circles, and the difficulty in getting alternative approaches published in influential journals, are major barriers to recruiting and retaining talented mental health researchers. This may be offset by an increasing momentum and recognition of the importance of mental health research in the post-pandemic climate. It is difficult to align biomedical measures with more psychological ones which are less physically tangible and (arguably) rely more upon subjective measures. The weighting of objective measures as more ‘accurate’ in traditional evidence frameworks can be viewed as subtly undermining psychological and qualitative approaches. Academics also described a lack of consensus on appropriate proxy social outcomes (for example, relating to educational achievement, employment or housing status) linked to mental health. Yet without appropriate measures it is difficult to meaningfully study these factors within the timescale of a research project.

Traditional hierarchies of evidence favour Randomised Controlled Trials and systematic reviews. Commissioners and policymakers sometimes want to see this ‘higher quality’ evidence in order to justify spending on new interventions. This is not, however, applied consistently. Political will and personal or professional interest can still over-rule robust evidence in policymaking and commissioning across many sectors. And the height of the barrier to investment may vary according to the extent to which an issue is seen as politically important or needing an urgent solution.

*“...research funding, research activity, and the published evidence base are all heavily skewed towards studies that attempt to identify simple, often short term, individual-level health outcomes, rather than complex, multiple, upstream, population-level actions and outcomes...”* Rutter *et al.*, 2017 (40)

Nutly *et al.* (41) highlight that hierarchies based on study design neglect other important and relevant issues around evidence. Such hierarchies:

- Undervalue good observational studies
- Can lead to the loss of useful evidence when ranked and synthesized according to a hierarchy
- Pay insufficient attention to the need to **understand what works, for whom, in what circumstances and why**
- Do not give sufficient information for clinical or public health decision-making.

In many mental health and public health settings, it is not possible to develop this controlled environment, and this may not be an appropriate way of gathering evidence.

Chicago Beyond (36) and the Patient Experience Library (42) highlight the problems with the way these hierarchies of evidence undervalue the insights of communities and of people with lived experience. This leaves a gap in alternative frameworks for valuing appropriate evidence for different purposes. In order to effectively address real world challenges, new frameworks or ‘typologies’ could be developed.

An example of a typology of evidence is shown in Figure 5 (43). There are also some more creative approaches that have been developed with the University of Exeter’s Index of Evidence project cataloguing our changing relationship

with what constitutes evidence in a ‘post-truth’ world. Importantly, alternative typologies or frameworks should acknowledge that **valuable evidence can be generated from outside academia.**

**Figure 5: An example of a typology of evidence**

Research question	Qualitative research	Survey	Case-control studies	Cohort studies	RCTs	Quasi-experimental studies	Non experimental evaluations	Systematic reviews
<b>Effectiveness</b> Does this work? Does doing this work better than doing that?				+	++	+		+++
<b>Process of service delivery</b> How does it work?	++	+					+	+++
<b>Salience</b> Does it matter?	++	++						+++
<b>Safety</b> Will it do more good than harm?	+		+	+	++	+	+	+++
<b>Acceptability</b> Will children/parents be willing to or want to take up the service offered?	++	+			+	+	+	+++
<b>Cost effectiveness</b> Is it worth buying this service?					++			+++
<b>Appropriateness</b> Is this the right service for these children?	++	++						++
<b>Satisfaction with the service</b> Are users, providers, and other stakeholders satisfied with the service?	++	++	+	+				+

*Reproduced from Petticrew and Roberts, 2003 (43), adapted from Muir Gray, 1996 (56)*



## Doing things differently

In this section we highlight some approaches that have been used in practice to overcome inequities and structural failings in mental health research. These are by no means exhaustive

and not the only examples of good practice. But they are illustrative of the kinds of approach that have been tried and may help to spark further innovation, development and system change.

### Centre for Society and Mental Health: Building sustainable community-research partnerships

In early 2020, the **Economic and Social Research Council's Centre for Society and Mental Health** launched its vision to develop research which promotes and sustains good mental health in communities, and to assess the impact of rapid social change on mental health, through working in partnership with groups most affected. This work is structured within three interrelated programmes of research, underpinned by platforms exploring new and existing theoretical, methodological and conceptual approaches across multiple disciplines. As an example of this, the “Young People and Social Transitions” and “Marginalised Communities” programmes utilise co-design and coproduction approaches with experts by experience, peer researchers, and community sector partnerships, such as Black Thrive Global and Thrive London, to embed research with schools and their surrounding communities, contextually and collaboratively.

This structure enables the development of a robust set of principles centred on collaborative models for knowledge production. It places emphasis on the practice of inclusion in research and translation of evidence into practice across sectors. This means:

- Facilitating research with and by communities that have been silenced and marginalised (demonstrating the value of experts by experience and peer research models)
- Demonstrating respect for the existing leadership within communities
- Building trust, defining and rethinking power distributions to practice reciprocity
- Building sustainability through committed time and resource.

In other words, researchers' intentions, processes and actions have to be critiqued as rigorously as research questions, ethics and methods.

Diverse models of working are also being explored, including hybrid community/voluntary sector/university joint research, and community engagement posts that challenge notions of everything from essential job role criteria to what constitutes evidence. Key learning points thus far include:

- Ensuring upfront, transparent conversations about fair pay (e.g., beyond university pay grades) and markers of esteem
- Ownership of data and intellectual property
- Resource accessibility
- Crediting work and co-authorship (e.g., reports and publications)
- Maintaining accessible communication and feedback
- Sustaining adequate resource
- Being flexible and responsive to changing needs
- Fostering relationships which are sustained and mutually beneficial.

## **ON TRAC: A partnership between mental health services and faith communities**

The ON TRAC project, funded by the Guy's and St Thomas' Charity, is a collaborative partnership between King's College London, South London and Maudsley NHS Foundation Trust, and Black faith community groups in Southwark and Lambeth (44). The project is underpinned by the need to address mental health disparities in Black communities and to address stigma. It is sensitive to the local context – recognising that the borough of Southwark has the greatest concentration of African Christianity outside Africa and that many Black service users consider a positive relationship with their faith as central to wellness. Many hold parallel religious and moral explanations alongside accepting a medical model (45). Local research has also suggested that there is a desire for social distance from those with mental illness and their families.

The project involves training of Mental Health Champions, nominated members of church congregations who will act to promote mental health awareness and signpost individuals and families to services. This aims to improve mental health literacy and access to support.

The project will also create a register of trained Faith Consultants, who have a leadership role within their community and can offer advice to health professionals seeking to provide culturally informed care. Finally, by designating Faith Community Lead staff within SLaM, there is an acknowledgement of the importance of cultural competency within an NHS organisation. Project leads acknowledge that this cannot be tokenistic, but instead requires long-term commitment to work closely with the community that it serves. In the long term, this partnership aims to promote mental wellbeing, increase access and improve the experience of mental health services for this population.

## **Taraki: Championing intersectional mental health needs**

The voluntary, community, and social enterprise sector is essential to ensuring mental health research is diverse and inclusive. The understanding present in the sector can be seen through the number of culturally appropriate services that are both led by and tailored to support the needs of racialised communities.

Taraki is an organisation working with Punjabi communities to reshape approaches to mental health. Taraki sought to respond more closely to the experiences of Punjabi communities during the Covid-19 pandemic. It wanted to look beyond research that sought to explore the experiences of racialised communities as a whole.

In July 2020 Taraki worked with other community-based organisations to develop a research project which explored mental health in Punjabi communities during Covid-19 (46). This involved data collection through surveys and interviews which were conducted by a team of citizen scientists, all motivated to improve mental health in Punjabi communities. The results of the research showed that Punjabi LGBTQ+ communities, first generation Punjabi migrants and those with comorbidities were sub-groups particularly impacted by lockdown, indicating the importance of an intersectional approach to this topic. The research also found that those interviewed were most likely to seek support through family, friends and faith, and would prefer integrated physical and mental health support.

As a community sector organisation, Taraki was well placed to both communicate results and drive change in communities, using social, local and international media as well as academic conferences and engagement with policy stakeholders. From this research, Taraki has successfully applied for grants which helped to scale mental health and wellbeing support for Punjabi LGBTQ+ communities, and develop a workstream around mental health and faith which has reached hundreds through workshops.

## Mental Health and the Developing Mind: Young people's involvement in a funding panel

**UKRI Adolescent Mental Health and Developing Mind Programme** is a £35 million programme of research funding looking at the different factors that shape the developing adolescent mind, and how they affect lifelong mental health, educational attainment, wellbeing, social relationships, and behaviour. From the outset, there was recognition that young people should play a key role in shaping the funding calls.

In the main funding call to date, a total of 31 young people between 17 and 24 years of age have been involved. UKRI approached a variety of different voluntary and community sector and academic organisations (e.g. National Children's Bureau, the McPin Foundation, YoungMinds, Anna Freud Centre, Institute for Mental Health) as well as investigators from prior awards to advertise for the role across their networks. This approach aimed to attract a diverse group of young people who were also geographically spread.

Care was taken to support the skills, confidence and capacity of the young people collaborating with this work. Documentation was designed to be as accessible as possible and there were in-person opportunities for questions and support, as well as flexibility around when meetings were arranged. Workshops were run which focused on general knowledge and understanding of research, co-facilitated by young people. This covered scientific terminology to ensure understanding of the more complex science in the applications, and explored the criteria that they were asked to assess applications against.

Programme leads reflected that young people provided particularly valuable input in assessing applications in relation to:

- **Inclusion:** whether applicants appropriately considered how to effectively involve young people, including those with lived experience of mental health issues, throughout their project
- **Relevance and importance:** how relevant proposals were to the mental health and developing mind of those between 10-24 years old, and their potential for high impact on the lives of young people.

In relation to the main £24 million research call, young people were involved in:

- Establishing a pre-call advisory group, to shape how young people were engaged.
- Scoring applications and participating in the Experts Panel as full panel members with equal voting rights
- Co-facilitating a compulsory workshop for successful Stage 1 applicants in order to help them strengthen young people's involvement in their proposed research for Stage 2
- Attending Stage 2 interview panels as full panel members with equal voting rights, with all interviews including questions from a young person reviewer.

## Keeping Control: Supporting dignity and respect for service users

'Keeping Control' was a 16 month qualitative study funded by the NIHR School for Social Care Research (47, 48). The research sought to address a gap in knowledge relating to experiences of targeted violence and abuse against people with mental health problems in light of changes to adult safeguarding policy. The topic was identified as particularly appropriate for user led research as it was directly concerned with user experience. The authors said that the aim was 'to enable service users to find the voice and the freedom with which to talk about these profoundly sensitive issues, and enable us to reach practitioners and policymakers with a view to effecting change' (48).

The principal investigator was a service user researcher and the study was coproduced with practitioner academics alongside service user researchers. The work focused on not only producing knowledge but stimulating change. Preliminary findings from the service user interviews were discussed with key stakeholders such as the police, mental health and adult safeguarding practitioners, researchers and policymakers.

Shared aims and values and working to a set of agreed principles supported the coproductive working in the core research team. This meant that collective approaches to decision making, data analysis and interpretation were taken as far as was practicable within a hierarchical university culture. The research was conducted according to ethical principles of user-led research: transparency, respect, flexibility, accessibility, empowerment, a commitment to change, clarity about the underlying theoretical approach, accountability and reward for participants' time and support.

The project found differences between mental health service users' experiences and concepts of risk, and those of practitioners. Histories of trauma, living with fear and stigma as well as mental distress, the effects of 'psychiatric disqualification' and individual blaming added to the distress and often prevented service users seeking help. Fragmented responses from services led to an experience of being 'lost' rather than well supported. Service users reported that they needed mental health and adult safeguarding practitioners to listen and believe them; to be accountable and responsible; to take ownership of the issue; and to help them pursue justice.



## Hearing the Voice: Interdisciplinary research on hearing voices

**Hearing the Voice** is a large interdisciplinary research project funded by the Wellcome Trust and based at Durham University. Since 2012, the project has brought researchers in anthropology, cognitive neuroscience, literary studies, history, linguistics, medical humanities, philosophy, psychology, religious studies and theology together with voice-hearers, clinicians and other experts by experience in order to deepen collective understanding of hearing voices. The project has focused on the experiences of people who hear voices across multiple sites and contexts, past and present, challenging received distinctions between so-called ‘normal’ and ‘pathological’ experience. In addition to its published academic outputs, Hearing the Voice has developed a digital health intervention for use in psychosis services, mounted the world’s first major exhibition on hearing voices, and produced the most **comprehensive website** to support voice-hearers, their allies and mental health professionals.

Enabling 38 core team members from different disciplines to work with over 148 cross-sector collaborators has required a significant investment of care, time and specialist expertise. Barriers to effective interdisciplinary working include the absence of a shared vocabulary, conflicting methodologies, a lack of trust, and divergent views concerning the value and desired outcomes of research. Creative facilitation has been a cornerstone of the programme’s practice and key to tackling these challenges. Fortnightly research meetings led by a Creative Facilitator enabled the core team to exchange ideas, present preliminary findings and identify cross-cutting research questions. Innovative tools and approaches ranging from the design hackathon to arts workshops helped to flatten existing hierarchies, as well as generate new approaches to research. The emphasis on a multiplicity of perspectives worked against the dichotomisation of ‘expert’ clinical/scientific knowledge and ‘lived experience’. This dedicated space for interdisciplinary inquiry and experimentation, not tied to specific outputs or outcomes, was key to achieving the research goals of the project.

Hearing the Voice’s interdisciplinary practices are further elaborated in the “**Working Knowledge**” publications.

## Monitoring the mental health of NHS staff during the pandemic: Rapid cross sector collaboration

At the start of the pandemic, a group of London based researchers and clinicians recognised the importance of monitoring and addressing the mental health of NHS staff and wanted to explore this in three major South London NHS trusts where they worked. This began as “own account” work, but they were able to sustain projects by acquiring small seed funding from King’s College London and University College London, awarded via internal competition. The project team was then able to secure a £30,000 grant from a small charity, the **Rosetrees Trust**, with an interest in medical research. This allowed the team to complete data collection from an initial pilot study in London and obtain preliminary data.

This initial pilot work and data enabled the team to successfully bid for substantial (over £500,000) UKRI Research Council funding (from the Medical Research Council) which facilitated nationwide expansion of the study. The national expansion afforded the project “Urgent Public Health Priority” status from the NIHR, which opened the door to using local resource across a broad geographical area via the Clinical Research Networks supported by NIHR Applied Research Collaborations, NHS England and NHS trusts. At the time of writing, the study now includes 27,000 participating NHS staff across 18 trusts.

The study leads reflected on the importance of leveraging local and charitable funding streams to provide initial ‘proof of concept’ to enable substantial support for projects later on. Larger funders and policymakers were then able to release research and development support on the ground for expansion of projects, working in a complementary manner. The research was developed in incremental steps and recognised that many voluntary and community organisations have limited resources, but which, when harnessed appropriately, can act as a “force multiplier” to unlocking national funding which would not have been accessible at the outset. In this example, the VCS contribution was a key and valuable addition for the project, leveraging a twenty-fold increase in the amount available for the research.

## Shifting the Dial: community action, evaluation and charitable funding

**Up My Street** was a series of community projects working with young Black men in Birmingham to support resilience through the use of creative arts. It was funded by Mind and led by local organisations in the city, including Birmingham Repertory Theatre and First Class Legacy. Up My Street’s evaluation report by Centre for Mental Health, funded by Comic Relief, found that the projects successfully challenged racist stereotypes that affected the young men’s wellbeing – for example, by celebrating Black culture and providing positive adult role models. The evaluation was conducted by peer researchers – young men from the Black community – who produced a video about the project and presented the results in the Houses of Parliament, as well as producing a written report (53).

Following the evaluation, the National Lottery Community Fund encouraged and supported the project’s partners to develop a new, larger-scale project to build on Up My Street’s work and bring about system change. The result, **Shifting the Dial**, seeks to boost young men’s resilience and life chances, including by creating platforms for them to influence how public services such as education, public health and policing in the city affect their wellbeing through their policies and practices. This has already resulted in citywide events focusing on schooling, public health, youth violence and the impact of Covid-19, attended by local leaders and MPs. And it led to the development of a resource for schools (54) and a policy briefing on the experiences of young Black men of the pandemic (55).

## Looking forward – ambitions for the future

In this section we outline suggestions for addressing current inequities to improve mental health research over the next 5-10 years. All of these have been attempted before and there are many successful examples. We advocate an enhanced focus on doing more of what has already worked where appropriate, reflecting on the values inherent in the research and learning from others' experience and skillsets. While we recognise that everyone has a role to play, funders and policymakers may often be best equipped to facilitate these changes.

It is important to acknowledge that there are many unknowns in terms of the most appropriate approaches to address mental health needs, meaning genuine collaborations are important, alongside appropriate ways to evaluate outcomes of these complex approaches. While there may not be one right answer to addressing inequities in mental health research, there may be many better ways of doing research to get there.

**1. Better representation:** Research funders and producers must ensure wider representation of groups and communities that have been silenced or overlooked. This can be achieved through:

- a. Measuring and enhancing ethnic representation in datasets and research funding, and increasing the expectation for high quality work in this area
- b. Enhancing representation of other key dimensions of 'invisibility' in datasets, including gender, sexuality, neurodiversity and digital exclusion
- c. Improving the quality, quantity and value of contribution that service users and those with diverse lived experience can make, from agenda setting, providing peer review, making or influencing decisions on publication, and communicating findings and recommendations.

**2. Equalise opportunities to create, share and use knowledge:** Research funders and producers must invest in widening the range of people and organisations that can get research funding and build their research capacity. This can be achieved through:

- a. Investing in research infrastructure and skills development in academia, statutory services and the voluntary and community sector that allows meaningful two-way engagement with communities and, where possible, coproduced and participatory research
- b. Developing values-based research funding that identifies equity, accountability, trust and partnership as core considerations of good mental health research
- c. Creating opportunities for non-traditional organisations, especially those that are user- or survivor-led, and those bringing alternative and complementary research models, to access research funding
- d. Providing gateway educational opportunities to help people with diverse identities and backgrounds become involved in and, where possible, lead research
- e. Increasing training opportunities to support clinical academics across the whole mental health workforce
- f. Widening the target audiences for research communication activities outside academic journals and conferences: to engage with people, communities, policymakers and practitioners to create 'on the ground' change.

**3. Developing research in key areas:** Research funders and policymakers must ensure resources are targeted towards key areas that will help to build the evidence base for tackling mental health inequalities. These include:

- a. Early years, children and young people
- b. Prevention and promotion
- c. Using complex systems approaches to improve population mental health.

**4. Integrating different types of knowledge:**

Research funders and producers must find ways to bring together different types of knowledge in the production of evidence to inform policy and practice. This can be achieved through:

- a. A cross-sector programme of work to develop a best practice framework for policymakers and practitioners which addresses the value of different forms of mental health evidence
- b. Investing in collaborative and joint datasets that engage with social determinants of mental health alongside other factors, and which include data from varied sources
- c. Piloting a new funding model to build a more integrated approach to research which values a wider range of evidence and research. This could be tested within one topic area to identify what works, what hinders progress, and what helps to overcome any barriers.



## Glossary of terms

### Positivism

A philosophical system or perspective which recognises only knowledge which comes from things that can be experienced with the senses or proved by logic/mathematics, and therefore can reject other ways of knowing including metaphysics and spirituality.

### Colonialism

Colonialism is the control or governing influence of a nation over a dependent country, territory, or people. In relation to the UK context, this relates to the ongoing impacts of the British Empire and includes migration and the history of oppression, subjugation and slavery of people from colonised countries in particular from Asia, Africa and the Caribbean. It is also closely linked with ideas around race and power.

### Race and racism

Race itself is a socially constructed criteria that contributes to social positioning, life chances and experiences, and health status of individuals; with associated prejudice and discrimination when some races are seen as superior to the 'othered' groups (50). It is closely linked with being of an ethnic minority and also with religious or other beliefs.

Racism can be interpersonal. It can take more subtle forms such as internalised beliefs of being lesser or shameful. It can also be structural – linked to structural disadvantages which include poverty, unemployment, housing, poor neighbourhoods and schooling opportunities being experienced to a greater extent by ethnic minorities through historical, political and cultural landscapes and legacies of colonial rule that shape the opportunities and position of these groups (51) (52). Institutional racism can occur when services may fail to provide appropriate and professional services to people because of their colour, culture or ethnic origin (50).

### Inequality

A situation in which money, health or opportunities are not shared equally or are unevenly distributed between different groups in society.

### Inequity

Inequity refers to unfair or unjust and differences, which are avoidable. Often these arise from poor governance, corruption, unconscious bias, prejudice or cultural exclusion.

### Syndemic

A syndemic or synergistic epidemic is the aggregation of two or more concurrent or sequential epidemics or disease (or risk factor) clusters in a population with interactions which exacerbate the prognosis and burden of disease: for example, domestic violence, substance misuse and mental health problems.

### Complex systems

In a complex system, the system itself has properties that are more than just the sum of its parts. Examples of complex systems include ant-hills, human economies, climate, human beings. Complex systems science takes into account the interactive properties of these parts of the systems, sensitivity to external changes (openness to environment outside the system), feedback loops within a system, and the existence of stable states or properties which can be disrupted to cause major changes. In relation to mental health research, complex system methods and approaches look at the interaction and combined properties of different determinants of mental health in a system.

## References

1. Marmot M, Allen J, Goldblatt P, Herd E, Morrison J. Build back fairer: The COVID-19 Marmot Review. The pandemic, socioeconomic and health inequalities in England. London: Institute of Health Equity; 2020.
2. Fancourt D, Steptoe A, Bu F. Trajectories of anxiety and depressive symptoms during enforced isolation due to COVID-19 in England: a longitudinal observational study. *The Lancet Psychiatry*. 2021;8(2):141-9.
3. Pierce M, Hope H, Ford T, Hatch S, Hotopf M, John A, *et al*. Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. *The Lancet Psychiatry*. 2020;7(10):883-92.
4. Pierce M, McManus S, Hope H, Hotopf M, Ford T, Hatch S, *et al*. Different Mental Health Responses to the COVID-19 Pandemic: Latent Class Trajectory Analysis Using Longitudinal UK Data. Available at SSRN 3784647. 2021.
5. International Alliance of Mental Health Research Funders. The inequities of Mental Health Research Funding. November 23rd 2020.
6. Demkowicz O, Panayiotou M, Parsons S, Feltham A, Arseneault L, Ingram B, *et al*. Looking Back to Move Forward: Reflections on the Strengths and Challenges of the COVID-19 UK Mental Health Research Response. *Frontiers in Psychiatry*. 2021;12(391). Available from: <https://www.frontiersin.org/article/10.3389/fpsy.2021.622562>.
7. Lin Y-H, Chen C-Y, Wu S-I. Efficiency and quality of data collection among public mental health surveys conducted during the COVID-19 pandemic: Systematic review. *Journal of Medical Internet Research*. 2021;23(2):e25118.
8. Wykes T, Bell A, Carr S, Coldham T, Gilbody S, Hotopf M, *et al*. Shared goals for mental health research: What, why and when for the 2020s. *Journal of Mental Health*. 2021:1-9.
9. Holmes EA, O'Connor RC, Perry VH, Tracey I, Wessely S, Arseneault L, *et al*. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *The Lancet Psychiatry*. 2020.
10. O'Connor RC, Hotopf M, Worthman CM, Perry VH, Tracey I, Wessely S, *et al*. Multidisciplinary research priorities for the COVID-19 pandemic – Authors' reply. *The Lancet Psychiatry*. 2020;7(7):e44-e5. Available from: <https://www.sciencedirect.com/science/article/pii/S2215036620302479>.
11. Wykes T, Haro JM, Belli SR, Obradors-Tarragó C, Arango C, Ayuso-Mateos JL, *et al*. Mental health research priorities for Europe. *The Lancet Psychiatry*. 2015;2(11):1036-42.
12. Woelbert E, Lundell-Smith K, White R, Kemmer D. Accounting for mental health research funding: developing a quantitative baseline of global investments. *The Lancet Psychiatry*. 2020.
13. MQ Mental Health Research. UK Mental Health Research Funding 2014-2017. 2019.
14. Agorastos A, Pervanidou P, Chrousos GP, Baker DG. Developmental trajectories of early life stress and trauma: a narrative review on neurobiological aspects beyond stress system dysregulation. *Frontiers in psychiatry*. 2019;10:118.
15. Katikireddi SV, Lal S, Carrol ED, Niedzwiedz CL, Khunti K, Dundas R, *et al*. Unequal impact of the COVID-19 crisis on minority ethnic groups: a framework for understanding and addressing inequalities. *J Epidemiol Community Health*. 2021.
16. Nazroo JY, Bhui KS, Rhodes J. Where next for understanding race/ethnic inequalities in severe mental illness? Structural, interpersonal and institutional racism. *Sociology of health & illness*. 2020;42(2):262-76.

17. Baskin C, Zijlstra G, McGrath M, Lee C, Duncan F, Oliver E, *et al.* Community interventions improving mental health in minority ethnic adults in the UK: a scoping review. *European Journal of Public Health.* 2020;30(Supplement\_5):ckaa166. 1046.
18. Plöderl M, Tremblay P. Mental health of sexual minorities. A systematic review. *International review of psychiatry.* 2015;27(5):367-85.
19. Fancourt D, Steptoe A, Bu F. Trajectories of depression and anxiety during enforced isolation due to COVID-19: longitudinal analyses of 59,318 adults in the UK with and without diagnosed mental illness. *medRxiv.* 2020.
20. Yang H, Chen W, Hu Y, Chen Y, Zeng Y, Sun Y, *et al.* Pre-pandemic psychiatric disorders and risk of COVID-19: a UK Biobank cohort analysis. *The Lancet Healthy Longevity.* 2020;1(2):e69-e79.
21. Rains LS, Johnson S, Barnett P, Steare T, Needle JJ, Carr S, *et al.* Early impacts of the COVID-19 pandemic on mental health care and on people with mental health conditions: framework synthesis of international experiences and responses. *Social psychiatry and psychiatric epidemiology.* 2021;56(1):13-24.
22. San Juan NV, Shah P, Schlieff M, Appleton R, Nyikavaranda P, Birken M, *et al.* Service user experiences and views regarding telemental health during the COVID-19 pandemic: a co-produced framework analysis. *medRxiv.* 2021.
23. Public Health England. Covid-19 Mental Health and Wellbeing Surveillance Report. 2021. Available from: <https://www.gov.uk/government/publications/covid-19-mental-health-and-wellbeing-surveillance-report>.
24. UK Trauma Council. Beyond the pandemic: Strategic priorities for responding to childhood trauma. 2020.
25. Zaninotto P, Di Gessa C, Steel N. The experience of older people with multimorbidity during the COVID-19 pandemic 2020.
26. McKinlay AR, Fancourt D, Burton A. It makes you realise your own mortality: A qualitative study on mental health of older adults in the UK during COVID-19. *medRxiv.* 2020.
27. Whitley E, Reeve K, Benzeval M. Tracking the mental health of home-carers during the first COVID-19 national lockdown: evidence from a nationally representative UK survey. *medRxiv.* 2021.
28. Mak HW, Bu F, Fancourt D. Mental health and wellbeing amongst people with informal caring responsibilities across different time points during the COVID-19 pandemic: A population-based propensity score matching analysis. *medRxiv.* 2021.
29. Lund C, Stansfeld S, De Silva M. Social determinants of mental health. *Global mental health: principles and practice:* Oxford University Press, Oxford; 2014. p. 116-36.
30. International Union for Health Promotion and Education. Critical Actions for Mental Health Promotion 2021.
31. Stansfield J, Bell R. Applying a psychosocial pathways model to improving mental health and reducing health inequalities: practical approaches. *International Journal of Social Psychiatry.* 2019;65(2):107-13.
32. Beresford P, Nettle M, Perring R. Towards a social model of madness and distress. Exploring what service users say. York: Joseph Rowntree Foundation. 2010:27-41.
33. Crawford MJ, Robotham D, Thana L, Patterson S, Weaver T, Barber R, *et al.* Selecting outcome measures in mental health: the views of service users. *Journal of Mental Health.* 2011;20(4):336-46.
34. Anna Freud Centre. The evidence-base for psychoanalytic and psychodynamic psychotherapy with children and adolescents, an update and narrative synthesis. 2020.
35. Ronaldson A, Chandakas E, Kang Q, Brennan K, Akande A, Ebyarimpa I, *et al.* Cohort profile: The East London Health and Care Partnership Data Repository: using novel integrated data to support commissioning and research. *BMJ open.* 2020;10(9):e037183.

36. Chicago Beyond. Why am I always being researched? A guidebook for community organizations, researchers, and funders to help us get from insufficient understanding to more authentic truth. 2019.
37. Terry L, Cardwell V. Refreshing perspectives: Exploring the application of peer research with populations facing severe and multiple disadvantage. London: Revolving Doors Agency & Lankelly Chase. 2016.
38. Wahab S. Creating knowledge collaboratively with female sex workers: Insights from a qualitative, feminist, and participatory study. *Qualitative Inquiry*. 2003;9(4):625-42.
39. Abrams R, Park S, Wong G, Rastogi J, Boylan AM, Tierney S, *et al*. Lost in reviews: Looking for the involvement of stakeholders, patients, public and other non-researcher contributors in realist reviews. *Research Synthesis Methods*. 2020.
40. Rutter H, Savona N, Glonti K, Bibby J, Cummins S, Finegood DT, *et al*. The need for a complex systems model of evidence for public health. *The Lancet*. 2017;390(10112):2602-4.
41. Nutley SM, Powell AE, Davies HTO. What counts as good evidence. 2013.
42. Sibley M. Inadmissible evidence: the double standard in evidence-based practice, and how it harms patients. *Patient Experience Library*; 2020.
43. Petticrew M, Roberts H. Evidence, hierarchies, and typologies: horses for courses. *Journal of Epidemiology & Community Health*. 2003;57(7):527-9.
44. Codjoe L, Barber S, Thornicroft G. Tackling inequalities: a partnership between mental health services and black faith communities. Taylor & Francis; 2019.
45. Codjoe L, Byrne M, Lister M, McGuire P, Valmaggia L. Exploring perceptions of "wellness" in black ethnic minority individuals at risk of developing psychosis. *Behavioural and cognitive psychotherapy*. 2013;41(2):144.
46. Taraki Wellbeing. COVID-19 + Punjabi communities. 2020.
47. Carr S, Faulkner A, Hafford-Letchfield T, Megele C, Gould D, Khisa C, *et al*. Keeping Control: Exploring Mental Health Service User Perspectives on Targeted Violence and Hostility in the Context of Adult Safeguarding. 2019.
48. Faulkner A, Carr S, Gould D, Khisa C, Hafford-Letchfield T, Cohen R, *et al*. 'Dignity and respect': An example of service user leadership and co-production in mental health research. *Health Expectations*. 2019.
49. Carr S, Hafford-Letchfield T, Faulkner A, Megele C, Gould D, Khisa C, *et al*. "Keeping Control": A user-led exploratory study of mental health service user experiences of targeted violence and abuse in the context of adult safeguarding in England. *Health & social care in the community*. 2019;27(5):e781-e92.
50. Synergi Collaborative. The impact of racism on mental health. 2018. Available from: <https://synergicollaborativecentre.co.uk/wp-content/uploads/2017/11/The-impact-of-racism-on-mental-health-briefing-paper-1.pdf>.
51. Lassale C, Gaye B, Hamer M, Gale CR, Batty GD. Ethnic disparities in hospitalisation for COVID-19 in England: The role of socioeconomic factors, mental health, and inflammatory and pro-inflammatory factors in a community-based cohort study. *Brain, Behavior, and Immunity*. 2020;88:44-9. Available from: <https://www.sciencedirect.com/science/article/pii/S0889159120311016>.
52. Nazroo JY. The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism. *American journal of public health*. 2003;93(2):277-84.
53. Khan, L., Saini, G., Augustine, A., Palmer, K., Johnson, M. and Donald, R. (2017) Against the odds: Evaluation of the Mind Birmingham Up My Street programme. London: Centre for Mental Health
54. Harris, A. and Whittle, R. (2019) This is me: A handy guide for schools to help young black men thrive. London: Centre for Mental Health
55. Abdinasir, K. and Carty, S. (2021) Young Black men's mental health during Covid-19: Experiences from the Shifting the Dial project. London: Centre for Mental Health
56. Muir Gray JM. Evidence Based healthcare. London: Churchill Livingstone, 1996.





## Fit for purpose?

Published July 2021

Photograph: SDI productions, iStock

Centre for Mental Health is an independent charity and relies on donations to carry out further life-changing research. Support our work here: [www.centreformentalhealth.org.uk](http://www.centreformentalhealth.org.uk)

© Centre for Mental Health, 2021  
Recipients (journals excepted) are free to copy or use the material from this paper, provided that the source is appropriately acknowledged.



Centre for  
Mental Health



Centre for Mental Health

Office 2D21, South Bank Technopark,

90 London Road, London SE1 6LN

Tel 020 3927 2924

[www.centreformentalhealth.org.uk](http://www.centreformentalhealth.org.uk)

Follow us on social media: @CentreforMH

Charity registration no. 1091156. A company limited by guarantee registered in England and Wales no. 4373019.