# Progress and priorities for mental health sciences research since COVID-19

Summary report of a joint Academy of Medical Sciences/MQ virtual workshop on 23 April 2021





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MQ is the UK's leading mental health research charity. We are transforming lives through research, helping to create a future where mental illnesses are understood, effectively treated, and one day prevented.

Our scientists investigate a huge range of issues: depression, anxiety, schizophrenia, bipolar disorder, eating disorders and more. We are bringing together everything from cutting-edge neuroscience to social studies to find the answers we need.

Our approach is international, interdisciplinary and collaborative. By connecting a community of supporters with a world-class network of experts, we are bringing real change to the millions of people affected by mental illness.

Opinions expressed in this report do not necessarily represent the views of all participants at the event, MQ Mental Health Research, the Academy of Medical Sciences, or its Fellows. All web references were accessed in May 2021.

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## Executive summary

The COVID-19 pandemic has had a major and diverse set of impacts on the mental health of people living in the UK and globally. These impacts have arisen through a number of routes, both direct and indirect. Although primarily a respiratory condition, COVID-19 can also affect the brain, triggering or exacerbating a wide range of neurological and neuropsychiatric disorders.

SARS-CoV-2 infection has direct effects on mental health, via the direct effects of the virus or the body's response to it. In addition, COVID-19 has also had indirect effects on people's mental health. Many people have experienced high levels of stress related to the pandemic, the risks to themselves, and its impact on others. Public health and social measures put in place to control infection, particularly lockdowns, have created an additional set of stressors, including social isolation and financial concerns. It has also become increasingly clear that both the direct and indirect impacts of COVID-19 are not uniform across the population, with demographic factors and pre-existing mental illness both predispositions to greater adverse impacts.

As well as its immediate effects, the pandemic is likely to have long-term impacts that will affect the mental health of many. Surveys suggest that more than a million people in the UK are experiencing post-acute COVID-19 syndromes, commonly known as 'long COVID', including mental health difficulties.<sup>1</sup> In addition, the stress and disruption experienced over the course of the pandemic may have long-term consequences for many, while socioeconomic impacts could trigger changes in life circumstances that adversely affect mental health.

However, the pandemic has affected different groups of people in markedly different ways. For some, mental health has improved over its course. For many others, however, their mental health has deteriorated, existing mental health problems have been exacerbated, or new ones have emerged. Typically, it is the most vulnerable groups that have experienced the worst mental health impacts.

In 2020, at the beginning of the UK COVID-19 epidemic, the Academy of Medical Sciences and MQ convened a multidisciplinary group of experts, including people with lived experience, to define a set of mental health sciences research priorities.<sup>2,3</sup> At the same time the UK mental health sciences research community rapidly pivoted to refocus on COVID-19. This response was marked by extensive collaboration across disciplinary boundaries, with neurologists, clinical psychologists, psychiatrists, scientists and others working together to identify the full range of impacts of COVID-19 on the brain, cognition and mental health.

As the UK response to the pandemic moves from an emergency phase to a more considered long-term response, strategic research priorities must be revisited. In April 2021, representatives from multiple disciplines, as well as people with lived experience, came together at a workshop organised by the Academy of Medical Sciences and MQ to discuss progress in mental health sciences research to date and future research priorities.

Meeting participants identified a range of key priorities for future research:

**A holistic approach to unpicking mechanisms**: Participants noted the critical importance of an integrated 'mind-body-brain' view of mental health. Multiple mechanisms and pathways – biological, psychological and social – all impact on mental health and need to be considered

holistically in order to fully understand the key drivers of mental health problems and how they act together to increase the risk of mental health conditions. This is the case for both the direct and indirect effects of COVID-19.

This mechanistic perspective also needs to incorporate the interplay between COVID-19-related physical and mental health problems. Identifying factors associated with resilience could suggest ways to protect mental health. More work is needed to identify the core features and mechanisms underlying long COVID, including its cognitive and mental health dimensions.

**Focusing on solutions**: To date, much attention has focused on describing the extent of mental health problems related to the pandemic. Although quantification and characterisation remain important, participants agreed that it was now important to focus on solutions. Specifically, there is a need to develop and evaluate interventions to improve mental health, particularly low-cost and scalable interventions; the potential for additional digital interventions was also highlighted. The importance of involving people with lived experience in intervention development was also emphasised.

**Focusing on vulnerable populations**: A greater focus is needed on vulnerable populations, including young people, older people, the financially insecure, people with pre-existing mental health conditions, members of ethnic minority communities, and frontline workers, among others. For ethnic minority populations, the need to take a more granular view was emphasised, to take account of marked differences in the experience of different ethnic communities and across generations.

**Mobilising data**: The need to focus on mental health trajectories over time was stressed, as single point 'snapshots' may be of limited value. The importance of sample diversity was also emphasised, to ensure that ethnic minorities and other vulnerable groups are fully represented. Other important priorities included addressing governance issues that restrict timely analysis of data, exploring innovative data linkage, and promoting open science practices.

**Involving people with lived experience**: The mental health sciences research community has a strong track record of working with people with lived experience of mental health difficulties. It was suggested that this engagement needed to be maintained and strengthened through all stages of the research process, including research prioritisation and the co-design and co-production of interventions.

**Strengthening interdisciplinary collaboration**: Participants agreed that the collaborative cross-disciplinary approach established in 2020 should be maintained and built upon, for example with greater engagement with social researchers, mental health practitioners and other healthcare staff, and with other stakeholders such as people with lived experience and policymakers.<sup>4</sup> The UK's mental health research goals can provide a framework for orienting the work of researchers across different disciplines around common objectives.<sup>5</sup>

**Embedding COVID-19-related responses within a broader mental health context**: It was noted that the mental health impacts of COVID-19 are not experienced in isolation. Its consequences are heavily dependent on wider social determinants of health. COVID-19 may provide an opportunity to focus more attention on the mental health impacts of social determinants of health.

As the response to the COVID-19 pandemic shifts from an 'emergency' to a 'chronic' phase, it will be important to map out future directions for mental health sciences research. COVID-19 has not disappeared and will remain a public health priority for the foreseeable future. Reported incidence of 'long COVID' illustrates that the impact of COVID-19 will be felt in the longer term, while the socioeconomic consequences of the pandemic could have significant implications for health. Participants emphasised that increasing attention should therefore be given to the aftermath of initial waves of infection, and the mental health consequences of COVID-19 will need to be considered equally to physical health impacts.

The initial response to COVID-19 was characterised by extensive cross-disciplinary collaboration. The workshop revealed a strong appetite to maintain this integrated approach, with full involvement of people with lived experience, to address the longer-term consequences of the COVID-19 pandemic, and to ensure a greater degree of preparedness for future health emergencies.

### References

<sup>1</sup> Office for National Statistics (2021). *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 April 2021.* 

<u>https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddi</u> <u>seases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1</u> <u>april2021</u>

<sup>2</sup> The term 'mental health sciences' covers the many different disciplines, including psychology, psychiatry, clinical medicine, behavioural and social sciences, and neuroscience, that will need to work together and with people with lived experience of mental health issues or COVID-19 to address research priorities.

<sup>3</sup> Holmes EA, et al. (2020). Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. Lancet Psychiatry **7(6)**, 547-560.

<sup>4</sup> Holmes EA, et al. (2020). Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. Lancet Psychiatry **7(6)**, 547-560.

<sup>5</sup> Whitty C (n.d.). *Mental Health Research Goals.* The Academy of Medical Sciences <u>https://acmedsci.ac.uk/policy/uk-policy/mental-health/mental-health-research-goals</u>.

## Introduction

In February 2020, the World Health Organization designated COVID-19 a Public Health Emergency of International Concern. Since then, the global research community has responded at unparalleled speed and with unprecedented levels of coordination to address this novel threat to health.

Although the primary focus was on respiratory illness, it rapidly became clear that COVID-19 had the potential to affect health in other ways – including impacts on mental health. These impacts could be direct, for example, following SARS-CoV-2 infection of brain tissue, the infiltration of inflammatory mediators into the brain, or cerebrovascular events. They could also be indirect, reflecting high levels of stress related to impact of the illness on self or others, the consequences of the public health and social measures used to contain the virus, delayed help seeking, or economic harms linked to the pandemic and measures put in place to control it.

The potential for serious adverse effects on mental health was rapidly recognised by the UK mental health sciences research community. A publication coordinated by the Academy of Medical Sciences and MQ in *The Lancet Psychiatry* early in the pandemic raised awareness of these issues and identified a set of multidisciplinary research priorities to address them.<sup>1</sup>

In April 2021, the Academy of Medical Sciences and MQ jointly convened a virtual workshop to take stock of progress in mental health sciences research since the start of the COVID-19 pandemic, to discuss longer-term research priorities and to consider how the mental health sciences community could move forward collaboratively to address them. Furthermore, as the pandemic moves from an 'emergency' to a 'chronic' phase, there is a need to take a longerterm perspective to consider the consequences of the initial phase of the pandemic in 2020 and the longer-term neurological, psychological, and social consequences of the pandemic for mental health.

The workshop, chaired by **Professor Ed Bullmore FMedSci** (Professor of Psychiatry and Deputy Head, School of Clinical Medicine, University of Cambridge) and **Professor Emily Holmes** (Professor of Psychology, Uppsala University, Sweden), included presentations from funders, members of the mental health sciences research community, and people with lived experience. At the meeting, **Alison Tingle** (Senior Research Liaison Manager, Department of Health and Social Care) summarised the response of the National Institute for Health Research (NIHR), while **Dr Joanna Latimer** (Head of Neurosciences and Mental Health Board, Medical Research Council, MRC) described the initiatives launched by the MRC. **Professor Tamsin Ford CBE FMedSci** (Professor of Child and Adolescent Psychiatry, University of Cambridge) discussed impacts on children and young people, and **Professor Ann John** (Professor in Public Health and Psychiatry, Swansea University) focused on the experience of ethnic minorities. **Dr Ben Michael** (Senior Clinician Scientist Fellow and Honorary Consultant Neurologist, University of Liverpool) summarised ongoing and planned work on neurological and neuropsychiatric impacts, including the CNS-COVID study<sup>6</sup>. **Professor Chris Whitty CB FMedSci**, Chief Medical Office for England, provided his reflections on the mental health sciences challenges and response since the beginning of the pandemic, highlighting a range of additional priority areas for action, and responded to questions from participants.

Three people with lived experience – **Sanisha Wynter**, **Francesca Lo Castro** and **Bo Rutter** – provided powerful first-person testimonies describing for example the impact of the pandemic on mental health conditions, the impact of long COVID on mental health, the challenges experienced in accessing support services, and their involvement in projects such as those to support other young people.

In breakout sessions, participants addressed two key questions:

- What are the gaps for mental health and brain sciences research?
- How can the mental health sciences community work together at pace to address the identified gaps?

The content of the speaker presentations and breakout group discussions are summarised in this report. Opinions expressed in this report do not necessarily represent the views of all participants at the event, MQ, the Academy of Medical Sciences, or its Fellows.

### References

<sup>6</sup> University of Liverpool (n.d.). *COVID-19 Clinical Neuroscience Study (COVID-CNS)* <u>https://www.liverpool.ac.uk/neurosciences-research-unit/research/covid-cns-study/</u>

# Immediate response to the COVID-19 emergency

UK-based health research funding agencies responded rapidly to the COVID-19 pandemic. At the meeting, NIHR and MRC provided an overview of their funding strategies to respond to the COVID-19 emergency and investigate the impact of the COVID-19 pandemic on mental health.

The NIHR response builds on prior activity, including the Framework for Mental Health Research, published by the Department for Health and Social Care in 2017 and the subsequent mental health research goals.<sup>7</sup> Joint funding calls were launched with UK Research and Innovation (UKRI) in February 2021, including a £24.6m rapid call and a joint rapid rolling call which included a mental health-specific highlight notice.<sup>8</sup> Joint calls have also been launched focusing on long COVID.<sup>9,10</sup>

Consortia funded include PHOSP-COVID examining post-hospitalisation patient health and recovery, and CNS-COVID, focused on impacts related to mental health and neurology.<sup>11,12</sup> The PHOSP-COVID study is a nationwide collaboration spanning 24 academic institutions and 40 NHS trusts. The CNS-COVID consortium brings together partners with a range of expertise, including neurology, infectious disease, immunology, genetics, and cognition and neuropsychiatry. Extending the work of the CoroNerve initiative, which published the UK's first data on neurological and neuropsychiatric impacts of COVID-19, CNS-COVID will fully characterise the clinical spectrum of neurological and neuropsychiatric disease, identify risk factors for brain-related complications, and provide new insights into mechanisms of disease.<sup>13</sup>

NIHR-programme specific activities included an initiative by the Policy Research Programme to support research to inform policy responses to COVID-19 (Recovery, Renewal, Reset call).<sup>14</sup> In addition, the Health Technology Assessment (HTA), Health Services and Delivery Research (HS&DR) and Evidence Synthesis Programmes launched a Recovery and Learning call to support longer-term research to generate evidence to inform health system recovery.

Urgent public health studies have focused on issues such as domestic abuse, patients with multiple long-term conditions, impacts on NHS staff, and long-term effects post-hospitalisation. Six studies have been funded following the mental health-specific highlight notice, with a particular focus on vulnerable groups such as young people, people with existing mental health issues, and frontline workers. At the same time, wherever possible, work has continued on existing mental health projects.

As outlined in its 2019 Delivery Plan, mental health is also a strategic priority for the MRC <sup>15</sup>. As well as its joint initiatives with the NIHR, COVID-19 is also being addressed through the Adolescence, Mental Health and the Developing Mind Programme (a partnership with the Economic and Social Research Council (ESRC) and the Arts and Humanities Research Council (AHRC)), while MRC Institutes, Centres and Units have undertaken COVID-19-related mental

health research; COVID-19-related studies have also been integrated into work on existing cohorts.

Over the longer term, COVID-19-related studies will be funded through existing MRC mechanisms, and efforts will be made to disseminate the results of research carried out to date. Awards are due to be made in the summer of 2021 through the Adolescence, Mental Health and the Developing Mind Programme.<sup>16</sup> A mental health data hub has been funded and will be expanded, and a wider platform to facilitate mental health research activities is being developed. In addition, the MRC is also working to ensure that mental health is embedded within other priority areas, promoting interdisciplinary research in areas such as neuroimmunology and multimorbidity.

The mental health sciences research community has been similarly agile and responsive, reorienting research to address COVID-19-related priorities. Notably this has been characterised by high levels of interdisciplinarity. The CoroNerve consortium, for example, which published some of the first data on mental health impacts, has been based on unprecedented collaboration between neurologists, psychiatrists and researchers from other disciplines across the UK.<sup>17</sup>

People with lived experience have also made important contributions to COVID-19-related research, informing the development of research priorities and the design of research projects. They have also developed resources to help people with lived experience make sense of their experience and to support other people going through a similar experience. One such example is Planet DIVOC-91, a nine-part webcomic, which follows the journey of two young people transported from a disaster-stricken Earth to a new home on Planet DIVOC-91.<sup>18</sup>

### References

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<sup>8</sup> National Institute for Health Research (2020). *Highlight notice – COVID-19 and mental health*. <u>https://www.nihr.ac.uk/documents/highlight-notice-covid-19-and-mental-health/24978</u>

<sup>9</sup> National Institute for Health Research (2020). *New £20m call for research into physical and mental effects of 'long COVID'*. <u>https://www.nihr.ac.uk/news/new-20m-call-for-research-into-physical-and-mental-effects-of-long-covid/26163</u>

<sup>10</sup> National Institute for Health Research (2021). *NIHR launches second £20m Long COVID funding call*. <u>https://www.nihr.ac.uk/news/nihr-launches-second-20-million-long-covid-funding-call/27331</u>

<sup>11</sup> University of Liverpool (n.d.). *COVID-19 Clinical Neuroscience Study (COVID-CNS)* <u>https://www.liverpool.ac.uk/neurosciences-research-unit/research/covid-cns-study/</u>

<sup>12</sup> PHOSP-COVID (n.d.). *The post-hospitalisation COVID-19 study (PHOSP-COVID)*. <u>https://www.phosp.org</u>

<sup>13</sup> Varatharaj A, et al. (2020). Neurological and neuropsychiatric complications of COVID-19 in 153 patients: a UK-wide surveillance study. Lancet Psychiatry **7(10)**, 875-882.

<sup>14</sup> National Institute for Health Research (2021). *Policy Research Programme COVID-19 research*. <u>https://www.nihr.ac.uk/documents/policy-research-programme-covid-19-</u> <u>research/24757</u>

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<sup>16</sup> UK Research and Innovation (n.d.). *Adolescence, Mental Health and the Developing Mind.* <u>https://mrc.ukri.org/research/initiatives/adolescence-mental-health-and-the-developing-mind/</u>

<sup>17</sup> Varatharaj A *et al.* (2020). *Neurological and neuropsychiatric complications of COVID-19 in 153 patients: a UK-wide surveillance study.* Lancet Psychiatry **7(10)**, 875-882.

<sup>18</sup> Planet DIVOC-19, (n.d.). <u>https://planetdivoc91.com</u>

## The current state of play

Before considering future priorities and next steps, meeting participants were asked to discuss the current state of play and what has already been learnt about the impact of the pandemic on mental health.

#### **Direct impacts**

COVID-19 has had significant mental health impacts, through a multitude of pathways. Infection with SARS-CoV-2 is associated with a wide range of neurological and neuropsychiatric complications, particularly depression and anxiety. A study of US electronic health records found that one in three patients received a new neurological or psychiatric diagnosis within 6 months of SARS-CoV-2 infection.<sup>19</sup>

Early data from the PHOSP-COVID study found that 5 months after discharge, only 29% of patients felt fully recovered, 20% had a new disability and 19% had been forced to change jobs.<sup>20</sup> A quarter of patients experienced symptoms of anxiety and depression, 12% post-traumatic stress disorder (PTSD) and 17% cognitive impairment.

#### **Indirect impacts**

There is also evidence that many people who have not been infected with SARS-CoV-2 have also experienced poorer mental health. At the meeting, participants discussed how this may be related to may be related to concerns about the possible consequences of catching COVID-19, having family members affected, or being exposed to more stressful situations as a frontline worker. Public health and social measures have helped to control the spread of SARS-CoV-2 but have also had many detrimental impacts, restricting human contact and socialising. The economic fallout from COVID-19 has contributed to increased levels of stress for many. Future socioeconomic prospects remain uncertain, as emergency central government support begins to unwind, while the future trajectory of the pandemic is unclear.

Previous research has found that economic downturns can be followed in the longer term by increased rates of death by suicide.<sup>21</sup> While there is little evidence that suicide increased during the first year of the pandemic, this requires monitoring over the long-term.

Many **panel surveys** were rapidly undertaken to capture mental health impacts. Although these provided some useful insights into short-term fluctuations in mental health, they were typically based on convenience samples, and hence often did not provide meaningful data on commonly under-represented groups. They also tended to provide a single 'snapshot', with relatively few studies examining mental health trajectories over time or taking into account baseline mental states. Since September 2020, Public Health England has maintained a regularly updated report on mental health and wellbeing during the pandemic, drawing on a wide range of indicator data and the results of published studies.<sup>22</sup>

An analysis of data from the UK Household Longitudinal Study, a large, long running and nationally representative study, identified five distinct **mental health trajectories** during the first six months of the pandemic. Two groups showed consistently good or very good mental health. A 'recovering' group (12%) experienced poor mental health initially but had recovered by October 2020. A further group (4.1%) experienced initial marked deterioration and did not recover, while the final group (7%) experienced a slow decline in mental health.<sup>23</sup> In all, one in nine people experienced consistently bad or deteriorating mental health, with those with pre-existing mental or physical health problems, the socioeconomically disadvantaged and ethnic minorities being particularly at risk.

#### Children and young people

Very few data are available on mental health impacts in **young people**, particularly those under 16 years of age. In addition, data governance practices can be a significant obstacle to research.<sup>24</sup> In the UK, the most recent benchmarking data are from the 2017 National Survey for Children. Official national statistics on the mental health of young people were published in July 2020 but, at the time of the meeting, had not yet been analysed further.

Follow up of respondents to the 2017 National Survey found an increase in mental health difficulties among children aged 4–16 – of concern given the significant decline in mental health between 2004 and 2017 surveys.<sup>25</sup> Half had delayed seeking help for mental health problems, consistent with other evidence that help-seeking dropped during the first wave of the pandemic and then rebounded late in 2020. The highest prevalence of probable mental health problems was in young women (27%).

There is a strong association between parent and child mental health. It is of concern that parents with young children were most likely to struggle early in lockdown, and with increasing numbers of families in financial distress, the potential for longer-term impacts on the mental health of young people is considerable. High levels of reported loneliness and sleep disruption in young people during lockdown are also of concern.

#### **Vulnerable groups**

Other **vulnerable groups** include younger adults in marginal employment, who often have low skills and few economic opportunities. Although obesity is a known risk factor for poor COVID-19 outcomes, it is an area where communication with patients and the public can be highly challenging. One possible unintended consequence is the risk of exacerbating mental health issues among people who are overweight and those with eating disorders. Although the true eating disorder disease burden is hard to determine in young people, the number of referrals to specialist care increased dramatically in 2020.<sup>26</sup>

**Older people** have borne the brunt of COVID-19 mortality. As large numbers have been shielding, many have also been badly affected by social isolation, loneliness and by the fear of COVID-19. As restrictions lift, participants noted that there will be a need to reintegrate older people into positive social environments and enable them to re-establish supportive and protective social networks.

**Ethnic minorities** have been badly affected by COVID-19, in terms of mortality rates.<sup>27</sup> Effects on mental health are more difficult to determine, however, as data are incomplete, and have mostly been drawn from existing sources that may not be representative. Moreover, a wide range of intersecting factors influence the risk of COVID-19 infection and poor mental health, including pre-existing socioeconomic and health disparities.

Data from the COVID-19 Social Study, which has collected data on more than 70,000 people, show that black and minority ethnic groups have experienced consistently poorer mental health than people of white ethnicity over the past year.<sup>28,29</sup> However, reported COVID-19-related stress does not differ between black and minority ethnic groups and people of white ethnicity, suggesting that much of the excess mental health burden may have other underlying causes.

Furthermore, combining data on different ethnic communities into a single category does not provide a sufficiently nuanced view of how people of different ages, cultures, immigration status and so forth are affected by COVID-19. The term 'BAME' (black and minority ethnic) was introduced to provide a collective voice for under-represented communities, but for this kind of research, disaggregated data are needed to disentangle very different life experiences.<sup>30</sup> It was suggested that a race equality impact assessment could be incorporated into draft research proposals, and researchers could be encouraged to report on how their findings might affect people from different ethnic backgrounds.

#### Long COVID

In March 2021, surveys suggested that more than 1 million people in the UK were reporting ongoing symptoms after COVID-19 infections.<sup>31</sup> Although the term has been widely adopted, having been developed by the patient community, it is likely to cover a wide range of conditions.<sup>32</sup> Fatigue and neurocognitive abnormalities ('brain fog') are among the most commonly reported symptoms, but a wide range of other symptoms are experienced, including chills/sweats, appetite loss, dizziness, insomnia and seizures.<sup>33</sup> Although long COVID may particularly affect those who have experienced serious COVID-19 disease, a number of people report relatively mild acute disease with either persistent or worsening symptoms.

Long COVID has been shown to disproportionately affect vulnerable groups, being more common in women, those with pre-existing health conditions and those in the lowest socioeconomic groups. People living with long COVID may also face scepticism, sometimes even from health professionals, and service provision remains limited.<sup>34</sup>

#### Looking beyond negative impacts

There are important lessons to learn about the drivers of good mental health and factors associated with **resilience**. While many people experienced worsening mental health during 2020, three-quarters of people maintained good or very good mental health and 12% recovered relatively rapidly.<sup>15</sup>

Participants noted that COVID-19 also has ushered in some changes that have been beneficial, for example in the area of virtual service provision, which is preferred by some (but not all) service users. The pandemic has also led to the dramatic acceleration of some

research, as well as the forging of new collaborations. New research platforms have been established and regulatory processes have been adapted to accelerate the development of interventions. There are opportunities to learn lessons from these changes and to consider which might be embedded in research or clinical practice going forwards.

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<sup>21</sup> Matsubayashi T, Sekijima K & Ueda M (2020). *Government spending, recession, and suicide: evidence from Japan.* BMC Public Health **20**, 243

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<sup>26</sup> Solmi F, Downs JL, Nicholls DE (2021). *COVID-19 and eating disorders in young people*. Lancet Child and Adolescent Health. **5(5)**, 316-318.

<sup>27</sup> Office for National Statistics (2021). Updating ethnic contrasts in deaths involving the coronavirus (COVID-19), England: 24 January 2020 to 31 March 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/ar ticles/updatingethniccontrastsindeathsinvolvingthecoronaviruscovid19englandandwales/24jan uary2020to31march2021

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<sup>34</sup> Rubin R (2020). *As Their Numbers Grow, COVID-19* "*Long Haulers" Stump Experts.* JAMA **324(14),** 1381-1383. <u>https://jamanetwork.com/journals/jama/fullarticle/2771111</u>

# Future research priorities and next steps

In the UK, an emergency response to COVID-19 is beginning to give way to more sustainable longer-term planning, as vaccination rollout proceeds at pace and public health and social measures are eased. However, the course of the pandemic remains uncertain, particularly given the continuing evolution of variants of concern. In addition, the long-term effects of past infection and the socioeconomic impact of the pandemic have yet to play out in full. It is therefore important to map out longer-term research priorities for mental health sciences research, taking into account what has been learned since the beginning of the pandemic.

In breakout sessions, participants identified the following priorities for mental health sciences research:

#### A holistic approach to unpicking mechanisms

COVID-19 has illustrated how mental health is influenced by a multitude of factors – biological, psychological and social – and by interactions between these factors.<sup>35</sup> Participants agreed that there is a need to take an integrated view to better understand the diverse range of drivers of COVID-19-related mental health difficulties, their interactions, and the pathways through which they act.

For the link between COVID-19 and mental health, contributory pathways are wide ranging and encompass direct and indirect effects, including impacts on the brain due to inflammatory responses to viral infection, co-existing physical ailments, pre-existing mental health problems, psychological predispositions, social isolation during lockdowns, social and economic disadvantage, and many others. A deeper understanding of risk factors and underlying mechanisms will point the way to potential interventions and help to identify who would benefit most from which intervention.

In particular, participants indicated that **long COVID** needs to be disentangled and further defined. Currently, it comprises a heterogeneous set of symptoms affecting multiple organ systems, including the brain. Some cases might reflect well-characterised neurological conditions for which treatments are available. For other cases, there are opportunities to learn from research into other post-viral syndromes, including their mental health impacts.

Long COVID also illustrates the need for **greater integration of physical and mental health research** (and treatment), as physical and mental symptoms rarely exist in isolation from one another, and the two can have reciprocal effects on each other. As well as reaffirming the importance of parity of esteem between mental and physical health, participants also highlighted the importance of not devaluing mental health symptoms when physical causes cannot be immediately identified. It was also pointed out that not all members of vulnerable groups experience mental health difficulties, following infection or in response to other aspects of the pandemic. It will be important to explore mechanisms of **resilience**, again in an integrated way that considers mechanisms and pathways at all levels, from the biological to the psychological and social.

#### **Focusing on solutions**

Much of the research efforts since the beginning of pandemic have been devoted to quantifying and characterising mental health problems. While such work remains important, participants felt that there was a need to focus on solutions and development of interventions to change mental health trajectories.

It is clear that mental health services in the UK are already stretched. Participants indicated that there is a need to explore the potential for **practical**, **scalable interventions**, including digital interventions. It was suggested that, wherever possible, research should be embedded in clinical practice, although it was acknowledged that limited service capacity would make this challenging. The potential to use health services research and implementation research to explore innovations in care delivery and rollout of new practices was also highlighted.

The importance of better **integrating mental health and physical health services** was emphasised, which will require research on integrated models of care.

The critical importance of **prevention** was also highlighted. A deeper understanding of risk factors and mechanisms of **resilience** will help to suggest interventions to maintain good mental health in response to adversity.

## Focusing on vulnerable populations, particularly ethnic minorities

Certain groups have been particularly badly affected by COVID-19. COVID-19 has markedly different impacts across age groups, ethnic groups and gender. Groups felt to warrant specific consideration included those with mental health problems pre-pandemic, those in marginal employment or in financially precarious situations, young people, women (especially those with young children), older people, and frontline workers.

It was suggested that a more granular view of **ethnicity** was required, to take account of heterogeneity in the experiences of non-white populations, and of people in the same ethnic group (such as first- and second-generation individuals). Participants therefore stressed the need for more nuanced and granular data collection, including the recording of protected characteristics.

Participants also emphasised the need to improve the representation of minority ethnic groups in research studies. For surveys, one possible approach is deliberate over-sampling of such populations. For example, this could be incorporated into the 2022 Adult Psychiatric Morbidity Survey. More in-depth engagement with minority ethnic groups may also be required, including work with translators, peer researchers and community groups to build relationships and trust and encourage participation.

#### **Mobilising data**

Questions were raised about the quality, utility and representativeness of some of the data gathered in the initial phases of the pandemic. Panel surveys and convenience samples provided rapid results but often of limited value.<sup>36</sup> In particular, cross-sectional surveys provided limited insight into individual trajectories and the impact of past mental health states or existing vulnerabilities. In addition, it was suggested that they lacked the depth and representativeness to capture insights from some of the most vulnerable groups, including those from specific ethnic minorities.

Participants identified a range of measures to address this question. **Cohort studies** are often suggested as a useful approach, but they are typically expensive to set up and labour-intensive to run; it was suggested that other options should be considered unless questions can only be addressed through cohorts. Other suggested ways forward included improving the representativeness of existing cohorts or surveys (for example through over-sampling), including large population cohorts, and better recording of protected characteristics. Use of routine data was mentioned repeatedly as high priority.

Many data already exist that are relevant to COVID-19 and mental health but are often not easy to access or link. Efforts need to be made to make best possible use of these data, while preserving patient privacy.<sup>37</sup> There is a need to ensure that **data governance** does not create unnecessary barriers to research, and further efforts are needed to address existing barriers.<sup>16</sup> Streamlined processes were seen to be essential to ensure the timeliness of data analyses. Strong engagement with patients and the public will continue to be essential to ensure public trust in data access mechanisms.

Innovative **data linkage** provides opportunities to explore associations between physical and mental health and a wide range of social and other factors. Participants suggested that adoption of **open science practices**, including data sharing, was important to ensure the credibility of research and to facilitate secondary and meta-analyses.

#### Involving people with lived experience

The mental health sciences research community has a strong track record of working with people with lived experience of mental health problems. This has included involvement in all stages of the research process, including identification of research priorities, design of studies, the conduct of research and dissemination of findings.

Delegates commented that the need for rapid responses during the pandemic period may have led to reduced input from people with lived experience, and there was a need to reaffirm its importance and strengthen mechanisms of engagement. As the focus begins to shift to the development of interventions, participants suggested that there was an opportunity for **codesign and co-production** of solutions with people with lived experience.

Another area identified as a priority was **public communication** of research activities. It was suggested that funders and researchers could do more to make their work and findings more accessible to other audiences, particularly through digital platforms. Again, partnerships with

people with lived experience could help to identify information needs and appropriate channels and mechanisms of communication.

#### Strengthening interdisciplinary collaboration

Researchers from many academic disciplines have contributed to work on the mental health impacts of COVID-19, including psychiatrists, neurologists, clinical psychologists, social scientists, intensivists, epidemiologists, data scientists, laboratory scientists and others.<sup>38</sup> This high degree of collaboration was felt to have been a critical aspect of the response to COVID-19, reflecting the intimate association between neurological and psychiatric complications of COVID-19 infection, as well as the wider links between mental health and a multitude of biological, psychological and social factors.

It was felt to be vital that such collaborations should be maintained and extended, for example to include more mental health practitioners and nursing staff. Although researchers from different academic backgrounds tend to view issues in a different way, combining these perspectives can provide a more integrated and holistic view of mental health. Opportunities for interdisciplinary dialogue were highlighted as particularly valuable. In addition, shared strategic frameworks such as **mental health research goals** can orient researchers around priority questions and needs, whatever their specific interests, and promote more integrated research.<sup>3</sup>

Participants suggested that links could be strengthened with **social researchers** to ensure a strong representation of social as well as medical risk factors, and to support qualitative as well as quantitative exploration of impacts. Links could also be strengthened with other groups, including **people with lived experience and policymakers**.

The distribution of **research funding** was also discussed. Participants agreed that mental health sciences research remains underfunded given the associated burden of disease.<sup>39</sup> In addition, it was noted that the compressed timetables associated with emergency funding mechanisms had disadvantaged certain groups of researchers, such as those with caring responsibilities.<sup>40</sup> Participants urged funders to consider such issues and equity in funding in future planning.

#### **Embedding COVID-19-related responses within a broader mental health context**

It was noted that the impacts of COVID-19 on mental health should be seen within the wider mental health context. COVID-19 has shone a light on deep-seated structural inequities, with the burden of disease falling heaviest on the most vulnerable populations. In terms of mental health impacts, the stressors created either by SARS-CoV-2 infection or its sequelae, or by social countermeasures have added to and exacerbated those that already existed.

This suggests that solutions focused solely on COVID-19 may not necessarily be the most effective way to address the factors that have greatest impact on mental health. Participants suggested that it may be possible to leverage COVID-19 and the spotlight it has shone on mental health to focus greater attention on the wider social determinants of poor mental health.

## References

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<sup>36</sup> Demkowicz O, et al. (2021). Looking Back to Move Forward: Reflections on the Strengths and Challenges of the COVID-19 UK Mental Health Research Response. Frontiers in Psychiatry **12**, 622562.

<sup>37</sup> The Goldacre Review. <u>https://www.goldacrereview.org</u>

<sup>38</sup> Holmes EA, et al. (2020). Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. Lancet Psychiatry **7(6)**, 547-560.

<sup>39</sup> MQ Mental Health (2015). *Mental health research: how much does the UK spend*? 7 April. <u>https://www.mqmentalhealth.org/mental-health-research-how-much-does-the-uk-spend/</u>

<sup>40</sup> Viglione G (2020). *Are women publishing less during the pandemic? Here's what the data say.* Nature **581**, 365-366.

## Conclusion

COVID-19 has presented an unprecedented challenge to healthcare, medical sciences and society. People all over the UK have been affected by some combination of infection and its sequelae, the psychological impact of a global pandemic, and the impact of public health and social measures introduced to control it. As well as the direct mortality associated with COVID-19, UK society has experienced significant short- and long-term impacts on mental health.

Developing effective solutions to mental ill-health was identified as a critical priority during the next phase of the response to COVID-19 and for its long-term aftermath. During the emergency phase, there was a need for rapid data, which was not always of the highest quality. Going forwards, it is imperative that the highest quality research methods are employed, with particular attention given to issues such as lived experience, prior mental health history, and representative and disaggregated sampling, to provide robust, relevant and comprehensive data.

COVID-19 has exacerbated existing health inequalities, having greatest impact on the most disadvantaged. Participants highlighted the need to tackle health inequalities directly, particularly those affecting ethnic minorities, and emphasised how this should be central to the next phase of the mental health sciences research response to COVID-19.

COVID-19 has impacted on mental health in multiple ways. Biological pathways include the effect of inflammation on the brain as well as cerebrovascular events linked to COVID-19induced vascular abnormalities. Key psychological aspects include fear of infection or transmission, bereavement and stressors associated with the exacerbation of previous mental health problems, as well as the impact of pandemic circumstances in creating new disabilities. Social influences include social isolation, caring burden and financial insecurity. From a patient-centred perspective, mental health problems emerge from the complex interplay of these factors – none is experienced in isolation.

Metal health sciences researchers have taken important steps to work together to understand the impacts of COVID-19 on the brain and mental health, with neurologists, clinical psychologists, psychiatrists and others taking an integrated approach to understanding its cognitive and mental health impacts. As the COVID-19 pandemic moves into a new phase, there are opportunities to maintain and extend this spirit of collaboration, for research focusing on those that have had COVID-19 and the rest of the UK population. Workshop participants expressed considerable enthusiasm to continue close collaboration.

Participants agreed that adopting an integrated 'mind-brain-body' and 'bio-psycho-social' approach will require some shifts in current structures and systems but promises to generate a more complete understanding of the mental health consequences of the pandemic and suggest more effective ways to protect mental health and treat mental health difficulties in the longer term. Application of this approach will be dependent on close engagement with people with lived experience and a focus on the most vulnerable populations. The lessons learned from COVID-19 have the potential to focus more attention on safeguarding mental health, and to ensure the UK is better prepared to manage the mental health consequences of future health emergencies.

# Annex 1: Participant List

**Professor Kathryn Abel**, Professor of Psychological Medicine, University of Manchester Professor Louise Arseneault FMedSci, Professor of Developmental Psychology, King's College London, and Mental Health Leadership Fellow, UKRI Economic and Social **Research Council** 

Ms Charlotte Augst, CEO, National Voices

**Mr Noah Carey**, Person with lived experience

Professor Clive Ballard FMedSci, Pro-Vice Chancellor and Executive Dean, University of Exeter

Dr Niall Boyce, Editor-in-Chief, The Lancet Psychiatry

Professor Gerome Breen, Professor of Psychiatric Genetics, King's College London Professor Ed Bullmore FMedSci (co-Chair), Head of Department of Psychiatry, University of Cambridge

**Professor Felicity Callard**, Professor in Human Geography, University of Glasgow Professor Patrick Chinnery FMedSci, Clinical Director, Medical Research Council Professor Cathy Creswell, Professor of Developmental Clinical Psychology, University of Oxford

Dr Jayati Das-Munshi, Senior Lecturer in Social Epidemiology, King's College London **Mr James Downs**, Person with lived experience

Professor Tamsin Ford CBE FMedSci, Professor of Child and Adolescent Psychiatry, University of Cambridge

Mr Conor Giblin, Person with lived experience

Professor Paul Harrison, Professor of Psychiatry, University of Oxford

Dr Colette Hirsch, Reader in Cognitive Clinical Psychology, King's College London Professor Emily Holmes (co-Chair), Professor of Psychology, University of Uppsala Ms Asha Igbal, Person with lived experience

Professor Ann John, Professor in Public Health and Psychiatry, Swansea University Medical School

Dr Gail Johnston, Programme Manager, Health and Social Care Northern Ireland Professor Edgar Jones, Professor in the History of Medicine and Psychiatry, King's College London

Dr Thomas Kabir, Head of Public Involvement, McPin Foundation

Ms Sara Kenney, Director, Wowbagger Productions

Ms Fatema Khabotli, Person with lived experience

Ms Kate King MBE, Adviser on lived experience

**Dr Alex Kwong**, Research Fellow at the Division of Psychiatry, University of Edinburgh Dr Joanna Latimer, Head of Neurosciences and Mental Health Board, Medical Research Council

Mr Nathaniel Lawford, Person with lived experience

Professor Anne Lingford-Hughes, Professor of Addiction Biology, Imperial College London

Ms Francesca Lo Castro, Person with lived experience

Ms Whitney Love, Person with lived experience

Dr Georgina MacKenzie, Portfolio Manager, Neuroscience and Mental Health Wellcome Trust

Professor Paul Matthews OBE FMedSci, Head of the Department of Brain Sciences, Imperial College London

Dr Joan Marsh, Deputy Editor, The Lancet Psychiatry

Mrs Joanne Metcalfe, Royal Foundation

Professor Andrew McIntosh, Professor of Psychiatry, University of Edinburgh Ms Sally McManus, Senior Health Lecturer, City, University of London

Dr Alan McNair, Senior Research Manager, NHS Scotland

**Dr Ben Michael**, Senior Clinician Scientist Fellow and Honorary Consultant Neurologist, University of Liverpool

**Professor Susan Michie FMedSci**, Professor of Heath Psychology and Director of Centre for Behaviour Change, University College London

**Professor Michelle Moulds**, School of Psychology, University of New South Wales **Dr Tamsin Newlove-Delgado**, Senior Clinical Lecturer and Honorary Consultant in Public Health, University of Exeter

Dr Helen Munn, Trustee, MQ

**Professor Rory O'Connor**, Professor of Health Psychology, University of Glasgow **Dr Praveetha Patalay**, Associate Professor, UCL Institute of Education

**Professor Hugh Perry FMedSci**, UK Dementia Research Institute Honorary Consultant & Theme Lead (Neuroinflammation), University College London

**Dr Matthias Pierce**, Research Fellow in Psychology and Mental Health, University of Manchester

**Dr Inês Pote**, Research Advisor for Mental Health Priority Area, Wellcome Trust **Professor Andrew Przybylski**, Director of Research of the Oxford Internet Institute, University of Oxford

Ms Bo Rutter, Person with lived experience

Ms Anita Shervington, Founder, BLAST Fest

Ms Frances Simpson, Person with lived experience

Mrs Nikki Smith, Person with lived experience

Dr Victoria Swann, Programme Manager for Adolescent Mental Health, MRC

**Ms Alison Tingle**, Senior Research Liaison Manager, Department of Health and Social Care

**Professor Rachel Upthegrove**, Professor of Psychiatry and Youth Mental Health, University of Birmingham

**Dr Ursula Wells**, Head of Research Liaison - Health Protection, Mental Health, DHSC **Professor Sir Simon Wessely FMedSci**, Professor of Psychological Medicine, King's College London

**Dr Pauline Whelan**, Co-Director, CAMHS Digital and Digital Lead, Greater Manchester Mental Health & Centre for Women's Mental Health, University of Manchester

**Professor Chris Whitty CB FMedSci**, Chief Medical Officer for England **Dr Louise Wood**, Director of Science, Research and Evidence, NIHR

**Professor Dame Til Wykes DBE FMedSci**, Professor of Clinical Psychology and Rehabilitation, King's College London

Ms Sanisha Wynter, Person with lived experience

**Professor Lucy Yardley**, Professor of Health Psychology, University of Southampton and University of Bristol

#### Secretariat

Dr Claire Cope, Head of Policy, Academy of Medical Sciences Alice Fletcher-Etherington, Policy Intern, Academy of Medical Sciences Dr Anna Hands, Policy Officer, Academy of Medical Sciences Ian Jones (event science writer), Director, Jinja Publishing Ltd Lea Milligan, Chief Executive, MQ George Phillips, Policy Officer, Academy of Medical Sciences

**Gaby Richter**, Communications Officer, Academy of Medical Sciences **Holly Rogers**, Acting Head of Communications, Academy of Medical Sciences **Sarah Shenow**, Head of Research, MQ

Dr James Squires, Policy Manager, Academy of Medical Sciences

Samuel Usher, Policy Intern, Academy of Medical Sciences

Angel Yiangou, Policy Manager, Academy of Medical Sciences

# Annex 2: Workshop Agenda

08.55 - 09.00	Participants join meeting
09.00 - 09.10	Welcome and introduction
	Professor Ed Bullmore FMedSci, Professor of Psychiatry, University of
	Cambridge and Professor Emily Holmes, Professor of Psychology, Uppsala
	University Session 1: What have we learnt about mental health sciences
	since the COVID-19 pandemic began?
09.10 - 10.10	Perspectives from the mental health sciences research community
	A series of presentations from researchers across the mental health
	sciences research community outlining what has been learnt so far about
	the impact of the COVID-19 pandemic on different groups. Funders will
	also provide an outline of their top-level mental health sciences funding allocations and future funding strategies.
	Scheduled speakers:
	<ul> <li>Ms Alison Tingle, Senior Research Liaison Manager, Department of</li> </ul>
	Health and Social Care
	<ul> <li>Dr Joanna Latimer, Head of Neurosciences and Mental Health</li> </ul>
	Board, Medical Research Council
	<ul> <li>Professor Tamsin Ford CBE FMedSci, Professor of Child and Adelessont Development University of Combridge</li> </ul>
	<ul> <li>Adolescent Psychiatry, University of Cambridge</li> <li>Professor Ann John, Professor in Public Health and Psychiatry,</li> </ul>
	Swansea University Medical School
	Dr Ben Michael, Senior Clinician Scientist Fellow and Honorary
	Consultant Neurologist, University of Liverpool
	<ul> <li>Professor Chris Whitty CB FMedSci, Chief Medical Officer for</li> </ul>
	England and UK Government's Chief Medical Adviser
	Chair: Professor Ed Bullmore FMedSci, Professor of Psychiatry, University
	of Cambridge
10.10 - 10.30	Q&A and discussion
	An opportunity for participants to reflect on the presentations and share
	thoughts on the progress in our understanding of mental health sciences
	research since the pandemic.
	Chair: Professor Ed Bullmore FMedSci, Professor of Psychiatry, University
	of Cambridge
10.30 - 10.35	Break
	Session 2: The future of mental health sciences research
10.35 - 10.50	Perspectives from experts by experience
	A panel of 5-minute presentations from people with lived experience,
	outlining their experiences throughout the COVID-19 pandemic and the
	impact on their mental health.
	<ul> <li>Scheduled speakers:</li> <li>Ms Sanisha Wynter</li> </ul>
	<ul> <li>Ms Francesca Lo Castro</li> </ul>
	Ms Bo Rutter
	Chair: Professor Emily Holmes, Professor of Psychology, Uppsala
10 50 11 20	University Proclaut cossion
10.50 - 11.30	Breakout session Participants will be split into breakout groups and invited to discuss the
	following questions:

	<ol> <li>What have we learnt about mental health sciences since the COVID-19 pandemic began?</li> <li>What are the gaps for mental health and brain sciences research?</li> <li>How can the mental health sciences community work together to address the identified gaps at pace?</li> </ol>
11.30 - 11.50	Reporting back and plenary discussionBreakout group rapporteurs will be invited to share key points from theirgroup's discussions. This will be followed by a plenary discussion with allattendees.Chair: Professor Emily Holmes, Professor of Psychology, UppsalaUniversity
11.50 - 12.00	Summary of key points raised and next steps Chair: Professor Emily Holmes, Professor of Psychology, Uppsala University
12.00	Close of meeting



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