Coordinating the collection of high-quality data on the mental, cognitive and neurological health impacts of COVID-19

Report of a virtual workshop on 5 May 2020

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Opinions expressed in this report do not necessarily represent the views of all participants at the workshop, the Academy of Medical Sciences or its Fellows, or MQ.

All web references were accessed in May 2020.

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Executive summary

The COVID-19 pandemic is having a profound effect on society, and potential long-term impacts on the mental health and brain function of some of those infected. Understanding the mental, cognitive and neurological health impacts of COVID-19 must therefore be a high priority in the UK response to tackle the COVID-19 pandemic.

A recent position paper, published in *The Lancet Psychiatry* by an expert group convened by the Academy of Medical Sciences and MQ, highlighted an urgent need to tackle the harmful impacts of the COVID-19 pandemic on mental health and potentially brain function. [1] It called for research on these areas to be central to the global response to the pandemic.

As part of the follow-up to this work, on Tuesday 5 May 2020, the Academy and MQ co-hosted the first of two workshops to facilitate the implementation of the recommendations of the position paper. This workshop convened experts in mental, cognitive and neurological health to explore collaborative, consortium-based approaches to consolidate and refine an existing research proposal to collect high-quality data on the neurological, cognitive or neuropsychiatric impacts of COVID-19 in the UK. It was chaired by Professor Hugh Perry FMedSci, UK Dementia Research Institute, University College London. Attendees ranged from basic through to clinical researchers.

Participants felt the following key considerations were important for a successful consortium proposal:
- Clear articulation of the database scope and how it will link with other consortia and datasets.
- Refined short-term and long-term project deliverables, drawing clear distinctions between these. An example of a short-term deliverable discussed was improving patient care in the acute phase of the infection, and a long-term example was carrying out faster and more cost-effective clinical trials of possible treatments and interventions.
- Adequate representation of relevant expertise in the consortium membership and clearly defined roles for each group.
- Cohort recruitment which will facilitate detailed follow-up, and mitigation of risks including the potentially slow recruitment of acute-stage patients.
- A strong and transparent patient and public involvement (PPI) component which considered the views of patients and those with lived experience.
- Strong geographical representation in the consortium membership to ensure a truly national proposal using harmonised measures.

References

[1] https://www.thelancet.com/pdfs/journals/lanpsy/PIIS2215-0366(20)30168-1.pdf

Following the workshop, the application was refined and strengthened. In light of these refinements, this consortium-based approach could be an effective response to the call set out in the position paper for a coordinated approach to address the immediate priority of collecting high-quality data on brain function, cognition and mental health across a broad population and importantly in patients with COVID-19.

Introduction

The COVID-19 pandemic is having a profound effect on the mental, cognitive and neurological health of the UK population. In March/April 2020, the Academy and MQ convened a multi-disciplinary expert group to define the mental health research priorities for the COVID-19 pandemic, which were published on 15 April 2020 in The Lancet Psychiatry.[1] The paper called for a coordinated approach to ensure that these priorities are most effectively addressed, and highlighted the urgent need to collect high-quality longitudinal data on the mental health effects of the COVID-19 pandemic across the whole population, and on brain function, cognition and mental health of patients with COVID-19.

The paper called for more widespread mental health monitoring of the UK population in response to the pandemic, and for better ways to protect against, and treat, mental ill health – both of which will require new funding and better coordination. Funding calls for COVID-19 research are highly-competitive, and there is an appetite from funders for high-impact, collaborative proposals that are coordinated across the mental health sciences sector. As such, this workshop, chaired by Professor Hugh Perry FMedSci, UK Dementia Research Institute, University College London, brought together leading mental health and neuroscience experts from across the UK to explore a consortium approach to collecting high-quality longitudinal mental, cognitive and neurological health data.

This workshop focussed on an existing consortium proposal led by Professor Gerome Breen, Professor of Psychiatric Genetics, King's College London and Dr Ben Michael, Senior Clinician Scientist Fellow and Honorary Consultant Neurologist, University of Liverpool. The primary objective of this proposal is to enrich the NIHR BioResource platform with the recruitment, and detailed and repeated neurological, psychiatric, cognitive and immunological assessment, of 1,700 severe, hospitalised COVID-19 cases and 300 frequency matched controls. Discussion of this proposal revealed a number of general themes and considerations which could be relevant to other prospective consortia of this nature.

Participants included both consortium members and non-members, and ranged from basic to clinical researchers. These discussions took place in the context of open calls for funding for 12-18 month projects focussing on urgent COVID-19 and public health research priorities from a range of Government funders.

 The workshop aimed to:

1. Address and refine key issues with the development of the bid to ensure it is nationally representative and well received by funders.
2. Take stock of existing relevant activities and proposals across the research community, and explore how these can be incorporated or aligned so that initiatives are complementary and coordinated.
3. Consider any additional research activities on the mental health and neurological impacts of COVID-19 that will be needed to complement the database or inform its design.

Opinions expressed in this report do not necessarily represent the views of all participants at the workshop, the Academy of Medical Sciences or its Fellows, or MQ.

Summary of discussions

Section 1 – Project characteristics

Project scope and representation of expertise
Participants identified the need to bring together different disciplines including psychiatry, neurology, neuropsychology, intensive care, infectious diseases, genomics, epidemiology and immunology among others. It was felt that this multidisciplinary approach across the UK would be required to best examine the various neurological and psychiatric complications arising from SARS-COV-2 infection, and to explore underlying biological mechanisms. It was also recognised that input from this range of disciplines would be important to build a large-scale, nationally representative, deeply phenotyped cohort.

The range of disciplines involved was identified as a particular strength of the proposal. Participants felt that a clear illustration of the full spectrum of disciplines involved would be important to the proposal's success.

Machine learning and neurological rehabilitation were identified as important additional components, particularly in the later stages of the project. Participants also highlighted the importance of pure data scientists in managing the large quantity and variety of data, working towards multimodal predictive models for outcomes.

Participants particularly valued the proposal to investigate various aspects of patient clinical status, from the psychological and mental health factors to the underlying neurological pathways. The urgency of capturing data in the earliest possible stage of the epidemic was emphasised, and it was considered important to ensure opportunities to involve other disciplines at this early stage are not lost.

It was suggested that convening a neurocognitive interest group, after the workshop, may be useful to feed in to the proposal by exploring methods for the collection of data across a range of cognitive domains. This was thought to be important given the current lack of knowledge about the potential cognitive health complications in recovery, and to ensure that the data sets will be of maximum utility to researchers.

When considering the consortium in an international context, participants felt that this proposal represented something truly unique in breadth and scope.

Linkage with others datasets and initiatives
A prevalent theme in discussions was the importance of integrating any new consortia with existing relevant initiatives and activities. Importantly, this proposal effectively builds on existing national infrastructure, including the NIHR Bioresource. It was felt that a successful proposal make it clear which datasets and services it will link with, such as addiction services and social services, which may be relevant to patient outcomes.

Participants felt that due to the pace of change in the epidemic, and the rapid developments in the various fields of study involved, a successful proposal should be explicit about taking an active approach to engaging with new consortia as they emerge.

Patient and public involvement
It was agreed by participants that incorporation of the views of patients and those with lived

experience would be essential for ensuring the maximum impact on patient care and outcomes. The need to involve patients in the design and development of the proposal, processes, questionnaires, and consent and information forms associated with the project was emphasised.

Participants emphasised the importance of clearly outlining and evidencing how PPI has shaped this proposal, including at different local sites.

Cohort recruitment
There was consensus among participants that a proposal must mitigate the risks of slow recruitment of acute-stage patients, due to the possibility that admission rates continue to fall as the rates of infection decline. A proposal should be flexible enough to mitigate this risk, ensuring numbers of patients and the parameters for their recruitment can be revised without compromising the strength of the database, and potentially recruiting from other sites.

Participants emphasised the need to design the trial to allow detailed patient follow-up, in order to meet the project deliverables.

Geographical spread
Participants acknowledged the importance of a wide national distribution of groups in the consortia membership to ensure the bid is truly national in nature. Participants discussed the geographical spread of groups involved and identified gaps which could be filled by those present at the workshop. A new site was added to the consortium as a result of the discussions.

Identifying potential confounding factors
The importance of identifying any potential confounding factors was stressed. For example, the indirect effects of the pandemic on mental health, such as an increase in the incidence of post-traumatic stress disorder, must be distinguished from the direct effects of infection.

Section 2 – Project deliverables

Participants felt that in the context of the current COVID-19 funding landscape, it is essential for a consortium proposal to clearly outline what will be achieved in the initial 12 month period, and define what can be achieved in the longer term if the proposal lays the foundations for further high impact research.

The short-term 12 month deliverables discussed in the context of this project included the stratification of patients to inform patient management strategies; establishing a re-contactable cohort for follow on studies of potential novel treatments and interventions; identifying at risk groups and associated markers; and determining the relationship between mental health complications and factors such as infection, immune response, genetics, psychology and environment. It was felt that impacting patient care in the short timeframe would be possible due to the harmonised measurement and assessment of patients across multiple sites, which would allow the identification of COVID-19 patients who may be at increased risk of neurological impacts.

In the longer term, this cohort and database could be used as a platform to enable faster and cheaper clinical trials of interventions and treatments, and for data scientists to produce predictive models for health outcomes. For the database to have predictive power it will be important to know how the disease first presents in given patients, and their subsequent long term outcomes. Opportunities to make biological material collected through this study available for further research should also be explored.

It was acknowledged that understanding the long-term psychological and social outcomes of the pandemic would not be possible within the initial 12 month funding period. A key question will be to better understand whether COVID-19 patients experience a transient increase in mental health problems, or whether a subset of patients will experience persistent problems following infection.

Conclusions and next steps

The workshop was successful in bringing together experts from across a wide range of disciplines, including those within and outside the existing consortium, to consider key features of a consortium approach and to identify clear recommendations to strengthen the proposal before submission. Prevailing themes of discussion included clearly articulating the project scope; adopting a multidisciplinary approach; ensuring timely patient recruitment; incorporating patient and public views; achieving national coverage in recruitment; and linking effectively with other relevant consortia and research projects. The workshop helped to clearly articulate and differentiate the potential short- and long-term deliverables of the proposal. There was a feeling that this consortium would be nationally and internationally unique in providing an opportunity to investigate the neurological, cognitive and neuropsychiatric impacts of COVID-19 in the immediate and longer term, and that this workshop was valuable in coordinating with and involving other research groups. A new potential site was added to the consortium as a result of the workshop. A further impact of the meeting was the formation of a multi-institution neuropsychology special interest group, to support development of the proposal by ensuring the assessment of a sufficiently broad range of cognitive domains. This group has met several times since the workshop to develop and refine a neuropsychological test protocol comprising both initial baseline screening for cognitive impairment, and a follow-up protocol for the assessment of longer-term outcomes whilst ensuring data linkage to the NIHR Bioresource.

Following the refinement of the proposal and incorporation of the elements discussed at the workshop, the Academy feels this consortium-based approach responds well to the call set out in the position paper published in *The Lancet Psychiatry*.[1] It takes a coordinated approach to address the immediate priority of collecting high-quality data on brain function, cognition and mental health across a broad population and importantly in patients with COVID-19.

Annex 1: Programme

13.55 – 14.00	**Participants join meeting**
14.00 – 14.10	**Welcome and introduction** *Chair: Professor Hugh Perry FMedSci, UK Dementia Research Institute, University College London*
14.10 – 14.20	**Introduction to the King's College London-led consortium proposal** *Project lead: Professor Gerome Breen, Professor of Psychiatric Genetics, King's College London*
14.20 – 14.30	**Q&A** An opportunity for participants to ask questions about the development of the proposal
14.30 – 15.00	**Discussion of proposal** *Chair: Professor Hugh Perry FMedSci* This session will focus on feeding in to the development of the bid to ensure it is well received by funders. Issues to discuss/refine include: • Have any disciplines been omitted? • Are any patient cohorts missing? • How can the proposal be truly national? • What can be achieved in a 12-18 month timeframe, and beyond?
15.00 – 15.20	**Aligning proposal with other activities** *Chair: Professor Hugh Perry FMedSci* This session will provide an opportunity for participants to highlight current relevant activities and proposals with a view to: • Incorporating or coordinating with other current activities where appropriate • Ensuring future activity is coordinated and compatible
15.20 – 15.30	**Summary of key points raised and next steps** *Chair: Professor Hugh Perry FMedSci*
15.30	**Close of meeting**

Annex 2: Attendee List

Professor Hugh Perry FMedSci (Chair), UK DRI, UCL UKDRI

Professor John Aggleton FMedSci, Professor of Cognitive Neuroscience, Cardiff University

Professor Cherie Armour*, Professor of Psychological Trauma and Mental Health, Queen's University Belfast

Dr Neil Basu*, Clinical Senior Lecturer in Rheumatology/Honorary Consultant, University of Glasgow

Professor Gerome Breen*, Professor of Psychiatric Genetics, King's College London

Professor Ed Bullmore FMedSci*, Professor of Psychiatry, University of Cambridge

Professor Jonathan Cavanagh*, Professor of Psychiatry, University of Glasgow

Professor Patrick Chinnery FMedSci*, Programme Leader, Medical Research Council Mitochondrial Biology Unit

Dr Jonathan Coleman*, Lecturer in Statistical Genetics, King's College London

Professor Anthony David*, Professor of Mental Health Director & Sackler Chair, University College London Institute of Mental Health

Dr Alexandru Dregan*, Senior Lecturer in Psychiatric Epidemiology, King's College London

Professor Neil Harrison*, Clinical Professor in Neuroimaging, Cardiff University

Professor Emily Holmes, Professor in Clinical Psychology, Uppsala University

Professor Matthew Hotopf FMedSci*, Professor of General Hospital Psychiatry, King's College London

Dr Muzaffer Kaser, Clinical Lecturer, University of Cambridge

Professor Charles Leek*, Head of the Institute of Life and Human Sciences and Professor of Cognitive Neuroscience, University of Liverpool

Professor Paul Harrison, Professor of Psychiatry, University of Oxford

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

Professor Andrew McIntosh*, Professor of Psychiatry, The University of Edinburgh

Professor David Menon*, Head of Division of Anaesthesia, University of Cambridge

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

Dr Helen Munn, Acting CEO, MQ Mental Health

Dr Timothy Nicholson*, Clinical Lecturer, King's College London

Dr Stella-Maria Paddick, Newcastle University

Professor Dame Pamela Shaw FMedSci, Professor of Neurology, University of Sheffield

Professor Leonie Taams*, Professor of Immune Regulation & Inflammation, King's College London

Professor John-Paul Taylor*, Professor of Translational Dementia Research, Newcastle University

Dr Jonathan Underwood*, MRC-NIHR Clinical Academic Research Partnership Fellow, Cardiff University

Professor Rachel Upthegrove*, Professor of Psychiatry and Youth Mental Health, University of Birmingham
Professor Nick Wood*, Professor of Clinical Neurogenetics**,** University College London
Dr Katherine Young*, Lecturer, King's College London
Dr Michael Zandi*, Honorary Associate Professor, University College London

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