**POLICY BRIEF 39** 

# In the wake of the pandemic Preparing for Long COVID

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#### **Declarations of interest:**

KK is Chair of the Ethnicity Subgroup of SAGE; KK and MM are members of Independent SAGE, all in the UK.

This policy brief is one of a new series to meet the needs of policy-makers and health system managers. The aim is to develop key messages to support evidence-informed policy-making and the editors will continue to strengthen the series by working with authors to improve the consideration given to policy options and implementation.

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#### What is a Policy Brief?

A policy brief is a short publication specifically designed to provide policy makers with evidence on a policy question or priority. Policy briefs

- Bring together existing evidence and present it in an accessible format
- Use systematic methods and make these transparent so that users can have confidence in the material
- Tailor the way evidence is identified and synthesised to reflect the nature of the policy question and the evidence available
- Are underpinned by a formal and rigorous open peer review process to ensure the independence of the evidence presented.

Each brief has a one page key messages section; a two page executive summary giving a succinct overview of the findings; and a 20 page review setting out the evidence. The idea is to provide instant access to key information and additional detail for those involved in drafting, informing or advising on the policy issue.

Policy briefs provide evidence for policy-makers not policy advice. They do not seek to explain or advocate a policy position but to set out clearly what is known about it. They may outline the evidence on different prospective policy options and on implementation issues, but they do not promote a particular option or act as a manual for implementation.

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#### **CORRIGENDUM**

The following correction has been incorporated into the electronic file on 22<sup>nd</sup> March 2021:

• On page 11, the following sentence has been added: 'Further data is needed to establish the clinical relevance of such findings in children.'

symptomatology in COVID-19 patients. As part of the Network of University Medicine in Germany, the National Pandemic Cohort Network at University Hospitals (NAPKON) investigates long-term organ damage and subsequent morbidities after infection with SARS-CoV-2 across all disease severities through population-based cohort studies at several sites (ClinicalTrials.gov, 2020a), while others in Munich, Germany, are also examining lung function to help to establish treatment protocols and to target follow-up care.

Another study at the University of Tübingen investigates the long-term consequences of individuals with mild courses of COVID-19 who have never been admitted to hospital due their illness. The researchers closely collaborate with GPs and public health offices. Finally, the Hradec Králové study on Long COVID from Czechia (described in section 2.4) also plans to repeat all physical examinations twice over the course of the year to establish whether lung function resolves in sufferers of Long COVID and will assess antibody levels and cell-mediated immunity, which is also being examined in the COVIMMUNE study in France (ClinicalTrials.gov, 2020b). There is a hope that the use of standardized methods will facilitate the production of a meta-analysis as findings from these studies start to emerge. Similarly, in Belgium, researchers at the Health Care Knowledge Centre (KCE) are also are working to establish the clinical segualae and risk factors. They are also investigating the experiences and unmet needs of patients.

#### 4. Implications for policy

## Although Long COVID is not yet fully understood, health policy-makers should be preparing to address it

Although there are still many unanswered questions about the natural history of Long COVID, in particular relating to its likely duration in those affected, it is probable that there will be considerable numbers of people with ongoing symptoms for several years at least. Health policy-makers should be preparing responses to those with this condition.

## First step towards dealing with Long COVID should include implementing effective patient registers or other surveillance systems

A first step will be to ensure that there are effective systems of surveillance in place, ideally creating patient registers which are not entirely dependent on diagnosis by lab confirmation and including these figures within reported outcome measures for COVID-19. Identification, monitoring and recording of people with Long COVID is imperative to facilitate long-term follow-up and prevent an epidemic of chronic disease with detrimental impacts on health systems and economies and can also act as a critical basis for research. These registries should collect sufficient data to characterize factors that influence the risk of ongoing problems, including initial presentation and sociodemographic data, including ethnicity and occupation. They should also monitor the impact of this condition on the lives of those affected, including conventional measures of quality of life but also the impact on psychological condition, employment and economic situation.

#### Care guidelines and multidisciplinary services need to be developed to ensure appropriate assessment and management of the condition

In countries where this has not yet happened, it will be important to develop contextually appropriate guidelines for health professionals caring for those affected, especially in primary care. As described in this policy brief, there is already considerable material that can be drawn upon. Patient groups have emphasized that new nomenclature must not be developed by each individual guideline, but that a proper consultative process occurs by WHO to determine terminology. This will ensure consistency in diagnosis across different regions of the world and therefore better tracking of the impact of COVID on long-term morbidity.

In parallel, it will be necessary to develop multidisciplinary and multispecialty services that can evaluate individuals and ensure that they have access to appropriate management. There is considerable scope for implementation research and, as knowledge accumulates, evaluation of different forms of treatment, ideally in clinical trials. This is an area that will benefit from international cooperation.

### Effective response can only be achieved by involving Long COVID patients themselves

Patient groups have already proven themselves to be instrumental to recognizing, characterizing this condition and advocating for it to be properly and fairly managed. Again, there are many opportunities for cross-country learning and such initiatives should be welcomed, encouraged, and where possible, supported by policy-makers.