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Recommendations for a voluntary Long COVID Registry

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Long COVID has had a profound impact on the lives and health of many people around the globe.[1] Estimates of the number of people affected vary, but on the 6th May 2022, the Office of National Statistics (ONS) identified that there were 1.8 million (2.8%) people living in private households in the UK alone who were experiencing self-reported long COVID symptoms.[2] The same data identified that symptoms adversely affect the day-to-day activities of 1.2 million people in the UK.[2] However, the long-term consequences of SARS-CoV-2 infection and the subsequent impact on public health are still largely unknown and present a major challenge to health and care systems moving forward. A mechanism to facilitate long-term monitoring of long COVID is therefore essential to support research, service improvement and enhance understanding of the disease as it evolves. In response to this, the aim of this commentary is to outline key recommendations for a voluntary Long COVID Registry in Wales. In this paper, five key recommendations are highlighted that should be considered in the development of a Long COVID Registry. These include: 1) a dual purpose of research and service improvement; 2) experiential co-design with end-users; 3) recruitment of a self-referred population and inclusion of a control group; 4) utilisation of digital infrastructures and 6) a prudent and integrated approach.

Long COVID

Long COVID can affect those with very mild acute disease to those with the most severe form.[1] Symptoms are known to range between mild and disabling, can involve multiple organs and systems, and have differing manifestations. The diversity in presentation and severity of symptoms makes long COVID difficult to define, but the current clinical definitions developed by the National Institute for Health and Care Excellence (NICE) broadly identify it as signs and symptoms that develop after acute COVID-19 infection, which cannot be explained by an alternative diagnosis. This definition includes ongoing symptomatic COVID-19 from 4 to 12 weeks and post-COVID-19 syndrome lasting longer than 12 weeks.[3] The prevalence of long COVID remains highly uncertain,[1] but modelling suggests a significant increase.[4] Managing the long-term sequelae of all variants of SARS-CoV-2 infection in the population will therefore remain a major challenge for health and care services during the next stage of the pandemic.

Long COVID Registry

Despite not knowing the extent of the resultant public health burden, it is undeniable that long COVID has long-term population health and socioeconomic implications.[5] The Minister for Health and Social Services in Wales recognised this and asked the leading independent think tank for health and care in Wales, the Bevan Commission, to make recommendations on '*how to set about establishing a voluntary registry for Long COVID in Wales in order to undertake long term monitoring of the condition*'. Through exploratory desktop research and co-production with an expert advisory board, inclusive of patient representatives, the main recommendations of a Long COVID Registry in Wales are identified below. These recommendations have informed health policy decisions related to long COVID and provide insights for other voluntary patient registries.

Key recommendations for a voluntary Long COVID Registry

Dual purpose

The majority of registries are traditionally observational and research focused, but insufficient understanding of long COVID currently, makes the ability to respond to changing needs and information essential. Therefore, this work concluded that a Long COVID Registry should be agile and responsive, with a dual purpose of both research and service improvement. This should accommodate both longitudinal and comparative research. It should also encompass a communication strategy to facilitate service improvement and positively influence the patient journey. Two-way exchanges with end-users will ensure that views and experiences are properly addressed, allow identification of local and national services for care and treatment, and provide rapid feedback for patients, clinicians and policymakers. It will further help recruitment into clinical trials of interventions that could improve outcomes for patients.

Co-production with end-users

A key recommendation in the development of a long COVID patient registry is co-production, particularly with the end-users such as patients, healthcare professionals and other collaborators. In this instance, patient groups such as LongCovidWales and the Long COVID Doctors' group should be involved through experience-based co-design,[6] which is an important element of prudent healthcare.[7] Co-production improves healthcare quality through appropriate representation of the perceptions of individuals and networks,[8] encompassing a full range of patient perspectives and ensuring rigorous evaluation in the short, medium and long term. Co-production with patient groups also promotes shared responsibility for equity of access to healthcare.

Recruitment of self-referred population and control group

Both the expert panel and patient representatives deemed the potential for self-referral into a voluntary Long COVID Registry to be essential for two reasons. First, the lack of testing for COVID-19 during the first wave means no confirmation of infection exists. Second, the poor understanding of mechanisms underpinning long COVID makes objective inclusion criteria difficult. Self-referral promotes equity of access, overcomes patient consent challenges in relation to personally identifiable information and allows sufferers to access support regardless of testing or diagnosis.

The inclusion of a control group was also deemed essential by the advisory group, as recommended in The Academy of Royal Medical Sciences Report.[5] Many symptoms of long COVID align with other diseases in the general population and therefore a control group is necessary to enable analysis and comparison of data. Furthermore, motivation from the self-referred population will help to support long-term observational studies that are needed to understand the evolution and prognosis of the pathophysiology of long COVID-19, its symptom clusters, syndromes and long-term sequelae.[9]

Digital infrastructure and linkages

Digital infrastructure and database linkages are needed to harness the capabilities of technology and optimise the success of a registry,[7] but this is hampered by current disconnects in technology. The consolidation of existing technology and databases could enhance the coordination and interoperability of such resources within and across different organisations. A unified approach would allow access to data retrospectively and prospectively, to inform understanding of long COVID as the disease evolves. This coordination needs a lead digital agency to provide greater clarity of purpose and initiate collaboration across organisations. Collaborative effort and large-scale electronic data collection is required in order to realise the full potential of a registry and to inform research, service improvement and patient care.

A prudent and integrated approach

The concept of prudent healthcare provides principles that can ensure the best value from a Long COVID Registry.[7] The approach considers how to collaborate with others, make effective use of the available resources and to ensure high-quality and consistent care for long COVID within Wales. This is particularly relevant considering resource challenges within the health and care context and the need for services to meet changing needs as understanding of long COVID develops. Collaboration between key stakeholders is inherent in a prudent approach and an integrated healthcare perspective is necessary to address the multidisciplinary demands of long COVID.[1] Prudent healthcare promotes innovation and transformative change. This is of relevance in the establishment of any comprehensive registry to optimise opportunities, technological advancements and new ways of working to ensure that it is fit for purpose.

Conclusions

The aim of this paper was to provide valuable recommendations and insight to inform both health policy decisions and patient registries in alternative contexts. Despite the uncertainties of long COVID, the need for long-term monitoring is essential to support research, service improvement and patient engagement. This work proposes co-production with end-users, consolidation of digital infrastructures, inclusion of self-referred populations and control groups, and an integrated and prudent approach as key recommendations in the development of a comprehensive Long COVID Registry. These factors also provide valuable considerations for other voluntary patient registries in the future.

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