

# **Establishing a Long COVID Registry for Wales**

## **Executive Summary**

December 2021

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Since the emergence of COVID-19, the Bevan Commission, in its capacity as the leading think tank for Health and Care in Wales, has provided advice and support to the Minister and Welsh Government. This includes publications such as the COVID-19 Evidence Series, Beyond the Curve and Doing Things Differently series. More recently, the Bevan Commission has been asked to make recommendations to Welsh Government on how Wales should set about establishing a voluntary Long COVID Registry. This report provides an overview of the findings, including insight from the exploratory desktop research, the Advisory Board and wider stakeholder consultation.

## Summary of Findings and Recommendations

The following summarises the findings and recommendations from the exploratory desktop research, Advisory Board meetings and patient representative input.

- The Advisory Board and patient representatives confirmed the importance of a Long COVID Registry to address unanswered questions, improve the management of Long COVID and the experience of patients.
- There are currently a range of organisations, databases, apps and systems within Wales that contribute to and/or support Long COVID. These include Health and Care Research Wales (HCRW), Digital Health and Care Wales (DHCW), Public Health Wales (PHW), the Office of National Statistics (ONS), the Secure Anonymised Information Linkage (SAIL) database and HealthWise Wales (HWW).
- Digital infrastructure and data linkage are key to the success of a registry. In particular, connecting current systems and databases to link primary care and hospital records, coronavirus and antibody testing data, vaccination records and death registrations.
- Greater clarity and coordination is needed across agencies and organisations to realise the full potential of a future Long COVID Registry in Wales.
- A Long COVID Registry should be interventional and have a dual purpose for both research and service improvement to enable a greater understanding of the patient experience as it evolves.
- A Long COVID Registry offers many advantages prospectively and retrospectively for research and service improvement. These include long-term monitoring, a consistent and coordinated database, treatment stratification and prudent use of resources across services, databases and stakeholders.
- Other key issues considered included: the adoption of Prudent Healthcare to support service improvement, equitable access, data and information protocols, inconsistency in coding particularly in primary care and the need for knowledge transfer and collaboration.
- A potential framework has been developed to understand how to set about establishing a Long COVID Registry. Key steps identify the purpose, operational requirements, inclusion criteria, data and ethics, communication and intervention strategy, and key outcomes.
- The most feasible configuration for a Long COVID Registry was confirmed through an option appraisal exercise. This includes the consolidation of existing databases, recruitment of self-referred population and a communication strategy.
- DHCW has been identified as the most suitable body to lead a proposed Long COVID Registry, with SAIL, HWW, ONS and PHW as key collaborators.