- 13. HDR UK is a research Institute. Its mission is to unite the UK's health data to enable discoveries that improve people's lives. It is supported by 12 researchfunders including the Medical Research Council, Wellcome, Cancer Research UK, British Heart Foundation and health research departments in the devolved administrations. In its first five years it has built on its £53 million of core funding to reach a total of £250 million in funding for its work. I also convened the International COVID-19 Data Alliance (ICODA) funded by the Bill and Melinda Gates Foundation and the Minderoo Foundation which coordinated COVID research across 19 countries, and am a member of the JBC (Joint Biosecurity Centre)/UKHSA Data Science Advisory Board. HDR UK is a "virtual institute" and works with 38 Universities and research institutes across the UK and ~80 NHS, charity and public sector bodies.
- 14. To deliver its mission, HDR UK focuses on (i) the assembly of UK-wide data infrastructure and services for health data research so that data from different sources can be linked and analysed in a secure and trustworthy way; (ii) using data to perform UK-wide research through a set of flagship projects; and, (iii) working in partnership across the UK and internationally so that data is used at scale for research that is beneficial to the public and improves lives.
- 15. This work has been recognised by an international peer-review panel convened by the MRC and other funders in 2022 as "establishing itself within a complex UK landscape and as an international leader in the health data research field" [AM3/002 INQ000326315]. It is this experience spanning health system design, health policy, patient care, and biomedical health data research which qualified me to contribute to the C19AG.
- 16. The UK is in a unique position to realise the potential of health data, thanks largely to the NHS and its cradle-to-grave records for a population of over 65 million people. However, safe and secure access to this data for researchers is often a lengthy, fragmented process, meaning the potential for improving healthcare is not being realised in full. It can take two years or more for researchers to find, safely access, link and wrangle data from different places into a workable state they can then use for analysis to give new insights. This arduous process serves no one, least of all patients. This is the problem that HDR UK is trying to solve, in partnership with the NHS, universities, charities, industry and regulators. Current data assets that are necessary for research in health care and biomedicine are often poorly documented and siloed. For example, in the NHS, health data relevant to research are held in operational systems controlled by national bodies (e.g. NHS England, UK HSA, PHS (Public Health Scotland)), regionally (e.g. in NHS Trusts) and locally (e.g. GP practices). Inaddition,