Indirect effects of the pandemic: highlighting the need for data-driven policy and preparedness

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Whether through government reports, such as the Health and Social Care Committee's 'Clearing the backlog caused by the pandemic' publication[1] or recent media coverage, NHS backlogs, now estimated to affect over six million people, are in the spotlight.[2] How we tackle such backlogs in cardiovascular disease and cancer (diseases which together constitute the largest disease burden in the UK and globally[3]) is critical for citizens' health and healthcare delivery during and beyond the pandemic and can inform our response for other diseases.

Waiting lists are not new but have been significantly worsened by COVID-19. In the early pandemic, infection dynamics underpinned models of the impact of COVID-19 on mortality (so-called 'direct effects' of SARS-CoV-2 infection). Since early reports from Wuhan, it was clear that age and underlying health conditions increased the risk of COVID-19 severity. These parameters are captured in routine electronic health records and can be used to predict excess mortality among people with a wide range of prior health conditions and risk factors who develop COVID-19.[4]

The syndemic concept describes 'how COVID-19 clusters with pre-existing conditions, interacts with them, and is driven by larger political, economic, and social factors'. Moreover, unlike pandemic frameworks, syndemics recognise how political and social factors 'drive, perpetuate, or worsen the emergence and clustering of diseases', varying by country and context.[5] As the pandemic progressed, 'indirect effects' emerged, where non-COVID services were challenged by increased system strain and changed health behaviours, causing health service delays and increased morbidity and mortality.

These indirect effects are measurable. We employed routine data for common cardiovascular diseases across UK hospitals in the early first wave of the pandemic to measure total admissions and emergency department attendances, showing over 50% reductions after the first lockdown, compared with the previous year. We detected important variations in hospital activity by arterial territory.[6] We also observed declines in urgent referrals for cancer by over 70% and for chemotherapy attendances by over 40% in the early first wave.[7] Similar declines have been shown across surgical and endoscopic procedural activity,[8,9] facilitating projections of the burden of missed care, and informing strategies for staffing, resources and policy to address the impact of indirect effects. Relevant healthcare data are already gathered as part of standard care or performance metrics. Such methods and approaches should be deployed across the entire health system, yet currently disease communities are collecting, mapping and reporting their own data separately – these silos are not in the public health interest of the population.

These indirect effects are predictable and should be informed by data intelligence. Initially, researchers could use pre-pandemic data to create predictions of direct and indirect effects based on demography, assumptions about viral dynamics and underlying risk. We modelled impact of high COVID-19 rates in people with cancer, particularly those with multimorbidity, projecting significant numbers of indirect excess deaths. In the last two years, the landscape and regulation of health data use have been transformed to enable urgent, policy-relevant analyses. The British Heart Foundation Data Science Centre's CVD-COVID-UK/COVID-IMPACT Consortium is an example where data have been

collated and linked from diverse national datasets covering a population of >60 million people across the UK, from primary and secondary care, from COVID-19 surveillance data to disease-specific registries, from cardiovascular risk factors to history of medications and vaccinations (https://www.hdruk.ac.uk/projects/cvd-covid-uk-project/).[10] Over 250 researchers have been involved in analyses on near real-time data, working with clinicians, policymakers and patients throughout the pandemic, deploying this intelligence to reduce COVID-19 impacts. Similar opportunities in cancer are being fulfilled through DATA-CAN, the UK's Health Data Research Hub for Cancer.[11] Deploying health intelligence to inform health policy and its implementation must become the 'new normal.'

Crucially, these indirect effects are preventable with pre-emptive knowledge and policies. The basis for the waiting list estimate of six million is unclear.[2] Our approach, working through Health Data Research UK infrastructures to deploy open phenotypes (e.g. https://portal.caliberresearch.org/), open statistical code (e.g. https://github.com/BHFDSC/About) and open metadata about datasets (e.g. https://www.healthdatagateway.org/), allows indirect and other effects to be estimated in a more transparent, timely, accurate and robust manner, informing early, preventive action that is evidence-based and driven by insights derived from the data rather than by supposition.

A major success of the UK's COVID-19 response has been the use of up-to-date, publicly available information regarding acute COVID-19 from cases and intensive care admissions to mortality and vaccinations, which has influenced policy in the UK and many other countries. However, the approach to gathering systematic intelligence about the indirect and long-term (i.e. Long Covid) effects of SARS-CoV-2 has been comparatively reactive, passive and ineffective. Deployment of health data must become predictive, adaptive and effective to save time, resources and ultimately lives. Availability of near real-time data and data intelligence-informed management of the impact of pandemics on non-communicable diseases must be part of pandemic preparedness if we are to avoid the huge cost in terms of lives and resources beyond direct deaths from COVID-19 and future emerging infections.

Declarations

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