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COVID INQUIRY

Effective knowledge mobilisation: creating environments for quick generation, dissemination, and use of evidence

Raheelah Ahmad and colleagues examine how knowledge mobilisation worked during the covid-19 pandemic and call for successful models to be embedded in UK research and policy environments

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Key messages

- Effective response to the pandemic required real time use of research knowledge
- Some existing infrastructures for generating and mobilising research findings accelerated collaborative working during the pandemic, and helped direct research appropriately
- Investment is needed in integration of data, particularly for social care
- Successful knowledge mobilisation needs to be sustained and expanded to support our recovery from the covid-19 pandemic and respond to further threats

The simplest definition of knowledge mobilisation is the process of optimising the use of knowledge generated from research.[1] Connecting academic research with non-academic decision makers, including those involved in public policy and professional practice, is a complex process, but can be facilitated if problems are defined and solutions are tackled collaboratively. Knowledge mobilisation (the process) is focused on producing action that benefits society. It broadly encompasses dissemination, knowledge transfer, and knowledge exchange.[2 3] Effective knowledge mobilisation occurs when research knowledge is perceived as relevant and usable and there is minimal duplication of effort through "unused" research findings.[4]

The covid-19 pandemic presented a previously unseen level of demand and urgency for research based evidence and for mechanisms to enable use of evidence almost in real time. The United Nations research roadmap for covid-19 recovery[5] puts knowledge mobilisation at the top of a list of required investments along with implementation science, rapid learning systems, scaling up data infrastructure, and the science of science.[5] It is therefore important that the UK covid inquiry examines how knowledge was mobilised during the pandemic and what can be done to improve use of research evidence in future.

Pandemic mobilisation

From a UK perspective, notable examples of generating usable evidence quickly include the development and trial of the Oxford-AstraZeneca covid-19 vaccine led by the University of Oxford's Jenner Institute and Oxford Vaccine Group, and well coordinated rapid clinical trials such as the Recovery trial, which helped guide treatment. Existing infrastructure, technology, and expertise at the host centres enabled studies to start much quicker than usual, with joint working with centres across the world and regulatory bodies, open access research protocols, and rapid dissemination of summary results.

Investment in these projects in the face of high uncertainty was justifiable in the context of a pandemic of a novel virus.[6] The situation required "intelligent and informed risk taking" and mobilisation of collective action, rather than all the answers.[6 7] Subsequent trials that helped to understand what aspects of immunity contribute to protection also relied on existing infrastructure. For example, the Instinct Covid-19 Household Contacts Study built on the sustained research infrastructure established by the National Institute for Health Research (NIHR) Health Protection Research Unit in Respiratory Infections at Imperial College and wider collaborators.[8]

These large scale trials also contributed to progress in methods of participant recruitment. Covid trials differed from previous large trials as there was an immediate need for volunteers and the disease was not confined to a specific group. Public participation in research had begun to increase before covid, with the NIHR clinical research network recording a 20% increase in participants from 2017-18 to 2018-19. Additional mechanisms used during the pandemic included mass campaigns, endorsements by the chief medical officers of the four UK nations and NHS medical directors,[9] and the NHS vaccine registry allowing any member of the public to volunteer.

Participation is likely to have been encouraged by the increase in accessibility of scientific language and democratisation of knowledge. The R number, modelling, evidence, and data featured in wider public discourse,[10] and epidemiologists, infectious disease specialists, and global health experts became household names.

What facilitated knowledge mobilisation?

Below we consider three examples of successful knowledge mobilisation during the pandemic. The lessons from their success can be built on to help deal with routine health system challenges as well as epidemic and pandemic threats.

Integrated care records make studies quicker and easier

Availability of linked data to support patient care and research across health and social care in England remains patchy. The main national database, Clinical Practice Research Datalink, is based on linked primary care records and provides data for around 16% of the UK population, with links to hospital records, the national cancer registry, area level social deprivation information, and national mortality data. However, inferences are limited to specific regions and extracts are not updated in real time.[11] This limited its usefulness in research to inform the response to covid-19.

A better system was offered by the whole system integrated care database in northwest London, which was set up before the pandemic to provide comprehensive integrated medical and social care records in near real time (table 1). It covers a population of 2.4 million people and the database can be used for tracking the patient care journey, operational planning, research, and evaluation. Data are de-identified for research, but care organisations, including general practices, are still identifiable, which allows mapping and linkage to healthcare provider variables such as staffing.[11]

Table 1 | Examples of knowledge mobilisation mechanisms and potential for development

Example	Existing mechanisms	Developments resulting from covid-19	Non-academic users	Benefits	Wider value	Challenges to sustainability and expansion
Northwest London linked datasets—linked credible real time data for health decision making	Medical and social care records for 2.4 million people. De-identified patient data, including healthcare provider variables, available through a cloud based system. Curated subsets allow researchers to tailor the filter data extraction query, facilitating rapid comparisons over time, setting, and patient population. Local governance structures	Data review panel established to assess the research for methodological rigour and relevance to policy and practice. Public and patient involvement in assessment process. Rapid response to research proposals. Near real time data linkage and accessibility	Local NHS	Condensed timeline from study conception to use of findings. Ability to examine immediate operational and applied research questions	To understand longer term population health outcomes. To inform health service planning	Expanded governance structure required to ensure safe and equitable access without protracted lead times. Technical expertise needed in working with linked datasets generated from different sectors and understanding limitations. Lack of data on populations excluded from or with limited access to formal healthcare services. Costs of maintenance and expansion
Adaption of REMAP-CAP trial to include treatments for covid-19	The trial system allows for multiple interventions to be tested simultaneously. Response adaptive randomisation information from patients already participating in the study can also be used to help guide the treatment of patients joining the study. Strong international peer network and well established spirit of collaboration and commitment	Rapidly responded to test new therapies for covid-19	National NHS	Multidisciplinary experts with credibility. Data safety monitoring board allowed for a fast process to address covid. Greater pool of participants and a larger group	Application of this method to other infectious and non-communicable diseases	Strengthening local capacity in relevant global settings to contribute to such studies. Investment is needed to maintain infrastructures for ready response to smaller and larger scale threats
Smartphone technology for capturing patient generated data	Existing technology to collect self-reported data from public participants for ZOE trial. Ease of use on personal mobile devices enabled recruitment of large populations	App adapted as a symptom tracker for covid-19 and launched in the UK and US by end of March 2020	Public and policy makers	Enabled data collection from asymptomatic and symptomatic people (including symptoms, hospital admission, PCR test results, demographic information, and pre-existing medical conditions, vaccine status). Provided information that would have taken substantial resource and time to get using traditional data collection and epidemiological research methods	Real time cost effective method. Could be used for communicable and non-communicable conditions and as early warning. Inclusion of a wide section of the community. Promotes citizen science	Costs of maintenance and expansion. Potentially missing particular subsets of the community. Need to expand reach among those who are less confident with technology

To enable expedited research access at the start of the pandemic this data infrastructure was rapidly expanded to include Imperial College Healthcare NHS Trust inpatient data, from January 2020, in addition to the existing primary and secondary linked data from 2005, and then maintained in de-identified form on a cloud based data analytics platform. The platform is hosted by the NIHR Imperial

College Biomedical Research Centre and approved by a Health Research Authority research ethics committee.

A covid-19 data prioritisation review panel was set up, including a patient and public involvement representative. Research protocols were assessed within a week for methodological rigour and, importantly, for relevance to policy and practice. This structure enabled interdisciplinary research teams to quickly pivot to investigate relevant health service management and delivery in surgical care, for example, and to consider important operational and applied research questions, such as the uptake and effectiveness of the vaccination programme.[12]

The breadth of multidisciplinary, multiprofessional, and cross sectoral projects could not have been conducted when needed without credible and relevant linked data and analysis to inform real time context and population specific problems and decision making across the health and social care sector from studies on mental health to trends in antibiotic prescribing. Near real time feeds were used from local pathology laboratories as well as daily feeds of patient level data from the five northwest London trusts using information such as the NHS England situation report on covid deaths and shielding lists.

This infrastructure is now even more useful for understanding the consequences of covid-19 on population health outcomes and for planning healthcare as the pandemic eases. The challenge will be maintaining it as the system grows and is used more widely beyond covid-19. There is potential for other regions to replicate this infrastructure, particularly the agile methods used for development, access, and permissions. With dedicated resourcing, it has the potential to be a global exemplar of integrated applied research and informed decision making.

Value of adaptive trials

Unlike traditional "A" v "B" randomised controlled trials, participants in randomised, embedded, multifactorial adaptive platform (Remap) trials are randomised to receive one intervention in each of one or more categories of treatment ("domains"). This allows for multiple interventions to be tested simultaneously. Response adaptive randomisation allows information from patients already participating in the study to be used to help guide the treatment of new patients joining the study, weighting randomisation probabilities to the better performing treatments.

The Remap Trial for Community Acquired Pneumonia (Remap-CAP) was set up to evaluate the effect of different interventions on outcome of patients admitted to intensive care with community acquired pneumonia and operates in over 300 sites across 21 countries. In March 2020, the protocol was rapidly adapted to allow timely generation of evidence for treating severe covid-19.[13] The specification of pathways enabled the data safety monitoring board to liaise directly with public health authorities as results arose.

The research showed that the interleukin-6 receptor antagonists tocilizumab and sarilumab save lives in people with severe covid-19 and speed up recovery, as do corticosteroids.[14 15] These results were incorporated into NHS treatment guidelines the day after they became publicly available and formed part of WHO treatment guidelines.[16]

This infrastructure worked because it had the foundation of a strong international peer network and well established spirit of collaboration and commitment to contributing research evidence for those who urgently need it. If this adaptable method is replicated and scaled up it will enable rapid investigation of responses to future health emergencies.

Potential of technology for mass public participation

The ZOE app was developed for the Predict study to understand how different people respond to food and what determines these variable responses using data self-reported by public participants. The research team rapidly adapted the app as a symptom tracker for covid-19 and launched it in the UK and US before 30 March 2020.

The app collected data from asymptomatic and symptomatic people (table 1) and enabled the ZOE Covid Study, which was highly efficient compared with traditional data collection and epidemiological methods. In the first month 2 450 569 UK and 168 293 US residents reported symptoms through the free smartphone app, and results were published on the study website and in peer reviewed journals.[17 18]

This infrastructure worked because of the unique reach and usability of the technology, coupled with the wider cultural shift in terms of public involvement. The challenge is to expand the reach even further among people who are less confident with smartphone technology, especially in accessing and making sense of the results and feedback.

The app shows the potential of recruiting the public for symptom tracking as part of routine infectious disease surveillance, providing early warning systems. Similar web based systems exist for healthcare professionals and researchers to report and disseminate events related to emerging and re-emerging infectious diseases in humans, animals, and plants (eg, Program for Monitoring Emerging Diseases (ProMED) of the International Society for Infectious Diseases).

Adapting research infrastructure for effective knowledge mobilisation

These examples are a small subset of the many excellent knowledge mobilisation journeys since covid-19. Existing infrastructure such as NIHR biomedical research centres, health protection research units, patient safety translation centres, and notably the clinical research networks, encouraged multidisciplinary working and collaboration. For example, the existence of clinical research networks, which facilitate research on national priorities, contributed to the success of the Recovery trial and helped the UK lead global recruitment in the Remap-CAP trial. Many of these infrastructures also improve commercialisation of ideas by bringing together researchers, practitioners, and managers across clinical and academic disciplines.[19 20]

The Research to Access Pathway for Investigational Drugs for Covid-19 was key to getting new treatments to patients quickly.[21] It brought together the NIHR, NHS, National Institute for Health and Care Excellence, and Medicines and Healthcare Products Regulatory Agency to rapidly review results, allowing assessment of preprints as well as peer reviewed publications. Preprint platforms such as bioRxiv and medRxiv allowed rapid global reach of findings, but the sheer volume of research studies available before peer review was difficult for individual readers to evaluate. Editorial boards of journal families (eg, Lancet Group) combined their submission systems given the volume of submissions, saving time for themselves and researchers.

A more permanent shift in early posting of research protocols and results for other less immediate but serious global threats would help reduce duplication of effort, allowing a focus on much needed implementation studies. Such repositories could also help funders when commissioning research; researchers likewise would benefit when refining research plans given the length of time it takes from announcement of funding calls to finally contracting work.

Additional resources shared between global interdisciplinary research networks (eg, Global Challenges Research Fund hubs) provided methods for efficient workarounds and for protecting researchers and participants during field work.[22]

What can we do better?

The experience of knowledge mobilisation during the pandemic suggests some questions that should be considered during the UK public inquiry (box 1). Although contemporary literature rightly emphasises the complexity of uptake of research based knowledge,[23 24] the pandemic has created an opportunity to pause and reflect on simpler models. The scale of the problem created universal demand for solutions. Infrastructure, track record, and credibility of scientists contributed to enhanced knowledge mobilisation, but there was also a unique opportunity to innovate and for people from outside the systems to help tackle this multifaceted problem.[25] Researchers and industry took leadership and were given freedom and autonomy to get on with the work because of the urgency of the problem. We may now need to be more open to the full range of supply push, demand pull, and integrated approaches to routine decision making, so that our systems for generation and use of research knowledge acquire flexibility, memory, and resilience.

Box 1: Questions for the public inquiry

- What were the conditions and infrastructure that allowed NHS and academia to implement successful knowledge mobilisation measures?
- How should successful infrastructures, networks, and registries be maintained outside the pandemic?
- Are adequate data available on the complete patient pathway across health and social care and was maximum benefit derived from existing platforms?
- Where did knowledge fail to be mobilised, and why?
- How can pragmatic and adaptive trial methods, particularly for the management of infectious diseases, be more widely applied and supported?
- How can trust and strong public commitment best be fostered and harnessed early, to participate and contribute data?
- How can we build on the positive cultural change and choreograph informed citizen science to shape and raise questions for research?

The importance of investing in knowledge mobilisation is already recognised. NIHR health protection research units have assigned knowledge mobilisation leads, for example, and the science grants of the Canadian Institute for Health Research Knowledge Mobilization are aimed at achieving equitable health outcomes. But knowledge mobilisation for other global health problems, including the threat of antimicrobial resistance, requires substantial strengthening.[26 27] Additionally, gaps remain in research in some parts of the system, notably social care. This was exemplified by the harm caused by the failure to assess the risk of discharging patients from acute care to residential and care homes at the start of the pandemic.

The practice of knowledge mobilisation needs to be evidence based[28] and to incorporate advances in innovation diffusion and implementation that help embed knowledge mobilisation mechanisms into research and avoid "superficial and wide" or "deep but localised" implementation.[24] It is surprising to see the dangers of groupthink listed among the lessons from covid-19 in the report of the House of Commons select committees[29]; the phenomenon is a well known risk, and mitigation strategies are documented in seminal and contemporary publications in decision science, health

management, organisational behaviour, and strategic management.[30]

We must ensure that the learning from covid-19 will be systematically applied to other global challenges to avoid both duplication of effort and repeatedly missing opportunities. The Recovery trial investigators, for example, are now involved in the NIHR commissioned and funded clinical trial for potential treatments for monkeypox. However, the ZOE study has lost government funding. This seems a missed opportunity for transformational change to increase use of patient generated data, which could have a key role in strengthening research and public involvement and ownership.

We also appreciate that this pandemic has provided a greater awareness of the uncertainty of our knowledge and of the consequences of our actions, both in terms of being "situated in time and of aiming at timeliness."[31] We must ensure that future knowledge mobilisation processes are mindful not to force extreme positions but learn how to communicate the continuum of evidence and be transparent about uncertainty.[32]

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