Health research in England is grinding to a halt

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Wes Streeting, the UK health and social care secretary, announced in 2024 that " the NHS is broken" (1) against a background of ballooning waiting lists, delays in disease detection, and reduced staff productivity. As clinicians and researchers who have worked on many national, publicly funded, research studies over the past 15 years, we believe that the state of UK health data research is equally bleak

In the decade prior to the covid-19 pandemic, the UK established: the National Institute of Health Research (NIHR) as the main funder of frontline health research; the Integrated Research Application System to streamline ethics and regulatory approvals; and the NIHR Clinical Research Networks to facilitate research delivery. These were all substantial changes that supported research using or collecting health data. Nevertheless, challenges in accessing data for research remained (2).

During the pandemic, the urgency to find new treatments and vaccines forced organisations to work together to minimise bureaucracy (3,4), elevating UK health research to global leadership (5–7). Since the pandemic, a perfect storm of increasing regulation, staff shortages, decreased productivity and rising inefficiency, have diminished the gains made and risk wasting the learning and infrastructure built for covid-19 research.

<u>Regulation</u>

All healthcare research must be legal, ethical, and adhere to data governance principles with clear and proportionate processes. However, the regulation process has become increasingly unworkable, with studies often experiencing long delays (8,9). A typical research study requires sponsor review by the lead scientist's university or hospital which frequently takes several months, Health Research Authority approval potentially including NHS ethics committee approval, and NHS site approvals (2,10). Studies that require routinely collected, non-consented retrospective data also require Health Research Authority Confidential and Advisory Group approval and individual data applications to data controllers and data processors. The end result is that a research study takes at least a year, and often much longer, to get started.

Workforce challenges

Every step of the process is now affected by staff shortages, especially skilled and experienced staff who understand the complex regulations. This feeds a vicious cycle - staff shortages increase the workloads of remaining staff who process applications. This reduces productivity, increases stress, and causes long delays. There is reduced accountability for processing applications, since several people might work sporadically on the same application over a period of months. The absence of a single point of contact and use of generic email addresses by data providers can be frustrating for researchers.

Studies will be made even more challenging by the uncertainty introduced by changes to NHS England and the additional loss of workforce. While we have every sympathy with staff working in the system under unmanageable workloads and job insecurity, the result is that studies will remain stalled for months or years.

System inefficiency

Improvements in one part of the process are often offset by worsening issues elsewhere. While the Health Research Authority integrated research application system (IRAS) has helped to streamline health research approval applications, the additional steps required prior to and after approval have multiplied. There appears to be little communication between the different approvers and no accountability or recourse for delays. This includes a lack of integrated procedures between universities and hospitals (10) and between different hospitals, where studies that require access to multiple NHS sites need to navigate different processes and checklists for each site.

Despite NHS research being nominally centralised, systems are fragmented and siloed. Fear of misuse of data, while noble, has led to a pervasive culture of risk aversion and counter-productive levels of oversight. Increasingly, approvers at each stage try to cover the responsibilities of other stages in the pathway leading to a proliferation of steps, forms and layers to approval. Approval processes should instead be designed so that each approver can layer their approval on all the aspects already approved.

These issues are well known. Ben Goldacre's government commissioned review calls out the irrational duplication in NHS approvals (8). The Sudlow review of the UK health data landscape identified several barriers including the complexity and fragmentation of the system and capacity gaps following a loss of specialist staff (9). For prospective trial data collection, the O'Shaughnessy report (11) highlighted that the number of patients enrolled onto NIHR-supported commercially-led studies nearly halved from 50,000 to 28,000 a year between 2017 and 2022.

For the many researchers who face difficulties through this process, they are either once bitten twice shy, or never even try to undertake health services research due to the difficulties involved. The enormous potential of health research in England is all too rarely being realised.

The way forward

To act on a problem one needs to understand its extent – and cost. The problems have been well documented, but there needs to be formal tracking of the cost and extent of delays. A coalition of health research funders could capture these markers. Data controllers themselves ought to record, make public and be accountable to their timeframes for approval and data release. Mapping all the current approval processes and avoiding duplicating them, so that there is one common application form or standard components for all ethics, information governance, and other permissions is one obvious step (8). Another is better communication between different data controllers/processors and between them and researchers, with named contacts to help unblock problems.

The platforms set up during the covid-19 pandemic (5,12) show what can be done if the will is there. The absorption of NHS England functions within DHSC provides an opportunity to strategically rethink health research governance. This is an opportunity for genuine centralisation and simplification – a re-imagining of the system. The focus must be on enabling ethical, secure research *swiftly* to enable genuinely transformative research.

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