What Medicare for All could mean for US medical research: Lessons from the UK

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Healthcare in the United States is currently provided and financed by a variety of public and private institutions, resulting in a fragmented healthcare system. However, proposals to transition to a single-payer system are circulating in the House and the Senate, and a number of candidates for US President have committed their support to “Medicare for All” in some form.[1] If support for an expanded or exclusively single-payer system continues to grow, it is worth considering the impact of this potential transformation of the US healthcare system on clinical care and medical research. While the implications for cost, patient satisfaction and outcomes, and equity are worth serious consideration, so, too, are the implications for medical research.

Unraveling the specific pathways by which diseases develop is vital for targeted treatment, prevention, and drug development. For some disease-exposure relationships (eg ischemic heart disease and smoking), large observational studies (ideally involving >100,000 participants) can provide definitive evidence on their association (and, increasingly, novel methods like Mendelian randomization can further support causality). Large-scale clinical trials (often involving >10,000 participants) are needed to confirm or refute the possible benefits and side effects of treatment (eg statins for the prevention of cardiovascular disease). In both cases, a national single-payer system may dramatically improve the scope, cost-effectiveness, and hence potential impact of these studies. For decades, Nordic countries like Norway and Sweden have shown how nationalized healthcare systems and their centralized health registries can be used to conduct standard-setting medical research. More recently, other countries with single-payer systems have developed novel approaches to maximize the research potential of these databases. Here, we describe examples of how the UK’s single-

payer system, the National Health Service (NHS), has enabled and improved medical research, and how these lessons might translate to the US if a single-payer system were to be adopted.

Consider the UK Biobank, a prospective cohort study of 500,000 adults aged 40-69 years when recruited in 2006-2010. Established to study the potential genetic and non-genetic causes of a wide range of conditions, the study collected information on lifestyle habits, personal and family medical history, physical measurements, and samples of blood, urine, and saliva.[2] Physical specimens could enable a thorough examination of genetic, genomic, metabonomic, and proteomic disease pathways, while further detailed phenotyping in a subset of participants will further characterize a wide range of exposures. Crucially, thanks to the NHS, the study's comprehensive exposure data are linked reliably to detailed information on the future health events of these participants through electronic health records and other data sources.

NHS Digital, the data informatics and IT branch of the NHS, collates and curates healthcare information nationally. It produces a database of all admissions, emergency visits, and outpatient appointments at NHS hospitals in England (including privately-insured patients treated in these hospitals), collectively known as Hospital Episode Statistics (HES).[3] HES data include demographic information, diagnoses, procedures, and geographical and administrative details about when and where care was provided. Further strengthened by linkage to national cancer registries, death registries, data from general practitioner clinics, and other data sets, this follow-up information is a critical part of what makes studies like UK Biobank so powerful.

In the US, this healthcare information is currently spread across a number of healthcare providers and is consequently processed and stored in varied formats, making systematic follow-up difficult. This may be one of the biggest limitations of large prospective studies being conducted in the US. The All of Us Research Program, a prospective study similar in ambition to the UK Biobank, is currently seeking to establish a cohort of one million US adults prospectively followed for health events in the coming years. Like UK Biobank, exposure information promises to be exceptional. Follow-up, however, will rely on novel methods to access and standardize participant health records longitudinally.[4] This will require substantial ingenuity and effort, and its systematic feasibility remains to be seen, especially in the long-term. The adoption of a more centralized healthcare system could remedy the current challenges in comprehensive, long-term follow-up in such observational studies. Given that these studies are only as precise as the exposures and outcomes they capture, the implications for research are considerable.

The UK's single-payer system has also streamlined the conduct of clinical trials. For example, the ASCEND (ASpirin for Coronary Events iN Diabetes) randomized controlled trial leveraged the UK's consolidated healthcare system to simultaneously expand the size and reduce the cost of the trial.[5] ASCEND is a randomized '2 × 2 factorial design' study of aspirin and omega-3 fatty acid supplements for the primary prevention of cardiovascular events in people with diabetes. Potential participants were identified from diabetes registers in the UK – held both centrally and locally at general practices (primary healthcare centers) – and subsequently invited to participate by mail. This methodology allowed for the study to be conducted entirely

by mail: study participants were sent treatments by regular mail and followed-up by mail and through central registries. The result is one of the largest-ever randomized trials among people with diabetes, with more than 15,000 patients ultimately recruited and followed up for an average of 7 years. Such a trial would normally be expected to cost hundreds of millions of dollars, but by working in partnership with the NHS, ASCEND was conducted for less than £10 million (approximately $13 million).

In addition to lowering the costs associated with trial recruitment and follow-up, use of a centralized health information system like that of the NHS may address two other major limitations in trials: slow recruitment and short follow-up times. Identifying eligible participants individually as they present with disease is a slow process. As evidenced by the ASCEND trial, however, individuals for whom these trials are relevant, and potentially beneficial, can be identified systematically and on a large scale outside of the clinical setting.

Ongoing research is being conducted to systematize this approach to even more quickly and reliably enroll patients eligible for clinical trials. Similarly, this linkage to routine health records reduces, and in some cases may eliminate, the need for costly active follow-up of participants, allowing longer-term monitoring of trial outcomes. Thus, with careful planning and execution, the NHS's health information system is being harnessed to conduct trials at a larger scale, more rapidly, at lower cost, and with potentially longer follow-up, than would otherwise be possible.

These two examples of how the NHS has strengthened medical research illustrate some of the potential benefits of conducting both observational studies and randomized, controlled trials within a single-payer system. Of course, there are limits to how these examples might translate to the US depending on a number of factors, namely, whether a single-payer system is ultimately adopted, the specifics of its design and implementation, and public support for this use of the data for research. Although many surveys and other health data sources are already extensively used for medical research in the US, including Medicare data, concerns raised by public and private actors would have to be addressed. For example, the loss of data confidentiality through participant re-identification or as the result of a data breach is unlikely, but possible. Further, the possibility of participants' information being sought by third parties for legal claims (eg, using DNA for criminal investigations), or for-profit activities (eg, by pharmaceutical companies), merit consideration.

In summary, partnership with the NHS has substantially strengthened medical research in the UK. If the Medicare for All movement gains traction, its possible consequences are worth serious consideration. If lessons from the UK are any indication, the possibilities for medical research, at least, are promising.

References

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