Using routinely collected data for patient benefit

My Cancer Research UK funded PhD in May 2022 on lung cancer diagnosis was conferred with a recommendation of research excellence. My research has focused on ways to utilise routinely collected data to inform clinical decision making and to widen our understanding of commonly used tests for cancer. Five papers resulting from my doctoral research have been published.(1-5) Having established that the available evidence for chest x-ray in lung cancer diagnosis was extremely limited with data on only 380 patients from high quality studies.(1) I undertook studies using clinical datasets to glean a much more comprehensive understanding of chest x-ray. This included a study using routinely collected data from a hospital trust, to estimate the sensitivity of chest x-ray with a much larger sample than the entirety of the literature to date (n=2192 compared to n=380 identified in previous studies) thereby generating a much more precise estimate of the tests' performance.(2) This study also demonstrated that patients with a 'negative' result on initial chest x-ray experience a substantial delay to diagnosis (an additional 161 days compared to those with a 'positive' result). Subsequent studies used data from an innovative self request chest x-ray service, which collected data on symptoms, to estimate the risk of lung cancer for those who had a negative chest x-ray for particular symptoms.

Finally, a study which used innovative methods to analyse the NHS's Diagnostic Imaging Dataset using additional from general practice profiles and NHS general practice staffing information, revealed a substantial variation in the utilisation of chest x-ray by general practices even after accounting for chance and recorded characteristics of the practices. Surprisingly, we found that only 18% of the large variation that exists (median rate of 34 chest x-rays per 1000 patients with interquartile range of 26-43) could be accounted for by all recorded characteristics (for example deprivation, smoking status, co-morbidities), thus suggesting that practices that utilise chest x-ray much less frequently than other practices could avail of more opportunistic testing, for example in patients that mention symptoms like cough when presenting for other problems.

Following my PhD research I have completed a study linking data from the Diagnostic Imaging Dataset to the National Cancer Registry, which is currently under peer review. This major study, which linked data on over 100,000 lung cancer patients with data on around 7,000 General Practices, has demonstrated that patients with lung cancer which use chest x-ray more frequently are diagnosed at earlier stages of disease and have improved survival. The results from this study have been presented at this year's Cancer in Primary Care conference (Ca-PRI) in Oxford, which has led to discussions with NHS England's diagnostics team as to how to ensure practices data on chest x-ray utilisation is made more widely available and how GPs can be encouraged to more readily investigate patients with possible lung cancer symptoms.

The impactful work on routinely collected data undertaken in my PhD has prompted a re-evaluation of how lung cancer should be diagnosed and has has informed important policy outputs from organisations including NICE(5) and Health Safety Investigation Branch(6) which in turn led to a major funding call from NIHR Health Technology Assessment.(7) I am leading a multi-disciplinary team which is applying for this funding call, having succeeded at stage 1 we expect to be notified of the final outcome in November.

In addition I am have recently been successful with a radiology colleague in obtaining grant funding to utilise thousands of general practice request chest x-ray images, linked to clinical outcomes data, in order to create a platform to evaluate the accuracy of commercially available artificial intelligence systems. Such research is urgently required given that such systems are now available to NHS services, but there is little independent validation of the performance of these systems. By

demonstrating how accurately these systems perform in detecting lung cancer we hope this will also create a dynamic whereby vendors of such systems compete and improve the performance and accuracy of their products. We expect this work to be timely as the need for independent validation of AI systems is likely to be a theme of a NICE assessment which is due to publish its findings soon.(8) Other aspects of AI other than performance of the technology itself are also vital to implementation, such as the views of patients. I have co-authored a review of the available evidence on this issue.(9)

Education, policy and advocacy

I have turned the insights generated from working with routine data to deliver wider benefits for benefits, the health service and society more widely. On starting my PhD, I authored a review paper in order to share the insights I had gleaned to serve as a 'primer' for benefit of other researchers using primary care data.(10) This paper has been cited nearly 30 times and I have received informal positive feedback from several colleagues noting how helpful the paper was in summarising data flows in primary care. Since 2022 I have taught on the Health Informatics with Data Science MSC at the University of Leeds and have received positive feedback from students and course leaders.

In using healthcare data I have become convinced that these important assets need to be curated and made accessible for the public good. In the second year of my PhD I was award the Doug Altman award (BMJ/Centre for Evidence Based Medicine Oxford) for proposals on improving research including through openly sharing protocols, research data and code. This led to a campaign based on these proposals (www.ImproveHealthReserarch) a review paper detailing proposals including sharing of code and other data, which has gone on to be cited almost 40 times.(11) I also co-ordinated an evidence submission to the House of Commons Science and Technology Select Committee inquiry on research integrity and reproducibility outlining measures including data and code sharing to reduce research waste and to improve transparency.(12) This submission, which was subsequently published in a separate review paper,(13) was extensively quote in the committee's final report.(14) In my own research practice I have endeavoured to make data and protocols available for scrutiny and so that they may be used by other researchers, reflecting a level of transparency and sharing that far exceeds contemporary standards.(15-17)

I have also published a paper in BMJ on the need for the value healthcare data to be considered when sharing data with commercial partners.(18) This publication, which prefigured and anticipated many of the principles for the Value Sharing Framework for NHS data partnerships(19), led to meetings with NHS England's Centre for Improving Data Collaboration and the leadership of a major London NHS hospital trust to discuss their data strategy.

Currently I am working on a further policy paper on health informatics, which will address the need for greater competition in the provision of Electronic Health Record systems, in order to drive improvements in user experience and innovation of these systems, particularly in primary care. Prof Bob Wachter has agreed to co-author this paper along with Dame Professor Carol Propper (an expert on markets and competition).

In my current leadership role of clinical lead for cancer for Leeds Integrated Care Board, covering a population of around 880,000, I am deploying the insights I have gained through my research to make data available to leaders and front line clinicians in the health system. This includes a programme to package up to date data on cervical screening attainment in an accessible way to general practices in order to incentivise progress to greater screening uptake (CASCADE) and a project ensure that data used as metrics to judge performance of cancer services incorporate are adequately adjusted to account for chance variation. I expect both projects could have important lessons for health leaders nationally.

Proposed Oral Presentation

Should I be awarded the Hildi Franke Prize I would be delighted to deliver an oral presentation that would provide an overview of my research using routinely collected data before explaining how these insights have informed my wider work and advocacy with respect to health informatics including campaigning for open data and recognition of the need to protect the value of healthcare data for the public good and my ongoing work on the need for competition in the market for electronic health records. I would also (briefly) summarise how what I have learned about using data in research, including validation and adjustment, applies to responsible utilisation of routinely collected data in health service leadership and has informed my work in Leeds Integrated Care Board.

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