



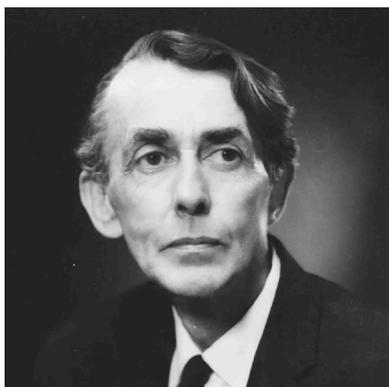
Improving health with data

Christopher Exeter

Brendan Krause

Joshua Wheeler

Why Titmuss?



In 1970, Richard Titmuss, Professor of Social Administration at the London School of Economics and Political Science (LSE) published *The Gift Relationship: From Human Blood to Social Policy*.

Richard Titmuss was born in 1907 and left school at age 14 with no formal qualifications. Despite lacking an academic degree, Titmuss pursued an interest in social topics through reading, debating and writing. His initial concerns were with issues such as insurance and the age structure of the population, migration, unemployment and rearmament, foreign policy and the peace movement. *Poverty and Population*, his first book, was published in 1936 and focused on the relationship between preventable death and poor diet as well as other environmental factors. In 1942, Titmuss wrote a volume in the civil series of the official war history, *Problems of Social Policy*. This led to his appointment at the LSE, where he became the first Professor of Social Administration. He held this Chair until his death in 1973.

The Gift Relationship centres on altruism and the connections between individuals, social benefit and public institutions. In the book, Richard Titmuss uses the topic of blood donation as a case study and explores who blood donors are and what motivates them to donate their blood. He provides a study of social relationships and examines the place of human beings in mass societies.

It is through the lens of altruism that this paper considers the use of properly governed personal health data for research in the pursuit of meaningful and rapid improvements in health outcomes. In short, the use of data for the good of the population as a whole.

Preface

**Professor Sir Julian Le Grand,
Former Richard Titmuss Professor of Social Policy, The London School of Economics and
Political Science**

My distinguished predecessor at the London School of Economics, Professor Richard Titmuss, was a key thinker in the development of welfare states throughout the world. But perhaps his most lasting contribution was a book — *The Gift Relationship: From Human Blood to Social Policy* — dealing with an even more fundamental issue: the role of altruism in a market-oriented society.¹

The central idea of *The Gift Relationship* was that, if the aim is to persuade individuals to part with something that is socially valuable but whose quality is difficult to assess, it is often dangerous to rely upon their self-interest either through market incentives by paying to buy the item in question, or through government compulsion, such as by regulation with penalties for non-compliance. This is because in these circumstances the individuals concerned have an incentive to conceal any quality defects in the item concerned — or, in the case of government regulation, to even conceal their ownership of it. Instead it may be preferable to appeal to people's desire to help: to present a gift. This is partly because for most people the desire to help is a strong motivating factor — one whose strength is often underestimated. But, even more importantly, because donors aim to help recipients, they have no incentive for concealment of either quality or of the item itself. Hence the item supplied is likely to be more in quantity and higher in quality. Titmuss concentrated his critique on the market and illustrated his points with the example of the system of voluntary blood donation in the UK, which he argues provides both higher quality and more blood than the system of paying for blood that was then largely prevalent in the US.

The clever idea in this paper is to take Richard Titmuss' arguments and apply them in a new and rather different area, one that is of equal if not more importance for improving health and healthcare than blood: data for research. Despite the enormous opportunities for data collection and use offered by an organisation that is national in scope, the story of data availability in the NHS is a miserable one, with both patients and staff becoming increasingly resistant to top-down pressures to 'release' their data — even when it is explained that the data in question will be anonymised and used for research purposes only. The proposal put forward here is that use of an individual's data is altruistic as it can be used to benefit the population as a whole. Following Titmuss' argument this could lead to better quality and greater quantity of data.

Of course, there will have to be safeguards and, with such safeguards in place, there is a real opportunity to use this idea to escape from the cul-de-sac in which the NHS currently finds itself in this area.

I commend the paper's authors and OptumLabs® for their inspiration and initiative in developing this idea and putting the proposal forward as a 'gift'. I believe that it could form the basis of a relationship between data donor and data user that will prove fruitful for both them and wider society as a whole.

The clever idea in this paper is to take Richard Titmuss' arguments and apply them in a new and rather different area.

1. Titmuss R. *The Gift Relationship: from Human Blood to Social Policy*. George Allen & Unwin: London; 1971.

Introduction

The quantum of health data generated through the provision of health and care services has reached critical mass in recent years, providing a profound resource for significant advances in prevention and treatment of disease. As much of this data comes from the real world of direct patient care, observations can be made retrospectively regarding various combinations of conditions and different patterns of care that patients actually experience. The UK is seen as being in a unique position for research, with the single general practitioner-held medical record and the unique patient identifier, the NHS number. In addition, however, we are seeing a diaspora in the sources of health data as wearables and smartphones collect increasing quantities of largely unstructured data.

Connecting healthcare data to other public sources, for example, socioeconomic and demographic data, can give meaningful insights into not only healthcare interventions but other important factors that contribute to the health and wellbeing of people and communities. Analysis of linked data through traditional statistical methods as well as innovative data science techniques such as machine learning presents researchers, clinicians and policymakers with an opportunity to speed both the discovery and translation of new clinical interventions, bringing with it meaningful improvements both to patient care and to health outcomes.

The use of data is not new, and has been an essential ingredient to improving healthcare delivery and public health. It was during the Crimean War of 1853 that Florence Nightingale collected statistics proving much of the mortality encountered by the British Army was down to the condition of hospitals away from the battlefield.² These statistics were later analysed by statistician William Farr and epidemiologist Thomas Rowe Edmonds, leading to the creation of the modern discipline of statistics in the assessment of public health.³ Around the same time, the Chief Engineer of the London Metropolitan Board of Works, Sir Joseph Bazalgette developed the London sewerage system in view of new thinking about the spread of infection.

However, the use of personal health data for research has become a complex issue in the UK and in particular, England, with polarised views about how and why the data is being used, and the governance arrangements for accessing personal information. This has the potential to threaten both patient and population health benefits that research and medical innovation promises. Whilst a substantial proportion of the UK population are agnostic about the subject of health data for research, a significant group are concerned — or at the very least confused — about the extent to which data generated from their encounters with the health system is used, even for their own care. This confusion is compounded by the complexities of the language used to describe different types of data by policymakers and researchers.

This particular concern was strongly expressed in the public's negative response to care.data, an initiative by NHS England to enable the use of health data for purposes ranging from direct care to research, which had to be abandoned due to a loss of public confidence. Poor communication and a lack of transparency were seen to have hindered the project, and subsequently hindered progress. Data released by NHS Digital suggests that one in 45 people or 2.2 percent have opted out of the sharing of their patient-identifiable information.⁴ Whilst the impact of the opt out is difficult to anticipate, there are concerns on the impact of high opt out levels on the robustness of research.

2. Nightingale F. Notes on Matters Affecting the Health, Efficiency, and Hospital Administration of the British Army: Founded Chiefly on the Experience of the Late War. By Florence Nightingale. Presented by Request to the Secretary of State for War. Harrison and Sons, St. Martin's Lane, WC; (1858).

3. Eyles J. "Constructing vital statistics: Thomas Rowe Edmonds and William Farr, 1835–1845." *Sozial-und Präventivmedizin*. 2002; 47(1): 6-13.

4. NHS Digital. Care Information Choices, May 2016. content.digital.nhs.uk/catalogue/PUB20718. Published May 17, 2016. Accessed May 11, 2017.

Recent polling of public opinion shows that in some circumstances, people see a public benefit if their data is used to benefit others as well as themselves. In the 2016 Wellcome Trust report, survey respondents demonstrated an openness to their data being used to help other people, but expressed strong preferences regarding how and by whom this data was collected, stored and used.⁵ A recent report by the Health Research Authority showed that 97 percent of the public think such health research is important.⁶

In England, the National Data Guardian's review of information governance provides clarity on the requirements for consent and the way opt out arrangements for research are communicated, potentially addressing some of the public's confusion.⁷ In their response to this review, the Government supported the National Data Guardian's view on consent, and the strengthening of controls around the use of anonymised data.⁸ The Royal Society and the British Academy's recently published paper, *Data Management and Use: Governance in the 21st Century*,⁹ and the UK Government's recent Digital Strategy seek to understand the principal social and ethical aspects of data governance.¹⁰ The need to get this right was underlined by the Life Sciences Industrial Strategy which calls for the implementation of the National Data Guardian's proposals (July 2016) and a "national conversation with the public enabling a true understanding of data usage" to ensure progress in healthcare outcomes through research.¹¹

Improving health with data, developed by a UK working group, examines and re-casts the public narrative surrounding the use of health data for the purposes of biomedical research, and health system and care improvement in the UK context. Drawing on this altruistic approach, the working group considered how similar socio-ethical debates can be applied to data. The question proposed is whether in the 21st century it is possible to extend the concept of altruism in considering data and its use for the good of the population as a whole.



5. Wellcome Trust. The One-Way Mirror: Public attitudes to commercial access to health data. [ipsos.com/sites/default/files/publication/5200-03/sri-wellcome-trust-commercial-access-to-health-data.pdf](https://www.ipsos.com/sites/default/files/publication/5200-03/sri-wellcome-trust-commercial-access-to-health-data.pdf). Published March, 2016. Accessed May 11, 2017.

6. NHS Health Research Authority. Assessing professional and public opinion of the HRA. hra.nhs.uk/documents/2015/03/assessing-professional-public-opinion-hra-2015.pdf. Published January, 2015. Accessed May 12, 2017.

7. National Data Guardian. National Data Guardian for Health and Care Review of Data Security, Consent and Opt-Outs. [gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF). Published July 6, 2016. Accessed May 11, 2017.

8. Department of Health. Your Data: Better Security, Better Choice, Better Care. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/627493/Your_data_better_security_better_choice_better_care_government_response.pdf. Published July 12, 2017. Accessed Aug. 31, 2017.

9. British Academy and Royal Society. Data management and use: Governance in the 21st century. royalsociety.org/topics-policy/projects/data-governance/. Accessed Sep 1, 2017.

10. Gov.uk. UK Digital Strategy 2017. [gov.uk/government/publications/uk-digital-strategy/uk-digital-strategy](https://www.gov.uk/government/publications/uk-digital-strategy/uk-digital-strategy). Published March 1, 2017. Accessed May 11, 2017.

11. Office for Life Sciences. Life Sciences Industrial Strategy – A report to the Government from the life sciences sector. [gov.uk/government/publications/life-sciences-industrial-strategy](https://www.gov.uk/government/publications/life-sciences-industrial-strategy). Published Aug. 30, 2017. Accessed Sep. 1, 2017.

The environment

Data defines the 21st century. In much the same way as the steam engine shaped the first industrial revolution and the discovery of electricity powered the second and mass computing defined the third, data has become both the engineering and powerhouse that shapes our lives.¹² The difference is that we, as individuals, have a sense of ownership of our data generated through the processes and activities with which we are somehow involved. It is this sense of ownership that at times underpins resistance to the reuse of this data, regardless of the fact that data on its own has little value until it is processed. However, it must be recognised that health data unlike other sources of data, for example financial, is much more personal to the individual.

Deaths from non communicable disease (NCD) have now reached pandemic levels, accounting for two-thirds of all deaths worldwide in 2013.¹³ In addition, the growing burden of disability and days lost due to NCD are having economic consequences. As this shift away from communicable disease towards NCD accelerates, understanding the underlying aetiology becomes more acute. With the rise of NCD comes the increasing prevalence of multimorbid patients, making the need for research to identify the incidence and cause of disease evermore vital.

To care for patients and populations, to enable advances in medical science that tackle and prevent diseases that make us ill and lead to premature death will require deeper analysis and understanding of real world health data. It is essential that societies establish new frameworks that provide people with confidence and assurance in how their data is used and make clear why their data is important. Increasingly, robust examples demonstrate that the study and analysis of data within health systems can bring constructive and beneficial results for patients. In the past, such insights would have required years of prospective clinical trials, but now through large, real world datasets, discoveries can happen at far greater speed. This prevents unnecessary delays in bringing new care models to the clinic, and thus prevents direct harm to patients who would otherwise have to wait for evidence about how best to care for their health needs.



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For example, one recent study published in the *British Journal of Cancer* begins to address why NHS cancer survival rates in England are lower than the European average. It has long been acknowledged that delayed diagnoses have been one of the main reasons behind this lower survival rate. Using the available datasets of Hospital Episodes Statistics and Cancer Waiting Times within the NHS, the study was able to define a methodology to improve the route a patient follows to receive a cancer diagnosis. This methodology can now enable healthcare workers to categorise the different routes that a patient may take to a cancer diagnosis, subsequently allowing more targeted and specified analysis to explain why these routes are resulting in delayed diagnoses within England.¹⁴

Another study using The Health Improvement Network data has shown that a different approach is required to offer the necessary treatment to people with dementia living in deprived areas in England. Analysis of the data has shown that higher overall anti-dementia drug prescribing in Scottish and Northern Irish practices and different clinical guidelines in Scotland may explain greater prescribing equality within these countries.¹⁵

12. Schwab K. The Fourth Industrial Revolution. Switzerland: World Economic Forum; 2016.

13. Smith R, Corrigan P, Exeter C. Countering Non-Communicable Disease Through Innovation. The Global Health Policy Summit; 2012.

14. Elliss-Brookes L, McPhail S, Ives A et al. Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets. *British Journal of Cancer*. 2012; 107; 1220-1226.

15. Cooper C, Lodwick R, Walters K et al. Observational cohort study: deprivation and access to anti-dementia drugs in the UK. *Age and Ageing*. 2016; 45(1); 148-154.

In the US, an observational study using the OptumLabs dataset, a large database including administrative claims data on privately insured and Medicare Advantage enrollees, revealed that caution should be exercised when prescribing patients older than 75 years of age with novel oral anticoagulants due to the increased risk of gastrointestinal bleeding resulting from these drugs.¹⁶

In the UK, data from the Medical Research Council's Cognitive Function and Ageing Study, which began in the 1980s, has demonstrated that dementia is more common than previously thought, rising from 6.6 percent in over 65s to 25 percent in over 85s. Along with showing the need for high quality data to identify prevalence and an understanding of the factors that can modify the risks of developing dementia, the research has also provided data on the costs of informal care to support people with dementia, showing this to be greater than earlier estimates.¹⁷



16. Abraham N, Singh S, Alexander G et al. Comparative risk of gastrointestinal bleeding with dabigatran, rivaroxaban, and warfarin: population based cohort study. *BMJ*. 2015; 350; 1857.

17. Medical Research Council. Economic Impact Report 2015/16. Medical Research Council; 2017.

Public engagement

Drawing on the social relationship articulated by Richard Titmuss, and the question of how, 45 years on, the concept can be applied to the use of data for research purposes, Ipsos MORI conducted a series of focus groups in England and Scotland to explore these questions further with the public. This followed prior Ipsos MORI research commissioned by the Wellcome Trust to examine the public's attitudes towards commercial access to health data for research purposes.¹⁸

Participants showed an initial understanding of the importance of uses of health data. Concerns were most prominently focused on the potentially malicious uses of data by third parties. Opinions were less developed regarding emerging consumer health technologies such as wearable activity trackers and medical monitors, and participants' awareness that these devices produced and collected health data was limited. The focus group saw a link between donating data from their wearable or other devices with blood donation, in as far as there was a choice to contribute one's data. However, people felt that donating blood was far more personal, and that its use helps another person directly and whilst participants found it more difficult to equate this approach with data, the idea nevertheless changed the tone of the discussion about what it means to be altruistic, especially when anonymised. This is supported by the Health Research Authority who found that 71 percent of people felt that the main reason to take part in research was to help society.¹⁹ The focus groups highlighted diseases related to genetic conditions or those that impact large populations, such as Alzheimer's disease, or tackling obesity, in which data sharing could make a difference.

Participants raised concerns which probably reflect this rapidly evolving area: first, was the misunderstanding about how data can help another person; and second, the issue of knowing where data goes once it has been shared — something which could be resolved through improved communications.²⁰

The altruism concept helped to mitigate some initial concerns with data sharing. Namely, it introduced a notion of knowledge and feedback amongst the group regarding the destination of personal data. As described by one participant, this would provide “feedback on what's happened with previous data and what it has helped to achieve.”

71 percent of people felt that the main reason to take part in research was to help society



18. Castell S, Evans H. The One-Way Mirror: Public attitudes to commercial access to health data. Ipsos MORI; 2016.

19. NHS Health Research Authority. Assessing professional and public opinion of the HRA. hra.nhs.uk/documents/2015/03/assessing-professional-public-opinion-hra-2015.pdf. Published January, 2015. Accessed May 12, 2017.

20. Evans H. Public perceptions of health data. Ipsos MORI; 2016.

Health data

There was a distinct perception that health data was already shared within the NHS and participants struggled to differentiate between the use of data for direct care and service improvement. More trusting participants thought that data should be shared within government dependent on the purpose. However, concerns arose on the subject of data sharing in general. This was because participants did not like the idea that either researchers or commercial organisations may use their data to advance initiatives with which they do not agree. Respondents also felt a general unease associated with the loss of control of their data, with one stating, “Once your health data is out there, you’re not in control anymore.” The Health Research Authority reported similar concerns with 28 percent of people worried about privacy and confidentiality, and 27 percent even suspecting a potential risk to their health from research.²¹

Health technologies

Opinions were less developed on emerging technologies such as wearable devices. Participants considered information input to these devices not to be personal data and few had considered the possibility of data sharing. Prominent users of health technologies considered the data collected by devices to be less personal than medical records and therefore felt it to be less risky that this information be shared. These users considered themselves to be in a commercial mindset and categorised this data as transactional.

Respondents’ views were in regard to data generated by three specific technologies.

1. Electronic medical records (EMR)

Participants generally viewed sharing EMR data as positive and something they expected to already be happening within the NHS. However, many respondents expressed security concerns, and less tech-savvy participants could not understand how this data could be used for research.

2. Wearable activity monitors

Participants expressed concerns about the honesty and quality of data, and generally required more explanation as to how this data could be useful. Areas of research identified by respondents as likely to benefit from the use of this data vehicle included obesity, diabetes and heart disease.

3. Medical monitors

Elderly participants saw the benefit of data generated by medical monitors due to the potential for information to be fed back to a doctor. Concern was most focused on the fact that less technologically literate patients would not benefit from their use, based on misconceptions that technology is always complicated to use.

Areas of research identified by respondents as likely to benefit from the use of this data vehicle included obesity, diabetes and heart disease.

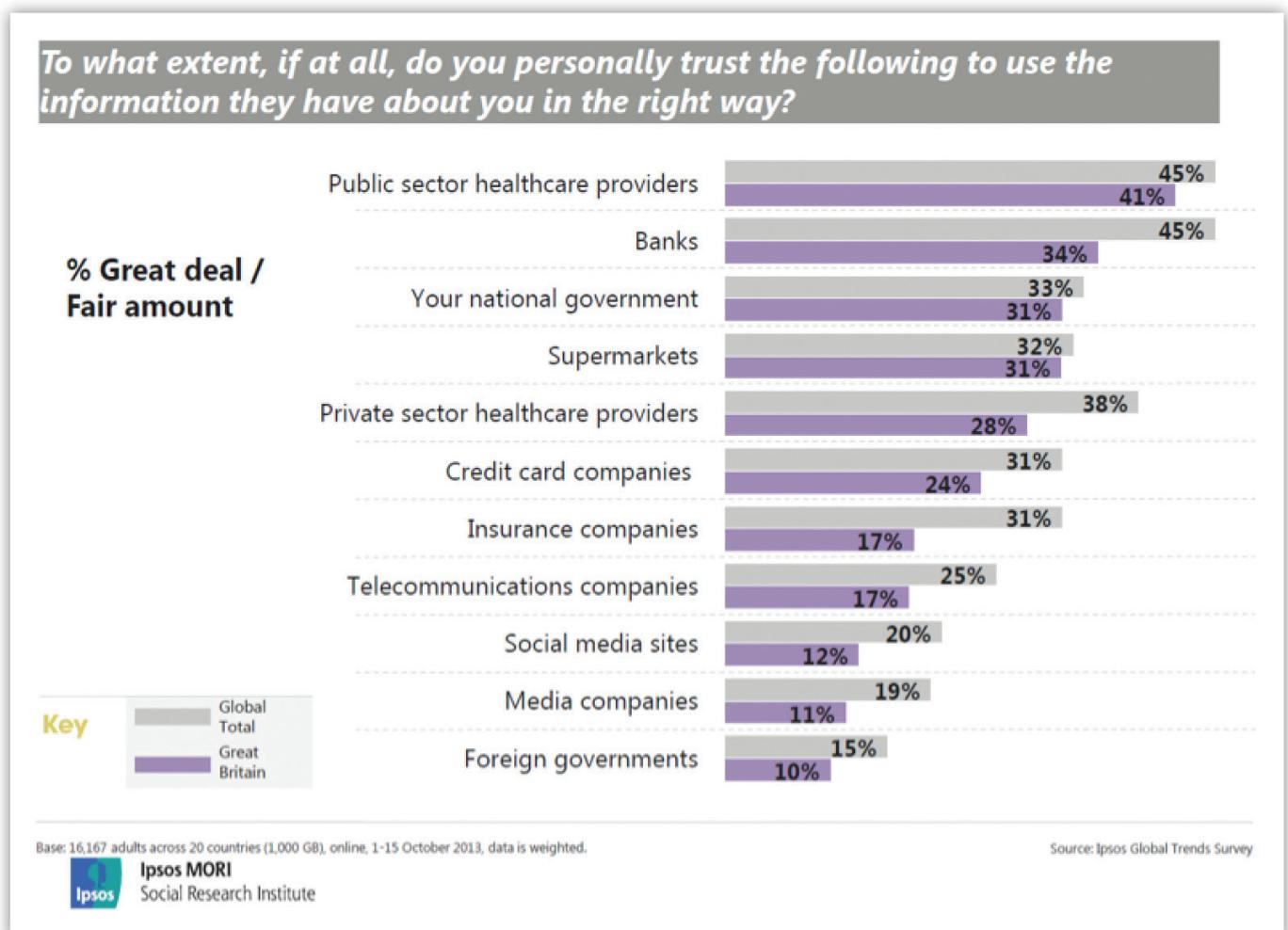


21. Ibid

Data and the NHS

Overall, participants expressed a strong preference for the NHS as the organisation of choice to use and share data. Key reasons for this preference included: the NHS' social purpose, the high trust factor associated with the NHS brand (63 percent of the public are satisfied with the NHS), and the idea that, as a result of its social value status, the NHS is seen as a more trusted authority than commercial entities.²²

The chart below shows that the public's trust with the NHS to use their information appropriately is higher compared to other organisations.



22. The Kings Fund. Public satisfaction with the NHS and social care in 2016 Results and trends from the British Social Attitudes survey. [kingsfund.org.uk/sites/files/kf/media/BSA_final2_Kings_Fund_Mar_2017.pdf](https://www.kingsfund.org.uk/sites/files/kf/media/BSA_final2_Kings_Fund_Mar_2017.pdf). Published March, 2016. Accessed May 12, 2017.

23. Evans H. Public perceptions of health data. Ipsos MORI; 2016.

Conclusion



It is more important to know what sort of person has a disease, than to know what sort of disease a person has.” — Hippocrates (c.460BCE - c.370BCE)

Whilst there was support in the focus groups for the idea that participants’ data could help others, some significant concerns were clear. One participant commented that “blood is donated; data is taken” which points to a trust deficit that surrounds data sharing. That said, the social relationship which exists between the National Health Service and the public suggests that levels of altruism are high, but there needs to be much higher levels of public engagement, taking the public on the journey, rather than pure communication in order to ensure success. This could include clarity around what data is used from medical records for research and how it is used; and that the data is not used as raw material, and requires a form of production for it to be of benefit to research.

Two potential proposals could assist here:

The first is that, the public debate would benefit from a common lexicon amongst researchers and policymakers when explaining how and why health data is being used, whether for direct care or for healthcare improvement at a population or system level. This was one of the significant conclusions drawn from the focus groups, as well as prior research. This must include clear ways of describing concepts such as data governance, data security and anonymisation. There is a general confusion, even amongst experts, as to the use of multiple terminologies. The Understanding Patient Data Group’s recent public attitudes research has provided helpful clarity on the terminology — and images — that the public find acceptable and meaningful.²⁴

The second is that there is an appetite from the public to receive feedback on how data is used for research. This needs to be capitalised upon and will help with providing a focus for improving engagement. Whilst both scale and the concept of anonymisation negates direct feedback, one of the public bodies responsible for research should produce an accessibly written annual report to the public on how data was used in clinical research, its impact and the benefits to health outcomes. Similarly, regularly sharing or even promoting examples of data sharing resulting in improvements in patient care could strengthen understanding of and support for research using health data. There is a public interest in health research; the fact that half a million people have volunteered to share the clinical and genomic data through UK Biobank demonstrates this fact and underscores the importance of openness with the public regarding research protocols and activities.²⁵

One focus group participant said that “no one will die if you don’t give up all your data.” Clinicians, policymakers and researchers have both the profound opportunity and responsibility to make the case that data can — and does — save lives every day. It is incumbent upon all healthcare stakeholders to call for meaningful action that establishes transparent protocols for the ways in which data will be protected and used, and how this use will bring benefits to patients and communities as rapidly as possible. More creative approaches should be considered: Alongside the National Data Guardian’s recommendations for consent, public interest could be increased

24. Understanding Patient Data. Patient Data Finding the best set of words to use Summary of findings. understandingpatientdata.org.uk/sites/default/files/2017-04/Data%20vocabulary_Good%20Business%20report%20March%202017_0.pdf. Published March, 2017. Accessed May 12, 2017.

25. UK Biobank. Participants. ukbiobank.ac.uk/participants/. Last updated Aug 23, 2017. Accessed Sep 1, 2017.

through, for example, encouraging donation of physiological data collected on wearables and smartphones or potential donation at death could be considered with proper safeguards.²⁶

Finally, as Hippocrates noted c2,500 years ago, the importance of knowing the sort of person that has a disease needs to be re-established as a core element of modern healthcare systems. This is brought front and centre with the epidemiological transition from communicable to non communicable disease as the pre-eminent cause of illness and premature death, and in particular the increasing prevalence of multimorbidities in patients.

Much more needs to be done to not only articulate the importance of data for research, but more widely how services can be reshaped and redesigned to prevent disease. Public involvement is essential. As is the public's active participation in the research process, and helping them understand how their data benefits both them and society. Further work is required: it is no less a task than the 19th century infrastructure projects to alleviate disease through poor sanitation and unhealthy living conditions.

Data, managed correctly, is the new engineering needed to the address these diseases and the health needs of the coming century.

26. National Data Guardian. National Data Guardian for Health and Care Review of Data Security, Consent and Opt-Outs. [gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF). Published July 6, 2016. Accessed May 11, 2017.

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Joshua Symons, Director, Big Data and Analytical Unit, Imperial College London

David Walker, Deputy Chair, Central and North West London NHS Foundation Trust



T 020 7121 0560 | E info@optum.co.uk | optum.co.uk
10th Floor, 5 Merchant Square, Paddington, London, W2 1AS