
Unlocking the value of healthcare data

The final report of the
Sowerby Commission



**Imperial College
London**



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Forward from Ara Darzi

Having the right information available is critical for providing good patient care. When multiple professionals and organisations are involved, sharing accurate information promptly is essential for integrating care for the individual patient. Analysing the data gathered while caring for patients is, furthermore, essential for understanding whether the best possible care is being provided, identifying how it could be improved and finding new treatments through research. Analysis can also reveal how healthcare systems can be run more efficiently. Many policymakers and clinicians consider better information sharing and more efficient use of the data in electronic health records (EHRs) to be important elements for providing safer and more effective healthcare that meets the challenges of financial constraints, increasing numbers of people with long-term illnesses and an ageing population.

The last few years have seen a surge of new digital technologies being used in healthcare, and as a consequence, ever-larger quantities of data are being generated. What is unique about the NHS, however, is the amount of valuable longitudinal data collected throughout various points in a person's healthcare journey. The potential that this data currently holds is not fully appreciated, but more and more, the NHS, like other healthcare providers, is being approached to share the data, with the promise of new and innovative solutions to longstanding problems and, possibly, the cures for conditions. The potential for data and artificial intelligence to revolutionise healthcare is incredible.



Professor the Lord Darzi of Denham OM KBE PC FRS

In February 2013, Dr Peter Sowerby — who established the Sowerby Foundation and co-founded EMIS, a supplier of clinical information systems to GPs, hospitals and pharmacies in the UK — and his wife Ann announced the provision of a grant to the Institute of Global Health Innovation (IGHI) at Imperial College London. The purpose of the grant was to establish the Peter Sowerby Commission, with the objective of developing a strategy to bring together primary and secondary care data, and then, through the Peter Sowerby Forum at IGHl, to seek to ensure the proposals are implemented and to open new avenues for research to improve patient care.

The present report summarises the work over the past five years. The Foundation's principal aim is to have a lasting impact by supporting well-researched initiatives that can effect positive changes; through our work, we can demonstrate that this is indeed the case for both patients and professionals. Our work is wide-ranging and has led to significant achievements — including support during the set-up of new endeavours such as the NHS Digital Academy and new areas of work such as cybersecurity in healthcare. In the process of delivering this commission we are making faster and more concrete progress, and in the process are improving the standard of care.

We need to work together to understand how the NHS, universities and researchers can gather and make the best use of the data to improve care now and in the future, forging ahead at a faster pace and with an unprecedented degree of innovation.

We are grateful to the Peter Sowerby Foundation for making this commission possible and to the trustees for their knowledge, advice and support over the years.

Forward from David Aspinall



The Peter Sowerby Foundation established the Sowerby Commission at Imperial College in 2013 with a major grant over five years. The Commission, which is now concluding, explored how the use of electronic health records, healthcare data and health informatics policy could transform the way that the NHS delivered safe and effective patient-centred care.

The associated Symposium has given crucial momentum to the development of digital innovation in health that is indispensable for the future sustainability of the NHS. It has been essential in demonstrating the vital importance of medical records and in arguing that electronic health records are essential to high quality care, helping to give patients more control, reduce the risk of harm, improving communication, assisting the management of chronic disease and providing a resource for the development of new treatments.

The Foundation is delighted to support the conclusions evidenced in this publication *Unlocking the value in healthcare data: The final report of the Sowerby Commission*. Understanding the pros and cons of digital health information is a big workforce issue - currently run by experts, researcher, early-adopters & entrepreneurs. It needs to be devolved to informed health professionals (who must advise patients appropriately). There is of course a societal/citizenship challenge but the medical, nursing and allied colleges need to get ahead of the curve - for the sake of professional ethics & harnessing the potential of digital health.



David Aspinall, Chair of Trustees, Peter Sowerby Foundation



Sharing records is vital

Good records are as essential to good care as the thermometer and the stethoscope. Yet most medical records are separated into siloes – in a GP’s surgery, the hospital and community and social care provision. A record that can only be seen by one member of the healthcare team – the GP, say – is of little use when the patient is admitted to the care of another, such as a hospital. The barriers that divide them are partly technical and partly cultural.

The Sir Robert Francis inquiry into the care delivered by the Mid-Staffordshire NHS Hospital Trust, published in 2013, highlighted the case of Gillian Astbury who died ten days after being admitted with a fractured hip in 2007, from what the coroner described as a “systemic failure in the most basic tenets of patient care: proper handovers between staff and proper record keeping.”

Ms Astbury lapsed into a coma after medical staff failed to record that she was diabetic and needed regular injections of insulin. Seven years after her death, in April

2014, the trust was fined £200,000 for breaching health and safety law. Had she had an electronic health record, detailing her diagnosis and medication consistently across the different care settings and through rotating shifts of healthcare professionals, she might be alive today.

The digitisation of medical records making them easier to share has reduced catastrophic errors like this. But more broadly, the introduction of record sharing schemes is transforming the medical landscape by improving care. In Scotland there was a 40 per cent fall in amputations among diabetics, following establishment of the diabetes collaboration database used to help manage the care of 288,000 patients. When electronic prescribing data was fed back to staff at Birmingham University Hospital, the proportion of patients receiving antibiotics within agreed time limits rose from 30-40 per cent to 90 per cent, reducing their length of time in hospital. The information contained in medical records has the power to improve care as much as any breakthrough drug.



The Peter Sowerby Foundation

The Peter Sowerby Foundation established the Sowerby Commission in 2013, with a £2million grant over five years, to explore how the use of electronic health records, healthcare data and health informatics policy could transform the way the NHS delivered safe and effective patient-centred care to people. The Sowerby E-Health forum subsequently built on the recommendations of the Commission through a number of initiatives examining the potential for primary and secondary care data integration to improve service delivery, healthcare research and population health.

We began by focusing on three domains:

- Patient Engagement: Conducting research into patient accessible electronic health records and understanding professionals’ and patients’ attitudes toward patient access and its impact.
- Integrated Clinical Delivery: Leveraging the linked data resources provided under the Clinical Practice

Research Datalink to conduct high-impact research with a clinical focus.

- Policy Intelligence: Conducting research and providing advice regarding the benefits and impact evaluations crucial to making worthwhile investments.

Over the course of the five-year programme, our focus has broadened to encompass e-health, digital technology and informatics. The Sowerby E-health forum has served as a critical hub that has leveraged funding from other sources, launched multiple research initiatives and made numerous innovations in the digital health arena. Among its major contributions has been establishment of the Big Data and Analytical Unit (BDAU), that ensures the maximum use, impact and dissemination of research using healthcare data; this has been a vital component of many projects.

In these ways the forum has given crucial momentum to the development of digital innovation in health that is indispensable for the future sustainability of the NHS.

Linking primary and secondary care data

We recognised the importance of data linkage from the start, reflected in the title of our first report: *Bringing together primary and secondary care data* to improve patient care, published in 2014.

The theme was taken up by Simon Stevens in his first major speech following his appointment as chief executive of NHS England in 2014. He explained why sharing records was essential, not only to provide safe treatment for individual patients but also to improve care for the whole population.

He cited the example of an unnamed diabetes drug linked to an increased risk of heart attacks, whose risks might have been identified five years earlier, had GP and hospital records been linked.

He also highlighted the one in four cancer patients diagnosed only when they attend A&E – too late and with a worse prognosis than if they had been diagnosed sooner. That was why creating population level databases of records was fundamentally important, he said.

If we could follow a suspected bowel cancer patient from referral for tests by the GP through to treatment by the surgeon, we should be able to remove obstacles on the convoluted NHS pathway, speed their transit and improve the outcome.

The importance of addressing risks

There are risks, however – threats to patient confidentiality, threats from the potential misuse of data by private organisations, and threats to data security. The failure to address these risks, raised as a result of digitisation, has damaged public confidence in the principle of record sharing.

The difficulties encountered by initiatives such as Care data, intended to create a database of medical records showing how individuals had been cared for across the GP and hospital sectors, stemmed from a failure to communicate the benefits of data sharing to a sceptical public who had become alarmed at the prospect of their records being accessed by people beyond the clinical staff directly responsible for their care, and even passed onto commercial companies.

Public confidence in IT organisations took a battering again in early 2018 when it emerged that data from the Facebook accounts of 1 million UK users had been improperly shared with the political consultancy Cambridge Analytica and that an unrelated data-scraping operation had extracted the data of most of the company's 2 billion users.

After a yearlong investigation, we concluded in *Bringing together primary and secondary care data*, published in 2014 before the recent Facebook revelations, that to rebuild that confidence, three measures were necessary. First, the data must be vigorously protected, second, only NHS or accredited academic organisations should be given access and third penalties must be imposed for improper use.



The challenge of data linkage

Aside from the question of public confidence, we recognised that while data linkage was vital, it raised many other questions before it could become a reality. From an IT perspective, there was no open standard on data – each company had its own system and data was held in different places which were inaccessible to each other. Integrating data made little sense when doctors still had to phone to get a patient's scan results.

Obtaining consent for research from the public remains our greatest challenge. That provided the stimulus for our subsequent report, *Shaping data, sharing values*, published in 2017, which called for clear explanations in accessible language of the benefits of data sharing, with robust protection and opt-out options.

The NHS cyber-attack

A key concern is data security. The global ransomware cyber attack in May 2017 which shut down computer systems in a number of NHS hospital trusts starkly demonstrated the vulnerability of the NHS. There is no quicker way of undermining the public's trust than by allowing essential systems to be compromised or personal data to be lost. A Sowerby E-Health Forum workshop in 2017, organised jointly with the Institute of Security Science and technology, concluded more investment, improved governance and greater accountability were essential to protect the NHS from future attacks.

The work begun by the Sowerby E-Health Forum is therefore ongoing. It has provided a springboard for consideration of issues vital to the future health of individual patients and of the population. Maintaining the security of patient data is paramount. But so too is maintaining the ability to share it among those committed to advancing medical knowledge. We must manage these twin aims for the sake of all those who depend on the NHS.

Which are the demonstrated benefits of EHR-based data sharing interventions?

	Patient-centredness	Effectiveness	Safety	Efficiency	Timeliness	Equity
Short-term	Patient experience e.g. PREMS	Health outcomes e.g. HbA1c	e.g. detection of medication discrepancies	Cost-effectiveness analysis	e.g. appointment delays, time-to-diagnosis	e.g. discrepancies between groups
Long-term	Perceived self-efficacy	Safety e.g. medication discrepancies		Proxy measures e.g. number of appointments		

1. Putting patients in control: Care Information Exchange

Giving patients electronic access to their medical records is a vital step in efforts to modernise the NHS.

In part, it will help ensure the records are up to date and accurate, and allow patients to book appointments and order prescriptions. But it is also a key means to encourage them to become more engaged in their care. Harnessing the energy of patients and the public, who have a unique interest in improving their own health, is a huge untapped resource.

In 2014, Imperial College Healthcare NHS Trust launched the Care Information Exchange (CIE) to provide patients and their GPs access to the medical records held about them throughout NorthWest London. Patients were given control of their records and who could access them, and were able to share them with their health and care professionals to give them better care. They were able to enter data such as glucose or blood pressure readings from home, review test results and care plans, and send messages.

Similar initiatives have been tried around the world, including by the Veterans Administration in the US and the health service in Denmark. But engaging patients has not proved easy.

Linked records across NW London

The CIE, funded by the Imperial HealthCharity, was rolled out in North West London from 2014, and used a personal health record web application supplied by the digital organisation, Patients Know Best. CIE is a leading example of digital integrated care, demonstrating the



interoperability of data across the whole NW London Sustainability and Transformation Plan (STP).

The Sowerby team evaluated its implementation and economic feasibility by capturing the perspectives of both patients and health care providers.

The findings from a survey of patients showed viewing test results and scheduled appointments were considered the most useful features, by at least two thirds. More than half wanted to view letters from the hospital to their GP, their diagnostic reports and information on GP consultations. More than one in ten detected errors in their records.

Patients must be empowered

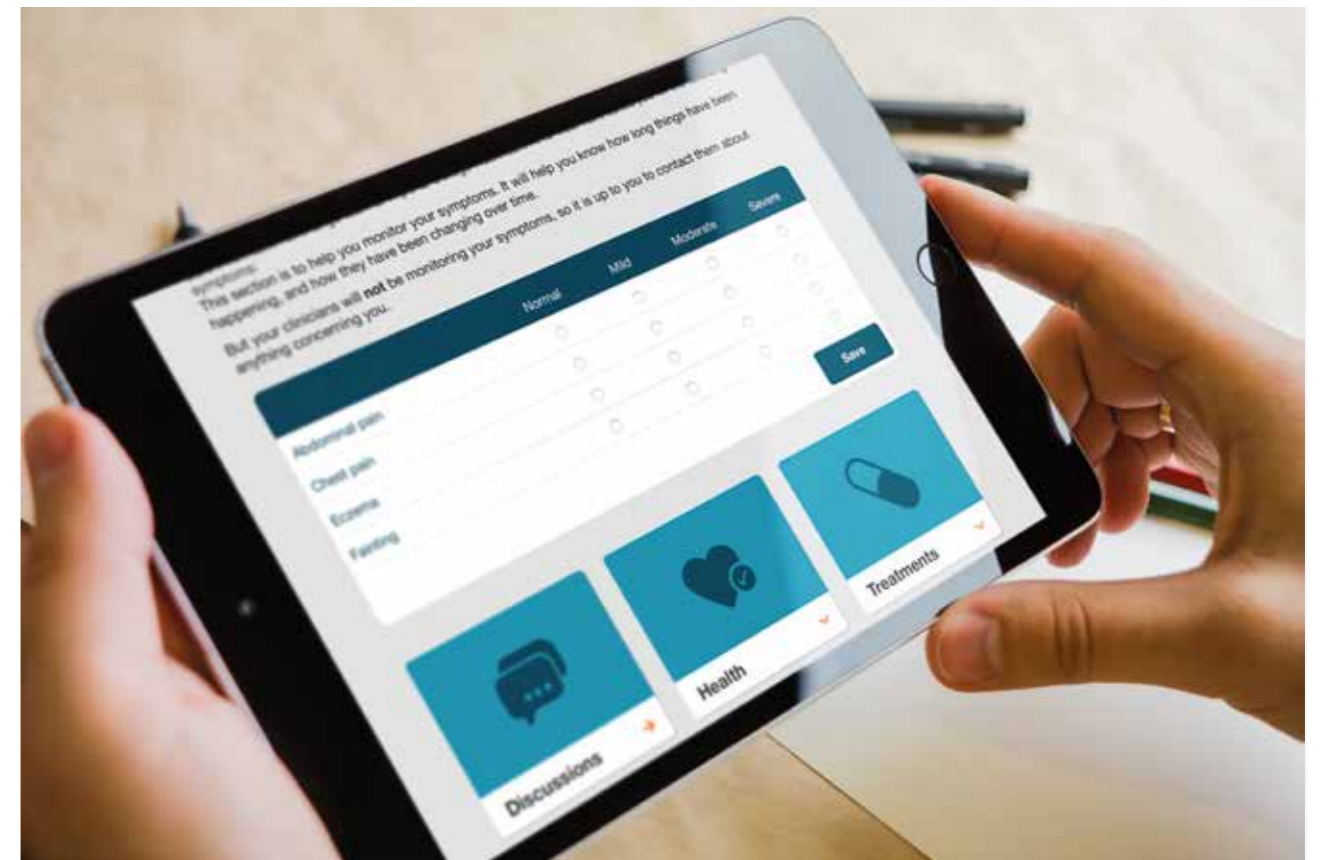
Sceptics have questioned whether providing patients with access to their records can improve health and a systematic review showed the impact on quality of care was uncertain. But the benefits cannot be simply willed into existence. The NHS must also empower patients to make use of their records. Patients need to gain new capabilities so that they can use the new information to make their own decisions.

There is now a growing body of evidence that patients who are more engaged in their care have better experiences of care and better outcomes, that they can be helped to build skills and confidence and that those at the lowest level of engagement tend to increase the most. There is, however, limited evidence about the impact on costs.

This suggests patients should be shaping the release of information, not simply waiting for the floodgates to open. Communities of interested patients and carers, especially those accustomed to self-management of their condition, could take the lead by creating apps and other means of accessing records that are customized to the needs of patient groups. We suggested that a digital “Redbook” – a child’s health record for parents – would be a good place to start and this was endorsed by NHS England’s National Information Board. The eRedbook is now being trialled across the UK.

Doctors fear increased workload

There are doubts among professionals too. Our survey of healthcare professionals showed most (75%) believed it would improve safety and create more patient-centred care. However, almost two thirds of GPs (62%) and more than a quarter of hospital doctors (29%) feared that giving patients access to their records



would increase their workload. Nearly two thirds (64%) believed it would increase patients’ anxieties.

Almost one in ten GPs (9%) said it would make patients’ health worse and less than one in five (19%) believed it would improve their health. Hospital doctors were only slightly more positive with just over one in four (29%) saying access would make patients’ health better.

The goal of the digital NHS is to put patients at the centre of care, making them truly partners in their care and better able to manage their conditions safely, thereby reducing the burden on the healthcare system. Healthcare professionals, however, have an understandable fear that the more patients trawl through their records, search the internet and consult “Dr Google”, the more problems they may bring to the surgery.

Challenges to data sharing

Our reports on the CIE detail what we learned from its implementation and how to maximise the uptake in the future. For some groups it worked well. Renal patients already had an existing web-based system into which they view test results – so CIE was just a change of

platform and uptake among this group was good.

For others there were difficulties. The registration process required a valid email address – but this excluded some groups such as residents of old people’s home who arguably stood to benefit most. It was assumed everyone would use the site in the same way, but both from a patient and clinician perspective and depending on the clinical service, there was variation in which of the functionalities on offer provided greatest benefit.

We also set out how to develop a business case for similar complex intervention projects, to help measure their sustainability and enable their implementation. In that respect, our work has leveraged interest in the direction that the NHS wants to go.

NHS England has launched the new Local Health and Care Record Exemplar (LHCRE) scheme, a national investment to create joined-up information capabilities across the health and care system. This will award five regions the opportunity to showcase interoperability, data sharing and partnering with patients. Our role in evaluating CIE has helped frame this approach for the future.

2. Providing the right care to the right people: Patient segmentation

The NHS has long been criticised as a one-size-fits-all service, organised around professionals with similar skills rather than patients with similar needs.

For example, most healthy adults want and need quick and easy access to routine care and preventive services. People with long term physical conditions may need more pro-active care to prevent deterioration leading to hospital admission. People with severe and enduring mental illness are likely to need regular access to specialist mental health care.

The report of the London Health Commission, chaired by Lord Darzi, was published in October 2014. One of its key recommendations was that care should be organised according to the needs and expectations of different groups. It proposed dividing the population into 15 groups, including healthy people of working age, older people with long term conditions and adults with serious mental illness.

Segmenting a population in this way, according to what kind of care they need and how often they might need it, means services can be better planned and delivered to meet them in a holistic way across the traditional boundaries separating acute, mental, community and social care.

An example from the US

In the US, a company called Chenmed in Miami, Florida has pioneered this approach, offering primary care exclusively to moderate-to-low income elderly people with multiple chronic conditions – the most expensive patients in the world’s most expensive health system.

Patients are seen once a month on average in its 37 neighbourhood medical centres across six states, normally by the same doctor, and have longer appointments than in comparable practices. With a pharmacy on site, medicines are dispensed on the spot and patients shown how to take them. The results show patients spend 38 per cent less time in hospital, health outcomes are better and spending is 15 per cent lower. Medication adherence is high.



Table 1. Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Population	Adult subjects	Individuals 16 years of age and under (e.g. mean age of study sample <16)
Intervention	Electronic health record-based interventions, including: <ul style="list-style-type: none"> • Patient access to EHR • EHR-based reminders/ messaging • Unidirectional or bidirectional online patient-provider communication systems (care information exchange platforms) 	Health reminders only
Comparison	<ul style="list-style-type: none"> • No intervention (e.g. usual care) 	
Outcome	Any measure related to: <ul style="list-style-type: none"> • equity (e.g. discrepancies in quality measures between different groups of patients) • Any measure related to: <ul style="list-style-type: none"> • patient-centredness (e.g. PREMs) • effectiveness (e.g. health outcomes) • patient safety (e.g. identification of medication discrepancies); • efficiency (e.g. economic evaluation measures and proxies; including service costs, number of consultations/admissions, • timeliness (e.g. waiting lists, time-to-treatment) • equity (e.g. discrepancies in quality measures between different groups of patients) 	Studies that only report cognitive outcomes (e.g. intent), motivational outcomes or other subjective psychological measures

The lesson is that by understanding the differing needs of different population groups the right care can be delivered to the right people improving overall population health.

A data-driven approach

Industries outside healthcare are much more advanced in using consumer data to shape the services they provide. For example, Tesco increased its profits dramatically following introduction of its ClubCard system which provided a continuous flow of data about the purchasing habits of different groups of customers, allowing the company to stock its stores differently based on consumer needs.

In health, various approaches to population segmentation have been tried, such as risk stratification - grouping patients by age and conditions - which suffer limitations because they focus on high use patients and do not expressly consider different care settings.

We adopted a data-driven approach, using data mining methods from computer science and marketing, segmenting patients according to their actual usage of GP, pharmacy and hospital care.

Based on a population of 300,000, we identified eight care user “types” such as “High needs but low risk of emergencies”, “High primary care users” and “Specialist care users” for whom distinct priorities could be identified and tailored care management programmes or public health interventions designed.

For example, though patients with high needs are very costly, those with lower needs make up 80 per cent of the population and are the prime target for prevention programmes. This large group has a great diversity of care needs which are not revealed by traditional approaches to segmentation based on number of long term conditions. Yet it is crucial that a population health strategy takes account of the different priorities of this group.

Similarly some patients with multiple problems cope with support from primary care services alone; others have a very high chance of needing emergency hospital care. Utilisation thus provides more detailed insight into the care requirements of different groups.

Important issues for policy makers to consider are trade-offs between simplicity and precision, between customised and off-the-shelf solutions and the availability of linked data sets.



3. Understanding how people feel about their care: Patient experience

The drive to make care more patient-centred - delivering services to match patient needs and encouraging patients' active participation in their care - intensified following the Francis report.

This has led to a focus on patient experience, one of the three domains of quality in healthcare alongside safety and clinical effectiveness, which is defined as “the sum of all interactions, shaped by an organisation’s culture, that influence patient perceptions across the continuum of care.”

However, measuring patient experience has proved problematic. Over the past decade it has moved beyond single “satisfaction” scores based on measures of comfort - so-called hotel services, such as the quality of the food - to embrace a range of measures.

Improving use of patient feedback

Despite these developments, feedback from patients is little used for quality improvement, often because patient-reported scores are only available aggregated across a hospital. This makes it impossible for specific wards or specialties to tailor improvements for their particular groups of patients.

We used data on patient experience in urological cancer

care as a case study to identify different population groups and their priorities for improvements in care. We used data from 17,000 responses to the National Cancer Experience Survey which included 57 questions in 15 sections ranging from patients’ experiences of seeing the GP to deciding the best treatment and their perceptions of the hospital doctors and ward nurses.

The results showed women, younger people and people on lower incomes had more negative views of care, indicating where providers might focus efforts to improve overall patient experience. In addition, patients who had had an operation were concerned about support for cancer patients, but this was less of a concern for those who had not had an operation. Being able to see a GP was also a key problem experienced by some patients.

In other research we found that waiting times e.g. in A&E, are more important determinants of a positive patient experience than hotel features such as the quality of the décor.

Using natural language processing

One barrier to using patient feedback for care improvement is the sheer volume of reports collected through the Friends and Family Test questionnaires which are presented in free text. The absence of any way of systematising this information has meant its usefulness has been low.

With the help of a grant from the Health Foundation, following the success of our earlier work, we embarked on an ambitious project to apply natural language processing and machine learning techniques to free-text patient stories collected routinely at Imperial College Healthcare NHS Trust (ICHT). We successfully extracted coded data which can be used to improve patient care, showing how patient experience may be collected and analysed.

We conducted a literature review of methods for evaluating the digital maturity of healthcare organisations from a patient-centric perspective and developed a framework for assessing how well digital systems communicate with each other and facilitate consistency in care pathways.

Our goal is to ensure that patient feedback can support a continuous cycle of improvement in the NHS.

4. Improving diagnostic accuracy: Decision-support in primary care

A key problem in cancer is diagnostic delay - patients are referred too late for curative treatment to be effective.

Two of the most significant barriers are appropriate decision making, for referral, by GPs and a lack of

evidence about which signs and symptoms accurately predict cancer. NICE recommends that any patient judged to have a risk of at least 3% should be referred for further investigation. However, patients may come with different symptoms at different times and sometimes only with hindsight it is possible to see the likelihood of a cancer diagnosis.

The introduction of electronic health records (EHRs) and rigorous outcome measurement opens up the possibility of learning from each patient who is treated. This could improve diagnosis and the safety and effectiveness of healthcare as well as saving costs.

We showed, in a project funded by Cancer Research UK, that GPs tend to rely on their initial intuition when diagnosing patients, and are hard to shift from it later.

Countering the dismissive tendency

We designed a decision support system (DSS) to assist GPs, by presenting them with a list of possible diagnoses at the start of the consultation to counter the tendency to dismiss “less likely but serious” diagnoses like cancer, and the inclination to “explain away” information that doesn’t fit the initial hypothesis.

Tests with simulated consultations using actors-as-patients found the system improved diagnostic accuracy, management quality and the coding of relevant data in the EHR. GPs were satisfied with the usability and

usefulness of the system, and the actors-as-patients did not consider it adversely affected their consultation skills.

Previous attempts to develop similar systems have floundered because they were judged too cumbersome, triggered too many alerts causing “alert fatigue” and disrupted GPs’ working style. Analysis of routine EHR data has shown it suffers from significant bias in favour of known associations with the leading diagnostic hypothesis.

To solve the twin problems of data availability and decision support for diagnosis in real time, an open ecosystem that supports the creation, maintenance and use of diagnostic knowledge, at the point of care, is required. That is what we are developing.

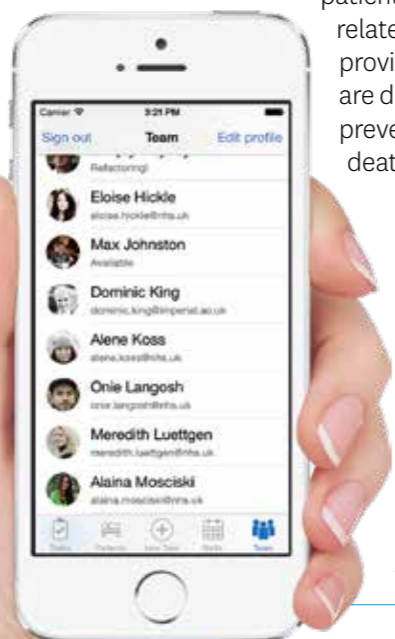
A new, three year, project (2018-21), also funded by CRUK, will focus on the development of a learning health system for three common cancers (pancreatic, lung and colorectal) and two rarer cancers (ovarian and myeloma). Delay in primary care diagnosis is a problem in all these cancers and there is a clear benefit from treatment at an earlier stage. In each case we will be supporting the wider differential diagnosis, not just the cancer diagnosis.

5. Prioritising patients to save lives: HARK and Streams

Hospital wards are busy places with many demands on doctors’ and nurses’ attention. With very sick patients at risk of rapid deterioration there is an ever present risk that the warning signs will be missed.

To deal with this problem we developed an intelligent digital platform, HARK, for managing and prioritising the thousands of clinical tasks that medical staff must carry out each day, such as writing prescriptions, inserting intravenous cannula and conducting patient reviews.

Instead of using out-dated paper records and pagers, which do not order the tasks to be done, HARK provides a secure mobile phone connection for clinical teams,



allowing tasks to be entered easily and allocated to the most appropriate health professional. These can be escalated to more senior staff as necessary, and easily handed over at the end of shifts, reducing the risk of information being lost.

A clinical task management system

The HARK digital platform was developed in response to three issues which compromise the delivery of safe, effective healthcare:

1 Clinical Handover

The European working time directive has resulted in altered working patterns and frequent shift changes in UK hospitals. Breakdowns in the clinical handover process, in which responsibility for patient care is handed from one clinical team to the next, are frequent and a leading cause of adverse events.

Research revealed 17 information systems or processes were used to support handover, most based on paper records, but none was considered good enough for the transmission of important information.

Breakdowns in communication have been shown to contribute to up to 70 per cent of adverse events on hospital wards. A study by the HARK team published in *Surgery* found effective care can be delayed in up to 50 per cent of patients at risk of clinical deterioration.

2 Failure to Rescue

The ability of a hospital to treat a complication in a patient’s care once it occurs is strongly related to the overall quality of care it provides. Failing to rescue patients who are deteriorating is a significant preventable cause of serious illness and death.

From 41 interviews with health professionals across London hospitals, failures in communication and task management were identified as key factors in these cases. There was strong support from doctors and nurses for new technologies to predict patient deterioration.

3 Escalation of Care



4 When patients are seriously unwell, care should be escalated to senior clinicians as soon as possible. Unnecessary delays are a key cause of avoidable patient deterioration.

5 Observations in three UK hospitals revealed 33 steps in current escalation processes and 18 common failures associated with them. The use of out-dated communication technologies, such as pagers, was an important reason for the delays.

The development of HARK

The problems above were related to how clinical tasks (e.g. blood tests, requests for patient reviews) were ordered and prioritised. All too often, tasks were completed in list order rather than in order of urgency. The use of pagers and unstructured text messages resulted in long waits and disrupted workflow. The research showed that effective task management was central to solving the challenge.

In developing HARK, a multidisciplinary team was assembled to conduct 600 hours of observations of front line staff, following doctors on their rounds and watching nurses as they updated paper lists. It emerged that many doctors were bypassing their pagers and using WhatsApp instead.

Staff wanted a task management platform that would be intuitive and fit with existing workflows, improve communication and collaboration within teams and support decision-making. Hospital managers wanted easy access to data to support planning, management and learning.

HARK was the result. It was successfully piloted with doctors and nurses at St Mary’s hospital, London with results showing doctors responded 37 per cent faster with HARK than with messages from pagers. A larger trial is planned at St Mary’s. The system may also be used to investigate patient safety incidents and to improve overall hospital performance.

Streams – a new approach

HARK was acquired by Google DeepMind, the artificial intelligence research arm of the internet giant, in February 2016. Google DeepMind is using novel technologies to automate complex tasks and plans to apply these principles to the clinical tasks carried out on hospital wards.

The newly named task management system called ‘Streams’ brings together both nurses and doctors to identify deteriorating patients earlier and respond in a more organised way.

Sharing information: The Big Data and Analytical Unit



The Big Data and Analytical Unit (BDAU) is a multidisciplinary team which collaborates with researchers across Imperial College to ensure the maximum use, impact and dissemination of research using healthcare data. It brings together experts from the fields of computer science, artificial intelligence, statistics, epidemiology and informatics to create a data-driven evidence base for healthcare policy.

The unit was founded in 2012 to advise on the use of healthcare data in research and has since grown to become a fully fledged research and data governance organisation. It is the first unit in Imperial College to be certified to ISO 27001, the highest level of data security, and the same as that required of NHS Trusts. It is also 100% compliant with NHS IG Toolkit Level 3.

This has allowed the unit to use NHS derived datasets on which to carry out advanced analytics – for example, on patient segmentation – making the results available for direct patient benefit.

The unit has advanced the use of healthcare data at a local and national level and has become one of the most secure and recognised analytic platforms in Imperial College.

As a result of this work, the College is believed to be the first university with security clearance, through an Information processing agreement, to enable it to share pseudonymised data with its local NHS Trust, allowing the creation of e.g. patient safety alerts which can be uploaded to individual patient records.

The BDAU provides advice to researchers on all aspects of information governance and data protection, sharing, acquisition, storage, analysis and visualisation. In 2017, over 110 researchers used its secure environment to analyse more than 90 unique datasets, ranging from custom-collected clinical datasets to large linked datasets.

In November 2017 the BDAU ran the first Data Provider Day, showcasing projects using routinely collected healthcare data and giving researchers access to experts from data providers.

The unit has also formed the Routine and Observational Data Analysis Network (RODAN) to promote multidisciplinary research involving experts across all college faculties and industry in data driven innovation.

Events hosted or supported by Sowerby



Beginning in 2014, the annual Sowerby Symposia brought together healthcare experts to discuss current policy and healthcare issues and provide updates on the Sowerby eHealth Forum's work.

● The first Sowerby Symposium, in 2014, focused on **E-Health for Better Care**. The conference marked the release of the report 'Bringing together primary and secondary care data to improve patient care' authored by the Sowerby Commission. The report set out how medical records are currently separated in siloes – hospital, GP and clinic – and there were technical and cultural barriers to sharing them, including a reluctance by doctors to give up control. Sharing records brings major benefits, by ensuring all staff caring for a patient have access to details of their condition, medication and test results, and by providing a resource to improve care for the whole population through audit and research.

David Stables, a trustee of the Sowerby Foundation, said the report was "timely and relevant" adding: "It informs us that if we do not share data in the way that is necessary, not only are we breaching the rights and obligations of the patients, we're breaching the rights and obligations of the clinicians. It is unsafe."

● In 2015, strategies on **Using NHS records to save lives** were debated at the second Sowerby symposium. Opening the event, Minister for Life Sciences, George Freeman MP, urged the healthcare sector to "embrace innovation so that we can deliver more health for every pound we spend and empower passive patients to become 21st century healthcare citizens".

Charles Gutteridge, Chief Clinical Information Officer at Barts NHS Trust called for a "people's data movement across the UK". Paul Aylin, Professor of Epidemiology and Public Health at Imperial College, described a mortality alert system based on patients' data to detect sudden rises in the death rate for every NHS hospital in England.

Professor the Lord Ara Darzi said: "We must convince the public that researchers need access to medical records. Confidentiality is, of course, a vital principle of the doctor-patient relationship — but it can also cause significant harm. No NHS policy explicitly forbids the sharing of records, but staff are reluctant because the confidentiality of those records is protected by law, under the Data Protection Act. Obtaining consent from the public for sharing its data for research remains our greatest challenge. Our best hope may be to show what can be achieved when researchers are allowed access to

Events hosted or supported by Sowerby



data. The Sowerby Symposium provided a platform on which to debate these key issues which can save lives and create a more cohesive and joined up NHS.”

● The third Sowerby Symposium in September 2016 explored **the benefits and challenges of sharing patient data** in front of an audience including clinicians, policy makers, industry leaders and academics. In a keynote lecture, co-founder of Google Deepmind Health, Mustafa Suleyman, said: “At present, patients have no control over their data. In order for patient data sharing to work, gaining patient’s trust is very important and generating that trust will be measured by the ability to engage patients in controlling access to their own data. Putting the patient in the driving seat with respect to their own data is going to be transformative for patient care and patient safety”.

Hilary Doxford, vice-Chair of the European Working Group of People with Dementia, gave a brave and heartfelt account of her own dementia diagnosis and how it was possible to identify ‘real life’ patient benefits from sharing patient data in dementia research. Des Holden, Medical Director at the Surrey and Sussex Healthcare NHS Trust, described how physiological monitoring in people’s homes could help those living with dementia.

● The fourth Sowerby Symposium, in October 2017, focused on the **Digital transformation of the NHS**. The first keynote came from Rachel Dunscombe, the CEO of the NHS Digital Academy who emphasised that people should be put before technology. Panel discussions addressed the questions of ‘How do we develop leaders for the NHS digital transformation?’ and ‘How can we evaluate digital solutions?’ Finally, a panel took questions from the audience regarding ‘How we can communicate data sharing to the public?’

● On the 24 March 2017, the Sowerby Forum hosted a meeting on **Sharing data, shaping views** in partnership with the Imperial College Science Communication Unit, to explore how national policy on the sharing of patient data could be effectively communicated to the public. The event brought together academics, patients, healthcare professionals, policymakers and other stakeholders to identify features that a communication strategy should include – and those it should avoid – to assist national patient data sharing policy by the Department of Health, NHS England and NHS Digital.

Key themes that emerged were:

(1) Patients and the public need a clear explanation of what data are to be shared, how, and with whom. This is key to increasing public acceptance. The benefits of data sharing must be clearly demonstrated in a way that resonates with different communities. Reluctance to share data may be overcome if the benefits to individuals and society are well understood.

(2) Information must be presented in an accessible way but must also be adapted to suit individual preferences. Simple language and a transparent policy are essential to aid understanding and build trust. People must be offered different levels of detail to allow them to choose between a simple or more complex understanding of the policy.

(3) Early and meaningful engagement of stakeholders is essential. Patients and the public should be involved in designing the communications strategy to ensure it is relevant and accessible. GPs and healthcare professionals should also be involved from early in the process as they are key to communicating the policy given their high levels of trust.



Opposite top: George Freeman MP at The Sowerby eHealth Symposium 2015

Opposite bottom: Rachel Dunscombe at The Sowerby eHealth Symposium 2017

Below: Hilary Doxford, vice-Chair of the European Working Group of People with Dementia at The Sowerby eHealth Symposium 2016



(4) The policy must be robust and well considered, especially with regard to how data will be shared and opt-out options. Good communication cannot compensate for poor policy. Flaws in the policy must be addressed, not glossed over by employing a communications strategy to minimise resistance.

● In April 2017, the Sowerby Forum supported a **Cyber-security in Healthcare** workshop co-hosted by the Institute of Global Health Innovation and Institute for Security Science and Technology at Imperial College London. The forum brought together leaders from academia, industry, government and the NHS to evaluate the current risks, and identify future opportunities to help ensure healthcare remains resilient and secure in the digital age.

The global Wannacry ransomware attack in 2017 affected 81 NHS Hospital Trusts and 603 other NHS organisations resulting in significant disruption to care and compromising patient safety. The attack showed that cyber-security should be viewed as a patient safety issue, not merely an IT issue.

The meeting heard that effective protection against

cyber attack requires investment in infrastructure and people. Instead the Government and NHS have ignored the threat. Many NHS organisations spend as little as 1-2 per cent of their budgets on IT, compared with 4-10 per cent in other critical sectors.

It is not only hospitals that are vulnerable – individuals are too. In 2016, patients in the US were warned of a vulnerability that could allow hackers to take control of one brand of insulin pump to deliver a lethal dose of the drug by remote control. These risks are likely to rise with the growth in mobile, wearable technologies.

Effective cyber-security requires good governance which is fragmented in the NHS, resulting in a lack of clear accountability among NHS Digital, the National Cyber Security Centre, the Department of Health and NHS Trusts for what is a national problem. The Wannacry attack was a wake-up call.

The NHS is complex, fragmented and chronically short of resources yet it holds large amounts of sensitive and valuable data in vulnerable systems. Cyber-security is not just about protecting data – it is fundamental for maintaining the safety, privacy and trust of patients.

Conclusion: enabling data driven research



The Sowerby E-Health Forum has been a key enabler of the developments described above over the last five years. As these projects demonstrate, digital technology is changing the landscape of healthcare, in terms of service delivery and the engagement of patients.

The work does not stop there. New digital technology will be transformative for healthcare, with burgeoning applications in digital records, big data, machine learning, telemedicine and the Internet of Things (IoT). The development of such important tools has lagged behind advances in other industries, yet they are vital in order to help ease the growing pressure on the NHS caused by an ageing population, the increasing complexity of care and rising costs.

The work we have undertaken has shown how digital technology and data science are key enablers to achieve a safer, more effective and patient-centred health system. Getting buy-in for data linkage and data sharing comes from showing what the benefits can be. For example, an analysis of data on the prescribing of generic vs branded drugs suggested the NHS could save £1 billion a year if GPs changed their prescribing habits. A study of anonymised medical records at a hospital in Washington, US found the biggest factor affecting a

patient's chance of readmission was their mental state.

Through robust academic research such as this, we can demonstrate **the value of data sharing and data linkage** to patients, healthcare professionals and policy makers. But we must improve our efforts at communication. In a study we carried out we found a number of barriers – the willingness of patients to share data, difficulty in understanding sharing processes and concerns about confidentiality and data security.

Banks, supermarkets and retailers have long recognised that the data the digital revolution has enabled them to gather on their customers is of huge commercial value. But in the NHS the realisation that it holds a unique resource of 60 million medical records has been slow to dawn.

In *Bringing together Primary and Secondary Care Data*, we demonstrated the vital importance of this resource, arguing that electronic health records were essential to high quality care by giving patients more control, reducing the risk of harm, improving communication, assisting the management of chronic disease and providing a resource for the development of new treatments.

We recommended five measures to achieve this outcome, including ensuring patients could check the accuracy of data, book appointments, order prescriptions, see test results and share their records with third parties. These have largely been met. We also said clinicians should have immediate access to up to date information, databases for research should be designed and used with respect for public opinion and information governance, systems should be open and interoperable and information should be shared across health and social care to promote integration.

We are collaborating with the Wellcome Trust to better understand the value of the NHS data asset and how this can be shared with commercial organizations in a responsible way that is acceptable to the public whilst ensuring that maximal benefit is derived for patients and the NHS, both clinically and financially.

Improving patient safety has been a key focus of our research. Arising out of our work on the Care Information Exchange, we are undertaking a further study as part of the Patient Safety Programme at the NIHR Imperial Patient Safety Translational Research Centre of the benefits and risks of sharing EHRs with patients, by mapping them across the six domains of quality of care of the Institute of Medicine (IOM) – that care should be safe, effective, patient-centred, timely, efficient and equitable. This work will demonstrate how digital technologies can be utilized to deliver safer patient care.

The expertise we have developed through the Sowerby E-Health Forum over the past five years has led to the Institute of Global Health Innovation (IGHI) being appointed to deliver training for 300 NHS digital leaders over the next three years through **the NHS Digital Academy**. The IGHI is leading a consortium, including



the University of Edinburgh and Imperial College Healthcare NHS Trust, with international strategic input from Harvard Medical School, in a world class collaboration with unrivalled expertise in blended learning, health informatics, leadership development and transformation programmes.

The aim is to create a workforce with the professionalism, ability and capacity to lead the NHS to a new digital future. The NHS Digital Academy was announced by Jeremy Hunt, Secretary of State of Health, in September 2016 following the Wachter Review of Health IT in the English NHS.

Our expertise in digital health will also be showcased at the **World Innovation Summit for Health (WISH)**, to be attended by 2,000 delegates from around the world in Doha from November 13-14, 2018. At this the third WISH, one of the main forums will be on Data Science and Artificial Intelligence and will highlight case examples from the UK and globally, featuring the work of IGHI. WISH, an initiative of Qatar Foundation with Lord Darzi as its executive chair, is dedicated to capturing and disseminating the best evidence-based ideas and practices in global healthcare.



The **Sowerby E-Health Forum** has provided IGHI with an invaluable resource from which to develop skills and expertise in digital health, building on the basic science strengths of Imperial College and the clinical experience of Imperial College Healthcare NHS Trust with its 1500 beds and 1 million patient contacts a year. The Trust is also a partner in three primary care centres and a member of the Academic Health Sciences Partnership, whose reach extends across the 2.4 million population of North West London.

We believe we are now in a unique position to deliver a comprehensive digital health translational research centre and bring together primary and secondary care data to improve patient care, producing results of wide benefit that can be implemented locally and spread nationally and internationally.

Our future ambitions are focused on three main areas:

- **To establish a national academic centre for healthcare cyber-security**

As described above, health systems are uniquely vulnerable to cyber attack yet have chronically under-invested in IT security. IGHI is collaborating with the Institute of Security Science and Technology (ISST) to carry out research to support national policy in this area. Programs of work will include: medical device security, modelling risk/harm to patients in the event of a cyber attack and resilience planning pre- and post-attack.

- **To use advanced analytics and artificial intelligence to improve the quality of care**

Investment in digital health has reached record-breaking levels with \$6 billion of venture capital earmarked for the sector by the end of 2017 in the US alone. Data science provides methods to extract value from unstructured patient information delivering benefits including predicting treatment outcomes, improving cancer survival and making care more efficient. We are working with partners at Google Deepmind and Cancer Research UK to explore how AI might be employed to improve breast screening leading to more accurate cancer diagnosis.

- **To provide evidence and support for the spread of digital solutions**

There are many barriers preventing the uptake of digital innovations. We will work to provide evidence of their benefits for academics, policy makers, commercial partners and NHS organisations to help foster their use and ensure sustained adoption. We will explore how public/private partnerships can help create a thriving market for the benefit of patients.

We are committed in all our work to listen to the voices of patients, the public and healthcare professionals to ensure that at all times it reflects their interests and responds to their concerns.



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