



This Al Life

Can artificial intelligence give the kiss of life to the UK's National Health Service?

About this report



The 'This Al Life - Ensuring our Al future works for us' conference, which took place at IET London: Savoy Place on 3 October 2018.

This report explores the potential impact of artificial intelligence (AI) on the health and social care sector. It examines the benefits that the technology could bring to healthcare systems such as the UK's National Health Service (NHS), but also the challenges that must be overcome in areas such as ethics, regulation and data handling.

It features interviews with leading commentators on the technology, as well as experts from across the healthcare sector; mini case studies on past and current applications of AI; factual references to other documentation and sources of information relating to this topic; and opinions from the authors on the effectiveness of previous attempts to implement AI technology in the health space, and where they see it going in the future.

The paper was co-authored by Peter Warren, a freelance journalist specialising in technology, computer security, undercover investigations and science issues alongside radio producer and artificial intelligence researcher Jane Whyatt. Warren and Whyatt are Editor and Broadcast Editor for Future Intelligence, an online news site and think tank that produces reports, videos, audio and podcasts, and is responsible for the technology radio programme *PassWOrd*.

Future Intelligence also co-organised a conference held at IET London: Savoy Place on 3 October 2018 titled 'This AI Life: Ensuring our AI future works for us', along with the IET and Cooley which featured presentations and panel sessions involving several of the interviewees contributing to this report.

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Foreword

This report's balanced and wide-ranging discussion of the opportunities and risks for AI in the NHS very accurately reflects the concerns surrounding the future of AI, which has led to polarised narratives and issues of public trust and suspicion in its application in healthcare.



Despite a history of professional ethics in medicine and nursing we are in new territory when it comes to the current reality of the application of AI solutions and the harnessing of big data in the Health Service.

Through the smoke of the narrative battle the message is that there is a constructive way forward for the safe application of AI in healthcare. Some fears are allayed, and opportunities illustrated. Augmentation of human skills is more likely than substitution, earlier diagnosis is on the cards, resources can be better directed.

And having entered the debate and offered a diagnosis, the report's authors are not afraid to deliver the prescription.

Relying on the Hippocratic Oath is not enough. Clear ethical architecture is needed. Better data control, greater transparency, the need for consensus on the monetisation of health data and proper certification of applications are essential. Greater diversity in those developing these applications and handling data is essential if we are to avoid inherent bias.

Health providers, politicians, regulators and patients and their representatives will benefit from this intelligent and well-considered paper both as regards to its discussion and conclusions.

Lord Clement-Jones

Chair, House of Lords Select Committee on Artificial Intelligence

Introduction

Artificial intelligence is the phrase of the moment, the panacea of all ills and, it is claimed, will be the defining technology not just of this century but of the next.

If we are to believe those promoting the technology, it will usher in a land of milk and honey, limitless opportunity, a life of leisure and contentment and enormous changes in the way that we live our lives.

According to its detractors, artificial intelligence (AI) will impoverish us all and take away job opportunities right across society. The future will become a land where we are harvested for our data and our behaviour and where we seek comfort and company from the machines that are monitoring us.

The two fields where AI is expected to be deployed first are health and transport, as those are both areas where it is thought the greatest contributions can be made by the technology. In this report, we have interviews with a number of leading commentators on the technology, as well as from the health sector.

We look at the impact of AI on the health sector in terms of the benefits it can bring to the UK National Health Service and to private individuals and companies; we examine what this means to those working in the sector and what it will mean to patients.

We do not claim to know which of these two competing visions of the development of Al will materialise. All we do is lay out the current position of Al development. We examine the claims that are being made for the technology in the health sector, why it is being deployed and what that will mean for society as more people live for longer, not only putting stresses on society and the NHS to look after them but also changing the way that society regards and treats the older generation.

To put that into perspective – according to Dr George Leeson of Oxford's Institute for Population Ageing (IPA) in an interview given to the authors of this report, in 2017 there were 14,500 centenarians in the UK. Yet within 30 years there will be some 500,000 people here who are aged over 100. By the end of the century the IPA's models predict that there will be over one million centenarians and that the elderly will have dramatically changed the balance of the population.

The Health Secretary Matt Hancock acknowledged this trend at the Conservative Party Conference in Birmingham on 2 October 2018:

"Anyone who knows the NHS also knows there are serious pressures, because our population is ageing and we're treating more people than ever before."

Matt Hancock, Health Secretary

It is a problem that Dr Leeson says will have a profound impact on our society because those changes will mean that to support this elderly population, older people will have to work for longer to support themselves and the costs of their care. That is something that will only be made possible by changes in the way that we view elderly people and by the adoption of technologies that will enable them to work for longer.



Chapter 1: AI - A trap or a cure?

The reasons for introducing AI into the NHS are complex but the chief ones are simple. The NHS is a victim of its own success. It has helped more people to live for longer and because of that the ever-increasing elderly population has led to funding pressures because older people have greater health needs than the young.

The result, according to research from the NHS' 'Five Year Forward View', is that three key challenges for health and care have been identified:

The health and well-being gap:

If the nation fails to get serious about prevention then recent progress in healthy life expectancies will stall, health inequalities will widen, and our ability to fund beneficial new treatments will be crowded out by the need to spend billions of pounds on wholly avoidable illness.

2. The care and quality gap:

Unless we reshape care delivery, harness technology and drive down variations in quality and safety of care, patients' changing needs will go unmet, people will be harmed who should have been cured, and unacceptable variations in outcomes will persist.

3. The funding and efficiency gap:

If we fail to match reasonable funding levels with wide-ranging and sometimes controversial system efficiencies, the result will be some combination of poorer services, fewer staff, deficits and restrictions on new treatments.

"We will also look very closely at the changes that will need to be made to data collection so that the promised benefits for humanity can take place while at the same time safeguarding people's civil liberties and privacy from the implications of that data collection.1"

It is this trend that is perhaps of greatest concern to those who are involved in Al and health. The collection of data presents great ethical problems, considering just how intrusive the process can become. It also introduces ideas about who has an interest in that data and who has the right to exploit that data. Without the data, the full benefit of the new Al systems will not be developed, for the simple reason that without ready access to data the area will become less attractive to both large technology companies such as IBM and Siemens and smaller entrepreneurial companies like some of those mentioned in this report.

All of these companies have identified areas of the NHS where efficiencies can be achieved by reducing bottlenecks and streamlining processes – ironically by using data already available within the NHS that has been provided by organisations like the NHS Information Centre.

¹ Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens - A Framework for Action. Nov 2014



Giving patients a choice

At the heart of this data debate – which has been gaining momentum since 2001 – are two key issues. Data enables the patients to make informed choices about the treatment that they receive. This can persuade them to buy in to the system so that it can improve and make efficiencies.

This is the greatest challenge that faces the government, no matter what its political complexion, because health and access to health data are viewed as the cornerstone of government data policy. This can be seen from former Home Secretary Amber Rudd's calls for a new ID card system based upon our health record. Our health will prove that we are who we say we are.

Uniting our health record with access to social services and other local government resources, first mooted by Sir John Banham under Prime Minister Margaret Thatcher (1979-1990), would achieve a long-held government objective of creating a single customer profile for an individual's contacts with government. But to achieve this the government has to overcome a traditional and long-held barrier, breaking its bond of trust with the public. Ever since the Domesday book there has been a widely held view in the UK that if the government wants your data, it intends either to tax you or deprive you. The challenge for the government is to prove benevolence and overcome suspicion.

Gaining trust

Another problem for the health service is suspicion. Data is needed in order for AI to work, and patient opt-in is required to obtain that data, but first the NHS faces the challenge of overcoming suspicion:

- among patients that their data will be used in their best interests and that this intensely personal data, given with the promise of utter confidentiality, is not simply making its way into the hands of big business by stealth.
- among demoralised staff working long hours often in poorly-paid positions – that the AI revolution is not the last indignity and that the aim of the exercise is simply to take away their jobs and replace them with robots.
- that the technology companies now queuing up to dispense the AI benefits of the 21st century are not only looking to exploit the NHS and the sacred bond of trust it has with patients.
- within the organisation itself that this represents just the latest attempt to force savings from the NHS with efficiencies that will lead to budget cuts and the privatisation and exploitation of lucrative parts of the organisation, while the least attractive parts become under-funded and unattractive.

Apps for prevention

As we have said, artificial intelligence holds great promise for the future of healthcare, and the companies that are able to bring AI to market in the form of easyto-use applications look set to make large profits.



What appears to be undeniable is that the interests of the patients, the NHS and the insurance industry are seemingly in a strange alliance. In his conference speech in Birmingham, Health Secretary Matt Hancock set out the position: "We've got to reform the system, so we spend more time on prevention not cure, with more integration between health and social care and more treatment closer to home."

This is a policy which is even being espoused by the insurance industry. In the same Forbes article that Babylon Health Founder and CEO Parsa laid out his vision for his company, Nic Nicandrou, the head of Prudential Asia, explained why the company had decided to include the health software in at least one app that it was releasing this year. "If something is diagnosed earlier, the cost of treatment will go down," Nicandrou said, adding that this can ultimately reduce the cost to Prudential of paying out claims, too. This message has not been lost on the Health Secretary.

Simplifying cancer screening

Aamir Butt's Tumour Trace system is a good example of the new systems aiming to make inroads into the health sector.

Tumour Trace has been developed to make early, swift and accurate diagnosis of several types of cancer almost universally accessible. It can make this claim because it relies on a small portable machine for reading the samples. Instead of having to wait for a hospital appointment and then wait again for the results to emerge from the pathology laboratory, patients' tissue samples can be read on the spot and the results produced almost instantaneously. Butt foresees this as an advantage – for example in rural India as well as in hard-pressed inner-city hospitals in the UK or elsewhere. Saving time and saving money are important for healthcare systems the world over. Saving lives is even more important. Butt claims that early diagnosis and treatment can prolong the lives of cancer patients because he says the evidence points to a far higher survival rate due to early treatment, achieving huge cost savings, improving and extending lives. His goal, he says, is to make testing for cancer as simple as testing for high blood pressure.

However, this claim is disputed by another of our contributors, the veteran health journalist and former *Sunday Times* Health Editor Lois Rogers:





L<mark>ois Rogers</mark> Health journalist

"That opens another can of worms because there is to date no evidence that early diagnosis changes the outcome². Particularly in breast cancer, there's been a huge amount of controversy over the screening programme and there is no evidence at all that there is any benefit across the board, other than people know for a longer period of time that they've got cancer. In other words, you might get an earlier diagnosis but that doesn't change the outcome, whereas using conventional diagnosis where you go to the doctor because you've got a lump in your breast – you might be on what they call the cancer journey for three years.

"If it was detected as a result of screening and it was a genuine cancer you would just know for a longer period of time that you were in for this long process of treatment so whether it's a benefit or a disadvantage I think is highly arguable at the moment."

Arguing in favour of his new concept Tumour Trace, Aamir Butt says:



"Cancer progresses in stages. It gets more and more established wherever you may find a cancer and it gets to a certain point where it begins to penetrate your blood system, or your lung system and it begins to spread to secondary sites. That stage is quite a critical stage in the development of cancer and if you're able to detect cancer before it's begun to metastasise, there's a good chance that you can treat the cancer.

"Perhaps with the exception of pancreatic cancer which is very pernicious, with most cancers if you detect them before they spread to secondary sites, there is a good chance that you can eliminate the cancer. In the 2014 'World Cancer Report' from the World Health Organisation ... one of the main conclusions was that government ought to invest in early detection of cancer as a means of battling the tidal-wave rise of cancer incidences around the world."

Tumour Trace

Tumour Trace has a patented method of testing for early-stage cancer using a portable microscope system.

The company has developed an innovative system for funding itself using blockchain technology under the umbrella of a sister company Lancor Scientific. Its technology, Opto-Magnetic Imaging Spectroscopy (OMIS) combines optical reflectance microscopy and Brewster angle microscopy.

Patients book screening tests and pay in cryptocurrency via their phones. Lancor Scientific's Initial Coin Offering aims to raise capital by selling the Medici³, its virtual currency.

CEO: Aamir Butt tumourtrace.com

 $^{2\} https://www.kingsfund.org.uk/press/press-releases/nhs-receives-mixed-scorecard-major-analysis-international-health-systems$

³ https://www.medici.health

The NHS opportunity

For the technology industry the attractions of the NHS are huge. It represents the largest store of health data over time anywhere in the world. To be able to mine through that data and find patterns that provide the clues to preventing and curing disease would not only be a boon to patients, it would also provide incredibly valuable data to companies that could either be used to develop products or simply sold to other companies.

Any artificial intelligence application needs to be trained on a large set of data in order to be able to spot patterns and make connections and predictions. However, there are issues with this. Detecting early-stage cancer, for example, will be more accurate if the algorithm has done its training on an appropriate dataset.

Dr Peter Bannister, a radiologist, Al and imaging expert, owner of Bannister Technologies in Cardiff and chair of the IET's Healthcare Sector Executive Committee explains:



Dr Peter BannisterChair, IET Healthcare Sector
Executive Committee

"For example, if you trained an Al algorithm to detect lung cancer and you trained it on data from a Chinese population, let's say from a polluted environment like Shanghai, the Al may behave in a very different way from an algorithm that's trained on lung CT scans from people in the Home Counties in the UK. That said, there is data that transcends these boundaries

"I think both from a national and an international basis, it's going to be difficult to find an organisation that has the oversight and the bandwidth to take complete responsibility. I certainly think that there needs to be very clear standards being set at the national level."

Bannister sees great potential for artificial intelligence in his specialist field, radiology. Its capacity for organising vast amounts of data can augment the work of human operatives. And Bannister does not believe this will mean jobs are put at risk. On the contrary:

"I think that's the way I believe that it is going to make a tangible, healthy impact on society and in particular on healthcare. I think radiology is an interesting example because there's a natural intersection between radiology, which is a very data-intensive profession, and AI, which is a very data-intensive technical discipline; a couple of years ago there was some, if you like, clumsy initial forays from the AI side into radiology. Very strong claims were made about AI taking over from clinicians or replacing them in the future. I know that message has been delivered in other industries.

Bannister continued: "Actually, within radiology, over a very short time scale, the message changed completely to: "Sorry, we're not going to take over your jobs. What we're going to do is make you go back to being clinicians again rather than data managers." I think that's exactly where I do believe there's going to be a real benefit from these technologies."

The RCP position

The Royal College of Physicians (RCP) takes a more sceptical view of the role of AI in diagnosis. Based in London, the RCP has 32,000 members worldwide and last year celebrated 500 years since its foundation. In its September 2018 position paper on AI, RCP President Professor Dame Jane Dacre called for greater transparency, clearer guidance about doctors' clinical and legal responsibilities and liabilities in relation to AI and more thorough testing using human patients, with the test results being widely disseminated.

The position statement followed closely after a disclaimer from the RCP⁴ about the test results from Babylon Health's in-house experiment, which pitted a human nurse and a hospital doctor against an Al triage system. The aim was to see whether the humans or the bots could make better diagnoses based on a set of fictional scenarios, with different symptoms being presented. The Babylon Health results claimed to show that on average the AI is faster and more accurate than the humans. The claim is contested by some doctors who said that the Babylon Health tests were not based on reallife situations. "We need studies in real patients, in real time, in the real NHS," was Dame Dacre's response.

Diagnosis via Al-powered app is just one of Babylon Health's services. Working with the National Health Service in a trial in London, Babylon Health offers NHS GP at Hand. This gives patients the chance to access the symptom-checker service for free, providing they opt out of their local GP surgery and opt in to Babylon. However, at the moment it is not an option for people who are elderly, disabled, expecting a baby, or have a range of other conditions specified on the Babylon Health website.

For private subscribers who use Babylon Health alongside their own GP, the services cost £25 for a one-off consultation, £49 for a specialist consultation (these consultations are held by video through the app). There is also the option of a monthly or annual subscription. Arguably the current opt-outs for Babylon Health from the NHS service make sense from a PR point of view, as using a relatively new technology on vulnerable groups could potentially create disastrous headlines for the NHS in the event of an error.

However, the medical profession itself has expressed a lot of concerns about the rosy view of AI that Babylon presents, an example of the scepticism and suspicion that we discussed at the beginning of this report. Due to this we look into the discussion surrounding Babylon in much more depth later on in this report and outline some of the concerns of the medical community.

Those who could be without AI

- Women who are or may be pregnant (if you are pregnant, NHS England advises that you register with a GP practice close to where you live)
- Adults with a safeguarding need
- People living with complex mental health conditions
- People with complex physical, psychological and social needs
- People living with dementia
- Older people with conditions related to frailty
- People requiring end of life care
- Parents of children who are on the 'Child at risk' protection register
- People with learning difficulties
- People with drug dependence⁵



4 https://www.rcplondon.ac.uk/news/rcp-clarifies-position-use-artificial-intelligence-healthcare 5 https://support.gpathand.nhs.uk/hc/en-us/articles/115003670889-Can-anyone-register-

Doctors' concerns

Criticism from some doctors centres around several concerns. One is that GP surgeries will be left with the difficult cases (listed on Page 11) and patients who are too poor to own a smartphone and pay for video consultations or not familiar with smartphone technology.

The charge from its opponents can be summed up as "a two-tier system" – that is, one health service for the young and rich and a second-class system for the rest. Another is that the National Health Service is a universal good for British people, funded by all citizens' National Insurance and tax contributions, and as such it should not be partly or wholly privatised. This could be seen as an ideological argument rather than an attack on the technology. It should be mentioned that Babylon Health's Founder Ali Parsa says that the company's long-term goal is in providing end-to-end clinical care on behalf of insurers and government providers like Britain's NHS. Parsa believes his software will help those clients keep a lid on rising healthcare costs for an ageing population. "We will always make more money from the provision of clinical care," said Parsa, in an interview with Forbes on 2 August 2018.

Further concern arises from the fact that Babylon Health is in a commercial partnership with Prudential Insurance, and that company is using Babylon subscribers' health data to predict risk factors and set insurance premium levels or even barriers to entry. Its opponents encapsulate this in the phrase "selling our personal health data". In addition, there are clearly some issues with the openness of Babylon Health's operations: the company tried to get a High Court injunction to stop publication of the Care Quality Commission's (CQC) inspection report from December 20176 and has only tested its symptom-checker inhouse without independent observers.

"Transparency issues" in relation to the CQC inspection report (which is now available online and is only mildly critical in some parts) are shrugged off by Babylon Health, claiming that the CQC inspectors themselves are connected to rival companies and therefore seeking to damage Babylon's reputation for commercial reasons.



Babylon Health Founder **Ali Parsa.** Photo: Babylon Health

Babylon Health

A private company that offers individuals automated diagnosis of symptoms, powered by Al.

In 2017, Babylon Health ran an in-house experiment to find out whether AI recognises symptoms more quickly and accurately than a human doctor or nurse. It also has 26,000 NHS patients in GP at Hand, a pilot project in Fulham, West London. Patients are offered video consultations.

Founder: Ali Parsa babylonhealth.com

The Medical and Healthcare Products Regulatory Agency (MHRA) of the UK government has received at least one complaint about a Babylon Health diagnosis, namely wrongly diagnosing heart infarction symptoms as a panic attack. It was reported in the *Financial Times* and *Daily Telegraph*⁷ on 13 July 2018, but the MHRA has a policy of not commenting on individual cases, so no outcome has been published at the time of going to press.

 $^{\ 6\} https://www.digitalhealth.net/2018/08/babylon-threatened-to-sue-cqc/$

⁷ https://www.telegraph.co.uk/technology/2018/07/13/ai-doctor-app-babylon-fails-diagnose-heart-attack-complaint/

⁸ https://www.theguardian.com/society/2018/jan/02/patients-missing-their-appointments-cost-the-nhs-1bn-last-year

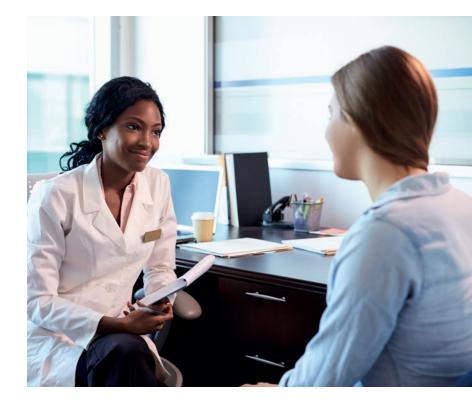
Automating appointment admin

Other apps for diagnosis are available now in the UK. Tim Mercer is the CEO of Vapour Cloud, based in Halifax, West Yorkshire. His Al app works with the system from healthcare software firm EMIS widely used in general practice. It allows a patient to book an appointment at any time of the day or night using an automated system, or to take part in a video consultation with the GP so that a home or surgery visit is not necessary.

Tim Mercer Vapour Cloud CEO

"We have the patient's phone number in our records and the app does a lookup to scrape the data that we hold about that patient and then it asks you what you want to do: Would you like to book an appointment? Which doctor would you like? Would you like the next available appointment or to choose a date and time for your appointment? You book that in and then it will send you an SMS to confirm that booking."

Mercer says the app has been designed to be easy to use even for elderly persons – like his own seventy-year-old mother – who are not online but who can use a mobile phone with SMS. The aim is to relieve pressure on GPs' surgeries, freeing up staff to perform more meaningful tasks than booking appointments – for example, call and recall of patients who are due for screenings or vaccinations.



Evidence: The missed appointments problem

Missed GP appointments are estimated to cost the NHS £36 for each ten-minute slot. One group practice in the North West of England estimates it lost almost £250,000 in one month (December 2017) because of patients who failed to turn up. Mercer claims that if patients have chosen the date and time themselves, there is a much stronger likelihood that they will attend. Across the whole NHS missed appointments are an expensive problem, totalling an estimated loss of one billion pounds in 2017.8

One consistent criticism of the deployment of AI systems in the health service is the conflict between commercially-driven technology companies and a health sector which theoretically has the patient's well-being at heart. It is a conflict which has frequently claimed that AI companies are concentrating on obtaining access to the massive pool of health data held by the NHS, rather than being focused on improving health outcomes.

On one level this may be true, yet many of those companies aiming to work with the NHS also point out that the data is 'noisy'. This means that it is not structured properly for analysis and needs to be expensively 'cleaned'. Successive failed attempts to solve this problem by creating a centralised NHS data system have meant that GPs have simply given up and often still keep paper medical records.

Dr Finn Catling, an anaesthetic and critical care doctor and Founder of DeCode Healthcare believes it would be wrong to try to unify all the personal health data in the NHS and proposes a different solution: first structuring and tagging the data contained in doctors' and nurses' case notes and then ensuring that they can be read by all computers needing to access data from the NHS:





Dr Finn CatlingFounder, DeCode Healthcare

"A much more modern approach to that is that any piece of software that we now commission in the NHS must use common data formats and must have an open API standard and what that means is ... when a computer program wants to talk to another computer program, it can make assumptions about the way that that computer program will talk to it.

"What we need from government – rather than saying we're going to stick all this data into one big database – is we need to have a common format for that data and a common language to enable all the computer programs to talk to each other. Rather than enforce a single system on everyone, we can have small companies that do one thing well, but those small companies need to have their software talking to other software in a common language. That's what I'd like to see."

Decentralising the system

Catling is not alone. Many other people have expressed a similar view, including Tim Kelsey, the former information head at the NHS who published in November 2014 'Personalised Health and Care: Using Data and Technology to transform outcomes for Patients and Citizens. A framework for Action'. Kelsey also suggests that the answer to the NHS' patient record database issues would be to use a decentralised system with common standards.

The sudden emergence of Al companies has thus in many cases been met with suspicion. Many commentators view them as a mechanism to either cut costs or privatise the NHS, or as a further attempt to try to install a national medical data system. Some health sector observers see the Al revolution as generating a piecemeal system of data integration that will create a distributed national record system. As Finn Catling says above, it will use common data standards using standard data input fields for medical records – like those supplied to GP practices by the EMIS computer system, or it will deploy Al systems that are capable of uniting unstructured data files – like IBM's Watson.

DeCode Healthcare

A private company founded in London in October 2017 by Dr Finneas Catling, the sole director.

It offers to use machine learning to drive new insights, better outcomes and improved efficiency for hospitals and GP practices.

Founder: Finn Catling decodehealthcare.com

The current situation has also seen another development: the entrepreneurial doctor or healthcare professional who sees the opportunities to develop systems that confer real benefit on their colleagues by solving a healthcare issue whilst also developing a lucrative business opportunity.

Again, this is a trend that has also been met with a certain amount of suspicion by those who have seen successive failed attempts to introduce technology into the NHS.

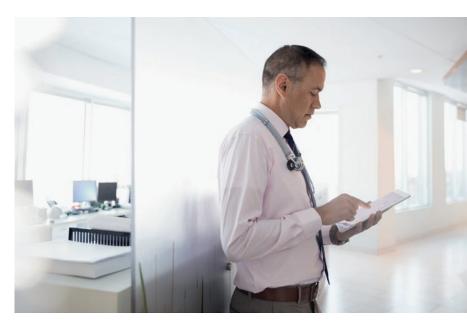
Whilst potentially saving the nation hundreds of thousands of pounds in missed or cancelled appointments, Tim Mercer is typical of the new face of technology in the NHS. If he can improve it he is confident of making his own fortune. On the Vapour Cloud website he states that it aims to become a £12 million company by 2020.

Vapour Cloud

A Yorkshire-based cloud computing company offering an appointment booking and video consultation app based on SMS messaging, to enable 24-hour access to doctors.

It aims to be easy to use for non-technical patients, to cut waiting lists and save money wasted on missed appointments. Vapour Cloud's Founder Tim Mercer is looking to acquire more Al-driven businesses in the North of England with the aim of building a £12 million business by 2020.

Founder: Tim Mercer vapourcloud.com



Digital diagnosis

In Germany, Florian Bundrup is developing a new app that combines the functions of triage and appointment booking. Called Docyet, it is powered by a database of all the doctors and medical specialists in the country, including their address, contact details and opening hours. At the front end, it asks a series of questions about the pain or discomfort that the patient is experiencing. Then it prompts the patient to click on extra aches, pains, fever or skin rashes until it finds a match for a complete set of symptoms and suggests a diagnosis. Then – if it does not recommend calling an ambulance immediately - comes the option of finding the nearest doctor who specialises in this condition. Of course, Docyet already knows where the patient is located, thanks to the GPS in the smartphone.

Bundrup explains how human medical expertise is built in to the app: "We have doctors in the team, we have data scientists. It needs a lot of different professions to build up enough knowledge."

Docyet has been licensed as a Category 1 healthcare device by the European Union. To get a higher level of classification would require clinical trials, which are time-consuming and expensive.

This regulatory hurdle has also been mentioned in interviews by Tumour Trace's Aamir Butt and many other companies involved in the Al revolution.

Docyet

A German smartphone app that offers diagnosis via mobile phone through an Al-powered symptom-checker and an appointment booking system.

Docyet has access to a database of every general practice and specialist consultant in the country, with their address and opening hours.

Founder: Florian Bundrup docyet.com

Chapter 2: Data – The infinite rocket fuel of the information age

The large profits being generated or forecast by the manufacturers of the apps mentioned in Chapter 1 reflect the tech world's adage that "data is the new oil". Why? And how has Al come to be seen as the pump that releases it into the market?

Perhaps a better analogy would be lignite, or brown coal – it is literally scraped from the earth at opencast mining sites. In the same way, data is scraped to form online datasets, cleaned, sifted and refined through cross-referencing, united with historical datasets and then analysed until patterns or profiles emerge that are useful.



Most of the use cases are commercial: advertisers can target the customers who are most likely to buy (or aspire to buy) their products. As has been shown by the 2018 Cambridge Analytica scandal, data can also be bought and sold for political power-grabs, in order to manipulate voters.

Large datasets can also prove invaluable to scientific researchers, enabling them to predict earthquakes and volcanoes, map climate change and observe behavioural changes in the way people use technology in their lives.

Patterns from personal data

In the case of personal health files, the data is especially valuable because of the patterns it can yield. If it is pooled and made available to researchers, the potential for tracking, predicting and preventing outbreaks of disease is immense. Rare diseases and chronic conditions occurring in only a few places in the world can be diagnosed, leukaemia clusters can be identified, and lives can be saved or the quality of life improved. Already in Japan, it's claimed that artificial intelligence deployed by IBM's Watson supercomputer has saved the life of a woman by diagnosing a little-known form of leukaemia in time to start the correct treatment.

In Belgium, the Country Director of Google, Thierry Geerts, has predicted in his utopian book *Digitalis*° that people will donate their personal health data for the benefit of society, in the same way that British people give blood. Geerts points to a new cluster of big data and big pharma companies in Flanders, representing by 2016 a 40 billion euro industry that accounted for more than 10% of Belgium's exports.

'Syndromic surveillance'

In the UK, Dr Beatriz de la Iglesia of the University of East Anglia is working on an academic project with Public Health England. It's called 'syndromic surveillance' and involves trawling through millions of Twitter messages to find examples of symptoms, people complaining about air pollution, asking questions about measles, and so on.

The aim is to create an early warning system, using Al to find patterns or spikes in the Twitter data that might indicate an outbreak of disease is imminent by identifying symptoms that people are tweeting about – even before doctors' surgeries and hospitals become aware of it.

Dr de la Iglesia admits that people do not like to think that their Twitter messages are being used in this way without their permission. She gives talks at public meetings to reassure the social media users that their tweets are being harvested for a good cause. She admits that she shares their ethical concerns:



Dr Beatriz de la Iglesia University of East Anglia

"The security might be breached, the data might be leaked to people that they didn't intend it to be leaked to, it can be used for example by drug companies to take advantage or to maybe preclude certain people in insurance. We do have to tackle all these ethical challenges. We have to bring people in. We have to explain the good outcomes and also the pitfalls. We have to also look at how we address the pitfalls and how we make the technology work in an ethical manner and how do we prevent the security breaches?"

But as an optimist, de la Iglesia foresees a future for public healthcare in which artificial intelligence is a smart, handy tool for the human professionals – a sort of Intelligence Augmentation (IA), the field of computer science which has traditionally rivalled AI. Instead of making the decisions, she believes the AI will simply work to eliminate and refine a mass of data so that the clinician finds it easier and quicker to make a diagnosis, as in this example:

"I think the ultimate goal is to automate a lot of the processing of data, so that you can extract the relevant information – information that you can make decisions with and present in a way that is quite understandable for humans. For example, if you are a radiologist looking at images there will be a lot of processing going on in the background, so that will mean that you can be shown areas that appear to be diseased, and areas that appear to be healthy, with a certain degree of accuracy hopefully a high degree of accuracy - and it will lead to quicker and better informed decisions.

"Some of the work will be done for you and you will only have to do the final stages of confirmation. I mean, ultimately you might be looking at total automation that removes the human. I think that we are quite far away from that."

Dr Beatriz de la Iglesia

Advances in voice recognition

This augmentation function is exemplified by many of Nuance's products in the healthcare realm. Using a synthesised voice, a doctor's online personal assistant 'Florence' can remind her of the patient's history, including any allergies or contra-indications. Then using artificial intelligence, Florence can find similar cases and derive useful information about their treatment and outcomes. The online helper records consultations and books referrals and follow-up appointments, responding to the doctor's spoken commands. It is like a highly-trained 1960s medical secretary with a 21st century supercomputer bolted into the back of her head.

Florence from Nuance

Voice recognition software driven by Al. It follows the doctor or nurse's verbal commands and makes notes during consultations, linking them to patients' records, test results and earlier appointments.

Machine learning offers guidance on side effects or contra-indications of prescribed drugs. Used in UK hospitals and GP surgeries since 2014, Florence aims to cut the time and money spent on administration, freeing clinicians for medical tasks. Nuance is a private software company based in Massachusetts, USA.

Representative: Peter Durlach nuance.com

Peter Durlach, the Senior Vice President, Healthcare Strategy and New Business Development at Nuance, uses the analogy of an aeroplane. The onboard computers basically fly the plane, but at crucial moments such as take-off and landing, or if the weather turns bad, the human pilot takes over, working with the equipment and taking responsibility.

Durlach told the report's authors that this voicecentred approach to administration is already in use in various UK locations:





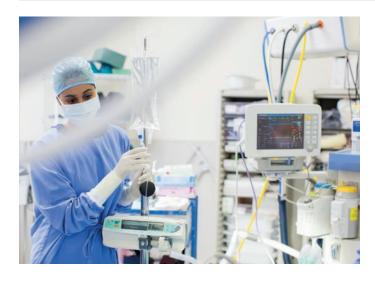
Peter Durlach

"These applications can give back time to doctors that would otherwise be spent on administrative tasks, and we are returning on average an hour or two a day per physician that uses technology (not just ours). At Worcestershire Health Trust the occupational health therapists used speech recognition and they were able to catch up with a backlog of two years in about three weeks.

"We have another example from Cambridge Community NHS
Trust where the feedback says
"I completed the paperwork at the end of the clinic. Now I have no need for an administrative afternoon or to come into the hospital to sign letters." At South Tees after implementing the speech programme each physician saved about three and a half minutes per patient which resulted in them being able to add a further three appointments."

Chapter 3: Do we need a Hippocratic Oath in data science?

The problem for the use of AI in health, however, is that those people deploying the systems have to trust that there are no weaknesses in them from either the software suppliers or the device manufacturers, because their expertise is in health and not computer software. Thus, healthcare professionals increasingly face the dilemma of deploying technology systems in critical care situations on the assumption that the devices will not do any harm, in line with the long-acknowledged Hippocratic Oath¹⁰ for medicine, which dates back to the Fourth Century BCE¹¹.



Laplante's plan

Dr. Phil Laplante is a Professor of Software and Systems Engineering at The Pennsylvania State University and since 2010 he has led the effort to develop a national licensing examination for software engineers. In 2004, Dr Laplante called for a Hippocratic Oath for computer programmers.

At the time Dr Laplante was concerned with the practice of reusing blocks of code without checking what they did. The consequences of such a practice were most notoriously exposed with the Heart Bleed vulnerability¹² which led to erroneous code being copied into parts of the security infrastructure of the Internet, with around 17% of the Internet's secure servers believed to have been affected.

The possibility of such weaknesses being introduced into medical devices has received significant exposure in the press. Much has been made of the fact that often games consoles have superior computer security systems than medical devices, and that heart pacemakers can be hacked, particularly now they are wireless. The WannaCry virus attack on hospitals¹³ running the obsolete Microsoft operating system XP introduced another cause of concern: one of the principal reasons for hospitals continuing with XP was because of the number of other medical devices that had XP hard-coded into them. If the hospitals had adopted later, more secure operating systems, then those devices - such as X-Ray machines would not have worked with the main hospital system and in many cases replacements would have been required, at great cost to an NHS already creaking under cash constraints.

¹⁰ http://broughttolife.sciencemuseum.org.uk/broughttolife/techniques/hippocraticoath

¹¹ Before Current Era

¹² https://www.us-cert.gov/ncas/alerts/TA14-098A

¹³ https://www.digitalhealth.net/2018/05/wannacry-one-year-on/



The misuse of data

Dr Laplante, in an interview for this report, said that the advent of Al has now intensified the need for a Hippocratic Oath. The use of data, he says, is now a huge issue:

Dr Phil LaplantePennsylvania State University

"We need to think about, when we're collecting certain data - how could that data be potentially misused? And if the risks are too high then perhaps we can't collect that data any more.

"It's interesting because some of those ethical decisions are made in university structures all the time when professors conduct research and they're collecting personally identifiable information, financial information, other kinds of information that if it were released to the public could be very harmful to individuals.

"So those university internal review boards or research boards wrestle with those decisions all the time. And then on a project-by-project basis they probably have to pass judgment on a project to determine whether it is permissible under whatever ethical rule sets they've created or not."

Due to this, Laplante has broadened his call for the deployment of ethics and due to the heavy reliance on technology now in society, says that it should be instilled into people at an early age even before it is put into technology.

He says ethically training the population is better than trying to retrofit ethics into computer programming:

"I would argue probably ethics should be part of every curriculum. At the post-secondary level and even before that. Everyone should have a sense of different ethical frameworks.

"Certainly in computer science and software engineering because you have the potential to do harm – more so than other disciplines. It should absolutely be taught.

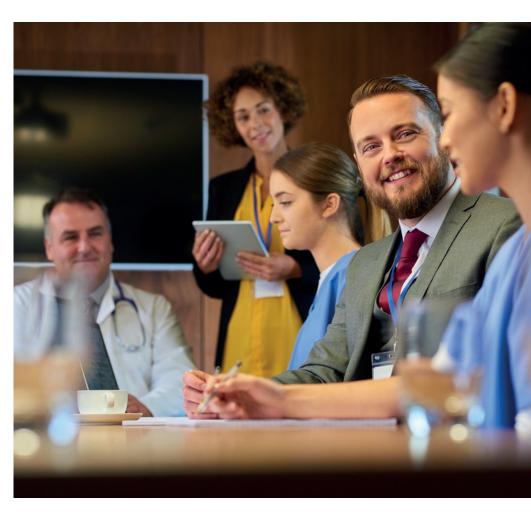
"At Penn State these are the kinds of conversations that happen all the time. I think it's well understood. Most universities that I know of have some ethical framework, some sense of philosophy, reasoning. Logic is an important part of a computer science education. You can't have it any other way."

Dr Phil Laplante

Ethical education

Laplante believes in spite of the difficulties of implementing it, ethical education is vital because it would at least mean that people would be aware that the work that they were doing with technology transgresses ethical guidelines.

"It may be controversial, but I do think it's essential and again this gets back to that whole notion of that Hippocratic Oath - in the absence of any standing ethical framework at the company where you work maybe the first thing is the simple rule that first you do no harm. That's not a bad place to start," he said. "I don't think you can impose ethics on top of programming as an afterthought, as some sort of auditing function."



Laplante's draft Hippocratic Oath for programmers

This draft was proposed by Dr Philip Laplante of Penn State University, USA, in 2004. It is based on the Oath devised by the Ancient Greek philosopher Hippocrates, which starts from the principle: "First, do no harm".

All doctors are obliged to swear before being admitted to the professional register. Nurses take the Nightingale Pledge, a variation of the Oath named after Florence Nightingale, the founder of modern nursing. LaPlante's draft promise for software engineers and data scientists is adapted from the Nightingale Pledge:

I solemnly pledge, first, to do no harm to the software entrusted to me; to not knowingly adopt any harmful practice, nor to adopt any practice or tool that I do not fully understand. With fervour, I promise to abstain from whatever is deleterious and mischievous. I will do all in my power to expand my skills and understanding, and will maintain and elevate the standard of my profession. With loyalty will I endeavour to aid the stakeholders, to hold in confidence all information that comes to my knowledge in the practice of my calling, and to devote myself to the welfare of the project committed to my care.

Proposer: Dr Philip Laplante https://queue.acm.org/detail.cfm?id=1016991 This 'ethical' use of data by Al technology is probably most problematic for the health sector due – ironically – to the medical community's focus on patient confidentiality – confidentiality that opponents claim is breached by allowing the analysis of anonymised patient data.

The contradiction is highlighted by Mark Deem, a partner in the law firm Cooley.





Mark Deem Cooley

"We have to be extremely careful if we are going to seek to implement or 'hardwire' ethical standards whether into the technology itself or into any legal framework – and the concept of transparency sits at the very heart of any such debate.

"In my view, any framework for transparency must almost be 'Newtonian' in its approach, in that it should recognise the fact that the desire for privacy on behalf of the data subject should be equal and opposite to the transparency afforded by those seeking the use of that data.

"If we are able to establish such an equal and opposite equilibrium, then we may be able to encourage individuals to allow access to their data in return for genuine transparency about the uses to which that data will be put.

"Only when you have a degree of transparency from the outset can you hope to get informed consent for the use of such data. As a practical matter, we all know and expect that those seeking data may not be initially aware of the uses to which that data may be put a month, six months or even a year in advance. But transparency about the use of data at an early stage forms a stronger basis for seeking informed consent as that use may change."

This is something that the European Union's new General Data Protection Regulations¹⁴ will almost certainly demand.



Rising public awareness

Behind Dr Laplante's call is a growing groundswell of opinion against the methods of many technology companies. The technological backlash has started because of increasing public awareness of how social media companies work, particularly in the case of Cambridge Analytica and its abuse of Facebook data¹⁵. It is a case that has also paradoxically focussed attention on Facebook's use of data and led to efforts by both Facebook, Twitter and other social media companies to change their data policies. They were also implicated in the allegations of Russians tampering in the US Presidential Election and in the run-up to the US mid-term primary elections to Congress.¹⁶

It is a perception of technology playing fast and loose with public data that is already concerning legislators, regulators and ethicists. Concern is already focusing on the use of health data as we can see with the incident of the Royal Free Hospital and DeepMind and the actions of the Information Commissioner.11

The incident at the Royal Free Hospital centred around the Information Commissioner's concern about the fact that the data from 1.6 million patients at the hospital was used without informed consent from the patients themselves beginning in 2015.

That point that was picked out by Lord Clement-Jones, Chair of the House of Lords Select Committee on artificial intelligence, in his interview for this report:



Lord Clement-Jones Chair, House of Lords Select Committee on Artificial Intelliaence

"I think the ground rules have been established, and we know we saw that the Information Commissioner was brought in. She basically censured DeepMind for what it had done. DeepMind, as a result, has set up a separate independent review board which has now produced two reports.

"Those reports have, to some extent, been critical about DeepMind's activities. It's led to actually quite a lot of new developments in terms of ethical governance but also in the way that the NHS safeguards its own data for the future."

¹⁴ https://ec.europa.eu/info/law/law-topic/data-protection en

¹⁵ https://www.theguardian.com/technology/2017/may/07/the-great-british-brexit-robbery-hijacked-democracy 16 https://www.theguardian.com/us-news/2018/oct/10/wikileaks-hacked-emails-trump-campaign-robert-mueller

¹⁷ https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2017/07/royal-free-google-deepmind-trial-failed-to-comply-withdata-protection-law/

Influences on life expectancy

Another exercise carried out at roughly the same time as the Royal Free Hospital study was undertaken by the University of East Anglia and sponsored by the insurance company Aviva. It analysed 3.4 million historical patient records dating back to the 1930s with a cut-off point of 1960 to find patterns of life expectancy.

In an interview for the PassW0rd radio programme¹⁸, carried out by one of the authors of this report in 2016, Professor Elena Kulinskaya elaborated on the work:

Elena Kulinskaya

Professor in Statistics, University of East Anglia

"So basically, we are estimating many various influences on your life expectancy. Your heart condition may be one of those but smoking, or if you start taking statins or betablockers would be other influences, and statins actually would, for example, extend your life expectancy by two years or so," said Professor Kulinskaya, who pointed out that the work was of benefit to both the NHS and to other government departments.

"So, it can be used for example by public health professionals to see how some new recommendations by Nice (National Institute for Health and Care Excellence) would expand if there were a number of patients who would be getting started on a course of treatment – how would that affect life expectancy? Or it may be used by social care services because they need to understand how much pension the state can afford to pay if the life expectancy bill increases by two years on average."

Though Professor Kulinskaya also pointed out that it may have some use to the patients themselves: "Or it can be used by individual people who would be retiring, and they have a pension fund. Now due to pension freedom we could perhaps start taking this money and spend it, but it would be nice to know for how long that money needs to last."

The data conundrum

This is one of the unexpected uses that this new world of big data and AI is producing and one that illustrates the dilemma behind the use of these technologies and the problem of introducing ethics.

One of the criticisms that the champions of technology often level at regulators is that ethics tend to shackle technology innovators with the mores of a preinternet age and prevent real value being obtained from modern technology.

It is a conflict underlined by Mark Deem at Cooley: "One of the biggest and the most practical difficulties I think we're going to experience is a huge tension existing between the privacy of the data subject and the ability of a data controller to exploit that data, whether for scientific research or commercial endeayour." he said.

"The reason this is particularly acute is because we [need] to ensure that the technologies being developed are able to access the very best data, to drive the very best learnings from that data before it is deployed in the healthcare sector. However, we also need to make sure that those who are prepared to give up their valuable data to help the wider pursuit are offered adequate protection in the way in which their data is used."

Mark Deem

¹⁸ https://resonancefm.com/schedule/2018-10-10 19 https://deepmind.com/blog/ico-royal-free/

These problems of using public data were outlined by DeepMind in the wake of the Royal Free incident referred to earlier.

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DeepMind Statement, 3 July 2017

"We welcome the Information Commissioner's thoughtful resolution of this case, which we hope will guarantee the ongoing safe and legal handling of patient data for Streams. Although today's findings are about the Royal Free, we need to reflect on our own actions too.

"In our determination to achieve quick impact when this work started in 2015, we underestimated the complexity of the NHS and of the rules around patient data, as well as the potential fears about a well-known tech company working in health. We were almost exclusively focused on building tools that nurses and doctors wanted and thought of our work as technology for clinicians rather than something that needed to be accountable to and shaped by patients, the public and the NHS as a whole. We got that wrong, and we need to do better."19

This conflict of interest is one that sits at the heart of the deployment of AI in the health service. As Dr Laplante points out, data scientists should aim to do no harm, in exactly the same way that clinicians should aim to do no harm. But what if the systems allow companies to create systems that do not work in the interests of patients, or that reliance on the infallibility of technological systems robs patients of rights?

Professor Kulinskaya in her interview with the PassWOrd radio programme in 2016 admitted that it was possible to identify people who had a predisposition to a certain condition and stated that this information could be used to advise people of lifestyle changes that they would need to make if they wished to change their life expectancy. That is a choice that many people would say represented a responsible attitude on behalf of the health sector, but one that other people might interpret as interference by the state in their lifestyle choices.

Data-led 'intervention'

The potential for data-led 'intervention' is raising hackles, as Lois Rogers pointed out on Page 8. One opponent is Margaret McCartney, a GP in Glasgow who writes for The Guardian and is a regular contributor to BBC Radio 4's Inside Health programme. McCartney is a vocal critic of Babylon Health, which was mentioned earlier. Babylon Health has secured contracts with the Chinese internet giant Tencent and the Saudi Arabian government, and is working on trials of its symptom diagnostic technology with the NHS on 26,000 patients in London.

According to Dr McCartney and a number of other GPs, Babylon represents the start of an Al-generated push towards a two-tier health system, where the healthy are looked after by Als on the basis of data that the unhealthy have helped to generate. Meanwhile the unhealthy are increasingly catered to by GPs in a poorly-funded rump NHS system. Its opponents say that private technology companies will cherry-pick their patients and eventually turn away those who are ill from its privatised system because sending a patient in to the clinic to be checked will cost the company money.

This is an evolution of the new AI world that defenders of the publicly-funded NHS argue harms their interests as patients and breaches part of the Hippocratic Oath, the duty of confidentiality to the patient. Dr McCartney has also questioned Babylon's claims that its software performed more effectively than a human doctor in diagnosing illnesses from a given set of symptoms. Babylon Health Founder Ali Parsa is adamant that the charges are groundless. According to Parsa, Babylon Health's technology does not seek to replace doctors but rather to augment them.

Like much of the AI technology now being deployed, Parsa claims Babylon will allow early diagnosis and change the way that healthcare in the UK and elsewhere has been practised: "In most diseases by the time they present their symptoms, a £10 problem has become a £1,000 solution," Parsa said in a July 2017 episode of BBC Radio 4's *Inside Health* programme in which he debated with McCartney.

Chapter 4: What are the rules?

Of course, artificial intelligence is not new. Professor Donald Michie discussed the ideas with Alan Turing during the Second World War. Later, in 1950, Turing published his famous paper on the topic and introduced the celebrated idea of a conversation between a person and a machine where the human could not tell whether the machine was human or not. This idea is now known as 'the Turing Test'.

The modern ideas behind AI gained broad academic recognition in 1956 at the Dartmouth College (USA) summer school when Marvin Minsky and John McCarthy organised what became known as the Dartmouth Conference on the subject, described by John Markoff in his book *Machines of Loving Grace*.

Yet the regulatory frameworks that govern its use are not well developed. Many were invented to deal with other types of medical interventions such as pills and potions.

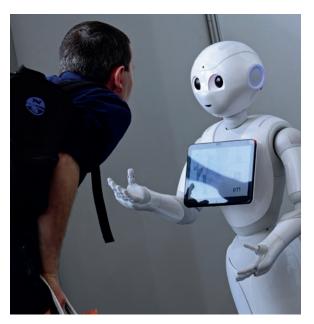
The science fiction writer Isaac Asimov was the first person to try to deal with machine ethics, albeit in a fictional setting when he proposed his Laws of Robotics in 'I, Robot' in 1950:

Asimov's Laws

Written by science fiction writer Isaac Asimov in a short story first published in 1942, the three laws of robotics are supposed to be part of a handbook for robots in the year 2058.

A robot may not injure a human being or, through inaction, allow a human being to come to harm. A robot must obey orders given it by human beings except where such orders would conflict with the First Law. A robot must protect its own existence as long as such protection does not conflict with the First or Second Law.

Writer: Isaac Asimov https://en.wikipedia.org/wiki/ Three_Laws_of_Robotics



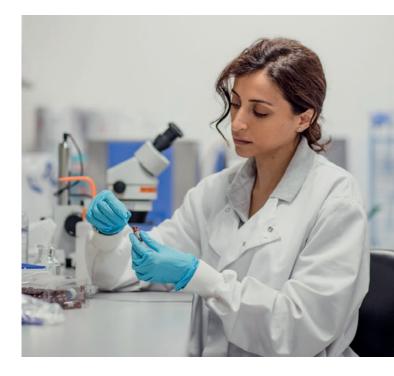
Those were fictional laws for fictional robots, playing to the popular moral panic that a Frankenstein's Monster would turn against its creator and destroy humankind. It was not until 2017 that the European Parliament passed its civil law on robotics and artificial intelligence and the UK House of Commons and House of Lords set up Select Committees to question experts on the subject. Both the authors of this report, and Mark Deem of Cooley contributed to the House of Lords study²⁰. It heralds the potential of AI to put Britain at the forefront of a new industry, harnessing technological expertise and the spirit of enterprise, and urges lawmakers not to stifle innovation with excessive regulation.

Trials and tribulations

However, the existing regime for testing medicines and healthcare devices is stringent. Clinical trials are required to prove that new interventions are both safe and effective. This can create problems for start-ups seeking to bring new apps to market. For example, Florian Bundrup's diagnostic and appointment-booking app Docyet (see Page 15) has been licensed under the European certification as Class 1 - the lowest point of entry.

After two years of research and development, and now supporting a team of 12 paid staff, Docyet is still only allowed to operate within a highly restricted framework. For Bundrup this is frustrating, and he believes the work of entrepreneurs in healthcare applications is undervalued: "It is not just something that is done in a cellar in four weeks of coding. It is years of work and decades of research."

However, Bundrup recognises that where public health is concerned - and potentially lives could be put at risk - it is vital to ensure that devices are regulated for safety, including cyber security and trustworthy systems for storing, anonymising and sharing data.



Florian Bundrup

Founder, Docyet

"On the one hand, I'm a start-up and I don't approve. Doing these tests, hiring a lawyer, doing these clinical trials is a lot of effort and it's expensive. On the other hand, especially for applications that do diagnoses, it is fair. If you use this application to determine how serious your symptoms are and if you should really visit a doctor, it's something you shouldn't do lightly. And therefore, the effort of the EU in raising those requirements is a good thing.

"So, I have two hearts in my chest: in the short term, it's a lot of pain. But it will also help the sector in the long term, and it will improve the public view of digital health."

Opinion: Scrutinising software

Peter Warren, one of the authors of this report has long argued that software, including the algorithms that power Al-driven apps, should be tested, inspected and licensed by a system similar to that of the American Food and Drug Agency (FDA). In his 2014 research study Can we make the digital world ethical?²¹ he emphasised the concerns of many in the industry that the underlying framework of the internet has flaws, and that many digital artefacts are created by copying and pasting blocks of code from earlier software. So, bugs or malfunctions are transmitted to new products, but may not be discovered until years later. If the creators of apps and algorithms do not have a Hippocratic Oath or any code of ethics, then the products they create must surely be subject to scrutiny.

Mis-diagnosis is only one problem that could potentially be built in to artificial intelligence apps.

There is also the question of diversity: how will all types of people and groups in society receive fair treatment? Entrepreneur Ida Tin, interviewed at the 2017 Ada Lovelace Festival of women in technology, expressed concern that in many American clinical trials, girls and women are not included because their hormonal swings tend to skew the results. This naturally results in healthcare products that are designed for men and may react differently in the female body.

²¹ http://www.netopia.eu/wp-content/uploads/2014/02/ Report-Can-we-make-the-Digital-World-ethical.pdf



"The key question is what is to the benefit of the users. I can imagine for instance with manufacturers of the Pill, having data about side effects that Clue users might experience could help them to build better formulas. But generally, we take great care of our users, honouring their trust, that they choose to share their intimate data with us."

There is broad concern over diversity. It was mentioned at the launch of the House of Lords Report into AI – AI in the UK - Ready, willing and Able?²⁰ by Dr Stephen Cave, Executive Director of the Leverhulme Centre for the Future of Intelligence, who stressed the need for input on the development of AI to be made from all sectors of society. This echoes the comment by journalism lecturer Linda Christmas that decisions that affect the population at large should be made by 'chaps of both sexes'.

Tin's app, Clue, redresses the gender balance a little by exclusively helping women to get better insight into how their bodies work. Clue tracks the patterns of menstruation in real time and logs the physical, mental and emotional symptoms at every stage. The intimate data it harvests is potentially of great value both to medical researchers and to marketing companies. Tin says in her interview that she would consider selling this confidential data, but only under certain circumstances.



Intimate data and how it can be shared whilst preserving patient confidentiality is the subject of a research project headed by Sir Nigel Shadbolt called Petras, which looks at the privacy implications of the data that is culled from the Internet of Things. This happens in our homes and in the increasingly personal data that is collected by the devices that we connect to our bodies using mobile phones via either fitness apps or medical devices that monitor heart rate, blood pressure, sweat and menstruation. The Petras IoT Hub is a consortium of nine UK universities. It is led by University College London and includes Imperial College London, Lancaster University, University of Oxford, University of Warwick, Cardiff University, University of Edinburgh, University of Southampton, and University of Surrey and will hold a two-day conference at the IET in May 2019²².

Vinett Taylor of Telefonica, the company that owns 02, has another example of a new app for improving diversity. It is designed for people with special needs such as autism or Alzheimer's. The app records medication taken, its effects and side-effects and uses machine learning to adjust the drugs or dosage. In this way the various carers and medical staff can always get an instant update. The app saves human carers' time that would be spent in clerical tasks and builds up a knowledge bank to guide the carers. And it enables the patients to feel they are more autonomous and knowledgable about their own conditions. Taylor is a strong advocate for Al in healthcare.





Vinett Taylor Telefonica

"It's not about a robot doing a job and a human doing a job. It's about working in collaboration. So, the humans are doing the best job that humans can do, but we're using robots and machines to do the tasks that ... they can do better. It's going to take decades. We are nowhere near general intelligence or superintelligence where AI can replace our brains."

Humans are neither perfect nor standardised and it seems to follow logically that their biases and preferences will be reflected in the algorithms they build. For Jana Eggers, CEO at Nara Logic, the problem is not intrinsic but rather flows from the data that is used to train the algorithms. In her interview, she cites an example from the automotive industry about testing self-driving cars.





Jana Eggers

"I think they were trained in Northern Europe somewhere and they had phenomenal results. They got to Australia and the cars started hitting kangaroos and they said they didn't understand why this was happening. They had done so well in all of the tests before in missing animals, why is a kangaroo different? Well, a kangaroo hops and that was different from any another animal that it had been tested around. Just adding that made a difference. Now imagine if they had had an Aussie on the team. Aussies think of kangaroos as a regular part of wildlife where the rest of us don't."

This serves as an analogy for several types of bias that may arise from characteristics of the data that is used to train the algorithms.

Earlier in this report, we had examples of lung cancer incidences in a region with bad air pollution (such as Shanghai) and a tendency for clinical trials to exclude women because of their hormone swings. Both datasets clearly influence the end result. The technology industry has an old saying, "Garbage in, garbage out", which encapsulates this problem. To solve it, more data is required from the very humans we intend to serve right now and also from historic records.

Eggers' example also points to the need for greater diversity within teams of software developers, since each human has his or her own attitudes and limitations. According to this argument, the more diverse the team, the greater the likelihood of eliminating implicit biases.

Making them explicit is another strategy and in the United States Project Implicit has been launched to help businesses, researchers and data scientists learn about their own attitudes and stereotypical ways of thinking. Anyone can log in and take a test for implicit bias across a range of social and health issues²³.

Evidence: The gender imbalance

A lack of diversity has been observed for a number of years in the technology industries' workforces. For example, men outnumber women by 4:1 in computer science and engineering in Europe. The EU country with the highest proportion of female technology workers is Bulgaria. Even there, only 26.5% of technology jobs are held by females, compared to an average of 17.2% in the other 27 Member States. The gender pay gap, lack of role models and negative stereotypes are some factors that dissuade girls and women from entering the profession. Women who do succeed – and even win awards – may suffer from so-called 'imposter syndrome' because of the male-dominated culture²⁴.

Lack of racial diversity is also perceived as an issue, as exemplified in the Mozilla Internet Health Report published in 2018²⁵.

²² https://events2.theiet.org/living-iot/

²³ https://implicit.harvard.edu/implicit/

²⁴ https://www.cnet.com/news/tech-employees-likely-to-suffer-from-impostor-syndrome/

²⁵ https://internethealthreport.org/2018/diversity-in-tech-not-yet/

https://publications.parliament.uk/pa/ld201719/ldselect/ldai/100/100.pdf

Chapter 5: Whose data is it anyway?

One more recent challenge to the new AI world predicted for the NHS is the ownership of data. It's a relatively recent concept, born from the sudden increase in awareness of the way that the cutting-edge technologies of the 21st century work.

Case Study: The Care.data controversy

More and more people are beginning to flex their muscles over who owns their data and medical data would appear to be one area where they are prepared to fight. This trend became apparent in the UK health field during the attempt to implement the now discontinued Care.data project, which asked patients whether they wanted to opt out of a scheme which aimed to share their data. It was widely considered to be yet another NHS data disaster because hardly anyone was aware that they had been asked. So most did not 'opt out' because they were unaware of Care. data. The leaflet drop by the Royal Mail had failed as it was often mixed up with junk mail for pizza deliveries and Chinese restaurant menus. And it was this failure that led to a united front against Care.data from bodies as disparate as the British Medical Association, privacy campaign group Big Brother Watch and the Association of Medical Research Charities.

More alarmingly, the media seized upon what was seen as a failure of transparency and pointed out that opting-in to the scheme meant that there was a possibility of their data being shared with private companies. This was a frightening prospect as in February 2014 it had emerged that the Health and Social Care Information Centre admitted giving the insurance industry the coded hospital records of millions of patients, pseudonymised, but re-identifiable by anyone with malicious intent. These were crunched by actuaries into tables showing the likelihood of death depending on various features such as age or disease, to help inform insurance companies about how much to charge in premiums²⁶.

The bad publicity had begun to generate in some quarters a demand for an informed opt-out. The writing was on the wall. At a time of huge big data success by social media companies and industry the decision to abandon the Care.data project in July 2016 was taken when the National Data Guardian for Health and Care, Fiona Caldicott, asked the government to consider the future of the programme.

The response from the Health and Life Sciences Minister George Freeman was swift. He said that due to Caldicott's request, "NHS England has taken the decision to close the Care.data programme," ending a woeful catalogue of failure that had seen the leaflet drop by the Royal Mail from NHS England missed by two-thirds of the population. A similar fate befell a video release which went out only on YouTube and the NHS England website. Critics also complained that there was no national press conference nor TV campaign.

However, this botched attempt to raise public awareness has had a significant impact on the NHS' plans and forced it into a nuanced breakdown of why it is seeking to open up NHS data²⁸. As a result of this history of failure and what some see as deliberate subterfuge, as we have pointed out, an atmosphere of suspicion now pervades the introduction of technology and data analysis in the NHS. This includes suspicion of government, suspicion of data companies and suspicion of well-informed patients. To move forward, this suspicion needs to be transformed into informed consent.





Mass participation

Public health policy often relies on a critical mass of people participating. For example, immunisation against epidemics of potentially deadly or life-changing diseases only works if the majority of children are vaccinated – this gives so-called 'herd immunity'.

British hospitals rely on blood supplies from willing donors. Sperm donors make it possible for thousands of infertile or LGBT couples to start families. And around four thousand lives are saved or enhanced every year by people who carry organ donor cards and are killed in accidents, or who give their organs whilst still alive, or donate bone marrow in the hope of providing a suitable match for a leukaemia patient.

The consent and authorisation rate for organ donation is less than 60% in the UK, according to the Kidney Research UK charity²⁹, so it is clearly not enough for the individual to offer body parts and there must be a more general acceptance in the family and in society. All these are 'opt-in' activities and for them to succeed on a mass scale then the population must trust the National Health Service with its children, and with its sperm, blood, bone marrow and vital organs. Perhaps instead of an opt-out, an opt-in approach to sharing personal health data would prove more acceptable.

The value of data

If people are not prepared to freely and consciously donate their personal health data, then perhaps the notion of payment should be introduced. Peter Warren, one of this report's authors, along with thought leaders such as Evgeny Morozov, has long campaigned for the right of individuals to have an interest in their own data. Lord Clement-Jones comments at length on this idea in our interview with him:

"I think it's very difficult to put a value on an individual piece of data. Aggregated data is where it's valuable, and actually, it's just as valuable if it's anonymised. I don't believe that just simply a person saying, "That is my data, you can identify me, I'm going to charge you for it," is actually a very useful concept. I'm a great believer that we have a duty in many ways to help society as a whole move forward. I don't think it's all a question of our own hugging, our own information to our chest. What I do think though is that we should have guarantees about anonymisation, guarantees about the public benefit from of it and so on and so forth," he said.

²⁶ Ben Goldacre, Guardian Bad Science Column, Goldacre is a Senior Clinical Research Fellow at the Centre for Evidence Based Medicine in the Department of Primary Care in the University of Oxford.
28 https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/
29 https://www.kidneyresearchuk.org

Chapter 6: How can we trust technology with our health and our care of the elderly?

How can healthcare systems be built so that people will willingly and consciously entrust them with their personal health data? In general, Cooley's Mark Deem believes that the law and ethics have not kept pace with the speed of technological change and welcomes moves by some companies to put this right.

"At the moment a lot of the very largest companies are starting to consider having people on their board, charged with the responsibility of reporting on the use of data from an ethical perspective. This can be prohibitively expensive for smaller companies," said Deem.



The privacy problem

More specifically, he identifies privacy as a key concern. Deem mooted the idea (at the 2017 'Living and working in an AI world' conference hosted by the IET) that a new kitemarking system might work. Instead of the long-winded, legalistic and widely ignored Terms and Conditions which usually pop up to ask for consent to use one's personal data in return for free or freemium online series, there should be a universally accepted standard.

Perhaps it could be offered at different levels -Bronze, Silver and Gold, say. These would be clear and simple to understand, and any additional privacy requirement could be added by the individual vendor or user. A similar system works

in Creative Commons for allowing intellectual property rights to be waived in certain conditions, so this would seem to be a workable solution.

To display transparency, a pop-up or watermark might be devised. Cookies are never enabled on websites unless the user clicks the consent box. Many companies handling sensitive data use a yellow canary icon to signify that they will never share users' data with the security services nor allow any backdoor access to the personal data they hold on file. These examples prove that it is technically possible to provide opportunities for more meaningful consent to terms and conditions.

Foreseeing a medium-term future in which AI, trained on big data, can always out-perform humans at diagnosis, and robot surgeons have an excellent record of safety and success, Florian Bundrup of Docyet argues that soon we may need to pay extra to have a human in the loop, because of the legal liability,

"Not all parents of a sick child will just stay at home with him because an app tells them to stay at home. It should still be possible to distrust technology and consult a doctor anyway. And this is something that we need to have a debate about. Once these algorithms get better and are publicly recognised as being valid all the time, if people trust technology less, are they still allowed to go to a human doctor? Do they have to pay extra for this? Imagine a robot is operating on you ... it's a scary feeling. But an independent study proves that the robot is right 98% of the time and the human is right 93% of the time.

"Some people will still choose the human. Those 5% errors carry liability afterwards, because those mistakes could injure the patient permanently. Who pays for that? It's the same as autonomous cars. At the moment when most cars are autonomous, those humans who still drive cars have to pay extra because they are less safe."



The impact of our ageing population

With an ageing population, demands on health services increase. Old age is not an illness, but it brings frailty and disabilities, so that the promise of an Al to act as a care-giver and/or surveillance system becomes attractive to cash-strapped public health services.

Dr George Leeson of the Oxford University Centre for Population Ageing says: "The UK Government – all governments – have taken a long time waking up to the consequences and challenges that this ageing population presents. It is a huge challenge."

In Japan, humanoid robots have been developed to replace human nurses or carers³⁰. And in the UK and elsewhere in Europe, developers are creating apps and gadgets to improve the quality of life for elderly people. For example, Germany's Fraunhofer Institute produces the Care-O-Bot4, in use at Stuttgart's Parkheim Berg nursing home. It dispenses drinks to Alzheimer's patients, recording their liquid intake and heading off dehydration. It combats dementia by displaying memory games on its 'face' screen, playing songs and even 'singing' along with them.

South Korea has developed a 'sniffer bot' called KiroM5 that patrols the nursing homes, detecting soiled incontinence pads. It alerts the nurse at once, with a discreet message on the tablet. This prevents prolonged discomfort and embarrassment for the elderly resident and possible complications such as pressure sores

or sepsis. Kiro M5 and Care-o-Bot are machines that look like machines, but in Japanese care homes for elderly people, the machines are built and dressed to look and feel like people, with warm "hands" and "arms" and synthetic "skin".

Japanese-Australian Adrian Cheok, Professor of Pervasive Computing at City University London commented in an interview for the PassWOrd radio programme in 2013:: "If you want to put someone's grandmother to bed you've got to make her comfortable so (the robot)'s got to have hands and things – you can't have industrial pincers. So, Japan has become a world leader for humanoid robots".

Some ethicists such as Emeritus Professor Mary Anderson at the University of Connecticut, who was interviewed for the report "Can we make the digital world ethical?" oppose the use of human-like characteristics in robots. Anderson argues that it is wrong to pretend a machine is like a person since this will result in misplaced trust, possibly even unrequited affection. And when the European Parliament passed its Civil Law on Robotics and Al in 2017³², this issue was also addressed by Mady Delvaux Sèhres MEP, the rapporteur for the research study and debate, and was written in to the final wording for the new law.

Not only humans but also pets can be simulated by small robots. Dr Leeson enthuses over the calming and stimulating effects that PARO³³, a smart seal pup (robot covered in synthetic fur) can have on its elderly "owner".

³¹ http://www.netopia.eu/new-report-can-we-make-the-digital-world-ethical/

³² http://www.europarl.europa.eu/RegData/etudes/STUD/2016/571379/IPOL_STU(2016)571379_EN.pdf



Picture: Amazon

Personal assistants

Elderly people, whether or not they live in care homes, can benefit from AI in the form of a standard or customised virtual assistant such as Apple's Siri and Amazon's Alexa.

Responding to verbal questions with a sympathetic, human-like voice, the virtual assistant can keep the elderly person company, dispelling feelings of loneliness and isolation. Alexandra Montgomery Whittington at the University of Houston, Texas, describes how such a Personal Assistant is perfectly adapted to a caring role with dementia patients. The Siri or Alexa does not care how many times the elderly person asks the same questions, and mechanically answers it up to 20 times an hour, giving the elderly person a reassuring sense that a conversation is continuing. She was interviewed for the PassWOrd Woman radio show produced by Future Intelligence in 2017. Numerous wearable apps, monitors and sensors offer the possibility for elderly people to live in their own homes, whilst still being observed by machines that watch out for abnormal behaviour, know the person's position within the home and check that he or she is taking medication and eating and sleeping appropriately. In Chapter 1, Tim Mercer's video consultation app, for example, will facilitate interventions by a human doctor or care worker, if they are needed.

It's been suggested that an AI could become the memory, or a memory prompter, for an elderly person with AIzheimer's. PARO the seal pup could be the proxy, presenting old photos, songs or souvenirs to jog the memory of a person with dementia. But this could then create its own ethical difficulties: at what point does the AI, which knows and recalls more about the person than the person knows herself, actually become that person?

And what should happen to the stored memories that amount to that person's intellectual and emotional legacy, when dementia becomes extreme and later after their death? Ethical dilemmas such as these need to be addressed, and soon.

Health journalist Lois Rogers sums up the situation: "Everyone's living longer so they are an increasing burden on the health service. There's ever greater pressure on doctors to see more patients so they're using Al and robotics. It might be devices that will talk to people in their own home or do blood pressure tests in the home. The problem is these are the very patients who are least likely to be able to respond to the technology, to this type of kit. If you've got kit that people can't work or can't afford the money to buy it or the time to train on it then you've got a real problem."

The Oxford Institute for Population Ageing announced on 26 September 2018 that the trend towards longer life expectancy in the UK has ended and it may even start to go in reverse.

"Life expectancy is stalling and may even be going backwards in the UK and given the unbelievable rise in diabetes and obesity I am not surprised," added Rogers. So, although the clock may have stopped on the demographic time bomb, the poor state of health of a growing proportion of the population still gives cause for concern.

Cyber security – a health warning

Though cyber security has not been a specific subject of either this report or the 'This AI Life' conference in 2018, it is evidently of crucial importance to the adoption of technology in the NHS.

In numerous interviews that the authors have carried out either for the Cyber Security Research Institute or for the *PassWOrd* radio programme on Resonance FM there has been total unanimity about the vital importance of cyber security to the health service. Given the value that the NHS is quite evidently attaching to the use of patient data, it goes without saying that the integrity of that data is essential.

Perhaps the most useful contribution to this matter is a comment made by Melissa Hathaway, the former Acting Senior Director for Cyberspace for the US National Security and Homeland Security Council. In an interview for the *PassWOrd* radio show, Hathaway stated her belief that servers and systems holding health data should be considered sacrosanct and that the highest penalties should be reserved for those interfering with them, due to the critical nature of the information they hold.

Recommendations

The authors of this report recommend:

- That there is an urgent need for public engagement about the reason why the NHS needs access to patient records.
- 2. This process should lay out extremely clearly what those terms of engagement are. The process must be completely transparent.
- 3. There must be a clear benefit to the public from this process and we recommend a Health Charter that strikes a bargain with the public on the basis that not only will the introduction of AI and big data into the health service improve the lives of patients, but also that people see a reasonable proportion of the profits made from the use of their data making its way back into the health service. In short: there should be a health tax on those companies' profits that flows back into the NHS.
- 4. That the government introduces education programmes in schools, colleges and universities that teach ethics and the ethical use of data in relation to computer programming.
- That a body is appointed to oversee the use of AI in the NHS to reassure the public that the systems are working in the interests of patients and staff.

- 6. That specific legal protections are given to patient data, making it a crime to interfere with it in any way and highlighting that servers and computer devices holding patient data are considered sacrosanct and very high penalties will be served on those who breach them or tamper with medical data.
- 7. That training is provided to healthcare staff and multi-disciplinary teams are created to develop a co-operative culture is in the NHS using the intelligence conferred by the AI systems to improving healthcare delivery.
- 8. That the system of providing startup grants should be broadened to include and promote business startups, headed by people in retirement so they can develop businesses that understand their needs as they become older and solve their own problems.
- 9. That this access to funding is matched by a more enlightened attitude from the financial services community so that old age is no longer seen as a barrier to loans.
- 10. That increased access to technology education is made available to older sections of the community so that they can develop the business skills necessary to build new businesses and to improve their own health and well-being through technology.

Conclusion – Where do we go from here?

We cannot predict the future, but we can learn lessons from the recent past to show the way.

Writing in November 2014, Tim Kelsey, then-Director of Patients and Information at NHS England, laid out his vision for the use of technology in the NHS.

Kelsey is a former *Sunday Times* News Editor and Co-Founder of the healthcare analysis company Dr Foster. Controversially, the government bought 50% of Dr Foster for £12m in 2006. Kelsey went on to take up several roles in government, finally becoming National Information Director in health and care and chair of the National Information Board of the Department of Health in addition to his role at NHS England.

Tim Kelsey

Former Director of Patients and Information, NHS England

"One of the greatest opportunities of the 21st century is the potential to safely harness the power of the technology revolution, which has transformed our society, to meet the challenges of improving health and providing better, safer, sustainable care for all. To date the health and care system has only begun to exploit the potential of using data and technology at a national or local level.

"Our ambition is for a health and care system that enables people to make healthier choices, to be more resilient, to deal more effectively with illness and disability when it arises, and to have happier, longer lives in old age; a health and care system where technology can help tackle inequalities and improve access to services for the vulnerable."

Is the NHS lagging behind with technology?

In 'Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens. A Framework for Action' Kelsey lays out in his 2014 paper a very familiar position for the use of technology in the NHS that very accurately mirrors the picture presented to the authors of this report.

It describes a healthcare system that is lagging behind big business in the use of technology. One where successive attempts to introduce centralised IT systems designed to free up patient records had failed, and thus had also failed to deliver the potential benefits that should have been possible from analysing patient data to NHS doctors and researchers.

Kelsey makes this point in his action framework: "At times, the health and care system has tried highly centralised national procurements and implementations. When they have failed, due to a lack of local engagement and lack of sensitivity to local circumstances, we have veered to the opposite extreme of 'letting a thousand flowers bloom'. The result has been systems that don't talk to each other, and a failure to harness comprehensively the overall benefits that come from interoperable systems. In future, we intend to take a different approach. We will be tight on standards and definitions, and clear on expectations regarding interoperability, but we will support local decision-making on systems, programs, interfaces and applications. Some of the key systems needed will remain national responsibilities, such as the sustainable



platform – the 'electronic glue' – enabling different parts of the health service to work together, and to capitalise on the wider gains of doing so. We will support local health and care communities, respecting their local needs and priorities and acknowledging their relative digital maturity, to decide upon and procure their own solutions, provided they meet nationally specified technical and professional standards."

Gradual tech conversion

In short, we will introduce common data standards and use what are known in the technology industry as 'best of breed' solutions, meaning that the systems that work will be gradually introduced across the NHS. Rather than a centralised dictated imposition of an IT system, the NHS will allow a gradual conversion of doctors and staff to the technology that they can see delivering provable benefits.

As Kelsey points out in his framework for action³⁴ this has the potential to achieve considerable cost savings if the technology works and proceeds at pace, because as Lois Rogers, a former colleague of Kelsey's points out, the NHS needs to make savings and deliver efficiencies now.

"We have an ageing population an increasingly unhealthy population beset by the side effects of obesity, heart disease, dementia, everyone's living longer so they are a burden – an increasing burden – on the health service for a longer period of their lives than was the case in the past," she said.

"It means that there is ever-greater pressure on doctors to see patients and the way that they're trying to deal with that is using new forms of technology. Robotics and artificial intelligence of one sort or another to monitor patients might be devices that will talk to people in their homes or do blood pressure checks and other basic bodily function tests in their own home. But the problem with that is that most of the people who are chronically sick tend to be elderly, tend to be less technologically minded than the rest of us and therefore they're going to be people who have much more difficulty adapting to this type of technology."

Making use of big data

As covered in the NHS' 'Five Year Forward View', mentioned in the Introduction, the system has to become much more adept at using big and open data systems to identify internal issues and address them. Rather than spending money on expensive treatments for an ever-increasing number of elderly patients the NHS has to find new technological methods to solve issues.

If the Al lives up to its promise the savings can be huge, as we can see with Tumour Trace in Chapter 1. According to Aamir Butt, the savings from the use of its technology are huge because each Tumour Trace scan costs just £10 and delivers instant analysis. In the case of cervical cancer, it should deliver instant savings as the current system costs between £20-£30 a scan, while the cost of a prostate cancer test can be between £250-£380.

There is a two-fold issue however that technology introduces. Time is against the NHS at the moment, so it has to be able to prove that technology works and introduce it. This is a tough challenge when Al is still seen as a very new technology, because any technology adopted must work and be trustworthy, due to the NHS's record of technology failure. Failing to introduce meaningful change will simply allow the conservative forces against change within the NHS to once again use failure as the justification for inaction.

The only way to overcome this is to present the technology in a way in which people can see it as useful, by creating new teams of people attaching big data scientists to departments within the NHS so that they become a core part of healthcare delivery.

Opinion: Evolution, not disruption

Much is made of 'disruptive technology', but this is a damaging misnomer. Technology is not disruptive. It is evolutionary, taking outdated systems models and making them fit for purpose with modern technology. To achieve this requires an ongoing system of education. So, to prove the value of new technology systems NHS staff will not only have to be educated in their use, they will also have to be convinced that they are being provided with tools to make their jobs better and not to replace their jobs.

As we saw from Peter Bannister's comments about radiologists having to be reassured they would not be replaced and from DeepMind's comment that it should have understood the issues of patient data better, introducing AI technology into the NHS will be a learning process for all. This new way of working will bring new people with different job descriptions into the NHS.

³⁴ Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens - A Framework for Action. Nov 2014

Florian Bundrup underlined the fact that the health teams of the future will be combinations of healthcare professionals and data scientists. Trust can be built in this way.

This process can only be achieved if the data is made available from the patients and this will perhaps be the hardest issue. In 2001 the then Health Secretary Alan Milburn told the BBC in response to the publication of the *Sunday Times's* first 'Good Hospital Guide' that: "The NHS has acted like a secret society. It has to recognise that people now expect to be treated like consumers."

He was perhaps unwittingly commenting on a broader failure of government, that for too long it has treated taxpayers' data as its property and not viewed the relationship from the other end of the lens.

Opinion: The need for transparency

It is this that is perhaps the most crucial part of the problem. Up to now, successive governments of all political colours have called on people to sacrifice civil liberties, privacy protections and personal data in pursuit of a common good. As Deem points out, a new compact has to be drawn up. Kelsey in his personalised vision for healthcare in 2020 talks about transparency and that has to occur. If it doesn't and the government is seen to be taking patient data and letting it move by osmosis from the NHS into the private sector with no benefit to patients then it will fail

International perspectives

One of the reasons that may tempt policymakers to let this happen is national interest. In the febrile atmosphere that now surrounds AI development an atmosphere of intensely fierce competition has begun. The French President Emmanuel Macron has stated his ambition of making France a world leader in the technology and similar pronouncements have been made in the UK, the US, China, and in all of the world's leading countries – data may be the new oil, but AI is the delivery system that makes use of it.

In Belgium, as we have read, a top technologist has suggested that in pursuit of the new Al world, its population should give their data like blood, so that new patentable discoveries can be made by companies unshackled by regulation. It is a race in which the Chinese are also keen to engage, and they demand unfettered access to data from their population. It can be argued that this is in the interests of everyone because you get a world-leading industry in return.

The long-term view embraced by the NHS would appear to be a little more nuanced, and perhaps disingenuous. 'We want to give you 'the consumer'

more choice, we want to empower you with information,' That is how they describe a policy that at heart is intended to introduce an internal market in the National Health Service.

The patient-centred approach

Promoting responsibility for your own health is one of the core aims of the NHS policy – as it is aware that there is a growing elderly population, it wants to counter growing issues of obesity, diabetes and ill health and promote a much more active old age and wishes to do this by early intervention. But this will involve using data to identify patients at risk and head them off with advice, while promoting a healthier lifestyle to the elderly population. It is a form of data analysis that could be mistaken for surveillance and resented.

This is an under-developed area – that of unexpected consequences from understanding data better – but it is certainly one that the government and the NHS are watching, though how it may develop is still unclear. One issue that may occur, touched on in our interview with Bundrup and in an interview with philosopher Professor Anna Marmodoro from Oxford University is that of technological dependence and whether people will be willing to override or question the opinion of a machine, for if as Babylon Health's claims that its diagnosis is currently superior to that of a doctor in the future will you go to a human for a second opinion?

And if you elect for a human doctor will you be penalised by the health service and the insurance industry?

The central issue for the public's relationship with the NHS is this commodification of health – the business of making markets from illness and death. This is what people and the staff in the NHS find uncomfortable. This can be seen from Dr Goldacre's response and the comment on the NHS website in Chapter 5. People do not want companies making money out of their data to their disadvantage. This goes back to the point that we made about the clerks gathering data for the Domesday Book at the beginning of this report. It is one thing to give information to your benefit, it is quite another to give information to your detriment.

Despite the competing views about data use, Bundrup and Butt for example both pointed out that there are other issues that are just as important for developing Al systems. Developing systems is enormously expensive because of the cost of clinical trials involving real people. According to Butt³⁵ the bulk of the cost of clinical trials involves getting real people through the door to be tested for a specific purpose – ironically perhaps a market failure that could be alleviated by obtaining more data from patient records.

^{35 &}quot;The bulk of the time taken to conduct clinical trials is access to patients that depends on the prevalence of the illnesses in question. Clinical trials for a detection or therapeutic product for an illness with a low number of incidences in the population would take longer than one where the illness is very common. The administration around conducting these trials often takes longer than the trials themselves; it is in this area that higher efficiency can be achieved that would materially reduce the overall time for completing clinical trials, reducing costs, and bringing diagnosis and therapy to the public quicker." – Aamir Butt.

Regulation and ethics

Unsurprisingly, there was unanimous agreement from all interviewees about regulation regarding the protection of patients' data. The most interesting finding from the reports authors' point of view was the view that ethics must in some way be bound into the entire AI process. Professor Laplante suggested that schools from primary level onwards should teach ethics – a view that we think merits consideration.

Many of the data abuses that have occurred to date within companies, such as the attitudes pilloried by many former exiting Facebook executives³⁶, may not have occurred in the first place with a more finely developed ethical antenna. If similar behaviour were discovered in Al healthcare companies on an ongoing basis, it could prove fatal to the relationship that the NHS needs to develop for its technological future. Further unpredictable challenges will inevitably be thrown up by the technology systems themselves. Already systems are being developed that help people with failing mental faculties by provoking memory recall. But that throws up the question: what happens with that data and who owns it? This will again require ethical debate because the snapshots that make up our memories, those parts of us that are known as our 'extended mind' will be contained for the first time in entities that are outside of ourselves that will need to be protected, as pointed out in Chapter 7.

What has been clear from this report is the urgent need for change. The NHS is facing huge pressures to deal with demographic changes. It has to do that at a time of shrinking budgets and has to embrace new and often untested technologies with little margin for error.

It has to build new teams that integrate people from those new technologies and it has to do so against a prevailing atmosphere of distrust. Those companies engaging with the NHS have to do so with equal caution. The NHS is universally loved by the UK population and celebrated its seventieth anniversary in 2018 with huge shows of public support. Britain is unwilling to see the NHS dismembered and sold off. As opinion polls have shown³⁷ the public want and trust the NHS and do not want to see any technology revolution damage that relationship³⁸.

Finally, there are significant changes that need to occur with our view of the elderly, retirement and of the role of old people in society.

As Professor Rana Gheerawo of the Royal College of Art and Design and Professor George Leeson of the Institution of Population Ageing state in interviews for this report, old people will live longer because of technology. Improvements in health developed by AI will simply mean we have more old people. Thus, the technologies being developed should not be palliatives for dotage. They should be developed to enable old people to be able to work longer and to contribute to society. The AI systems being developed for the NHS should take this on board and so should the technology companies. As well as developing systems that improve the health prospects of old people, the AI companies should recognise the opportunities to develop new systems to help elderly people change their lives and stay in employment for longer and recognise the contribution that they can make in this new AI world.

As Professor Gheerawo says:

"Every time an old person dies, a library burns."



The IET would like to thank the report's authors Peter Warren and Jane Whyatt for their efforts in compiling this report, along with the members of our Healthcare and Digital thought leadership panels who offered their knowledge, expertise and guidance and all of the AI and health sector experts who gave up their time to be interviewed.

³⁶ https://www.businessinsider.de/former-facebook-exec-chamath-palihapitiya-social-media-damaging-society-2017-12?r=US&IR=T

³⁷ https://yougov.co.uk/news/2018/07/04/nhs-british-institution-brits-are-second-most-prou/

³⁸ https://yougov.co.uk/news/2018/07/04/brits-still-love-nhs-they-are-nervous-about-its-fu/



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