What does the digitalisation of the NHS mean for patients?

BMA Patient liaison group symposium
26 September 2018
Summary of the symposium

On Wednesday 26 September 2018, the BMA patient liaison group¹ held a symposium attended by 55 delegates to discuss how the digitalisation of the NHS will impact patients in the UK. See Appendix 1 for a list of organisations that attended the symposium and Appendix 2 for the full programme.

The event was opened by Amanda Cool, Patient liaison group chair, who stressed how the digitalisation of the NHS was a key issue which would continue to have a profound impact on patients. The BMA places significant value on the work of the Patient liaison group in informing its work and monitoring the digitalisation of the NHS is a key policy area for both the Patient liaison group and the BMA. Amanda Cool emphasised the importance of the patient perspective being used to inform future developments on the digitalisation of the NHS and the need to ensure that all patients are supported in accessing services.

Empowering people to manage their health and care using digital tools and services

This first session set the scene of the event. Polly Bishop, Head of Digital Strategy and Engagement at NHS England, provided an overview of how digital technology had been empowering health and care.

NHS England’s goal is to empower people to manage health and care using digital services and it was working increasingly with self-care teams to do this. Better use of technology and information was fundamental to effective transformation as it was the only way to modernise and join up the health and care system to deliver better patient care, better patient experience and better sustainability.

NHS England’s plan to achieve its digital transformation portfolio was broad: it included digitalising systems, getting rid of slow paper-based ways of working and ensuring clinicians could access the insight and information they needed to make the best decisions for patients wherever they were. Local populations had their own local systems and it was necessary to work in partnership with them in providing key

¹ The BMA’s Patient liaison group (PLG) is the BMA’s internal patient reference providing the BMA with an informed patient view on matters of interest to the medical profession and to patients. PLG members come from a range of backgrounds and draw on their knowledge and experience as patients, carers, advocates or professionals working in a range of health-related fields.
components e.g. NHS logins (Citizen IDs), enabling NHS WiFi and issuing standards and guidelines such as the Digital Design Manual Code of Conduct. Principles underpinning NHS England’s ways of working included openness and transparency, collaboration with others and leading the way in digital accessibility.

Digital services and tools were already empowering many people to take control of their health and care but this was just the start of the journey; over the next ten years digital services were expected to become the first point of contact with the NHS for many. For this to be successful, there needed to be a point where people saw the online journey as simpler, more desirable and more convenient than calling their GP or going to A&E in the first instance. Key programmes to promote empowerment included access to free NHS WiFi and GP online services.

NHS England published a roadmap every three months to ensure colleagues inside and outside the system were aware of how they could get involved to provide feedback to help shape programmes. Other developments included the NHS website update which was now more user friendly, the redesign of the NHS Library (now integrated with the NHS website), and the launch of an NHS app. The NHS app included symptom checking, triage and appointment booking. By the end of 2018 it would be publicly available in the App Store and Google Play Store as well as being a desktop webpage. A national roll out was scheduled for March 2019.

The population was increasingly being referred to as ‘digital first’ i.e. having a preference to use digital and internet powered methods over traditional means of communicating with experts and interacting with services. The end goal was to improve access and services. The NHS long term plan would set out a vision for the future of healthcare supported by high quality digital, data and technology through the lenses of individuals, frontline staff, health and care systems, research and industry.

Digital patients and digital clinicians: how digital technology has been empowering health and care

Dr Manpreet Pujara, Director for Quality and Safety at NHS Digital, explained to the symposium how digital technology has been empowering health and care. As well as working for NHS Digital, Dr Pujara is also the prescribing lead for his CCG and a part time GP.

Dr Pujara said that the purpose of digitalisation was to improve care for patients and the public as well as clinicians and other frontline professionals. The empowered patient now had apps and wearables, access to personalised information, better tools to manage their care and more ways to communicate. In this way, information could be shared more easily and security was ensured. Technology also allowed the patient to take charge and self-manage conditions. It provided the means to record information so that both doctors and patients found it easy to access.

The population was changing, with the number of people aged over 60 in the UK set to rise by 46% over the next two decades (from 15 million to 21.9 million in 2039). The UK’s population of over 85s was increasing even more sharply and was set to more than double in the next dozen years. The demand for healthcare services had increased but expenditure had simultaneously decreased. As a result, an increased awareness on prevention was necessary; 70% of the NHS budget was being spent on long term conditions for example.

2 NHS Empower the person: Roadmap for digital health and care services [https://www.nhs.uk/transformation/](https://www.nhs.uk/transformation/)

3 Patients should visit [www.nhs.uk/nhsapp](http://www.nhs.uk/nhsapp) for the latest patient information.
Technology had also changed ways of communicating; 85% of the population presently owned a smartphone and more than one in ten people wore a fitness band. Healthcare needed to adapt and take advantage of all available tools.

It was also important to look at what had already been achieved, for example NHS Spine⁴, which had bound all the NHS clinical systems and services together. As a result, the national core information technology systems were working to transform the way care was delivered across the NHS. 96% of the UK’s population had summary care records giving health professionals access to the vital summary information regardless of geographical or organisational boundaries. Another major improvement was the e-Referrals programme, which had digitalised the passage of a patient from GP to acute care; 100,000 consultant led appointments were made from primary care settings electronically every day through the service and the volume of interactions could only increase.

The balance of information between doctor and patient was also changing, as doctors no longer had a monopoly on information. Digitalisation facilitated better communication, a better patient experience and better care. In this age of connectivity and ease of information access, patients were much more informed before they even had access.

Dr Pujara ended his talk by saying that digitalisation was the answer to many health and care system problems. If the problem was clear, it could be solved by starting with the patient and working backwards; he added one needed to be brave with the power of disruptive thought.

**Delegates’ perspectives**

The effect of the digitalisation of the NHS on patients is something which has the potential to impact patients and the public in a positive fashion, as well as pose risks to patients. Delegates commented on the opportunities presented by digitalisation for patients, such as improved accessibility to services through booking GP appointments online and online prescription systems reducing the need for appointments. Access to personal medical records could enhance a patient’s ability to self manage conditions and empower patients to take control of their own health and care. Improved integration

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⁴ Spine supports the IT infrastructure for health and social care in England, joining together over 23,000 healthcare IT systems in 20,500 organisations,
of health and care information would lead to increased efficiency and cost savings which would benefit the NHS, clinicians and patients.

Digitalising the NHS also poses risks to patients. Delegates raised concerns around the security and use of confidential and sensitive patient data and highlighted issues around patient choice on data sharing. Delegates commented on the potential of excluding different types of patients, such as older people, people with low levels of digital literacy and those who did not have access to smartphones or the internet. Despite providing opportunities for patient empowerment, digitalisation could place an unfair burden on the patient and also could impact negatively on the patient/clinician relationship by taking away the crucial face to face element.

Delegates thought that patients should be aware of relying on using the digital space for self diagnosis, national standards on digital use and the fact that there was variable access to online services for patients across the UK.

Positive impacts of technology and innovation on patients: how digital and technology can benefit disabled patients

Adi Latif, Accessibility and Usability Consultant at Abilitynet, highlighted the importance of digitalisation for disabled people and shared his own experiences. He began by noting how people differed in some ways, e.g. by age, colour and religion but were the same in others such as free will, independence and freedom. He added that everybody needed to live how they wanted to including disabled people and that advances in technology meant that physical barriers no longer prevented disabled people from experiencing the same freedoms as able bodied people. For instance, 20 years ago, a blind person would have been accompanied by a teacher to take notes in class, write in exams and do assessments. Today, screen readers allowed blind people to interact with the digital world so that they could read documents on computers. Screenreaders on phones could also help someone do everyday tasks such as ordering food and voiceovers could help to navigate over screen headings.

Wearable technology such as implantables and smart clothing empowered patients and allowed them to take control and monitor their own health. A GP Virtual Service could ‘help you out of the house’ i.e. you could book an appointment online via an app or website, have medication delivered to your door from a digital pharmacy and receive reminders for when you needed to take your medicine. Other devices included Alexa, a personalised virtual assistant developed by Amazon which gave disabled people independence and empowered them – so much so that some people didn’t have the option not to use it. A landmark new partnership between the NHS and Amazon could enable patients to diagnose symptoms using Alexa5. If Alexa had access to a patient’s medical records and was aware of spending habits it could help with lifestyle management. In the future, Alexa could also recognise and validate a service user by their voice, check health data and help book GP appointments.

The University of Southern California’s Institute for Creative Technologies had developed an AI therapist called Ellie6. Accessing therapy could be a long process but Ellie could facilitate it quickly. Some people e.g. autistic people could benefit from talking to a virtual therapist as they didn’t always find it easy to talk to a person. Ellie could read facial expressions by observing 66 points on a patient’s face and also read the variation in expressions throughout the session. These visual cues helped Ellie to

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5 The video sets out specific goals for the NHS to invest in tech such as Amazon Echo (Alexa) and VoiceOver
6 This video shows two interactive technologies recently developed for multimodal perception and healthcare support by the USC’s Institute for Creative Technologies.
Adi Latif ended his talk by saying that technology signalled an exciting era of independence never seen before. Digital products were being developed in such a way that they could be accessed by people with disabilities as they needed them the most; technology was helping to reduce disability by giving disabled people more independence and access to information.

Dr Farah Jameel, IT Information and Governance Executive Lead for the BMA General Practitioners Committee, explained that technology should be embraced as it could make big improvements to the NHS. Not too long ago, for example, all records were paper based. However, monumental advances had been made in the last 20 years that had improved the way the healthcare industry delivered patient care and the way the public expected to be treated. There were computers in every general practice consultation room, for example, and as healthcare had become increasingly reliant on technology, patients had also become tech savvy and expected to be treated as such.

However, despite the advances that had been made, there was room for improvement. This was highlighted by the 2017 cyber attack on the NHS which affected 80 of 236 NHS trusts. Approximately 19,000 appointments were cancelled and many more hospital operations were cancelled. In an age of digital disruption, it was important to understand that patients wanted to get on with their lives with minimal disruption and that they also needed to be empowered.

Dr Jameel explained that a high volume of data needed cost-effective and innovative forms of processing. Today’s data also came from multiple sources which could make it difficult to link, match, cleanse and transform information across systems. Multiple
data leaks could also quickly spiral out of control. High volumes of data could also be very valuable and enable vast change. For example, Genomics England’s 100,000 Genome Project\(^9\) was sequencing the genomes from approximately 70,000 people and combining genomic sequence data with medical records. This would be a very valuable resource for the health service.

New technologies had seen the creation of hundreds of data related apps, devices and wearables being used by individuals or organisations. According to Future Health Index data, 57% of patients owned or used a connected care device to monitor various health indicators. Only a third of them, however, had ever shared this information with their doctor. However, healthcare was the industry the general public trusted most with its personal data and what organisations did with the data mattered; it presented huge opportunities e.g. designing and deploying innovative packages of care by a workforce of technology-savvy clinicians and AI algorithms. Other opportunities included understanding re-admissions trends and operational performance, determining capacity issues and reducing morbidity and mortality.

For population health analytics to deliver value, comprehensive patient records were needed, incorporating information from GPs, local authorities and community, mental health and acute trusts among others. These records needed to ‘talk the same language’ and contain the clinical depth to support analysis; ultimately, the ability to store, share and analyse health information was directly tied to improved technology. The use of technology increased provider capabilities and patient access while improving the quality of life for some patients and saving the lives of others. The NHS was moving into an era where physicians could see patients remotely and diagnose a patient’s problems accurately via telemedicine even in the most rural areas. Technology had progressed from improving patient care and the healthcare industry, to impacting our society as a whole.

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\(^9\) Further information on Genomics England’s 100,000 Genome Project can be found here [https://www.genomicsengland.co.uk/about-genomics-england/the-100000-genomes-project/]
Widening participation: reaching the furthest first

Peter Nuckley, Delivery Manager for the Widening Digital Participation Project at the Good Things Foundation (a social change charity that supported socially excluded people in improving their lives through digital), outlined the aims of the project.

The Foundation was running a three-year Widening Digital Participation Project funded by NHS Digital which aimed to reduce digital exclusion in the UK and ensure people had the skills they needed to access relevant health information and health services online. The Foundation was working with 5,000 centres around the UK, covering the most deprived areas of the country to tackle digital and social exclusion. So far, it had trained up approximately 280,000 people – resulting in fewer doctors’ appointments and visits to A&E services. The next phase would focus on developing interventions and models and work with 20 Pathfinder projects across England. Each project (14 of which had been designed so far), would last 12 months and aimed to support the furthest to reach in society first.

One of the projects which had already been set up was a Facebook support page at a Stoke hospital for those suffering from atrial fibrillation. It was run by a nurse and enabled sufferers to get peer support and access to nurses and consultants more easily. Initial reports indicated that it was saving 25% of doctor appointments and that patients were feeling better supported. A breast cancer screening group had also advertised screening on Facebook with people on hand to help with bookings. This had increased the attendance rate by an average of 12.9% (against a backdrop of a 4% national annual decrease). A project in Sheffield saw digital champions offering digital skills in waiting rooms so that patients could then develop their digital skills further. Another project in Hastings working in conjunction with a homeless charity saw charity workers visiting rough sleepers at the local pier at 4am to talk to them about their health. They were taken through NHS Choices, helped to change behaviours and re-engage with the NHS. A project in an Orbit Housing Association block in Thanet saw digital champions in common rooms showing residents how the benefits of the digital world could enhance their lives and improve their wellbeing.

The Good Things Foundation was engaged in digital to enable change, tackle social exclusion and increase patient activity in managing their own healthcare. The projects had all increased patients trust in their GPs and what they had to say. Using the right language was key, simple language was always more successful than sophisticated language which could put people off. Barriers and context also needed to be understood; digital could cut across everything but more education was needed. So far 128,201 people had engaged with the NHS Widening Digital Participation programme and together with the Good Things Foundation, it was continuing to embed digital inclusion into healthcare. If successful, the programme could be rolled out across other areas of the country.

Delegates’ perspectives

The potential for the digitalisation of the NHS to exclude certain groups of patients and need for access to be improved for those hard to reach groups is something that must be focused on. Delegates agreed that many organisations had not gone far enough to combat digital exclusion. This may be due to cuts in local funding, poor infrastructure and WiFi access. Digital exclusion was also connected to issues such as poverty and housing. The NHS did provide information on various digital services online, but patients were not necessarily aware of this information and how to access it.

Delegates discussed how access can be improved for hard to reach groups. It was highlighted that hard to reach patients were not a cohesive group and each cohort had

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Further information on the Widening Digital Participation project can be found here: https://www.goodthingsfoundation.org/projects/nhs-widening-digital-participation-phase2
its own unique needs. In order to identify solutions, specific needs had to be understood and solutions developed in cooperation with these patients. Some delegates commented on the potential benefits of outreach work on a local basis to build peer support relationships for certain patient groups. There was agreement that access should be universal and equal, regardless of the type of patient.

**Use of patient data: an overview**

*Dr Paul Cundy,* GP and BMA General practitioners committee IT Policy Lead for past 18 years, gave an overview on the use of patient data.

During his 18 years as GPC’s IT Policy Lead, Dr Cundy had seen how simple ideas had become complex problems. The NHS was a four nation organisation; in England the NHS was structured in such a way that funding flowed from the Government, through to CCGs, NHS Improvement and the Care Quality Commission to providers. Dr Cundy illustrated this by noting the organisation structure of Swindon CCG, dated April 2018, which showed the data flow between the different parts of the CCG e.g. from the Chief Operating Officer to the Primary Care Associate Care Director to the Referral Support Centre Manager to the clinical advisors. He then showed the data flow of an east London general practice through PPG members, hospitals, insurers, solicitors, pharmacies and patients to illustrate that it was a very complicated web of dataflows.

As a result of more sophisticated technology, paper records were increasingly being converted to electronic records which saved money and made the records easier to audit. Technology also facilitated invoices, the distribution of funds, the allocation of resources, external and internal research and compliance with regulation.

Dr Cundy added that it was generally accepted that data was justified but it didn’t necessarily mean that it was safe; many NHS organisations were not sure how to handle data but it was still widely accepted that more data was preferable and better. Dr Cundy explained how the NHS managed its data i.e. NHS Digital was the trading name of the NHS Health and social care information centre, which was the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care in England. All NHS data securely collected from all NHS data sources was held in one safe place and managed by NHS staff. It was then distributed under strict control to others inside and outside the NHS for agreed, assured and openly accountable non commercial purposes according to the law for patient benefit. However, although it was widely accepted digital was preferable and that NHS Digital was supported by the BMA and clinicians, it could still be problematic.
Big data for health research: the promises and the pitfalls?

Dr Amitava Banerjee, Senior Clinical Lecturer in Clinical, Data Science and Honorary Consultant Cardiologist, University College London, discussed data and research. He explained he spent 30% of his time working in research looking at trends working in health information noting ‘what’, ‘why’, ‘when’, ‘how’, ‘where’ and ‘who’ were the most over used words in medicine. There were also five ‘v’ words used in medical research i.e. ‘velocity’, ‘volume’, ‘veracity’, ‘variety’ and ‘value’. They were not used in healthcare when they were first used in the ’60s but today, however, all these dimensions had got bigger. There was also a push to try and personalise medicine in five ways i.e. to make it ‘personalised’, ‘predictive’, ‘preventive’, ‘participatory’ and ‘psycho-cognitive’ (the five ‘p’ words).

Dr Banerjee said that machine learning was the new buzzword and there was always an element of chasing one’s tail with technology. Data wasn’t always valuable though. in 2016, for instance, 80-90% of science published was wasted. In the health system it was necessary to join up dots between patients, clinicians and communities and care, science and evidence. Big areas of healthcare included information analysis and presentation, biological science and clinical and health services research. These areas overlapped in bioinformatics, translation and health informatics. All these different types of research involved a lot of data and it wasn’t enough to look at one institute’s data. National data, micro and macro pictures were needed to provide different informatics so that research was always being undertaken at all levels of healthcare.

There were lots of different ways of collating data and a variety of sources including clinical registry, electronic health records and medical imaging. Combined data sources could form an analytical platform; methods to analyse data included data mining and machine learning. The analysis could then be applied in many different ways e.g. drug and medical device surveillance, precision medicine, decision support and population management. There was a general acceptance that data needed better treatment. Also, many digital companies who provided services to the NHS claimed to be patient centred but it wasn’t altogether clear whether they were research centred or data centred; the patient centred approach tended to be thrown around too easily and the biggest problem in the digital space was being told the work you wanted to do couldn’t be done.

Hype versus evidence was problematic. For instance, in 2013, a health technology corporation called Theranos claimed to have devised blood tests which only needed very small amounts of blood and raised more than US$700 million from venture capitalists and private investors. The media hyped the company as a breakthrough in the large blood-testing market but in March 2018, its claims were found to be fraudulent. There had been a lot of interest in the concept but the evidence had been overlooked.

Real threats versus perceived threats also had to be balanced; there were genuine positive aspects in data sharing. Dr Banerjee referred to Dame Fiona Caldicott, National Data Guardian, who stated the media was very interested in data breaches, and that was put before the public more often than successes and the good work that went on to protect data. He ended his talk by saying that data was ultimately all about people and that this mustn’t be forgotten. He quoted Melinda Gates who said “It’s important to remember that behind every data point is a daughter, a mother, a sister – a person with hopes and dreams.”

Delegates’ perspectives

Many delegates commented that the day had been very informative and that the needs of the patient were at the forefront of discussions. They agreed patients should drive the development of technology in order to make healthcare more equal. Delegates were struck by the lack of linked up leadership within the health sector and the huge amount of unlinked data held by the NHS.
Issues found most pressing by delegates were the lack of information for patients on use and confidentiality of their personal data and how behind the NHS is digitally on a national and international level. A range of options were needed to ensure negative impacts of digitalisation were mitigated for all patients and hard to reach groups had to be focused on. Ultimately messaging from the NHS and Government on the digitalisation of the NHS to the public had to be clear and easily accessible. Delegates were not aware of the extent of how disjointed computer systems were across the NHS and the inability to share information between them, the complexities of data storage and protection and also the positive work that had already been undertaken towards coordinating these systems.

Many delegates highlighted that their perceptions had changed on the digitalisation of the NHS by attending this symposium. They noted the NHS, despite issues with information sharing and data, had made a lot of progress and agreed its biggest priority regarding the digitalisation of NHS services must be to ensure that all patients were able to access and benefit from it.

Delegates’ Recommendations:

- Organisations responsible for the digitalisation of the NHS must adhere to a policy which combats exclusion of certain groups of patients, leaving no one behind.
- Community IT hubs should be available to patients and the public across the UK for education on accessing digital NHS services and how to protect their personal information.
- All NHS approved apps should be designed to support the patient’s needs, the patient/clinician relationship and be certified by an independent organisation.
- Developers of online service must create multiple solutions for different cohorts of patients and solutions must be developed in collaboration with these patients.
- Patients have the right to be digitally excluded, therefore a range of options must be made available, including face to face appointments.
- NHS organisations to produce an educational programme for the public on digitalisation, which could include creating posts for pupils in schools to become digital health ambassadors.
- NHS England to do more to provide and signpost patients to correct areas of information and also signpost to other organisations who could provide useful related information, such as the Citizens Advice.
- Meaningful partnerships must be built between different stakeholder organisations to minimise disruption caused to those excluded and improve access.
- A responsible organisation to be appointed to lead on improved access to patients.
Appendix 1

The attendees at the symposium represented the following organisations:

1. Abilitynet
2. Academy of Medical Royal Colleges (Patient Lay Committee)
3. Age UK
4. Alzheimer’s Research UK
5. Barts Health NHS Trust
6. British Heart Foundation
7. Cancer Research UK
8. Care Opinion
9. Diabetes UK
10. Forward Health
11. Good Things Foundation
12. Healthwatch
13. Kraydel
14. Mind
15. myAFK
16. National Association of Patient Participation
17. National Voices
18. NHS Digital
19. NHS England
20. Parkinson’s UK
21. Patient Information Forum
22. Primary Care Digital Transformation
23. Public
24. Royal College of Nursing
25. Royal College of Obstetricians and Gynaecologists
26. Royal College of Paediatrics and Child Health
27. Royal College of Physicians and Surgeons of Glasgow (Lay Advisory Board)
28. Royal College of Physicians of Edinburgh (Lay Advisory Committee)
29. Royal College of Psychiatrists
30. The Nuffield Trust
Appendix 2

‘What does the digitalisation of the NHS mean for patients?’

09.30 – 10.00  Registration

10.00 – 10.05  Welcome
Speaker: Amanda Cool, Patient Liaison Group chair

10.05 – 11.05  Empowering patients digitally:
– Empowering people to manage their health and care using digital tools and services
– Digital patients and digital clinicians: how digital technology has been empowering health and care

Speakers:
– Polly Bishop, Head of Digital Strategy and Engagement, Empower the Person, NHS England
– Dr Manpreet Pujara, Director for Quality and Safety, NHS Digital

11.05 – 11.30  Table discussions
– Positives of digitalisation for patients
– Risks and drawbacks of digitalisation for patients
– What do patients need to be aware of?

11.20 feedback from each table

11.30 – 12.00  Positive impacts of technology and innovation on patients: how digital and technology can benefit patients
Speaker: Adi Latif, Accessibility and Usability Consultant, Abilitynet

12.00 – 12.30  Supporting the clinician: the evolving role of technology in healthcare
Speaker: Dr Farah Jameel, IT Information and Governance Executive Lead, BMA General Practitioners Committee

12.30 – 13.15  LUNCH

13.15 – 14.00  Widening participation: reaching the furthest first
Speaker: Peter Nuckley, Delivery Manager, Widening Digital Participation Project, Good Things Foundation

14.00 – 14.30  Table discussions
– Have organisations gone far enough to combat digital exclusion?
– How do you think access can be improved for hard to reach groups?

14.20 feedback from each table
14.30 – 15.10 **Use of patient data**
- Use of patient data: an overview
- Big data for health research: the promises and the pitfalls

**Speakers:**
- Dr Paul Cundy, Information Management, Technology and Information Governance Lead, BMA General Practitioners Committee
- Dr Amitava Banerjee, Senior Clinical Lecturer in Clinical, Data Science and Honorary Consultant Cardiologist, University College London

15.10 – 15.30 **REFRESHMENTS**

15.30 – 16.15 **Table discussions & wrap-up**
- What has particularly struck you from the afternoon’s talks?
- What have you found most pressing?
- What were you not aware of?
- Taking the day as a whole, what are the challenges you see as most concerning for patients, and what are the opportunities?
- Have your perceptions changed on the digitalisation of the NHS?

15.50 Feedback from each table

16.15 – 16.30 **Closing remarks**