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Delivering healthcare's 'triple aim': Electronic Health Records and the health research participant in the UK National Health Service

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Abstract

The UK National Health Service (NHS) is changing. Consecutive UK industrial strategies have supported the shift from an NHS that provides free-at-point-of-delivery healthcare to one that also facilitates research. Said to promote healthcare's triple aim of "better health, better healthcare, and lower cost" (Wachter, 2016, p. 3), the digitisation of patient records is a core part in opening routine aspects of the health system to potential research. In this paper we thematically analyse 11 policy documents and ask, how does the NHS discuss its decision to digitise patient records and what are the implications of such practices on the citizen? We document how (1) digitisation is presented as a collective endeavour for patients and NHS professionals, offering new possibilities for patients to participate in their own health and that of the population through research; and, (2) digitisation contributes to the building of an efficient health system. Through this analysis we reflect on how discussions of digitisation present uncritically the potential of Electronic Health Records and big data analytics to improve care and generate wealth through research, and reconfigure patienthood, by placing research participation as a routine part of accessing NHS healthcare.

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Introduction

Healthcare delivery generates huge amounts of data. From the minutiae of the practices, knowledge and materials brought together to produce individual test results through to the work of recording, using, and housing such results, healthcare data are vast and increasing in volume and complexity (Davies, 2018). The bulging, brown envelopes common within the United Kingdom's National Health Service (NHS) less than 20 years ago have now been replaced in part with computer interfaces and databases. This paper examines policy documents discussing or advocating this push to digitise and integrate routine healthcare records, a process that is said to "promote what has become widely known as healthcare's Triple Aim: better health, better healthcare, and lower cost" (Wachter, 2016, p. 3).

Digitisation opens previously contained, geographically situated, physical paper records, to global mobility and big data analytics, broadly construed, which all have implications for quality monitoring, care delivery and health research. Big data has been "hailed as the next frontier in data-driven medicine" in numerous policy documents (Sharon, 2016, p. 570), part of a "datafication of health" (Ruckenstein and Schüll, 2017) and viewed as a "solution to refractory problems in clinical research, bedside, and policy decision-making, and organizational operations" (Hogle, 2016, p. 372). Yet, as Hogle (2016) stresses, discussions of big data in relation to routine healthcare and health data remain under-explored in social science literature, with focus resting instead on big data in basic science. Where social science literature has acknowledged big data in health, research has concentrated more on wearable technologies (see, for example, Lupton, 2016). This paper addresses this void in part. We ask how does the NHS discuss its decision to digitise patient records and what are the implications of such practices on the patient? In doing so, we explore the accounts of and innovations in routine health data practices, both in terms of care delivery and wider pushes within the NHS to develop its research capacity. Our analysis draws into stark relief two broad themes: (1) digitisation is a collective endeavour for patients and NHS professionals, offering new possibilities for patients to participate in their own health and that of the population through research; and, (2) digitisation contributes to the building of

an efficient health system. While these discourses link to the claimed power of (big) data and digitisation to improve the performance of the NHS as a healthcare provider, our analysis demonstrates a more complex picture. We argue such claims are predicated on an uncritical acceptance of the potential of digitised patient records and big data analytics, and on a reconfiguration of patienthood that assumes research participation is part of accessing routine healthcare.

Background

The digitisation of patient records is a small but important part of wider transformations in healthcare and data practices within the NHS. Consecutive UK government industrial strategies have focused on ways to compete in the global health knowledge market using, in part, the National Health Service (NHS) (e.g. Biotechnology Innovation and Growth Team (BIGT), 2003, Department for Business Innovation and Skills, 2011). This entered into Department of Health documentation with the publication of *Best Research for Best Health* (Department of Health, 2006). Signalling a step change in the aims and focus of the NHS, this document set out numerous goals and objectives on how the NHS will no longer solely provide free-at-point-of-delivery care but will also become a significant research organisation. One of the identified goals focused on "managing our knowledge resources" (ibid. 2006, p.27) and provided detailed objectives on simplifying data management systems and research processes. To achieve this, the document explained that the Department of Health would work with organisations "to ensure that electronic patient records and supporting infrastructures meet the needs of the research community in England" (Department of Health, 2006, p. 28). Initially part of a five-year plan to develop "a thriving research culture within the NHS" (Department of Health, 2006, p. 6), the impetus to digitise remained across subsequent UK governments, translating this "largest single pool of patients in the world" into a digital, searchable and knowable population for the needs of the research community and, by extension, the UK economy.

Acknowledging the power and potential of patient data, the then Prime Minister, David Cameron, announced:

> We're going to consult on actually changing the NHS constitution so that the default setting is for patients' data to be used for research unless of course they want to opt out. [...T]he end result will be that every willing patient is a research patient; that every time you use the NHS you're playing a part in the fight against disease at home and around the world (HM Government 2011).

This statement was followed by the assent of the Health and Social Care Act 2012 which allows the anonymised use of routine health data for research purposes. Furthermore since 2006, the Department of Health has worked to develop a research culture within the NHS (Department of Health, 2006, Malby and Hamer, 2016). Taken together, and acknowledged clearly in *Going the Extra Mile* (National Institute for Health Research, 2015), there has been a shift from promoting research participation towards expecting every patient to participate in research. In such accounts, the good patient (or "willing patient" to use Cameron's words, above) is the one who avails themselves of research needs in addition to their individual care needs.

Recording health

Medical recording practices have changed dramatically over time. From retrospective to contemporaneous, detailed narrative descriptions to more structured accounts (Siegler, 2010), medical records remain an enduring part of the clinical encounter. Historic, sociological accounts of medical records foreground some of the complex processes involved in producing and using these documents, such as the ordering, conciseness, presences and absences in written text and the necessary 'repair work' needed when reading such records to make sense of them in clinical practice (Heath, 1982, Berg, 1996). The meaning and utility of medical records are not necessarily self-evident, but generated through detailed interpretations predicated on medical expertise, practical reasoning, experiential knowledge, the records themselves, and interactions with the patient.

The adoption of electronic health record (EHR) systems further complicates documenting practices. Moving away from paper to electronic databases, EHRs can include prompts or even requirements for clinicians to provide certain details in specific formats, leading to new demands on clinician's time. Clinicians may develop workarounds to bypass these requirements and this may have

implications for patient safety and care (Blijleven et al., 2017). Even when free text is available, clinicians may copy and paste text templates into EHRs, removing a clear account of the "the orderly progression of thought and action" as well as the important, "humanising" narratives central to records (Siegler and Adelman, 2009, p. 495). In short, emerging recording practices suggest reconfiguration of the clinical encounter. Hunt et al's (2017) ethnographic study of two outpatient clinics in the US suggests that documentation practices which do not necessarily align with clinical need (and sometimes take precedent over clinically relevant information) are "monopolizing clinical time and structuring care" (Hunt et al., 2017, p. 417), an observation echoed by Hogle (2016) and Hoeyer (2016). These points speak to wider issues of the marketisation of clinical medicine and the NHS (Pollock, 2004), and the expansion of managerialism over clinical professionalism within healthcare delivery (Kitchener, 2000, Waring and Bishop, 2010), highlighting how corporate and wider interests are now embedded in clinical (recording) practices.

Despite such academic interest in the everyday practices of using EHRs within clinics and clinical encounters, and establishing them for other purposes, research has yet to explore the broader policy shift towards digital record keeping in healthcare and the implications of this shift on understandings of the patient at a general level. The accounts above do, however, draw into stark relief the central but complex role of medical records as a resource. In their digital form, EHRs offer potential beyond their original paper counterparts through (big) data analytics (Mayer-Schönberger and Cukier, 2013). As the accounts above stress, health data do not occur independently of organisational and professional input in both the form and structure of emerging digital recording practices. Big data analytics too are situated in a socio-technical landscape where social processes and decisions are deeply embedded within data and analytic practices (boyd and Crawford, 2012).

Studies on rationales for research participation highlight numerous factors, from notions of altruism and 'giving back' to moral duty, civic virtue and entitlement (Chadwick and Berg, 2001, Mitchell, 2012, Adams and McKevitt, 2015). From participating in a clinical trial to contributing samples to biobanks, the patient appears as a resource not only in the "fight against disease at home and around

the world" (HM Government 2011), but as a valuable asset in the global bioscience industry. This notion of patient as asset has been taken up by scholars. Wienroth et al. (2019) argues that National Institute for Health Research recruitment campaigns frame patients themselves as assets within the political economy of the NHS. In other contexts, such as the biobank, this value is argued to be something that is produced and maintained (as opposed to innate) through the ongoing, often invisible labour of both biobank participants and biobank staff (Harris et al., 2013, Wyatt et al., 2018a).

These accounts of the value associated with potential research participants as assets, however, do not examine, in particular, how routine and often mundane patient data enter research contexts. The failed care.data programme, a programme that aimed to collate and make available routinely collected primary care, hospital and social care records for the purposes of healthcare audit, service evaluation and research, received academic attention and may have offered such an opportunity yet focus rested instead on why it failed (see, for example, Carter et al., 2015) and not directly on the value associated with such routine data. Our own study of routine health records used for research and audit (Wyatt et al., 2018b) found that while participants were generally positive about the research use of primary care records, they viewed these records as their own, personal property. Routine health data here appear as something deeply personal, echoing wider understandings within the self tracking community where such data are not only viewed by some as providing access to objective truth about themselves, but a truth that is not possible to obtain through other, non-technologically mediated techniques (Ajana, 2017). This association between data and truth is particularly understandable when placed next to Stevens et al.'s (2018) review of editorials dealing with big data in academic health journals. Stevens et al. (2018) found that more than half the editorials assumed a direct correlation between big volumes of data and knowledge or truth. While simplistic correlations between data size and meaning have been problematised in the social science literature (e.g. Leonelli, 2014), the potential of big data and what Kitchin (2013, p. 263) refers to as the "promise of a data deluge of rich, detailed, interrelated, timely and low-cost data that can provide much more sophisticated, wider scale, finer grained understandings of societies and the world we live in" remains in lay and expert accounts.

Self-trackers, however, are not the only beneficiaries of self-tracking data. Through the inclusion of data sharing agreements in self-tracking apps and technologies, self-trackers participate in a wider economy of health data, predicated on their unpaid and often invisible digital labour (Lupton, 2016). The increased availability of health-related data has also resulted in what Sharon (2016) refers to as the "Googlisation of health research", with numerous large companies with data analytics capabilities showing a newfound interest in health fields. The emerging links between commercial industries and private data providers (such as self-tracking apps) are, however, different to the specific contexts of EHRs and the NHS. The data here are tied to the state itself: as highlighted above, the UK government is committed to the development of a research culture within the NHS and sees the cradle-to-grave records of patients as an important resource for the bioscience industry. Existing academic accounts do not consider how such commitment translates into the expectations on and vision of the patient.

Despite the research above and the common themes and overlaps, existing research lacks a consideration of how EHR adoption and the digitisation of patient records is framed by official actors, and the perceived role of the patient in emerging digital recording practices. In the following sections we explore the ways in which policy documents discuss the decision to digitise routine patient records and adopt EHR systems in an NHS which is striving to develop both its care and its research capabilities.

Methods

The documents analysed herein were not new to us at the time of commencing this study. Having been read, annotated and discussed, they were a core part of the policy landscape in which our wider research resides. We discussed a total of 30 publicly available, policy documents for inclusion in this review, identifying those that specifically consider the processes and practices of digitising health records and those that discuss digital data. We concentrated on texts published within the last 10 years (except for *Best Research for Best Health* (Department of Health, 2006) discussed above, which was seminal in setting out the research agenda within the NHS). Published by a variety of institutions, our final sample comprised of the 11 texts, selected using theoretical sampling (Glaser and Strauss 1967) to

best reflect the contours of the debate, taken from crucial moments in its unfolding and when accounts were likely to shift, such as after the Health and Social Care Act 2012, and before and after the care.data controversy. Our final selected texts are outlined in Table 1.

Table 1 Documents included in this review

Title of Text	Publisher of Text	Date
'Best Research for Best Health: A New National Health Research Strategy'	Department of Health	2006
'The Power of Information: Putting All of Us in Control of the Health and Care Information We Need'	Department of Health	2012
'Five Year Forward View'	NHS	2014
'Personalised Health and Care 2020: Using Data and Technology to Transform Outcome for Patients and Citizens'	NHS National Information Board	2014
'Information and Technology for Better Care" Health and Social Care Information Centre Strategy 2015-2020'	Health and Social Care Information Centre (now NHS Digital)	2015
'Review of Data Security, Consent and Opt-outs'	National Data Guardian	2016
'Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England'	Robert Wachter, Chair of National Advisory Group on Health Information Technology in England	2016
'Data and Information Strategy'	NHS Digital	2016
'Fit for 2020: Report from the NHS Digital Capability Review'	NHS Digital	2017
'Using Information and Technology to Transform Health and Care: Our Plan for 2017-18'	NHS Digital	2017
'The Future of Healthcare: Our vision for digital, data and technology in health and care.'	Department of Health and Social Care	2018

Texts were analysed thematically (Braun and Clarke, 2006). Each text was first open coded inductively for a descriptive account of its contents, identifying key areas where EHRs and digitisation were specifically discussed. These texts were then reviewed again in their entirety, although paying specific attention to areas identified in the first coding process, to generate a more analytic account. All documents were coded by two researchers (SL and DW). Emerging codes and themes were identified, amended and consolidated iteratively throughout the process. The final themes and codes were discussed and agreed by all authors.

Policy documents, like all documents, are produced with a specific audience and agenda in mind (Scott, 1990). They are not simply containers but function to inform, frame and influence the social and organisational worlds (Prior, 2008). Drawing from a diverse range of documents helps to even out some of the specific interests of different agencies, giving a broader picture of the landscape. We were specifically interested in the overall picture across documents. While 11 is a small number of texts, it is sufficient to demonstrate a direction of travel and raise key issues relevant to future policy, health research and understandings of patienthood, discussed in the following sections.

Expanding participation opportunities

The adoption of digital data practices presents new ways for patients to participate in their own health and the health of the nation. This occurs in two ways. The first focuses specifically on the potential new partnerships between patients and health professionals facilitated by technological advancement. The second, which spans both this section and the next, is a stress on the wider potential of repurposing digitised health data for research and service evaluation. Notions of partnership foregrounds issues of shared decision-making and self-management based on greater data access:

> Not only is there a strong ethical imperative driving the case for us to be partners in our own care, but evidence shows that involving us in making important decisions about our own lifestyle or treatment options improves our experience of care and the quality of our lives (Department of Health, 2012, p. 57).

> … there is a broad consensus on what (the) future needs to be. It is a future that empowers patients to take much more control over their own care and treatment (NHS, 2014, p. 7).

This push for patient-centred care (Little et al., 2001) is not new and is generally viewed positively by patients themselves. These documents, however, take patient-centred care further, stressing that patients should be viewed as partners in their own health, with the ability to access the data held within their EHRs records and, in doing so, "allowing individual citizens to take control of their health and wellbeing" (NHS Digital, 2016, p. 5). Here, there is an assumption that access to data equates to having control. Patients are presented as being empowered by this new access to data. These

documents outline policies to allow or often require patients to be involved in healthcare data practices to a greater degree than before. While government agencies encouraging citizens to interact with them digitally is typical of the time, this is noteworthy in relation to health and EHRs because of the themes identified below. One of the most frequent manifestations of this control is viewing the patient or citizen as an auditor of NHS health services:

> as users of health and care services and as citizens, we … want a new generation of citizen-reported experience measures that evaluate experiences across a person's entire experience of care, within and between services (Department of Health, 2012, p. 52).

There is also a significant emphasis on patients participating through administering, editing and managing their own health data via new mobile technologies linked, in part, to EHR infrastructures:

> By 2020, citizens will use our national systems routinely to access information, select care, order services and deal with administrative tasks quickly. Citizens will use innovative new services, 'apps' and wearable devices developed by a wide range of organisations… Citizens will be able to link to them or share the data they capture on the national systems where appropriate (Health and Social Care Information Centre, 2015, p. 13).

> citizens who wish to personalise their use of health and care services should be able to access their care record, contribute to it and use apps that enable them to self-care, knowing that the information is secure and available to care professionals in all settings, and having a consistent and convenient user experience (Department of Health and Social Care, 2018, p. 11).

There is insufficient evidence to support claims that the introduction and implementation of patient portals, such as those envisaged within these documents, improves the quality of care (Kruse et al., 2015, Goldzweig et al., 2013). Nonetheless, such measures represent new forms of participation for patients in healthcare delivery; feedback about the quality of services and access to data has never been so readily available nor more frequently collected at any point in the history of the NHS. However, there remains a question of the extent to which these forms of participation represent a 'partnership' with doctors and other healthcare professionals. Patients appear as both active participants in their own health, but also, through their choices, as auditors of the healthcare service. This responsibilisation of

patients also extends into the uses of data beyond individual care, particularly when faced with the potential offered by big data analytics to generate new knowledge that could improve the health of the nation. This assumption that patients will participate in health research through the repurposing of routine EHR data, however, has moved on since first mooted in 2012 when the Health and Social Care Act (2012) made possible the widescale, anonymous use of routine EHR data for research. The establishment and later delay and cancellation of the care.data programme is inferred within these documents, but rarely mentioned by name. In 2014, the NHS expressed a vision that the NHS will have:

> [f]ully interoperable electronic health records so that patients' records are largely paperless. Patients will have full access to these records, and be able to write into them. They will retain the right to opt out of their record being shared electronically. The NHS number, for safety and efficiency reasons, will be used in all settings, including social care. [...] Bringing together hospital, GP, administrative and audit data to support the quality improvement, research, and the identification of patients who most need health and social care support. Individuals will be able to opt out of their data being used in this way (NHS, 2014, p. 32).

The value of using routine EHRs as research data, like in the care.data programme, was inferred in discussions of the inefficient and ineffective past, in the need for relationships between different actors and NHS systems, and in the push for patient participation in health. While all examples acknowledge the importance of patients being able to "opt out of their data being used in this way" (ibid.), the National Data Guardian for Health and Care (2016, p. 25) states that sometimes, "the duty to share information can be as important as the duty to protect patient confidentiality." Furthermore, all health, social care, research and public organisations should share responsibility for making th[e] case [for data sharing]" (National Data Guardian for Health and Care, 2016, p. 10). As such, while citizens are encouraged to concede their data, professionals have a duty to support and promote this process and participate in research (National Institute for Health Research, 2015).

Whereas these are specific issues around the research use of EHRs, more broadly the documents present a diverse set of actors (technologists, administrators, different NHS bodies, the technologies, clinicians and the wider population) "all in this together", delivering and benefiting from digitisation:

> We can create new collaborations between the NHS, technology companies and patients to unlock the potential of data, technology and digital to create products for smarter, faster and better healthcare and thereby grow the digital health sector, an emerging area of UK innovation. (National Information Board, 2014, p. 43).

> We support the achievement of better health and wellbeing in the population by enhancing the ability of citizens, providers, commissioners, national bodies and researchers to use data (NHS Digital, 2016, p. 5).

Listing the stakeholder groups, these quotations place the potential of data at the centre. These lists serve in part to construct the idea of a collaborative effort in the digitisation of patient records. All parties involved in digitisation, including patients and citizens have a stake in the NHS succeeding. The NHS itself is presented as a symbol of national identity and pride: "One of the great strengths of this country is that we have an NHS that – at its best - is 'of the people, by the people and for the people'" (NHS, 2014, p. 9). This pride is reflected in accounts of public feeling towards the NHS and free-at-point-of-delivery healthcare as "one of their 'fundamental rights' as British citizens" (see, for example, The King's Fund and Ipsos MORI, 2018, pp. 10-11). These links to national identity and citizenship rights emphasise the symbolic importance of the NHS, actively used by the UK government:

> The Review notes the Government's decision to the name of HSCIC [Health and Social Care Information Centre] to NHS Digital. This will provide that organisation with a good opportunity to use the NHS brand to make it clear to everyone that it is part of the NHS 'family' (National Data Guardian for Health and Care, 2016, p. 7).

The renaming of the organisation central to the collection, use and dissemination of in the digitisation and sharing of digital data for purposes including but not limited to care from HSCIC to NHS Digital, demonstrates the significance the NHS brand has in policymaker and official understandings of the wider public and the public's view of the NHS. Such accounts infer the importance of public support and buy in to the digitisation agenda at a general level.

Developing an efficient system to harness data

While the previous sections demonstrate the wider expectation of and claims about digitisation, the most common and unsurprising theme is one of efficiency - changes in (data) practices will enable

the NHS to be a more effective system. Efficiency, however, is operationalised and understood in different ways across the documents. It is linked to improving quality of care, the need for real-time data and the potential offered by interoperable systems, but as we will demonstrate, also to specific understandings of the nature and potential of EHRs as 'data.'

Discussions of efficiency were often set against a presentation of past data practices as problematic:

> (T)he quality of the data held is variable, often conflicting in content, and difficult to synthesise into a safe and useful record that is focused on us as the individual at the centre of that care (Department of Health, 2012, p. 19).

> The failure to use information properly in health and care means people can experience unnecessary levels of preventable ill health. (National Information Board, 2014, p. 9).

> Many staff are resorting to paper-based processes as workarounds because the technology they use is slow and clunky and others still work in paper-based organisations where mobile working and digital technology could increase efficiency and productivity (Department of Health and Social Care, 2018, p. 11).

These quotations point to issues of poor data quality, poor data use and poor data systems/technology. Echoing the trope of patient-centred care noted in the previous section, the first quotation raises concerns about variable, conflicting data and the need for records that focus on the individual. The others stress the need to use, share and house data effectively to deliver healthcare. Across the documents and demonstrated above in the final quotation, innovations in data usage, particularly through digitisation and EHR systems are as necessary to solve issues of ineffective past data practices. Accounts, however, do not only stress the need for improved data practices, but for "better data." This better data will help researchers, commissioners and national bodies gain better insight", which will lead to "(c)linicians and care professionals [having] access to more and better information to inform better care" (NHS Digital, 2016, p. 8). Better data then are not just an issue of data quality in these accounts, but more detailed, patient data, with access facilitated through interoperable systems:

We want to empower the health and care system to be intelligent in the way it uses data and information to drive improvements in health and care, by delivering world class data and analytics services through the highest level of skills, expertise, tools, techniques and technology (NHS Digital, 2017a, p. 15).

Incompatible IT systems are too often getting in the way of joined-up health and social care services in England – but digital technologies have immense power to do the opposite. They can link up providers, drive efficiencies across the system and provide a more seamless experience for the public (NHS Digital, 2017b, p. 11).

Right now, we have too many systems that don't talk to each other [. ..] Central to our need for interoperability is the patient record – not a system or application but the patient's data itself. [...] Our technology infrastructure should allow systems to talk to each other safely and securely, using open standards for data and interoperability so people have confidence that their data is up to date and in the right place, and health and care professionals have access to the information they need to provide care. (Department of Health and Social Care, 2018, p. 8).

"Empowering the [...] system" coupled with the "immense power" of digital technologies aims to help the central problem of having "too many systems that don't talk to each other". These quotations present data and data practices as powerful if used effectively within carefully built systems. The need to change extant practices is presented as fact and digitisation and integrated systems are the solution. Yet these better data are not only about the volumes of data and the linking of systems. Accounts also press the need for "real-time" collection and "real-time" analysis:

As we move progressively towards real-time digital record-keeping, as described above, we will achieve the objective of collecting all the information required to support direct clinical care and the analytic needs of health and care, once and once only at the point of care. In the interim, it continues to be critical that we adopt a pragmatic step-by-step approach to unlock the rich insights available today (National Information Board, 2014, p. 32).

...the UK has an enormous opportunity to bring the promise of big data to life. Working through ambitious entities such as the Farr Institute, the UK could be the first nation to take data science to scale and build a truly national learning health system. The combination of a cradle-to-grave patient record (mostly digitised) collected for clinical (not billing) purposes, the NHS number, and a secure NHS network (the Spine) is unique and should be much better exploited for patient, population, and societal gains (Wachter, 2016, p. 41).

The power and promise of data are presented through the structure of data in NHS records

(each patient having a unique NHS number and developing interoperability between systems), the volume of data (cradle-to-grave records with developed capacity and potential offered by real-time data collection and analysis through a learning health system[1]) and the data science expertise health in the UK. The metaphor of "unlocking" data echoes Stevens et al.'s (2018, p. 5) review, discussed above, where many health journal editorials treat data as knowledge when analysed using data analytics techniques. Data are presented as valuable and powerful in and of themselves. Issues of interoperability are foregrounded with no discussion of what interoperable systems look like nor their mediating role in data practices. Instead we see a vision of data as unproblematically providing access to 'truth' when data quality is maintained and volumes are large. Minable, linkable, longitudinal, real-time and valuable, digitised patient data are portrayed as unmediated by systems and other actors - a neutral tool in healthcare delivery and research. This is particularly prevalent in accounts where research is stressed, presenting routine health data as an asset for the NHS, industry and the patient/taxpayer:

> Information will be taken from our records, combined and made anonymous. This will become a key source for all health and care service information, used in many ways: to assess clinical and professional performance, to plan and target services, research new treatments, improve the quality and safety of services and ensure value for money for taxpayers' (Department of Health, 2012, p. 29).

> The life sciences industry is a central plank of the UK economy. The health data held […] is world class and a major asset for the UK[. ..]Increasing the ability of scientists to combine the UK's strengths in technology and medical research with our health data could transform the power of medical research in this country and is a key objective of this framework. (National Information Board, 2014, pp. 43-44).

These accounts focus on reusing existing patient records as data and the value of such data for care, planning, research and the UK. Later documents, such as NHS Digital (2016), go beyond current data practices to acknowledge the need to make data and data collection directly relevant to the economy and "[e]nsure that we have consulted on and developed an appropriate charging model for

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[1] A learning health system, introduced by Etheredge (2007), draws on data science techniques to analyse patient data continuously to improve healthcare in real time.

our data and information services […] and will ensure that we are able wherever possible to offer services that are free to users" (NHS Digital, 2016, pp. 27-28). Such an account fits with wider shifts in UK politics towards market-driven neoliberalism and reiterates not only the value of data, but suggests the importance of such value in safeguarding free-at-point-of-delivery care in the NHS.

Despite these claims about the future and efficiencies offered by digitalised records to dramatically improve individual care, to improve health through research or maintain the NHS through capital generation, no concrete examples are provided of what this kind of digitisation will look like in practice. Instead, potential yet vague success stories of digitisation are used as 'proof' that a more efficient health system as a result of digitisation will facilitate a healthier future. Such accounts also describe efficiency as achievable by creating and streamlining systems and infrastructures that facilitate seamless data flow between different sites of care. They present a clean image of clinical work, not taking into account the different ways health data are created and move in non-standardised, paper forms even in the most digitally advanced areas, as discussed in the previous sections – for example, how clinicians both can conform to and actively work around data requirements of EHRs systems (Blijleven et al., 2017), how clinicians can disrupt and act against managerialism (Kitchener, 2000); nor do they acknowledge how EHR systems and the data requirements of these systems from each clinical encounter can affect the delivery and experience of care (Hunt et al., 2017). Accounts instead are predicated on the assumption that joined up, EHRs promise to transform the NHS and the country. Changes in infrastructure and identifying ways to make the system more efficient are seen to result in 'harnessing' the (straightforward) potential offered by data practices and technologies.

Discussion

The digitisation of routine patient records is clearly an important issue across the documents and significant in delivering "healthcare's triple aim." Discussions of digitisation, as the sections above demonstrate, can be placed under two broad themes. The first, that digitisation is not solely a technical process, but involves activity and buy-in from a number of actors, including the patient. The second, that digitisation supports the development of an efficient health system where "patient data" are used

effectively. These themes all infer and in places claim benefits for the individual patient, the population and the NHS. A more efficient and cost-effective NHS will enable better use of resources. Detailed patient data will help inform health service management. Digitisation will offer patients improved care through healthcare professionals having greater access to patient data from across the NHS. EHR systems will offer new ways for patients to participate in their health by collaborating with NHS staff on the production and contents of their medical records. Finally, digital record systems will facilitate the use of (big)data analytics to generate new knowledge, patient benefit and wealth for the NHS from routinely collected patient data, not possible with written records or digital records across multiple, not interoperable systems. Digitisation is presented across these documents as a wholly positive process and a collective endeavour. It is a partnership between different individuals and agencies, working together within the trusted NHS to realise the potential of patient data, via the digitisation process, for all. Both of these expansive themes and their associated claims, however, rest on an understanding of the contemporary NHS patient and of the "data" made available through the digitisation of EHRs. In this section we will reflect specifically on these issues.

We note above that the patient is presented as a collaborator in the production of their EHRs. However, the extension of this beyond care and into research has implications for how we understand patienthood. Adams and McKevitt (2015) highlights how existing literature and policy suggest patients should be available for and entitled to participate in health research, moving us away from accounts of research participation as solely an issue of altruism. A similar sentiment is echoed by the National Institute for Health Research (2015) who present a vision that every patient should be a research participant. Both these accounts, however, relate to defined research studies, such as a clinical trial, where individuals are able to give informed consent. Our analysis extends the discussion on health research participation away from participation in specific projects or for particular rationales, to research participation as a routine part of accessing healthcare. While there are processes in place for a patient to opt out of any data sharing, participation in research, particularly when data are aggregated or anonymised as provided for by the Health and Social Care Act (2012), appears as the expected norm.

Furthermore, with the association between the NHS, citizenship and national identity noted earlier, and the synonymous use of patient and citizen in the analysed policy documents, research participation not only appears to relate to contemporary patienthood but also to British citizenship; if access to the NHS is central to citizenship and research participation is a routine part of accessing NHS care, seeing all patients as research participants involves also seeing all citizens as research participants.

Realising this vision of the routine patient as research participant, however, is based on assumption about the research potential of EHRs and big data analytics. The analysed policy documents acknowledge the existence of poor data practices, but these are presented as past problems to overcome. Instead, patient health records, through the digitisation process and adoption of EHR systems, can be used to access new insights from data unproblematically. Echoing many of the health research editorials analysed by Stevens et al (2018), our reviewed documents present data collection, storage and analysis as facilitating straightforward access to new knowledge though emerging data analytics techniques. Documents do not consider some of the issues raised in the existing literature noted above, on clinical recording and sense making practices and wider discussion in the sociology of big data on how big data analytics incorporates technical and social processes. Instead, "data", EHRs and their potentials are valorised uncritically.

The emphasis on the power of data does, however, allows us to see the assumed value of integrated, interoperable, EHR systems. Drawing together cradle-to-grave patient records, becomes an important asset for the NHS both in the delivery of care but also in helping to "meet the needs of the research community" (Department of Health, 2006, p. 28). Digitisation facilitates the assetisation (Birch, 2017) of routinely collected patient data at a general level, unmediated by the patient and increasing in value as the volume of data expands. Whether disembodied from the patient through aggregation or anonymisation, or linked to the patient and the patient's ongoing interactions with and across the health system, the patient's joined-up data over time are a valuable resource for research and for the bioeconomy. With routine access to the NHS leading to research participation and the ongoing and increasing value of EHRs as in research (as well as in care), the convergence of research participation

and patienthood also leads the patient to become a resource for wealth and knowledge generation through research and the global bioeconomy. By the act of accessing NHS healthcare in the UK, contemporary patienthood, particularly the expectations on the patient to participate in their own health, and in the health and wealth of the nation through research, is becoming ever more complex.

This paper has plotted some of the policy landscape in the shift to digitise patient health records and adopt EHR systems, seen as helping to meet "healthcare's triple aim." Digitisation is far more than a change in recording practices. We document and problematise how discussions of digitisation uncritical accept the power of (big) data. We also highlight a significant consequence of the convergence of an NHS pushing to be a research organisation and the digitisation and adoption of EHRs for purposes beyond the delivery of care. This consequence, the blurring of the line between patient and research participant, has implications for how we understand NHS patienthood, UK citizenship and the act of seeking healthcare. It raises questions about how we manage these new patient (and NHS) roles and broader issues of consent, transparency, trust and data ownership, expressed in the existing literature noted above. Using routinely collected health data for research clearly offers huge potential to improve health and healthcare provision. Uncritical adoption, however, could undermine this work. Framing research participation as part of accessing healthcare, means the patient is not only a recipient of care, but a tool, a research participant, a knowledge resource, an asset and/or, when appropriate, a collaborator in facilitating health research for the benefit of the population.

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Data Availability Statement

The data (official documents) that support the findings of this study were derived from the following resources available in the public domain:

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