

## Central Lancashire Online Knowledge (CLoK)

Title	Computing, data, and the role of general practitioners and general practice in England
Type	Article
URL	<a href="https://clock.uclan.ac.uk/52523/">https://clock.uclan.ac.uk/52523/</a>
DOI	<a href="https://doi.org/10.1016/j.imed.2024.04.001">https://doi.org/10.1016/j.imed.2024.04.001</a>
Date	2024
Citation	Fisk, Malcolm (2024) Computing, data, and the role of general practitioners and general practice in England. Intelligent Medicine. ISSN 2096-9376 (In Press)
Creators	Fisk, Malcolm

It is advisable to refer to the publisher's version if you intend to cite from the work.  
<https://doi.org/10.1016/j.imed.2024.04.001>

For information about Research at UCLan please go to <http://www.uclan.ac.uk/research/>

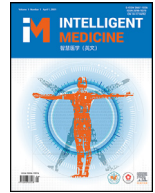
All outputs in CLoK are protected by Intellectual Property Rights law, including Copyright law. Copyright, IPR and Moral Rights for the works on this site are retained by the individual authors and/or other copyright owners. Terms and conditions for use of this material are defined in the <http://clock.uclan.ac.uk/policies/>



ELSEVIER

Contents lists available at ScienceDirect

## Intelligent Medicine

journal homepage: [www.elsevier.com/locate/imed](http://www.elsevier.com/locate/imed)

## Review

## Computing, data, and the role of general practitioners and general practice in England

Malcolm J. Fisk\*

School of Health, Social Work and Sport, University of Central Lancashire, Fylde Rd, Preston, PR1 2HE, United Kingdom

## ARTICLE INFO

## Keywords:

Artificial intelligence  
Commercialisation  
General practice  
General practitioners  
Health data  
Scientification

## ABSTRACT

This paper gave attention to two issues that arise because of the growth in the use of health data by general practitioners (GPs) and general practices in England. The issues were (a) the use and commercialisation of patients' personal health data; and (b) the propensity of GPs and general practice staff, in utilising those data, to see patients as fragmented bodies rather than as 'whole persons'. The paper included attention to the computing needs of general practice from the 1960s and notes the period of growth in GP computer use during the 1990s. The implications of recent increased computer use by GPs and general practices, as a contributor to the further scientification of health, were then explored. Significant is the fact that the paper finds consciousness, from the 1970s, of the two issues. Their importance was emphasised as the momentum increases around the utilisation and sharing of patient data. Related concerns about data privacy and confidentiality are highlighted. In this context, the paper recommended that further research be undertaken with urgency to explore the ways that caring relationships (that have been a hallmark of the work of GPs) can be safeguarded.

## 1. Introduction

Two issues associated with computing in general practices in England were selected. The selection of these issues did not follow any scientific process. It reflected a sense of inquiry on the part of the author—to establish whether there were antecedents to the issues that are of current concern as part of the 'scientification' of healthcare and what Bourke and Bourke [1] termed a 'tsunami' of (health) data.

The context is one where digital service transformations are being promoted within the UK's National Health Service (NHS). Supportive of the transformations was the 2021 Wade–Gery review that argued the need to 'put data and technology at the heart of how we transform health services'. The government's subsequent (2022) Policy Paper (from the Department of Health and Social Care, DHSC), taking on board some issues raised in the prior 'Goldacre Review' [2,3], pointed to how England's health and social care services could be 'transformed' through the gathering and use of data.

The backdrop is one that is familiar for health and care services in several countries. Central to that backdrop are challenges surrounding data management and concerns regarding their confidentiality and, therefore, patient privacy. The personal nature of those data is greater because of the imperative for health and care services to respond to an individual's, often private, health and care needs. The 2 issues that relate to general practitioners (GPs) and general practices considered in

this study are as follows:

- the use and commercialisation of (patients') personal health data, and
- the propensity of GPs and general practice staff, in using those data, to observe and respond to patients as fragmented bodies rather than as 'whole persons'.

The arrival of and use of computers within general practices approximately 50 years ago is initially examined to establish how the issues were considered at that time. The study then documents their impact over the ensuing decades. It finds parallels between some past and contemporary hopes and concerns for computing—with these now being influenced by the application, promise and use of artificial intelligence (AI) and machine learning.

## 2. Computers in general practices: early days

Over 40 years ago, Stanley Joel Reiser [4], a Harvard academic, pointed to the 'creeping amoeba of automation'—for which we can read, at least in part, 'computing' (viz. to 'use a computer' especially via mathematical means). He referenced the fear held by some doctors that computers and other devices might take over some of their roles. This reflected Reiser's recognition of the computer's ability not just to store and order data but also to facilitate their analysis—providing a means

\* Corresponding author: Malcolm J Fisk, School of Health, Social Work and Sport, University of Central Lancashire, Fylde Rd, Preston PR1 2HE, United Kingdom.  
E-mail address: [mfisk@uclan.ac.uk](mailto:mfisk@uclan.ac.uk)

<https://doi.org/10.1016/j.imed.2024.04.001>

Received 19 June 2022; Received in revised form 8 January 2024; Accepted 7 April 2024

Available online xxx

2667-1026/© 2024 The Author(s). Published by Elsevier B.V. on behalf of Chinese Medical Association. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>)

Please cite this article as: M.J. Fisk, Computing, data, and the role of general practitioners and general practice in England, Intelligent Medicine, <https://doi.org/10.1016/j.imed.2024.04.001>

by which diagnoses and treatment decisions could be made; thus, removing some of the ‘cobwebs of tradition covering many concepts and practices in medicine’.

However, Reiser [4] saw these laudable computer uses as coming with a price to be paid through a growth in ‘impersonal medical care’ associated with ‘undermining the physician’s belief in his own medical powers’—heralding, perhaps, what Montori [5] more recently described as ‘industrial healthcare that fails to notice patients’. Therefore, Reiser’s prescience around this aspect of the scientification of healthcare is now particularly evident as GPs grapple with the implications of computing because of the potential impact of AI and machine learning (with automated analyses).

Preece J [6] noted the interest in computers taken by the UK Government’s Department of Health and Social Security (DHSS) in the 1960s. This led to the establishment of project teams in Oxford (west of London) and Exeter (south-west England) ‘tasked with producing a unified computer record for each patient, which could be stored on a central mainframe at the health authority and accessed remotely’ [7]. As reported in the *British Medical Journal* (BMJ) in 1965, commercial organisations (naturally) were eager to encourage health and care service providers to use *their* proprietary computer systems.

The introduction of computers to a few general practices in England began in the 1970s. For those pioneers, it meant changing roles for GPs and other staff because of the capacity of computers to store data and help with service organisation and management. At that time, however, GPs gave little attention to any potential for data analysis that would greatly assist them in diagnosing and determining treatments. Rather, their focus was on tabulations of patient data such as age, sex, health conditions and prescribed medications, i.e. what today are recognised as very modest computing tasks. However, as noted by Preece J [6], this limited use gave benefit to GPs because of the ease with which they could list groups of patients for screening, routine appointments and home visits.

The broader context of the changes that were taking place can be seen as part of the ‘scientification’ of health care—with clinicians and others increasingly being dependent on the outcomes of tests and accompanying data analyses. For general practices, meanwhile, as noted by Gillam S [8], there was a change taking place—with moves from often single-handed practices (i.e. with 1 GP) towards ‘teams’ (practices including nurses and other support staff). Such teams stood to benefit from the scientification and, crucially, computer use; but they meant that contact with patients was ‘spread’ across team members rather than individual GPs.

Computerisation made sense in such teams—with the data being shared across terminals used by different staff. The potential of ‘sharing’ was demonstrated in the ‘IBM-Whipton’ project [6] in the 1970s. This linked a single-handed local practice (Whipton) in suburban Exeter (south-west England) to the Royal Devon and Exeter Hospital. Preece [6] was involved in that project’s design and was reported as the first GP in the UK to use computerised patient medical records shared with practice staff and others ‘through landlines with a remote mainframe computer’. The system was refined and improved (supported by the funding from the DHSS) for a general practice at nearby Ottery St Mary. This (in 1976) became the ‘first in the UK to achieve paperless status’ [6]. As noted by Dr Graham Ward (a former Ottery practice GP) the ‘thinking ... (had) the ultimate aim of having such records available across the country’. Ward G [7] and his former practice colleague Dr. Jeremy Bradshaw-Smith [9] pointed to the impact of the computerised system on their routines not being confined to the ‘unique ability of the computer to search for and marshal information’, but also to the incorporation of a computerised ‘scribbling pad’ for them to record patient histories and family details.

The desire for a ‘scribbling pad’ within a computerised system in the early years is of particular interest in view of it signalling a perspective on patients that could relate to their being ‘whole persons’, sometimes with complex health conditions that might defy easy datafi-

cation. Demographic and social changes were contributing to such a need (for a ‘whole person’ approach) because of increasing co-morbidity, polypharmacy and the varied family circumstances of many older people. Some concern was, therefore, evident regarding what might be lost with wholesale computerisation if GPs and general practice staff were to adopt views of patients, perhaps as ‘fragmented’ bodies—narrowly related to their test results, measurable symptoms or conditions, and potentially without wider understandings of their family and living circumstances. Relating to this, Armstrong D [10] reported on GPs in this period as still generally being reliant on ‘clinical observation’ to make diagnoses although welcoming of and supported by evidence derived from the data (e.g. through test results).

Summing up the GP perspective on computers and their initial expectations for patient records from the 1970s, Reiser SJ [11] affirmed that ‘in this modern, automated medical climate ... it was hoped that the patient record would ... enable physicians to more clearly and quickly match the initiation of an action to its outcome, thereby, providing better care to their patients and also learning from experience’. He added, with respect to the ‘growing anatomical and technological focus’ that ‘while this fractionation of wholes produces powerful agents of cure, it spawns powerful disincentives to care’. The potential adoption of such an instrumental perspective was described later [12] as one where ‘warm care’ might be increasingly substituted by ‘cold technologies’.

In England, the gradual ingress of computers into general practices in the 1970s related to a variety of functions. It occurred largely by dint of government initiative; and was, from the 1990s, helped by the availability of lower cost and more intelligent desk-top devices. Among these devices in the 1970s, Dr Richard Sloan (former GP, Airedale, northern England) reported, for his single-handed practice, buying an Amstrad computer which enabled him to record ‘an age/sex register for 3,000 or 4,000 patients’. He would later ‘migrate’ to a Meditel computer with a computer link to the local hospital ‘round about the year 2000’.

Helping the penetration of computers into general practices was the 1982 Department of Industry funded scheme ‘Micros for GPs’. However, Tudor-Hart J [13] (GP, South Wales) observed that for the early 1980s ‘only a minority [of GPs] were investing heavily in ... computer systems’. He accused the government of ‘giving partial and hesitant support to experiments in GP micro-computers’ and abandoning ‘general practice data collection to commercial firms ... in return for data which can then be sold to pharmaceutical companies’. Reflecting the latter, Preece [6] noted, for 1986, that AAH Meditel and VAMP (computing companies) had launched schemes to ‘provide systems, at virtually no cost, in return for anonymised ‘practice morbidity and prescribing data’. The companies, according to Benson T [14] ‘intended to recoup their costs by selling the data to the pharmaceutical industry for post marketing surveillance, market research and clinical trials’. The commercial stratagem, however, faltered because the ‘quality of data collected was less consistent and less complete than had been expected’. Nevertheless, Preece J [6] reported that computers were installed in 20% (1988), 70% (1992) and 96% (1996) of general practices in England—with the computing functions available to GPs steadily broadening. The ingress of computers was broadly welcomed by practices although the task of data inputting from paper records could be considerable. By 2002, Benson T could report that ‘almost all British GPs use computer-based patient records’ [14].

### 3. Computers and computing in general practice in the New Millennium

At the turn of the millennium, Preece [6] saw the extending role of general practice (to include public health advice, minor surgery and specialist clinics) as necessitating computer use. Non-use of computers would, in any case, soon become nearly impossible with the introduction, in 2004 by NHS England, of requirements for standardised data submissions (for general practices) as set out in the ‘Quality and Outcomes Framework’ (QOF). General practice teams, by this time, were

more in evidence and more readily able to fulfil the task of providing those data. The expertise in such teams might include nurses, nurse practitioners, occupational therapists, physician associates, healthcare assistants, pharmacists and social and community workers.

Regarding patient data, the extent of responsibility of the GP and practice team necessarily increases with their liability for patient care. The use of such data, however, does not necessarily lead to greater scientific certainty and, with the advent of machine learning (in today's context) might lead to greater uncertainty. This uncertainty arises because of the near impossibility of understanding some analytical processes involved in machine learning (sometimes captured in the term 'black box') and the inbuilt elements of risk that relate to biases or errors in the foundation data that are drawn upon (including those used for training the algorithms) [15-18]. For instance, Verdicchio and Perin [17], on data manipulated through algorithms (integral to AI), pointed out that the 'encoding of knowledge may be incomplete, contradictory, obsolete or plain wrong, leaving the AI incapable of formulating a proper solution to a problem or, worse, providing a solution that not only does not solve the problem but harms people'. Coekelbergh [19] asked if, through AI, 'objective and non-biased judgement is possible at all?' noting that it 'can, after all, be biased – if not always'.

Associated with such matters and placing the GP, other clinicians and practice staff in invidious positions, Armstrong's observation from the 1970s [10] was and has remained pertinent. He affirmed that 'a doctor failing to pursue a course validated by clinical trials is opening himself to recrimination' with the danger of 'clinical science' failing to recognise the 'arguments of clinical experience'. There is, in addition, the responsibility now carried by doctors that, per Verdicchio and Perin [17], 'cannot be allocated or shifted to autonomous technology'.

Simultaneously, patient expertise and expectations have been increasing [20-21]. Part of the increase, as emphasised by Lupton [22] and Roberts et al [23], has been associated with patients' understandings and sometimes (informed by their own health data and personal experience) becoming experts in relation to their physiology and particular conditions. More importantly, through the use of apps or simply because of greater awareness and knowledge, each of the researchers noted that patients were increasingly predisposed to self-care or, at least self-monitor, and to adopt and maintain healthier lifestyles. It follows that with such awareness and knowledge, patients may have increasingly viewed the GP as far from the sole arbiter when it comes to their health.

The technological (computing) advances available to and used by an increasing number of individuals in relation to their health are, of course, to be welcomed. As noted by Goodwin et al [20], general practice needs 'to embrace such technological advances' to make it 'fit for the 21<sup>st</sup> century'. The process of scientification undoubtedly continues and will continue to impact GPs and general practices—making them the repositories of increasing quantities of data. Requiring attention, therefore, is the issue of the increased value and potential sale of patient data for commercial benefit. This relates, for the earlier period of computerisation, to Tudor Hart's [13] observation about data collection by commercial bodies, and to the 'deals' noted by Preece J [6] and Benson T [14].

Because of the increase in the commercial value of data, the matter of their harvesting (including via commercial bodies) reverberates loudly in some contemporary debates [22,24]. However, there is limited information regarding the 'deals' that have taken place, with Cohen [25] lamenting that the terms of contracts with data processing companies are 'difficult to discover ... [with] networks of secret agreements that characterise the emerging personal data industry'. The extent of the threat relating to the harvesting of an individual's health (or other personal) data, therefore, remains unclear. Lupton [22], with similar concerns, called for more attention to the issue of the 'exploitation of people's personal data for commercial profit' in a context where 'the creators of these data' (i.e. patients) 'are excluded from full access to their own details ... while the internet empires profit from these'.

Cohen [25] referred to such exploitation of people's data as 'bioprospecting' undertaken by those who 'behave in ways that express unquestioned assumptions about their right to appropriate and exploit that which is freely available' ... 'harvesting personal data ... and to mark such data, once collected, as owned'. Montori [5] called for 'regulation banning excessive profit seeking' and for 'a new class of healthcare leaders that are effective managers of the precious resources (including patient data) placed in their hands'. To help protect against bioprospecting, data should be recognised 'in the first instance' as being 'owned by the patient' [26].

#### 4. Current issues for GPs, computing and data

In the most recent decade, the challenges for GPs around computing have grown further. Aside from the general process of scientification, their work is impacted by increasingly digitally (and health) literate patients accessing information and services through computing devices (whether desk-top computers, tablets, wearables or smart phones). This means that patients are potentially able to share more of their personal data in accordance with their own wishes and priorities.

Whether or not fully recognised by GPs and general practices, here lies the increasing potential for patient benefit through services that involve the use of different devices for either remote- (e.g. through telehealth or telecare) or self-monitoring and/or management of their physiological measures/vital signs. The DHSC [3] in their Policy Paper noted this potential under the banner of 'care technologies' in the context of more integrated working between health and social care service providers. Integrated working, they affirmed, will contribute to giving 'the public a more seamless experience'. However, the 2017 framework set out by the BMA/NHS England [27] had overlooked the wider context of 'care technologies' when it called for a 'digital first' approach that related, more narrowly, to 'web and video-consultations', online provision of repeat prescriptions and giving patient access to 'their full records'.

Will the advent of more computing in general practice give more time to GPs and practice staff, away from administrative tasks?. The British Medical Association (BMA) [28] noted the 'considerable potential to make efficiencies through the use of technology that would ease GP and practice workload' and increase 'the amount of time available for appointments'. The context was one where Clay and Stern [29] had pointed to 27% of appointments with GPs in England potentially being avoided if patients could be 'directed to someone else in the wider primary care team'. Not that more consultation time in practices is always necessary. Montori [5] noted that 'many clinicians will testify about a brief phone call in which a simple clarification was helpful for patients to overcome anxiety'—however, at the same time he wanted safeguards in place to avoid 'brief and shallow encounters' becoming the 'default'. His affirmation was important in that 'time' for care (whether a consequence or not of computer usage) is a key ingredient for understanding patients as 'whole persons' and ensuring that diagnoses and treatments are tailored to their needs [5].

The point made by Montori [5], about the increased time is echoed elsewhere. For instance, Topol [30], in reference to the potential of digital technologies in the fields of telehealth and telemedicine, opined that these 'should free up the clinician to spend more time with the patient, either in face-to-face meetings or remotely'. He more recently expanded his thinking when asserting that AI in the context of digital health 'could help restore the essential humaneness in medicine, primarily by providing the gift of time .... the ability to listen to a patient's story and the deep concerns, the necessity of a careful physical examination, reinforcing human touch and trust, and the genuine sense of care and compassion that lies in direct contrast to what software or machines can offer' [31]. The overall message is that computerisation and the use of digital data (as part of the scientification process) can create extra time for more 'whole person' care (and even 'warm care' [12]). However, the danger is that such time may be eroded for service efficiency and cost savings.

The pursuit of the benefits of more recent aspects of ‘scientification’, especially considering the developments in AI and machine learning, requires a brief reminder of the concerns regarding the risks of biases in the datasets used (viz. the training data for algorithm development). Such biases have special relevance in the field of healthcare in view of the potential to cause harm to the patient. Rosemann and Zhang [16] provided a summary of ‘problem areas’. The focal issue for them was the ‘control’ of AI in the sense of (an element of) decision-making being transferred to ‘machines’ together with (derived in part from the matter of bias) the (un)reliability of its outputs. Hence, the arguments, such as those made by Verdicchio and Perin [17], against ‘full automation’ lest trust in the technologies, whether held by GP or patient, is undermined. A further issue relates to the threat to privacy including, per Rosemann and Zhang [16] ‘the sharing of data with third parties’, its sale ‘for marketing or other purposes’ (i.e. its commercialisation) and/or its use for (though not discussed in this study) ‘security purposes, social and political surveillance’.

Meanwhile, the issue of the commercialisation of patient data has risen up the agenda for general practices and, unsurprisingly, is a matter of concern in view of the GPs’ and practices’ liability. As observed by Zhang et al [16] regarding the commercialisation, ‘patient control over data relies on opt-out mechanisms at the levels of primary care extraction’. However, Salisbury [32], a GP, asked, in view of planned statutory requirements to extract and transfer patient data records ‘unless patients opt out first’ ... ‘how does this square with my ethical obligation to my patients?’ Notably, the notion of the requirement for patients to opt-out (of inclusion of their health records in a national electronic health records system) was one of the reasons for the collapse, in 2014, of the government’s care.data framework [23].

The Goldacre Review, noted at the outset of this study [2], referred to the collapse of the care.data framework as, in part, due to the programme having been ‘launched and communicated before there were clear plans ... around who could access the data, on what basis, and for what purposes’. It affirmed that ‘concerns were expressed regarding privacy invasion, and the use of the data by commercial or insurance companies’. Much emphasis was placed in the Review on the issue of patient trust. The requirement for patients to ‘opt out’ was, nevertheless, retained in the DHSC 2022 Policy Paper—labelled as offering a ‘data strategy’ [3]. Regarding that strategy, the BMA [33] have cautioned the government to address the concerns lest the issue of data harvesting without appropriate safeguards ‘may irrevocably damage the patient-doctor trust relationship at a time when data has never been more critical to the functioning of the NHS’. It is, of course, invidious that GPs should be placed in a position where they may sometimes, ‘break the law or ... break faith’ with their patients [34].

## 5. Discussion

While specific research into the impact of computers and computing on GPs and general practices has been limited, it is possible to point to the 2 issues as relevant in the 1970s and having contemporary resonance. They have been shown as deserving attention in view of the increasing quantity of patient data being handled through computers in general practices. An important pointer has been additionally provided to the implications (though again research is limited) for the GP and patient relationship.

Over 5 decades, the context for computing (as part of the scientification of health) has dramatically changed. The pace of that change accelerated with the networking of computers and advent of the internet. Hence, as the turn of the millennium approached, a UK government White Paper [35] offered a new vision where computerised networks would ‘bring patients quicker test results, online booking of appointments’ ... ‘providing knowledge about health, illness and best treatment practice’. Further change is now necessary for GPs and general practices as operational frameworks for AI (and machine learning in particular) are determined.

While there is much merit in the NHS ambition for digital health (and *ipso facto* for computing and, more recently, the opportunities afforded through AI and machine learning), little reference has been made in contemporary strategy documents to the 2 issues at the focus of this study. The 2022 Policy Paper [3] carried statements that provided some reassurances (relating to the 2 issues), but fell short of offering the extent of guarantees around health data that several GPs and patients may have hoped for. Meanwhile, general practice reliance on increasingly data-rich computing systems is increasing; and the direct relationships that patients may have had with their GPs continue to diminish (in terms of time spent in consultations with them, as opposed to other practice staff).

### 5.1. Issue 1: Data use and the commercialisation of those data

There are undeniable and sometimes extraordinary benefits for patient care that derive from data analysis and data sharing in relation to health. Pharmaceutical companies are, to a substantial extent, dependent on such data (subject, of course, to their quality). Topol [31] pointed to the benefit—with, for example, the use of machine learning based on image recognition, to identify skin cancers. Such analytical techniques were, he affirmed, ‘empowering the family physician and general practitioners’. But it is a fact that there is a substantial commercial ‘market’ for patient data. This, as was noted Salisbury [32], has placed extra pressure on GPs—not simply because of the volume of data accessible to them, but also because of the associated moral and practical responsibilities for its safeguarding, understanding and use.

To accept Salisbury’s affirmations about the GP’s responsibility is not to disregard the public health and research benefits (e.g. for pharmaceutical companies) that accrue from data use and analyses, but it is to make the point that protections for individual patients (and respect for the confidentiality of their health data) must be recognised. Settlement of the matter of personal data ownership might help resolve the issue by either providing stronger frameworks for their protection (e.g. around consent and opt-ins), and/or by strengthening the position of GPs and general practices as the guardians of such data. The fact that the issue of ownership is difficult does not detract from this need—with Bourke and Bourke [1] arguing, in the context of machine learning, that ‘true control’ of personal data ‘by individuals is almost impossible’ as is the notion of consent based on full or reasonably full understanding of the options for sharing their data and the protections in a context of the ‘black box’.

As noted earlier, there is the issue of trust as emphasised by the British Medical Association (BMA) [33]. Relating to this, Chico et al. [36] referred to the ‘uncertain space’ within which the question of sharing data needed to be considered. They asserted that ‘people found it particularly difficult to accept commercial organisations having access to’ even anonymous patient-level data. Among the people (patients) engaged in their research, there was significant desire for greater regulation and for a critical focus on ‘unscrupulous commercial organisations which might not adhere to the regulations that are in place’. A clear conflict of interest was observed where a ‘company might prioritise its own commercial gain over the public benefit’.

The work of Chico et al. [36] was small scale (3 workshops in South Yorkshire) and undertaken in 2016; however, it is notable for its exploration of different scenarios for data sharing with different types of (profit and non-profit) organisations. In 2019, Hopkins et al, in a study commissioned (in part) by NHS England, held 3 citizens’ juries (London, Taunton and Leeds) that found ‘fairness’ for data sharing partnerships as conditional on ‘a system which enables the NHS to reap benefits ... with recognition that the data they provide is an essential resource’. The juries considered that ‘there was a significant risk in undervaluing it and that the NHS might sell itself short while industry could make excessive profits which are not shared’ [37]. A study in 2021 by Atkin et al [38], on data sharing in the context of research, noted patient ‘ambivalence’ and ‘greater reservations about industry’ (albeit among a small

sample, Birmingham), with a ‘central concern’ regarding ‘unauthorised data use’ and the potential for ‘discrimination’. Over 3-quarters of their workshop participants had not heard of the (then) opt-out option available to them—through which their records would not be shared except under certain specific circumstances.

This is not to say that the sale of data, with safeguards, is bad. Indeed, the Goldacre Review [2] called upon us not to automatically ‘view commercial users of data as uniquely less trustworthy’. However, it added that ‘there are certainly legitimate concerns around commercial conflicts of interest. These concerns might increase commensurately with the size (and, therefore, power and influence) of the companies concerned. Notably, in relation to this, Zhang et al [34] referred to ‘at least 460 non-NHS organisations’ that had ‘accessed, maintained or used data in the 2-year period to 2023’. These included 143 pharmaceutical, life sciences, data analytics and consulting companies.

Three important matters intersect in this context. First is that of people’s natural sensitivity regarding their personal data (linking with the matter of their privacy); and the second is their traditionally high level of trust with the NHS, noted as being under threat. But, the third is the imperative, as emphasised by Stahl [15], that data on which the analysis is undertaken should be relevant, of good quality and (preferably) available in large quantities. This is particularly the case, if the opportunities around AI and machine learning are to be realised (with bias understood and minimised) either within the NHS or via ‘partner’ commercial organisations.

However, if the level of trust in the NHS (and of GPs and general practices) diminishes, more people will opt-out of data sharing, and the relevance, robustness and validity of outputs from AI and machine learning will be reduced. The importance of trust cannot be easily overstated and was jeopardised in the failed approach to care.data ‘after many GPs opted out alongside many patients’ [23]. However, the government in their 2022 Policy Paper has held to a perspective that will require people to opt-out if they do not want their data to be shared in anonymised form without specific consent, albeit subject to certain conditions [3]. The promise is that the government (through the NHS) will ‘offer a new pact with the public which will reset the conversation on health data’ and put in place ‘commercial principles to ensure that partnerships for access to data for research and development have appropriate safeguards’. Details of those safeguards are yet to emerge, but some reassurances have been signalled by the affirmation that ‘data partnerships’ will be ‘developed in a way that is safe, lawful, ethical and transparent’, and the creation of ‘secure data environments’ (echoing the recommendations of the Goldacre Review on ‘trusted research environments’). Furthermore, various pointers have been made on data anonymisation. However, little is said regarding the specific risks around AI, though a White Paper on this topic is planned. Meanwhile, of additional concern is the planned inclusion of freedom for government ministers to access data for ‘purposes connected with the provision of health care or adult social care’ [3]. The mantra in the Policy Paper on the need to ‘embrace the digital revolution and the opportunities that data-driven technologies provide’ echoes the thrust of the Wade–Gery Review.

Therefore, concerns and uncertainties remain and it would appear unwise, despite some positive steps taken and promised in the 2022 Policy Paper [3], for the government to forge forward on the matter of (wider) data sharing until there is greater clarity on the frameworks and safeguards. Importantly, there is an explicit need for public consultation—potentially including attention to the merits and demerits of the intended opt-out approach as opposed to people’s ability to voluntarily opt-in. Linked with this is the desirability of options relating to the circumstances in which data sharing would be permitted and/or encouraged, perhaps via the GP or general practice, and the ability to follow (including by patients) audit trails that would show how, why, by whom, when, and outcomes whenever data are accessed—with, naturally, appropriate routes to redress where appropriate.

As Salisbury [32] argued, patients ‘consult with me with the presumption of confidentiality, and they don’t expect me to share their med-

ical information without their consent’, adding that ‘there’s something sacrosanct about a medical consultation, with similarities to a religious confessional: whatever they tell me, unless there is a risk to others, I don’t break my patients’ confidentiality’. A clear echo can be heard here of what Rothstein pointed to as the ‘Hippocratic bargain’ where ‘patients agreeing to be treated ... relinquished aspects of their privacy in exchange for their physicians’ assurances of confidentiality’ [39].

## 5.2. Issue 2: Scientification and the view of patients as fragmented bodies

The scientification of health care can be related to a process over a period of several centuries. The contemporary facet of this process now lies in the realms of computing and the challenges of the data ‘tsunami’ noted by Bourke and Bourke [1]. Cohen [28] and others have pointed to the sources of those data as now, in addition, deriving from the surveillance capacity of e.g. wearable computing, mobile and other devices—the range of some of which was pointed out by Roberts et al. [23].

This study has observed the extent to which the contemporary ‘scientification’ may lead to more fragmented perspectives towards patients among GPs and other practice team members. That process of greater fragmentation is fuelled by the increasing use of data and the associated commercial agenda. The dangers around the errors and inexactitudes for AI were noted in the affirmations of Stahl [15], Verdiccio and Perin [17], the Goldacre Review [2] and elsewhere. It follows that now, for diagnoses and treatment, an overemphasis on data would be inappropriate and would, perhaps, reflect an orientation that leans towards private commercial gains rather than individual (‘whole person’) patient benefit. Moreover, a narrow commitment to ‘data-led’ as opposed to ‘data-informed’ approaches to decision-making on matters of health, diagnosis and treatment would be inappropriate, except in certain circumstances. Narrow approaches would carry a greater risk of errors and could lead to the fulfilment of a promise, as noted by Montori [5], of a ‘cruelty’ through which the recipient of care becomes ‘object’ and ‘we, as clinicians, dehumanise patients’. Furthermore, the emphasis on data quantity may not always be appropriate when, in several circumstances, the real requirement is to understand the data, its representativeness and the triangulation of qualitative and quantitative information from different sources.

However, the process of ‘scientification’ has been hardly remarked upon in research studies except when noted as a part of innovation and ‘progress’. What may be an associated matter can perhaps relate to the gains in the longevity of several people that bear testimony to the successes of medical interventions. Those interventions can (at least for patients in their later years) be seen as ‘reshaping norms of aging and standard clinical practice ... where the emphasis of the health professions is on the management and maximisation of life itself’ rather than the quality of care provided [40]. By this tenet, it could be argued that patients, as they age, are likely to become increasingly subservient to the forces associated with a data-led technological imperative that aims and strains for longevity rather than life quality, even at the end of life.

Overall, the foregoing indicates an academic and clinical perspective that has tended to focus on medical advances for diagnoses and treatments that, in a large part, derive from technologies; but with a parallel assumption that more personal aspects of care, though diminished, would remain in place. Broadly speaking, this assumption may be justified but comes with the ongoing risk of a further shift towards more impersonal care. According to Montori [5] we could have a ‘corrupted mission’ [17] and have lost sight of medicine being ‘in part an art which can never be fully quantified or solved’. The related fragmented perspectives (or ‘fractionation’ [11]) will, it follows, reduce the propensity of GPs and general practice staff to see patients as ‘whole persons’.

The importance of patient data to health and care (and, therefore, to computers) is evident. Concerns raised in this study about these data should not, however, be taken as indicating that the clock should be turned back. Computers, computing and aspects of AI and machine learning have delivered much and signalled more in the way of help-

ing with the development of more efficient and effective health services with dramatic benefits (at least for some conditions) around diagnoses and treatments. Importantly, the computing power can (and often does, depending on the technologies and their configurations) also facilitate self-management and different forms of access by patients to health information and services - via the devices in their homes, on or in their bodies, in their hands or in their pockets.

Hence, as part of service reconfigurations, if the 'whole person' perspectives are to be given a renewed central place within general practices, there will be a need for a different and better use of the time facilitated by computing (potentially through AI), to allow the relationships with patients as 'whole persons' (for GPs and practice team members) to blossom.

The changed GP role and general practice context as signalled by Goodwin et al [20] and BMA/NHS, England [27] must be brought into focus. However, in response to this and the factors surrounding computers, computerisation, the use of data and their commercialisation, this study affirms the necessity of safeguarding and re-building the patient and community-oriented perspective of GPs. Considering this perspective, it is legitimate and right that GPs and general practices should be the guardians of patient data, ready to defend 'whole person' perspectives and maintain a place for meaningful discussions with patients on matters around the use of their data—fostering shared understandings as to where and how their data (whether or not derived from AI and machine learning) can help underpin decisions or support the advice provided on diagnoses and treatments.

By these means, key elements of the work of general practices and their accountability can be re-affirmed - with some aspects of the long-standing respect held for GPs retained or re-instated. It helps that, with computers now being widely accessible (including through portable devices), many patients are naturally more predisposed to engage with practices in new ways. GPs, general practice and community-based nursing and care staff must, therefore, be positioned to support patients in their use of such technologies and associated platforms.

In this context, there is plenty of work for GPs to do. And the nettle of re-building the 'whole person' oriented perspective of GPs and general practice staff should be grasped with speed given the generally favourable patient view of them—with 83.8% and 87.1% of them finding their needs being met for their last appointment with a GP or other practice member, respectively, via a video- or telephone-call (the Ipsos MORI 2023 GP Patient Survey). However, the British Social Attitudes Survey for 2022 found (for the UK) that the general satisfaction with GP services had fallen to 35%, the 'lowest since the survey began in 1983' [41]. The report noted that for the Survey, 'until 2018, general practice had been the highest rated NHS service each year'.

However, it is uncertain whether role and operational changes, more generally, within practices would be welcomed by GPs themselves. An online survey of nearly 500 GPs by *Pulse* magazine in summer 2021 revealed some ambivalence. For instance, regarding financial and governance issues there was overall, only weak GP support for the maintenance of a position as 'small, autonomous businesses' (rating 3.2 out of 5 for agreement).

The extended work of general practice teams is relevant here and suggestive of an adjusted role for GPs within such teams. The further ingress of computers, the associated growing importance of data and the benefits of AI and machine learning, means that most or all general practice staff will have to adjust to new roles that have the potential to take the pressure off of GPs and bring rewards for those patients in need of what Topol [30] referred to as the 'gift of time' and Montori [5] linked to 'whole person' care. Such adjustment may be the logical way forward in a context where, from 2013 to 2022 in England, there was a growth in general practice sizes, a 20% reduction in the number of practices, together with a 'decline in the GP workforce and an exponential drop in the number of GP partners'. These trends are likely to continue.

It is to be seen if the GPs have the stomach for a change in their roles within practice teams. It can be noted, furthermore, regarding the

'gift of time' (regardless of the risk that some gains in time might be lost to efficiency savings) that the level of GP commitment to such 'time' may be uncertain. The *Pulse* survey responses, having pointed to most (though by no means all) GPs wishing to stay as businesses, also rated 3.44 out of 5 (i.e. agreement) to the affirmation that 'GPs running a business takes time away from providing clinical care'. The same rating (3.44 out of 5) found agreement with the affirmation that 'it is the GP's role to provide co-ordination around chronic disease management, not the care itself'. At least the latter is suggestive of some openness to key roles in patient care being taken by other practice staff. However, it is unclear to what extent GPs truly want to be managers of commercial enterprises rather than coordinators of care in a context where several care tasks are undertaken by other practice staff and, increasingly, by patients themselves (through self-management of their conditions).

This study has offered insights into the use of computers in general practices in England. It noted that the introduction of computers, harnessed initially for documenting basic patient data and simple administrative tasks, progressed to transform the GP role and general practice perspectives in a way that has contributed to a move away from a 'whole person' patient orientation.

Two issues that have had resonance for general practices were explored over a period of over 40 years. But with regards to data, their commercialisation and the 'fragmentation' of patient bodies, what Reiser [4] and Tudor Hart [13] saw as a growing threat, are now considered as potentially undermining what have been some key tenets of GP services (and practices) around personal contact and the loss of the view of patients as 'whole persons' i.e. in the words of Pols [12] the loss of 'warm care'. Along with this are the facts around the increase in data-led perspectives for medical care (part of the process of scientification). Therefore, 'cold technologies' (including those that facilitate computer use and/or detract from 'warmer' approaches to patient care) can be seen as changing the nature of relationships with patients and at least necessitating a repositioning of GPs within practice teams.

Computing, the use of and greater reliance on data, has played a major part in the changes including those in relation to the elements of GP and general practice accountability. In this context, it can be noted that the Wade-Gery 'independent review' called for 'a digital, data and technology driven NHS oriented around the citizen'—first, in vague commercial terms, pointing to the need for 'driving innovations in the hard basics of operational resilience ... system management and technology productivity'; second, by apparently assigning the 'future tech-enabled citizen' to a subordinate role in which he or she is invited to place their trust in an NHS where 'boundaries between traditional technology organisations and the wider business are being increasingly blurred'. Therefore, the potential supremacy of the 'cold' technologies over 'warm care' [12] was indicated. This view was to some extent echoed in the 2022 Policy Paper [3]—necessarily with openings for commercial bodies. However, if safeguards are inadequate, the focus of some of these commercial bodies may be on money—greed—that will drive industrial healthcare away from patient care [5].

The raising of the 2 issues at the beginning of this study has been shown to be appropriate: (1) the use and commercialisation of (patients') personal health data, and (2) the propensity of GPs and general practice staff, in using these data, to observe and respond to patients as fragmented bodies rather than as 'whole persons'.

Regarding the first issue, given the strong commercial push and the associated concerns for GPs, general practices and patients about the sharing, usage and ownership of personal data, it is recommended that further research on this and interlinked matters (relevant to GPs and the wider range of health professionals and practitioners) be undertaken with urgency. This could provide pointers towards necessary regulatory frameworks that would (in the context of AI, machine learning and the use of computers) clarify how the responsibilities of GPs and general practices should be framed and exercised in order 'to protect the life and integrity of patients', including the personal data pertaining to their health [17]. The robustness of those frameworks will be crucial to the

extent of people's trust and the extent of willingness for their health data to be shared.

Overall, the initial, though limited stirrings about the 2 issues in the 1970s can be seen as prescient. The issues now need to be considered very seriously by the NHS, representative bodies, policy makers and others in the fields of health and care—given the importance of data and the implications of AI and machine learning. In this context, adjustments to the role of GPs, general practice teams and in the relationship with their patients, become essential and inevitable.

### Conflicts of interest statement

The author has no conflicts of interest with respect to the research, authorship and/or publication of this article.

### Fundings

This research did not receive any grant or other funding from agencies in the public, commercial or not-for-profit sectors.

### Author contributions

Malcolm J Fisk designed the study, did the literature search and drafted the manuscript.

### Acknowledgements

The author is grateful for the comments and guidance offered by the following individuals (via varied communications) during the evolution of this paper:

Professor David Armstrong (Department of Primary Care and Public Health Services, King's College London)

Dr Jeremy Bradshaw-Smith (retired GP, Ottery St Mary Medical Practice, Devon)

Professor Umesh Chauhan, (GP, Pendle View Medical Centre, Brierfield; Professor of Primary Care, University of Central Lancashire)

Dr Matthew Fay (GP, Willows Medical Practice, Bradford; Clinical Chief Executive - Affinity Care)

Dr Rebecca Fisher (GP, The Leys Health Centre, Oxford); Senior Policy Fellow, The Health Foundation)

Dr Hannah Marston (School of Health, Wellbeing and Social Care, Open University)

Dr Susannah Solaiman (GP, Harford Health Practice, Tower Hamlets)

Dr Richard Sloan (retired GP, Airedale Medical Practice, South Yorkshire)

Dr Graham Ward (retired GP, Ottery St Mary Medical Practice, Devon)

### References

- [1] Bourke A, Bourke G. Who owns patient data? the answer is not that simple. *Br Med J* 2020. Available from [blogs.bmj.com/bmj/2020/08/06/who-owns-patient-data-the-answer-is-not-that-simple](https://blogs.bmj.com/bmj/2020/08/06/who-owns-patient-data-the-answer-is-not-that-simple).
- [2] Department of Health and Social Care Better, broader, safer: using health data for research and analysis (The 'Goldacre Review'). London; 2022.
- [3] Department of Health and Social Care Data Saves Lives: Reshaping Health and Social Care with Data. London; 2022.
- [4] Reiser SJ. *Medicine and the reign of technology*. Cambridge: Cambridge University Press; 1978.
- [5] Montori V. *Why we revolt: a patient revolution for careful and kind care*. 2nd Edition. Rochester: Mayo Clinic Press; 2020. MC9025 297100.
- [6] Preece J. *The use of computers in general practice*. London: Churchill Livingstone/Harcourt Publishers; 2000.
- [7] Ward G. *A Dream of the Future*. Practice Team 1973;20:14–16.
- [8] Gillam S. The Family Doctor Charter: 50 Years On. *Br J Gen Pract* 2017;67(658):227–8. doi:10.3399/bjgp17X690809.
- [9] Bradshaw-Smith JH. A computer record-keeping system for general practice. *Br Med J* 1976;1(6022):1395–7 5. doi:10.1136/bmj.1.6022.1395.
- [10] Armstrong D. Clinical sense and clinical science. *Soc Sci Med* (1967) 1977;11(11–13):599–601. doi:10.1016/0037-7856(77)90041-5.
- [11] Reiser SJ. *Technological Medicine: The Changing World of Doctors and Patients*. New York: Cambridge University Press; 2009.
- [12] Pols J. *Care at a Distance: On the Closeness of Technology*. Amsterdam: Amsterdam University Press; 2012.
- [13] Tudor-Hart J. *A New Kind of Doctor*. London: Merlin Press; 1988.
- [14] Benson T. Why general practitioners use computers and hospital doctors do not – Part 1: incentives. *Br Med J* 2002;325(7372):1086–9. doi:10.1136/bmj.325.7372.1086.
- [15] Stahl BC. *Artificial Intelligence for a Better Future*. Springer, Cham: Springer Briefs in Research and Innovation Governance; 2021. doi:10.1007/978-3-030-69978-9\_1.
- [16] Rosemann A, Zhang XQ. Exploring the social, ethical and legal responsibility dimensions of artificial intelligence for health – a new column in intelligent medicine. *Intell Med* 2021;2(2):103–9. doi:10.1016/j.imed.2021.12.002.
- [17] Verdicchio M, Perin A. When doctors and AI interact: on human responsibility for artificial risks. *Philos Technol* 2022;35(1). doi:10.1007/s13347-022-00506-6.
- [18] Børøe K, Gundersen T, Henden E, et al. Can Medical Algorithms Be Fair? *Br Med J Health and Care Informatics* 2021(29):e100445. doi:10.1136/bmjhci-2021-100445.
- [19] Coekelbergh M. *The Political Philosophy of AI*. Cambridge: Polity Books; 2022.
- [20] Goodwin N, Dixon A, Poole T, et al. *Improving the Quality of Care in General Practice*. London: The King's Fund; 2011.
- [21] Baird B, Charles A, Honeyman M, et al. *Understanding Pressures in General Practice*. London: The King's Fund; 2016.
- [22] Lupton D. *Digital Health: Critical and Cross-Disciplinary Perspectives*. Abingdon: Routledge; 2018.
- [23] Roberts C, Mackenzie A, Mort M. *Living Data: Making Sense of Health Biosensing*. Bristol: Bristol University Press; 2019.
- [24] Ebeling MFE. *Healthcare and Big Data: Digital Specters and Phantom Objects*. New York: Palgrave Macmillan; 2016.
- [25] Cohen JE. The biopolitical public domain: the legal construction of the surveillance economy. *Philos Technol* 2018;31:213–33. doi:10.1007/s13347-017-0258-2.
- [26] Fisk M. GPs, patients and health data commercialisation in England. *Trends Telemed E-Health* 2022:000568. doi:10.31031/TTEH.2022.03.000568.
- [27] British Medical Association/NHS England Investment and Evolution: A Five-Year Framework for GP Contract Reform to Implement: The NHS Long Term Plan. London: British Medical Association; 2019.
- [28] British Medical Association Saving General Practice. London: British Medical Association; 2017.
- [29] Clay H, Stern R. Making Time in General Practice. Primary Care Foundation/NHS Alliance, 2015. Available from: <http://www.primarycarefoundation.co.uk/>.
- [30] Topol E. *Preparing the Healthcare Workforce to Deliver the Digital Future*. Leeds: Health Education England; 2019.
- [31] Topol EJ. Machines and empathy in medicine. *Lancet* 2023;402(10411):1411. doi:10.1016/S0140-6736(23)02292-4.
- [32] Salisbury H. Should GPs break the law on data privacy? *Br Med J* 2021;373:n1451. doi:10.1136/bmj.n1451.
- [33] British Medical Association. *Building the Future: Getting IT Right – Report No.2*. BMA, London, 2022.
- [34] Zhang J, Morley J, Gallifant J, et al. Mapping and Evaluating National Data Flows: Transparency, Privacy, and Guiding Infrastructural Transformation. *Lancet Digit Health* 2023;5(10):e737–48. doi:10.1016/S2589-7500(23)00157-7.
- [35] Health Department of. *The New NHS: Modern, Dependable*. CM3807. London: The Stationery Office; 1997.
- [36] Chico V, Hunn A, Taylor M. *Public Views on Sharing Anonymised Patient-Level Data Where There Is a Mixed Public and Private Benefit*. University of Sheffield /NHS Health Research Authority; 2019.
- [37] Hopkins H, Kinsella S, van Mil A. *Foundations of Fairness: Views on Uses of NHS Patients' Data and NHS Operational Data*. Hopkins Van Mil: Creating Conditions Ltd; 2020.
- [38] Atkin C, Crosby B, Dunn K, et al. Perceptions of Anonymised Data Use and Awareness of the NHS Data Opt-Out Amongst Patients, Carers and Healthcare Staff. *Res Involv Engagem* 2021;7(1):40. doi:10.1186/s40900-021-00281-2.
- [39] Rothstein MA. The hippocratic bargain and health information technology. *J Law Med Ethics* 2010;38(1):7–13. doi:10.1111/j.1748-720X.2010.00460.x.
- [40] Kaufman SR, Shim JK, Russ AJ. Revisiting the biomedicalization of aging: clinical trends and ethical challenges. *Gerontologist* 2004;44(6):731–8. doi:10.1093/geront/44.6.731.
- [41] Morris J, Schleppe L, Dayan M, et al. *Public Satisfaction with the NHS and Social Care in 2022: Results from the British Social Attitudes Survey*. London: The King's Fund; 2022.