HEALTH CARE IN THE INFORMATION SOCIETY

VOL. 1

FROM ADVENTURE OF IDEAS TO ANARCHY OF TRANSITION

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Preface

I was born in November 1945, as the Second World War came to an end. It was a time of transition out of war and into new beginnings for post-war society. In the United Kingdom (UK), it was marked by the Beveridge Report of 1942 on the causes of social disadvantage and deprivation, and the creation of the National Health Service (NHS), in 1948. Less momentous at the time, but massively significant over time, it was the beginning of transition into a new age shaped by information technology, marked by the construction of the earliest, valve-based computers. It was a both lucky and challenging time to be born!

This book is about how information and information technologies have evolved to become pivotal concerns at the heart of life and medical sciences, and health and social care services of the twenty-first century. It connects with many histories of development from earliest times–in philosophy, mathematics and logic; science, engineering, medicine, health and social care services; and society at large. These domains interact ever more immediately in the scientific, technological and social transitions of what have been called the Third and Fourth Industrial Revolutions. Electronics, telecommunications and computers heralded the Third; artificial intelligence, nanotechnology and robotics herald the Fourth. The Third created the Information Age; the Fourth is creating the Information Society. Medicine was invented in Classical times and evolved into and through the Industrial Age. Health care services have accelerated and then faltered in the Information Age and must now be reinvented for the future Information Society.

A book preface traditionally sets out how an author came to conceive of and write their book and how they became involved in its subject. In a book about the birth of a new field and era, eyewitness accounts of early participants are threads that help weave and link together different, sometimes quite loosely connected storylines, through what are typically both adventurous and anarchic times. In this book, the author is eyewitness and participant, as well as storyteller and commentator, concerning the ideas and events that unfold through its chapters. It is a tricky balance to

achieve, and this Preface is itself a chapter, to place the book in that personal context.

In matters of health and care, the balance of personal and professional interests and expectations, alongside population and societal perspectives, is also tricky beyond measure. It must reflect individual citizen, family and community needs and responsibilities, within diverse caring, healing and restorative environments, and respect the personal autonomy, dignity and rights of all concerned. Health and social care are essentially human matters, and we should always remember this when dreaming about and creating machine-based future 'solutions' for the complexity and difficulty they pose. These require a practised balance of head, hand and heart–a memorable phrase from the title of David Goodhart's recent book, well-suited to its 2020 publication date.[1] In writing this book, the human context of the stories told has been uppermost in my mind.

The coevolution of information technology with health care services is a story of seven decades of incremental and iterative innovation, achieving outstanding successes and persisting with perplexing failures. My career has spanned and connected widely and closely across this emerging landscape. I have been luckily positioned to listen to, read about, know and work with many who have battled and led the way–in academia, health care, professional institutions, governments, industries, non-governmental organizations (NGOs) and charities, across the world. Luck and staying power are primary qualities of successful innovators in such variable and challenging circumstances–well exemplified in many that the book describes.

The book has been written as a postscript to a career spent in exploring, supporting and connecting many and disparate interdisciplinary and multiprofessional endeavours. It emphasizes the crucial importance of creating environment and community where new approaches to the complex problems posed for health care in its transition through the Information Age can grow. It is, in turn, a preface to further transition, as the present-day communities of the Information Age create those of the future Information Society.

Histories can be told in many ways, especially when drawing extensively on first-hand experience. The book includes much personal narrative about people and teams, and their times: where and how they have worked; what they have coped with, made and done; and the connections they have forged along the way. This kind of narrative might be characterized as a Pilgrim's Progress, but that feels a bit too evangelical. Analogy with the

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1   D. Goodhart, *Head Hand Heart: The Struggle for Dignity and Status in the 21st Century* (London: Penguin Books, 2020).

story-telling songlines of the Australian Aboriginal community culture feels more appropriate.

Songlines are assemblies of stories, songs and art describing and recording a journey through a landscape, telling of its creation and history, and of the culture and beliefs of the communities with which it connects. They are told and sung to explorers, by people they meet as they travel through the landscape over time. I have been privileged to participate in the songlines of some iconic figures of the Information Age who have made things happen– telling their stories and singing their dreams into existence, as in the Dreamtime[2]–some loudly singing or sung about and some less so. The three parts of this book form a Dreamtime-like continuum of past, present and future perspectives of health care, before and during the Information Age, and in the Information Society to come.

Of course, dreams and their dreamers are sometimes typecast as unworldly and mindless nightmares. But unrefreshed by dreams, minds create real-life nightmares, too! This book is both history and personal songline. It connects widely through an evolving landscape of imaginations, practicalities and dreams, and some nightmares, as well!

Songlines are also long marches. My career songline has been a fifty-year long march. Navigating through the Covid-19 pandemic and writing this book has been a long march–the first rough draft from March 2020 to March 2021; the second to March 2022; and the final draft, after the publisher's peer review, in the six months to March 2023. Transition of society from the Information Age into the Information Society will be another long march– searching for and establishing common ground on which to cooperate and collaborate successfully. A paradox of the Information Age is that what was promised to connect and integrate, as easily led to unravelling threads of fragmentation and isolation. The challenge for the Information Society is to weave a new tapestry that makes whole.[3]

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2   '[…] the labyrinth of invisible pathways which meander all over Australia are
    known to Europeans as "Dreaming-tracks" or "Songlines"; to the Aboriginals as
    "Footprints of the Ancestors" or "Way of the Law". Aboriginal Creation myths
    tell of the legendary totemic beings who had wandered over the continent in the
    Dreamtime, singing out the name of everything that crossed their path–birds,
    animals, plants, rocks, water-holes–and so singing the world into existence'. B.
    Chatwin, *The Songlines* (New York: Random House, 2012), p. 2.
3   We need a term that represents the wholeness of health and social care. Their
    repetitive identification as separate entities becomes trite and tedious as well as
    potentially harmful. I toyed with health=care–symbolizing a bonded connection
    of health and care, adapting to the changing needs of society, locally and globally,
    today and into the future. But that becomes twee and tedious, too. From here on
    in the book, I use health care as an umbrella term that implies their inseparable
    connection. In later chapters, I introduce the idea of a care information utility,

I grew up in a small English village in rural Hampshire, and am now, as with increasing numbers of humankind, a citizen of an Internet-enabled global village. My parents were born as the first motor cars spluttered into life. They ended their days in times of traffic gridlock and environmental degradation. In 1899, the *Scientific American* journal predicted that the motor car would 'eliminate a greater part of the nervousness, distraction and strain of modern metropolitan life'.[4] Predicting the future is a dicey pursuit! How we join forces to make things happen will always matter more.

My mother went to Spain in the 1930s, to help shelter refugees from the Spanish Civil War. She and my father met in wartime when working in a residential care setting, sheltering children displaced to this country from elsewhere in war-torn Europe. Social care runs deep in my family history and personal experience. We lived for the first twelve years of my life in a large residential children's home run by my parents, caring for twenty-five English children who were separated from their broken families, and helping them develop and grow. Some have done spectacularly well, connecting with our family still, today. Good and connected human environments are a necessity for sustained growth and development, and for health. Inequalities of health have been further amplified and highlighted in the Information Age. In my childhood there was a dearth of information about health and disease and the care services. Today there is a lot of information–not all good, and not all helpful.

I was born just after Alan Turing (1912–54) and the team at Bletchley Park unravelled the secret wartime codes produced by the Enigma machine.[5] They built on insights of Polish mathematicians who had studied the machine's design, up until the time their country was invaded. The work was assisted by development of the Bletchley Park Bombe machine and Colossus computer, just a few miles from where I am writing, now. And in America, the ENIAC digital computer was created, alongside and gradually supplanting analogue computers of those times, that had been used by members of the physics team at Los Alamos in designing the first nuclear weapon–the nuclear fission-based atomic bomb. There was close connection between the ENIAC's use in calculations for military developments and

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to embody a coherent citizen-centred ecosystem of health care information–this seemed the most appropriate simple expression of the broad purposes such a utility must serve.

4   T. Conyngton, 'Motor Carriages and Street Paving', *Scientific American Supplement*, 48 (1899), 196660.

5   Wherever I have been able to discover them, I include dates alongside referenced names, to give context of time for the people being introduced. Context is important in discussion of ideas and events, and timeline provides important, often interesting, and sometimes forgotten context.

nuclear science, and this early computer remained a secret during the early post-war development of the much more destructive nuclear fusion-based hydrogen bomb. I sit here writing, with billions of Colossus or ENIAC amounts of computational resource in use and at my disposal–smartphone, desktop computer, broadband router, central heating controller, house alarm system–and connecting with trillions more in the Internet Cloud, as tools and support for everyday work and life. A truly colossal resource!

The organization of health care services and their underpinning professions and supporting technologies have evolved continuously from the immediate post-war years of my childhood to the 2020s of my retirement. The social and political cauldrons of two World Wars, and of the Great Depression that separated them, battered and shaped the lives of my parents. They brought to the fore new leaders of the era, determined and ambitious to explore and chart a better path into the post-war world. Richard Tawney (1880–1962) and William Beveridge (1879–1963) were close friends in their college days and became talismanic figures and reforming energies, with Sidney Webb (1859–1947) and Beatrice Webb (1858–1943) of the Fabian Society. The Beveridge Report and the establishment of the UK NHS, led by Aneurin Bevan (1897–1960), and the hopes they embodied, stem from those times. They form a vivid region of the landscape that my life has passed through and been shaped by.

The book connects from the earliest stages of what has been termed an information for health revolution, set within its historical context, and ends where we are today, looking forward from the 2020s and perhaps only midway in the changes in the nature and organization of health care services that it is accompanying and precipitating. It seems appropriate to describe these changes as revolutionary because, co-evolving alongside the computer, many paradigms of knowledge and practice have changed over that timeline, significantly and excitingly, and some almost beyond recognition. This era has seen an amazing 'adventure of ideas', a term I have borrowed from the title of a book by the famous philosopher and mathematician, Alfred North Whitehead (1861–1947), written nearly a hundred years ago, to which I have often referred. Impetus has come from accelerating advance and reformulation of academic discipline and professional practice: in mathematics, science, and engineering; in law and governance; and in technology, medicine, and health care. The book interleaves personal stories with accounts of these disciplines and professions, government policies and programmes, social and economic change, and the connections they embody. History of revolution is marked by the stresses and strains of uncertain, often anarchic transition.

My pathway into a career in health informatics was an unlikely one–adventitious but also, in retrospect, uniquely advantageous. I

studied theoretical physics at the University of Oxford in the mid-1960s and worked for several years in the medical engineering industry, before completing an early Master of Science (MSc) course at the innovative London Institute of Computer Science, parts of which were subsequently integrated within University College London (UCL).[6] I then completed a PhD in biomedical engineering at UCL, modelling the physiology of the human circulatory system, and worked for three years in the nearby hospital medical physics department.

Thus, by the age of thirty I had spent twelve early childhood years living in a children's home, achieved a good grounding in maths and computer science, completed a first degree in physics and a higher degree in engineering, and gained experience of work environments in large- and small-scale industries and hospital-based research and development. William MacAskill's eighty thousand hours organization[7] (this being the number of hours in a typical lifetime of work) advises that we should spend a good proportion of that amount of time considering and sampling work options, before deciding and committing to where we seek to put down roots for the longer term. My twenties were not quite that rational, but the experience gained in these widely diverse early stages of my songline stood me in good stead for a subsequent career in health informatics. There were what might have proved safer and better paid career options offered at the time–including one from a founder of the, subsequently very successful, Logica computer consultancy, and another from the scientific Civil Service–but I set off on a more adventurous path, to an academic post situated alongside clinicians at the heart of medicine and health care services. And as the poet wrote about taking paths less travelled, it did make all the difference.

In 1976, I was appointed as a lecturer in a post newly created for me in medical computing and physics, in the academic department of medicine of one of London's longest established medical schools, that of St Bartholomew's Hospital, known as Bart's, which dates from 1123. It was a bold move for them and a risky one for me and my young family!

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6   At that time, Peter Kirstein (1933–2020), a UK pioneer of the Arpanet and co-designer of the TCP/IP electronic data transmission protocol, taught practical courses on telecommunications engineering and programming at the London Institute. In the mid-1970s, the founder of the Internet, Tim Berners-Lee, also read physics at Oxford. In more recent decades, the fields of theoretical physics and computer science have incrementally aligned at Oxford, notably in the work of David Deutsch on quantum computation, and new stars, such as Vlatko Vedral, seeking towards unification of physical law within an information paradigm, descriptive of what can and cannot happen in physical reality.

7   *80,000 Hours: How To Make a Difference with Your Career*, https://80000hours.org/

This was both the best and worst of places in which to be based for such a challenge. Best in the sense of proximity to and everyday experience of real-world community and context of health care, with freedom to explore their interplay with information technology. Worst in the sense of academic isolation and resulting, sometimes onerous, dependence on personal resource and resilience. Academic appointments usually fit within a pattern of expectations that should be met and are judged accordingly. Mine had none but was bound to be judged as if it did, nonetheless. It was precarious for some years, stepping onto a virtual ladder of career progression in computational science and medicine, for which there was no bottom rung! Moreover, being situated in a community and environment eminent in the history, pomp and circumstance of medicine, that did not understand the nature and purpose of such a ladder or have a recognized place for it.

I was sponsored and protected in those early years by John Dickinson (1927–2015), who had been my PhD co-supervisor and had by this time become the courageous and far-sighted academic chief of medicine at Bart's. I had a bench, cupboard and desk, and a telephone line, and started on my own, at ground zero, to create my ladder as I ascended it.

I had to build mission and role from below, within an existing, not unfriendly, interested but largely uncomprehending community and environment, to help generate something new. I was otherwise alone, positioned at the centre of community, environment and professions of health care, at the start of their encounter with the computer.

How this unlikely scenario played out over the following decades unfolds in the storyline of the book. It did so in ways that could not have occurred had I not been able to work and survive in an interdisciplinary and multiprofessional environment, close to everyday health care practice, education and research. Such essential environment has been rare for health informatics, as my world of endeavour became known many years later, notwithstanding the huge amounts of sometimes ephemeral and confounding artefact and literature constructed under that banner, but often at a distance from the frontline of care. That is in large part why the field has been slow to crystallize, engage and evolve. It is a picture typical of paradigm-changing innovation in many fields and the computer has changed, and continues to change, all the people, disciplines, practices and organizations engaged in delivering and supporting health care. It has changed us all, as citizens and patients, too.

Fortunately, my sometimes-perilous adventure worked out luckily and well, and in 1989, halfway through my career, I was awarded the title of Professor of Medical Informatics, the first such conferment in the UK. I was honoured, also, to be made a Fellow of the Fellowship of Postgraduate

Medicine and subsequently an Honorary Member of the Royal College of Physicians of London, for services to medicine.

Much of the book has been written while locked down for many months at home in the UK, during the Covid-19 viral pandemic. What, several decades ago, was characterized as information explosion, might today, with some justification, be thought of as information pandemic. The inflationary growth in amounts and varieties of information, and their pervasiveness across the world, continues and accelerates. It expresses and communicates an enlightening cornucopia of knowledge and experience, to nurture what Abraham Lincoln (1809–65), and more recently Steven Pinker, described as 'the better angels of our nature'.[8] It also stirs and fuels darker energies and engines, revealed from a Pandora's box of unknowable futures. And, unsurprisingly, the transition of society into the Information Age has been chaotic and stormy, as are all manner of physical, biological and social transitions. Such storms tend to focus our attention nearby and make it difficult to see ahead. Health care services are going through complicated and stormy times–especially in the recent period of viral pandemic. But as storms subside, vision and perspective improve and pathways clear–those we want and need to follow and those that are, perhaps, best avoided.[9]

It thus seems timely to take stock at this midpoint of transition, where a revolution in technical infrastructure has already substantially occurred but the transformation of personal and professional practice and changing culture of society remain unstable and unformed, between the dissolving patterns that preceded and the emerging patterns that are taking root and will follow. We find ourselves poised between ambition and optimism, and caution and concern, about how best to approach the next stages of transition into the future Information Society. This ambivalence is captured in the tempered enthusiasm of Barack Obama's writing about 'audacity of hope',[10] and the caution of Mervyn King's advocacy of 'audacious pessimism'.[11] The latter emerged from torrid times as Governor of the Bank of England,

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8   S. Pinker, *The Better Angels of Our Nature: The Decline of Violence in History and Its Causes* (London: Penguin Books, 2011).

9   As I started to write the book, the year 2020 rang with metaphor of visual acuity. Being in possession of 20/20 vision, one can focus twenty feet ahead on detail that a normal person would be expected to see at that distance. The omen of the 2020 metaphor might not be so encouraging–20/25 vision is less acute! So, as with all metaphor and analogy, let us not take this one too far!

10 B. Obama, *The Audacity of Hope: Thoughts on Reclaiming the American Dream* (New York: Crown Publishers, 2006).

11 M. King, *The End of Alchemy: Money, Banking and the Future of the Global Economy* (New York: W. W. Norton and Company, 2016).

sceptical of science-driven mathematical models of financial markets and scarred by the near collapse of the world's monetary systems in 2008. Something like hoping for the best and preparing for the worst![12]

There is justification for both these positions. On the one hand, there is cause for optimism about the proven and now considerably more flexible, powerful and resilient connected information technologies available to us. These have significantly improved our capacity to work, iteratively and efficiently, in customizing computer applications to meet evolving and changing requirements. New software applications can be developed rapidly and spun into life on Cloud services and data stores, from anywhere on the Internet, within minutes. On the other hand, there is an accumulating legacy of considerable sunk cost in incompatible and outdated systems still in use, burdening frontline services and adding unproductive current cost. Information has become a pervasive but substantially chaotic utility, harvesting, generating, providing access to and pumping content through the globally connected infrastructure of the Internet. This proliferation has been accelerated by the pervasive standardization of methods for managing information content on the World Wide Web.

Of course, significant precursors of the 'information for health' revolution date a long way back in history–such as the perturbations caused by the work of William Farr (1807–83) and Florence Nightingale (1820–1910) in investigating and criticizing hospital statistics,[13] or Gottlob Frege's (1848–1925) formulation of the first-order predicate calculus, that led to description logic of the contemporary knowledge base era.[14] It felt fitting that, as I first wrote these paragraphs on 12 May 2020, the

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12 My wife, Bożena, and I combine English and Polish culture and sense of humour in our marriage. It is said that the former anticipates the future and hopes the worst projections will not happen. The latter does the same and knows that they will!

13 This well-known quotation captures the flavour of Florence Nightingale's concerns in those times: 'In attempting to arrive at the truth, I have applied everywhere for information but in scarcely an instance have I been able to obtain hospital records fit for any purpose of comparison. If they could be obtained, they would enable us to decide many other questions besides the one alluded to. They would show subscribers how their money was being spent, what amount of good was really being done with it or whether the money was not doing mischief rather than good'. F. Nightingale, *Notes on Hospitals*, 3rd ed. (London: Longman, Roberts and Green, 1963), p. 159.

14 Frege made the break from formal verbal argument based on term, proposition, predicate and syllogism–originating in Classical times and associated with the names of Aristotle (384 BCE–322 BCE) and the Stoic philosopher, Chrysippus (279 BCE–206 BCE)–to argument based on formal logic, expressed as mathematical reasoning with logical predicates, as discussed in Chapter Two.

two hundredth anniversary of the birth of Florence Nightingale was being commemorated.

Subsequent months of writing saw AlphaFold–a software method based on machine learning–demonstrate prediction of the three-dimensional folding structure of a protein, based on the genetic sequence of its DNA.[15] This extraordinary success, and others that preceded it, hold out the prospect of a time to come when such machines will learn for themselves about health care interventions, based on observed and elicited facts, to devise and enact machine-based methods that reason about, interpret and even act on them in real life–controlling surgical instruments or medical devices attached to or travelling within the body, for example. Notwithstanding the promise of considerable and significant improvements along this pathway, it must be countenanced that, humans having pursued human mastery of the computing machine, there may arise increasingly capable machines that might continue to serve us, or turn the tables to our detriment–or we ourselves might unwittingly turn them–such that their needs dominate and subjugate our human values, needs and skills. Such a future scenario might constitute neither manageable nor survivable loss for humanity. For sure, it will pose new challenges and difficulties.

We have learned a great deal, often simply by trial and error, about the opportunities and pitfalls when marrying information technology with health care. We have created and improved tools and methods that enable us to succeed in areas where we have hitherto lacked insight and capacity, failed or not met expectations. And society, more widely, has substantially adapted to the use of information technology in daily life, leading to the harbouring of new hopes and expectations for customized personal health care services. There has been success in some areas, counterbalanced by burdens imposed, to little or no benefit, or to some disbenefit, in others. And regarding the increasing imbalances of health care in our ageing populations, according to the King's Fund in London, in a 2012/13 review entitled 'Time to Think Differently', resources have moved proportionally away from social care into treatments of disease which cannot yet effect a cure, connected with long term conditions and accounting for seventy percent of total health and social care expenditure.[16] This demographic shift has, in itself, reflected scientific and engineering advances of the past century, that have combated and prevented disease.

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15   The company DeepMind, in London, announced this achievement on 1 December 2020.
16   The King's Fund, 'Time to Think Differently' (2012–13), https://www.kingsfund. org.uk/projects/time-think-differently

In an outstandingly thoughtful book, the eminent American clinician and medical scientist, Eric Topol, has emphatically and starkly attributed the accumulating, and now more widely apparent, ills of modern-day medicine to its having lost balance, through the pursuit of optimization and monetization of cure at the expense of too little time and attention paid to care ('Period', he says!).[17] I visit this book in Chapter Eight and have come to see things in much the same way, along my parallel songline. His is a physician's case history and diagnosis of what he sees as a very sick patient, and he seeks a remedy. He looks to a pathway ahead with services informed and supported by artificial intelligence, to assist in redressing the balance and enabling much greater time and attention to be devoted to care. His book focuses on doctor and patient relationships in hospital care settings of America, today. I look to a complementary, inclusive and community-wide pathway ahead, with the goal of framing, creating and sustaining a citizen-centred care information utility, anchored in the public domain, to support balance, continuity and governance of health care services.

The Covid-19 viral pandemic has starkly revealed the dynamics of unprecedentedly rapid global propagation of infection. Internet-mediated communication of malware viruses demonstrates a similar dynamic sting. Global travel routes and the Internet of electronic communication might be characterized as combinations of time compression and seven-league boots–they communicate ever more rapidly and widely. Decades of accelerating increase in the miniaturization and computational power of electronic devices, and the speed of deployment of software and systems based on them, have bypassed the additional checks and balances of time and distance that have helped society adjust to, shape and moderate diffusion and impact of innovation and change. Some kinds of stuff have always happened quickly–the Chicxulub meteorite impact or threshold phenomena in phase transitions of the natural world, for example–but information technology contributes to making man-made stuff happen on qualitatively different scales. Good stuff and bad stuff. This brings new instabilities and vulnerabilities. We shape them and they shape us.

The investments powering the helter-skelter ride into the Information Age seem now often to be out of kilter and out of control. These have been the recent Western decades of International Business Machines Corporation (IBM), Digital Equipment Corporation (DEC), Microsoft, Apple, Google, Meta (formerly Facebook), Twitter, Amazon and more, marked by trillions of dollars of expenditure and now billions of users, where inflated associated private wealth and monopoly are looming larger as international antitrust

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17 E. Topol, *Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again* (London: Hachette, 2019).

concerns. They are mirrored today in the Eastern world of Huawei and Alphabet. Flexing muscles of government cyberwarfare and cybercrime have also amplified mutual distrust.

The World Health Organization (WHO) has estimated that the world now spends of the order of eight trillion dollars per annum on health, in its transition to more domestic, as well as more public, provision. Global spending on health information technology is rising rapidly and has been anticipated to reach around four hundred and forty-one billion dollars by 2025.[18] Some fifteen years ago, Blackford Middleton's team at Partners Healthcare in Boston (now renamed to Mass General Brigham) estimated the consequential cost of disorganization of such information at nearly eighty billion dollars per annum, for the United States (US) health economy alone.[19] A decade earlier, the UK Audit Commission estimated that clinical professional staff in hospitals were, on average, spending of the order of twenty percent of their time on tasks interacting directly with information systems.[20] In late 2022, the British Medical Association assessed that NHS doctors are losing at least four hours a week through the inefficiencies of information technology (IT) systems.[21] And on 17 January 2023, as I worked on finalizing this text, the *Times* newspaper was reporting the first meeting of its new Health Commission, established to consider reform of health care. The page one headline was 'Rising levels of ill health costing the economy £150bn a year'.[22] The detailed breakdown leading to this figure, which they described as a conservative estimate, came from a report commissioned from the Oxera economics and finance consultancy. It is sixty percent higher than the amount estimated in 2016, using the same methodology. The Information Age is clearly not well. The Information Society needs to get better.

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18   Healthcare Facilities Today, 'Healthcare Information Technology Market to Reach $441 Billion by 2025', *Healthcare Facilities Today* (26 April 2019), https://www.healthcarefacilitiestoday.com/posts/ Healthcare-information-technology-market-to-reach-441-billion-by-2025--21259

19   J. Walker, E. Pan, D. Johnston, J. Adler-Milstein, S. W. Bates and B. Middleton, 'The Value of Health Care Information Exchange and Interoperability: There Is a Business Case to Be Made for Spending Money on a Fully Standardized Nationwide System', *Health Affairs*, 24.Suppl1 (2005), W5-10-W5-18, https://doi.org/10.1377/hlthaff.W5.10

20   L. Nicholson, 'Setting the Records Straight: A Study of Hospital Medical Records Undertaken by the Audit Commission', *Records Management Journal*, 6.1 (1996), 13–32, https://doi.org/10.1108/eb027083

21   B. Ireland, 'Millions of Hours of Doctors' Time Lost Each Year to "Inadequate" IT Systems', *BMA* (5 December 2022), https://www.bma.org.uk/news-and-opinion/ millions-of-hours-of-doctors-time-lost-each-year-to-inadequate-it-systems

22   Times Health Commission, 'Rising Levels of Ill Health Costing Economy £150bn a Year', *The Times* (16 January 2023), https://www.thetimes.co.uk/article/ rising-levels-of-ill-health-costing-economy-150bn-a-year-x5dkcn5jg

Progressive entrainment of professional services with information systems has featured more generally in society, starting in Western economies and industries but spreading now almost universally. And yet, health care services have failed repetitively to achieve a viable and sustainable ecosystem of electronic health information systems–notably those concerned with health care records–despite very considerable, repeated and much-fêted investments. I track that reality over the past fifty years in Chapter Seven. But it is not necessary to write or read papers and reports about this to understand what is happening. Just share the experience of the logistical problems that arise, continually, through failure of continuity of record keeping and communication across different levels and regions of health care services. Or of a relative, such as me, of a recovering but critically ill patient, in months accompanying them at their bedside, day by day, through life-supporting intensive care, watching how much staff attention is forced and required to focus away from patients and onto antiquated, difficult to work with, screens.

The book tells both encouraging and alarming stories, like these, and sets them within historical and contemporary contexts. It ranges across disciplines and technologies and follows patterns of change in the professions and organizations of health care services, alongside change in the everyday life of citizens and their experiences and expectations when being cared for and caring for themselves and for others. It draws lessons from repeated failures of government policies and sets out a case for why and how we can now set our sights higher and equip ourselves to do much better in the future. Whitehead wrote of the adventure of ideas as fundamental to a continuing programme for reform. It is on the foundations laid down in this adventure that we can now, and must, ground a long-term, adaptable and incrementally sustainable programme for reform and reinvention, to meet the changing needs of health care in the Information Society of tomorrow.

The stories about health care told in the book have historical contexts spanning thousands of years, from the evolved practice of indigenous communities, the invention of medicine and first records of care in Classical times, and recent centuries of advance in mathematics, science and technology, leading into the twentieth century. They have more immediate scientific and social contexts spanning the coevolution of science, engineering and health care services of the past century, with their increasing focus on computer science and the development of information technology. And connecting these stories together, there is personal experience and perspective, looking back along the timeline of my own life and career, growing up within social care services and employed first within industry, then within health care services and academia, and now in a, thankfully, still active retirement.

Family connections with our children's and grandchildren's generations have been equally important in guiding my understanding and approach, especially considering that the computer has always featured in their lives. Indeed, they are accumulating their own professional involvement in and experience of health care and information technology. My elder son, Simon, now carries executive board responsibility for the information technology sourced and deployed in an international market research business, in countries from the USA, through Europe and Africa, to Singapore. My daughter, Katharine, is a consultant anaesthetist and has held responsibilities for the professional training programme in the NHS East Midlands region. My younger son, Tom, combined PhD research on cardiovascular disease with training as a cardiologist. He is a founding board member of an innovative new multiprofessional royal college of echocardiography, helping to shape its focus on peer-based quality assessment of services and related workforce development and leadership. And closest to my everyday life is my doctor wife, Bożena, who came to England from a very different health care system, in which she pioneered endoscopy services in paediatric gastroenterology. Her father and brother were and are much-loved physicians in their home region of central Poland and her nephew is a rising star in New York investment banking. Numerous other close relatives and friends are also clinical professionals and I had uncles who were general practitioners (GPs) and surgeons long ago. My father had an extensive network of social work colleagues. In his later career he was head of training and then of childcare services for the London and South-East region of the Barnardo's charity in the UK.

These wide-ranging personal connections with family and friends, and with people, organizations, ideas and initiatives widely further afield, have stayed in my mind and helped crystallize my learning in this book. Much of the wider learning needed for success in shaping the transition of health care services into the future Information Society will centre on the experience of citizens and health care professionals in using and shaping the information technology that underpins them. For most of them, if the IT system is seen to meet their needs, it will become largely invisible. Few know about tuning and maintaining the engines of their cars these days and would be ill-advised to try! It will be the same with the information engines we come to depend on in health care. But the human values, goals and methods that underpin them will matter–they must be transparent, and their governance must be trusted.

This breadth of personal experience has also encouraged and led me to a forward-looking, largely optimistic view on how best, now, to address the wrongs that have accumulated and supersede the increasingly unsustainable legacy of technologically and clinically dysfunctional,

burdensome IT systems that currently dominate much of everyday health care services. This view further aims to achieve a practical rationale for constructive engagement with new ideas and their advocates, such as those encouraging us on from the stormy current dystopia of the Information Age, to a promised, but not proven, resolution, supported by connected, micro-electronically instrumented, information-driven, machine intelligence. This is a domain populated by many with the mindsets that led King to his advocacy of an approach based on audacious pessimism rather than hope. The world often proceeds through unintended consequences and many such may arise over the horizon of what has been termed an approaching Novacene era of intelligent systems.

There are good reasons not to despair of progress through times of such great change and uncertainty, as Pinker maintains in his book *The Better Angels of Our Nature*.[23] First, there is much that is amazingly good and remarkable in what has already been learned and achieved in the very wide range of endeavours encompassed in the book. Second, there remain complex intellectual and practical challenges that call for invigorated interdisciplinary, multiprofessional and community-wide commitment and cooperation. Third, scientific advance, combined with the technology and infrastructure resources now available, seventy-five years on, brings qualitatively new opportunities for tackling these unresolved challenges and connecting them successfully with core goals of affordable and high-quality health care services, supporting individual citizen health and wellbeing.

I do not seek, and am not well-equipped, to describe the details of all the domains of academic discipline, professional practice and health care services that the subject matter of the book traverses. There is almost no topic covered that could not be written more precisely or expertly than I am able to or have space for here. I have tried to communicate enough of their flavour, content and context, at levels that show how they connect with and have contributed to health care in the Information Age, and how and why they matter. Many of the stories and topics covered connect closely, and uniquely, with and along the timeline of my own career in the field, which has coincided with the emergence of health informatics as both discipline and practice. Health informatics has been termed a 'grand challenge' and such challenges have been a recurring theme of academic discourse of recent decades.[24]

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23 Pinker, *The Better Angels of Our Nature*.
24 Neil Gershenfeld at Massachusetts Institute of Technology (MIT) described the increasing grouping and cross-fertilization of disciplines, and the defensive boundaries between them that encourage and incentivize non-communicating silos of knowledge. He proposed the regrouping of academic disciplines around grand challenges facing society, in which all disciplines have a part to play–such as ageing society, artificial intelligence and clean energy. He wrote that 'The greatest

Success in meeting them transcends governments, organizations, industries, disciplines and professions. It requires cooperation and collaboration that engages these groups and the communities they serve, united in pursuit of common purposes and goals, honed by incrementally and iteratively tested implementations in real-world practice. This in turn depends on a trusted common ground of knowledge that is openly shared and sustained among participants and within the global public domain.

As will already be clear, the attempted scope of my book is very ambitious, and perhaps foolishly so! It travels widely into many and disparate histories, disciplines and professions, seeking connections on a common ground of health care services and the information systems that support and integrate them. This breadth of coverage risks becoming too complicated, and indeed of limited interest, even if admittedly of major potential impact, for those involved in the separate domains the book concerns. Its principal audience is therefore likely to be centred on those recognizing the importance of and engaging in endeavours which are intrinsically collaborative, interdisciplinary and multiprofessional. A key requirement for such endeavours is that there is an understood shared goal of the collaboration and that each contributing partner group is able and prepared to work towards mutual understanding of where its partner groups are coming from, and to learn, adapt and co-evolve with them, accordingly. In today's discourse and society, such polymath capacities are a receding reality. Culture, practice and leadership of teamwork across widely disparate disciplines, professions, services and communities are central to successful ventures–emphasizing all-important human factors, once again.

Recognizing the limitations that it entailed, the physicist and father of quantum mechanics, Erwin Schrödinger (1887–1961), opened with a caveat when introducing his book *What Is Life?*, in which he set out to characterize living organisms within then contemporary concepts and language of physics.

> We feel clearly that we are only now beginning to acquire reliable material for welding together the sum total of all that is known into a whole; but on the other hand, it has become next to impossible for a single mind fully to command more than a small, specialized portion of it [....] I can see no other escape from this dilemma (lest our true aim be lost for ever)

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consequence of improving information technology may be to organize intellectual inquiry around grand challenges rather than traditional disciplines', saying that 'if this turns out to be so, then a title like "the physics of information technology" may eventually become triply redundant. The truth is that none of those words can properly stand without all of them' (N. Gershenfeld, 'Bits and Chips', *New Scientist*, 169 (2001), 55).

than that some of us should venture to embark on a synthesis of facts and theories, albeit with second-hand and incomplete knowledge of some of them–and at the risk of making fools of ourselves.[25]

Schrödinger framed a very broad-ranging purpose and goal for his book–an elusive answer to the question he posed. He probed disciplinary insights directed to that end, illuminating the question as much as providing an answer. It was quite a short book, but a mind-stretching read for the audiences it sought to connect with–for the physicist familiar with that world but new to the life sciences, and vice-versa for the life scientist. It penetrated detail of these different disciplines and their bodies of knowledge when looking for useful connections that might throw light on his quest.

A similar caveat from me, about 'risking making a fool of myself' with this book, is infinitely more due! However, there seems little harm that can arise from it and not a lot to lose. It seems necessary to risk foolishness in venturing so widely, to seek greater understanding. And thereby to help facilitate traction in coping with and navigating the landscape of often anarchic encounters of information technology with life science, medicine and health care services, and in envisaging and shaping what might lie ahead. I am hugely indebted to Alessandra Tosi and Rupert Gatti, the founders of Open Book Publishers, and those who have contributed to the costs of publication, for trusting, encouraging and supporting me in bringing it to life as an open access work.

There is a very wide range of past and present participants closely involved and implicated in these matters, and the needs and available means to help join their disjoint goals, motivations and actions also vary greatly. Were we to place members drawn from all the constituencies involved in developing, delivering, receiving and regulating health care services in one room, they would likely mostly succeed only in swapping their stories, or discussing football or the weather! As the philosopher Arthur Schopenhauer (1788–1860) remarked, 'The doctor sees all the weakness of mankind; the lawyer all the wickedness, the theologian all the stupidity'.[26] Much confusion and confabulation of perspectives still pervades the airwaves! And yet, the human biology that accompanied the ideas attributed to Hippocrates (*c.* 460 BCE–375 BCE) and Galen (*c.* 130 CE–210 CE), from around 2000 years ago, leading to the invention of medicine, is very much the human biology of today. Schopenhauer also said that all human history

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25   E. Schrödinger, *What Is Life?* (Cambridge, UK: Cambridge University Press, 1948), p. 1.

26   A. Schopenhauer, *Parerga and Paralipomena: A Collection of Philosophical Essays* (New York: Cosimo, 2007), p. 66.

was encompassed in Herodotus's *Histories*, which was assembled some decades before *The Epidemics*, indicating that humankind does not change much, either!

In fairness, the landscape of new ideas, methods and practices involving information technology that has unfolded onto the health care scene along my songline, and much of it disappeared out of sight, has often been bafflingly multi-faceted and complex for everyone, me included. Each participating constituency has sought its own answers and asserted its own clarity. Few meaningful and useful answers can arise that way these days, save perhaps through extreme good luck or the diktats of *force majeure*. They require environments and common endeavours that join across disciplines, professions, services, industries, jurisdictions and society at large.

This is the inclusive perspective that the book is organized around and one of its principal goals is to describe and lay foundations that can help to support future inclusive endeavours. The audience for such a goal is not well-defined or formed in the fragmented world of health care in transition that we have come to inhabit. Such audience must be created and persuaded, it being characteristic of the reception of new and yet unexplored ideas, that they can be quickly dismissed as irrelevant and of no interest, or perceived as too difficult to engage with, or be allowed to pass by under the radar before being afforded opportunity and space to develop. I devote a section at the end of the Introduction to a more detailed consideration of the potential audience for the book and, to the extent that it has not existed hitherto, how, and why it can and needs to be created. This process will include a wider coming to terms with the realization that informatics, the science of information, is, like mathematics, now increasingly central to the framing of ideas central to many disciplines, and not just as a computational tool used by those disciplines. Bioinformatics is now central to life science and health informatics increasingly so to health care.

I was, in my academic grounding, a proficient mathematician and a capable theoretical physicist. Vainly, I can boast that I have the double first-class honours degree to show for that, though have not used it as once I might have hoped to–perhaps also wisely recognizing that I would probably not have succeeded! Theory and abstraction based on clear and critical thinking are important in physics. But they only progress beyond abstraction when grounded in experiment. And in such widely ranging domains as health care and information technology, they only make sense when grounded in wider social context and culture, and advances in engineering. Like medicine and politics, engineering is an art of the possible. Engineering advances, often underappreciated and overlooked, have been the driving force behind much of the scientific progress that has been made.

Like any skill, medicine included, people learn it and become good at it, by doing it and reflecting on their performance. This is a thought I return to often in the book, in recognizing and celebrating the importance of pioneers–makers and doers working at the interfaces of science, health care and society. Key figures I introduce have combined intellectual prowess with determination to see ideas into practice, experimentally at first, and progressively by turning their hands to making and doing things that work, putting them to use, and learning, thereby, how to make and do them better. A crucial liberation of the potential of information technology came from its democratization in this way, from the domain of its specialists into the multiple domains of its users, enabling them to use it themselves, creatively, in their own very different worlds, to create their own stories. We should focus more, now, on how to place health care back more closely into the hands of individual citizens and their communities.

By chance, my career has always been a marginal one. But from it has grown an international community and organization, the not-for-profit openEHR Foundation, created from my Department at UCL in the second half of my career in health informatics, and the openEHR International Community Interest Company (CIC), working within the framework of the Creative Commons, to which operational activity and governance is now devolved. Such entities are organic in nature and expressions of the many people and organizations in many countries that make them a reality. openEHR is a tree that I conceived of, planted and nurtured through its early decades and helped to grow into an increasingly successful and influential forest, with thousands of members and participants, now in a hundred countries, and an increasing number of successful businesses, health care organizations and municipalities in partnership. Most importantly, it now thrives and governs itself, without me occupying any role other than the self-indulgent celebratory one of its Founding President. It seeks to share the values and goals we set twenty years ago, and the culture and spirit of cooperation and ways of doing things that were adopted from the outset. It is doing influential work and involving and motivating a new generation of pioneers, much more able than I am, or ever was, to carry it forward. It has had its perilous and dispiritingly vulnerable moments, too, of course! This is a story, that of openEHR and its mission, that I tell in Chapter Eight and a Half. I explain, there, the inspiration for the half chapter in its connection with the novelist Julian Barnes. It probably should have a book of its own. Maybe and zobaczymy [we will see], which is the Polish response when confronted with all imponderables in life! More fatalistically, in English, we say that 'time will tell'.

The second initiative I have participated in for fifteen years is the OpenEyes open-source software for ophthalmology electronic medical

records, which had its origins nearby UCL, at the world-renowned Moorfields Eye Hospital. It is now being taken forward by the Apperta Foundation and a growing international and multiprofessional partnership of participants. This story is also told, but in less detail, in Chapter Eight and Chapter Eight and a Half. Like openEHR, it has been accelerating on a long runway spanning two decades, to the point where it is now creating records for approaching fifty percent of eye care consultations in the UK health services and flying over the Internet Cloud to be used by clinicians elsewhere in the world. In January 2023, OpenEyes was accredited by the Digital Square organization (Digitalsquare.org) as a global public good. In health care, these are described as '[…] tools that are impactful, scalable, and adaptable to different countries and contexts. These free and open-source digital health tools look to reduce fragmentation and duplication to accelerate scale and health impact'.[27]

Building and sustaining good teams and creating and supporting inspiring and creative environments that enable them to flourish, is central to success. The approach to the challenges of health informatics that I have pursued carries risks but is relatively inexpensive and already has vibrant communities of practice and substantial worldwide installed bases. In Nassim Taleb's terms, it is surely antifragile.[28] The potential upside benefits are very large, and the downside risks very limited. The time has come to open eyes, to projects and communities like those of openEHR and OpenEyes. There are many such initiatives emerging across the world in the Information Age and they need and deserve greater attention and support. They are tackling problems that have proved beyond governments, professions, communities and industries, alone, to solve, but which require solution if information is to extend beyond its technology into an essential utility, supportive throughout health care.

The balance, continuity and governance of care services form a trifecta of challenges faced in reinventing and reforming health care. In openEHR and OpenEyes we have come halfway, as dreamers, along a pathway of learning how to create and sustain what we might call an openCare utility, supportive of such reinvention and reform. In his epic history, *Seven Pillars of Wisdom*, T. E. Lawrence wrote thus of two kinds of dreamers: 'All men dream, but not equally. Those who dream by night in the dusty recesses of their minds,

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27   S. Bochaberi, V. Rathod and C. Fourie, 'Digital Square Announces New Software Global Goods Approved through Notice G', *Digital Square* (16 February 2023), https://digitalsquare.org/blog/2023/2/16/digital-square-announces-new-software-global-goods-approved-through-notice-g

28   N. N. Taleb, *Antifragile: How to Live in a World We Don't Understand* (London: Allen Lane, 2012).

wake in the day to find that it was vanity: but the dreamers of the day are dangerous men, for they may act on their dreams with open eyes, to make them possible'.[29] The openEHR and OpenEyes communities are hopefully neither vane nor dangerous, and certainly not all men! But they are, for sure, acting (i.e. implementing!) their dreams to make them possible!

After starting my life living in a small and isolated rural village, I am now living in the ancient English city of St Albans, which is busily reshaping itself as a set of globally connected local small villages, where daily life and relationships are both global and local, in both scope and application. I look back along my songline with a mixture of amazement and bemusement. Amazed by the advances in science and engineering and my personal good fortune to have lived and worked so closely with people who have been at the heart of those achievements. Bemused by the countervailing tensions that have arisen in the wider context and global reach of information technology and communications, and their demonstrated capacity to reshape everyday life in ways that both improve and draw people together and impoverish and split them apart. I look forward with equal amazement as AlphaFold, ticking away just a few hundred metres from UCL–its chess- and Go-playing co-founding genius having commenced his professional life at the UCL Queen Square Institute of Neurology–demonstrates the progression of machine learning into the life science and clinical domains. Perhaps Jeremy Bentham (1748–1832) would have been pleased to observe how my story connects with engineering and medicine at UCL, the University that celebrates its close connection with him to this day. I am delighted by its many connections, also, with physics and engineering at my alma mater, Magdalen College at the University of Oxford, and medicine at Bart's.

The book has been growing and metamorphosing in my mind for several years, alongside the very diverting new obsession with my wife, Bożena, in keeping fit and getting rather good and having fun in all manner of ballroom, Latin and Argentine Tango dance–we have drawers full of medals to justify that boast! It was a happy moment when youngsters in the teaching crew at a sailing club in Greece, saw us dancing at the social evening, asked to dance with us, and enquired whether we had been professional dancers! We wish! With these diversions, it has never felt a good time to sit down and spend the many months I have, to write the book. Marcus Tullius Cicero (106 BCE–43 BCE) may or may not have written that 'Times are bad. Children no longer obey their parents, and everyone is writing a book', as legend avers. But bad times, recently, facing enforced house lockdown for many months because

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29   T. E. Lawrence, *Seven Pillars of Wisdom* (Chatham: Wordsworth Editions Limited, 1997), p. 7.

of the pandemic, presented an opportunity and accelerated my writing of this one, now.

I started to write at the beginning of what, it seemed, might progress into a twelve- or twenty-four-month period of locked-down life, at the start of the first wave of the Covid-19 pandemic. The science on which hopes are pinned for better treatment and prevention of the infection, making the world safe again, would have been unimaginable to those who lived through the Spanish flu, immediately after the First World War. The communication of and about the virus itself–the speed of its transmission and of cooperative responses seeking to understand, treat and guard against it, in countries across the globe–would likewise have seemed dreams about another planet. They would have been Utopian dreams in the 1950s at the start of my songline, when many of the people I encountered and the ideas they brought to fruition in science and technology (transforming medicine and underpinning the networks of communication, data processing and computation on which everyday life now depends) were in their early adult lives and formative career stages.

The imperative to write the book also resonated with me strongly when in receipt of the piercing interrogations of the young. 'What have you been up to, grandpa?' is a great question–for me as much as for our family's nine gorgeous, growing, enquiring and challenging grandchildren. It is wonderful to have them alongside, at the start of their own songlines and with more acute eyes and ears, peering forward and listening. The Information Age is just normal life for them. Like any grandad, I am anxious for the Information Society to evolve well for them.

This has been a long preamble aimed at illuminating the origins and content of the book. There are very many people acknowledged throughout for their contributions. With regards the content of the book itself, of course, the buck stops with me. I hope it is interesting, fair, balanced and useful. And, hopefully, also thought-provoking and controversial. Nothing useful could be written about this very wide-ranging field, that was not! It has been a privilege to have been trusted with freedom in my work, to focus on creating and enabling innovation that is significant and will endure alongside the uncertain and changing contingencies of our anarchic times, mirroring how MacAskill has encouraged us to focus, when deciding what to do in our lives.[30] My greatest hope is that my family, friends and colleagues will feel pleased and proud to have been part of it all, alongside me, while also, no doubt, quite relieved, as I am, that the writing is now done!

<div align="right">David Ingram, St Albans, March 2023</div>

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30   W. MacAskill, *What We Owe the Future* (New York: Basic Books, 2022).