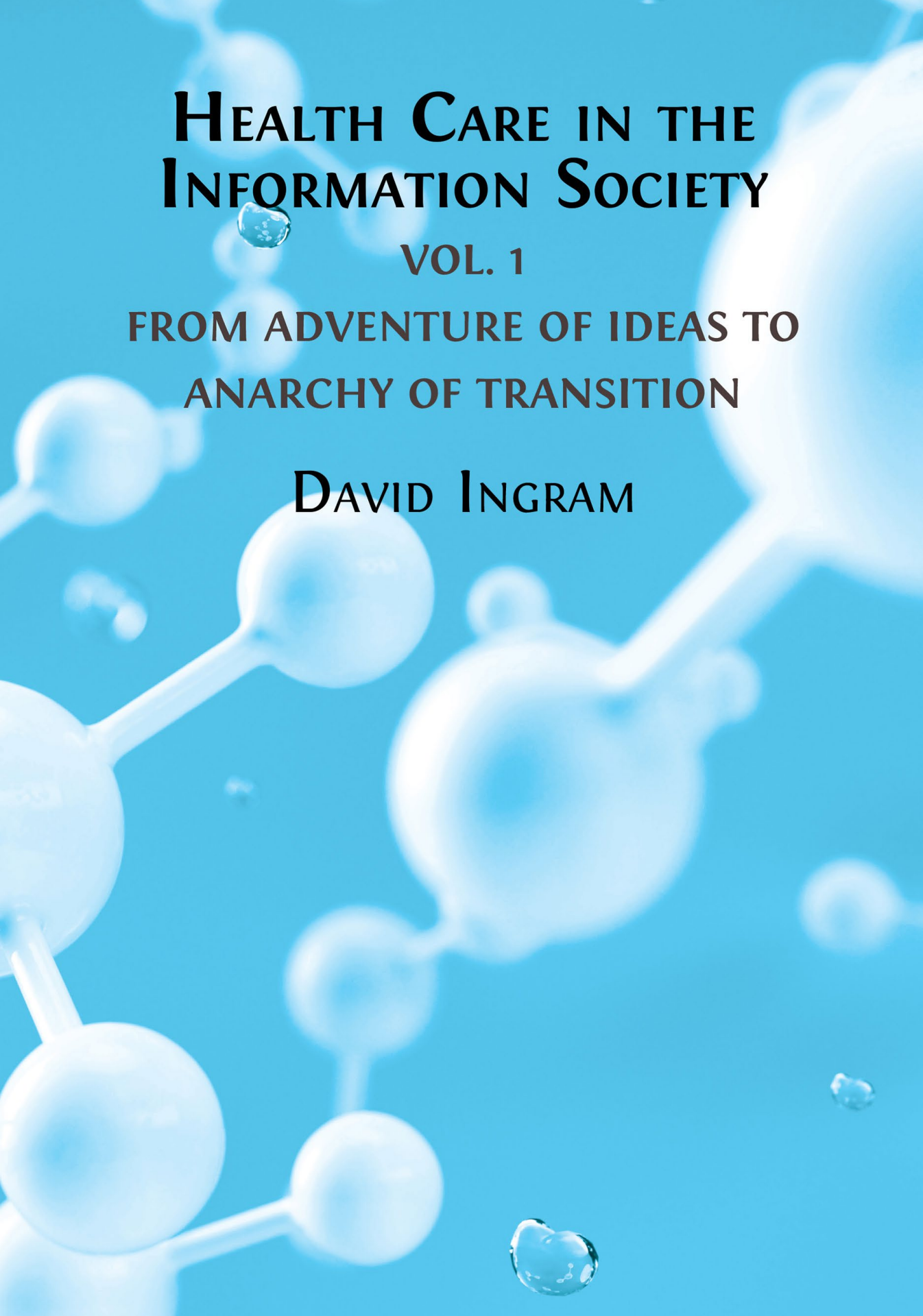
Health Care in the Information Society

Vol. 1

From Adventure of Ideas to Anarchy of Transition

David Ingram



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1. Introduction–Connecting for Health

> Only connect! That was the whole of her sermon. Only connect the prose and the passion, and both will be exalted, and human love will be seen at its height. Live in fragments no longer. Only connect, and the beast and the monk, robbed of the isolation that is life to either, will die.
>
> –E. M. Forster (1879–1970)[1]

> A good environment is not a luxury; it is a necessity.
>
> –Richard Wollheim (1923–2003)[2]

> Sometimes reality is too complex. Stories give it form.
>
> –Jean-Luc Godard (1930–2022)[3]

This book connects two domains that are integral to every human life and increasingly to almost every other domain of human knowledge, appraisal, decision and action. The first of these, the unity of health and social care, has become progressively fragmented into separate entities, and needs wholeness restored. This reunification has been a long-expressed ambition of national policy in the United Kingdom (UK). Other countries, such as Finland, in my observation, are taking this more seriously and doing better. The second domain, information technology, can play an important role in fulfilment of this ambition, but as a component of an organic information utility, not as a machine. Organic, that is, in the sense of 'relating to, or derived from living organisms' and, in the context of health care, in the sense of being adaptable, evolving and human-centred.

1 *Howards End* (London: Edward Arnold, 1910), p. 174.
2 Quoted in J. Z. Young, *Programs of the Brain: Based on the Gifford Lectures, 1975–7* (Oxford: Oxford University Press, 1978), p. 1.
3 NB: this quote is widely attributed to Godard, but no explicit source has been identified.

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Connection, environment and storytelling are central themes of this book, hence the introductory quotations above. It seems fitting to start here by revisiting the often-quoted perspective of Forster, writing a hundred years ago, when cars and telephones were new and electronic computers unknown. He was prescient of the potential for harm wrought by technology on social interaction. In his novel, *Howards End*, 'only connect' was about the connection of opposing elements of human personality–beast and monk, prose and passion–and the importance of the quality, not the number, of personal relationships. In the short story *The Machine Stops*, Forster painted a picture of a future society that had become dependent on connection with and through a worldwide machine–for shelter, food, communication and health care–and where personal life characterized by ubiquitous connections had retreated into a state of isolation and immobility, communicating only via 'the Machine'.

Connection is about joining and binding together; about nexus–a common theme and method and means of binding. Communication is about sharing and making common–common ground joins community and environment. I shared common ground with Richard Wollheim, who I also quoted above in relation to the importance of environment. Wollheim was as an undergraduate at the University of Oxford (where he studied Philosophy, Politics and Economics (PPE)) and a professor of philosophy at University College London (UCL). A 'good environment', as Wollheim suggests, in which to connect and communicate is essential for creativity, growth and development. Many strive to make connections and help build and sustain good environments and communities–some are lucky and successful in this, and some are not. People work and feel better, and trust more, in environments where they feel connection and a sense of personal identity and worth.

It would be naive not to recognize the power of disconnection, too. Polarization of opposites is a feature of the physical world, and, as Primo Levi (1919–87) expressed in *Other People's Trades*, the tendency to gravitate to repelling poles of extreme perspective is a natural human trait, seeking and prizing a feeling of certainty over the pain of confronting uncertainty.[4]

The storyline of this book opens onto a field of view encompassing the connection of information and information technology with the multiple disciplines and professions, and social and organizational contexts, of health care services. There are abundant connections that can and might be made across these domains, viewed from historical, contemporary and future perspectives. Nonetheless, the connections that persist throughout

4 P. Levi, *Other People's Trades* (London: Sphere Books, 1990).

are with the lives of individual citizens and the environments in which they live, work and receive or give care.

The book is a story of these many and disparate connections and interactions. It offers a perspective on how they can assist and support health care services as they evolve in the decades to come. Information, as a scientific construct, has emerged as a unifying concept of science and communication. Information as a utility akin to water and electricity supply, has emerged as an essential resource for everyday living. Information utility will be central to the future balance, continuity and governance of health care services. It is more complex than water, though: it is organic and can thus exhibit pathology. And it will reshape relationships of trust between individual citizens and the multiprofessional teams that serve them. Information utility for health care, as a co-creation of citizens and health care professionals, will be an essential shared and growing repository of knowledge and a resource for everyone, for learning and living.

As also quoted above, Jean-Luc Godard spoke of the importance of stories in giving form to complex ideas. As a film maker, he would likewise have spoken up for film and image, which also give form to ideas. Such an image as that in Figure 1.1 might be taken to symbolize the exploratory and incremental connections of multiple disciplines and professions in simultaneously creating and ascending a staircase of new knowledge and services in support of health care. It was produced by an online artificial intelligence program[5] that creates images from text.[6]

5 Several of the images that I had originally hoped to include in the book were not available under an open-access license. This led me to experiment with Stable Diffusion Online (https://stablediffusionweb.com) to create images using artificial intelligence software, based on descriptive text in the book. The images that the software created from extracts from poems by William Blake and T. S. Eliot (quoted at the start of Chapter Two (Vol. 1) on knowledge) were fascinating, thought-provoking and funny!

6 Thinking of the start of my career in health informatics, as described in the Preface (Vol. 1), the image might also be taken to represent me, 'stepping onto a virtual ladder of career progression in computational science and medicine, for which there was no bottom rung! [... starting] on my own, at ground zero, to create my ladder as I ascended it. I had to build mission and role from below [...] to help generate something new'.

Fig. 1.1 Ascending a staircase of new knowledge, professions and services. Image created by David Ingram using Stable Diffusion Online (2023), CC0 1.0.

The connections of information with medicine, health care and society today, have historical context of more than two thousand years. The book draws on a personal and subjective set of these connections–people and community, discipline and profession, science and practice, team and environment. It is a collection of stories, drawn from many sources and expressing many points of view. History as told by Herodotus (*c.* 484 BCE–420 BCE), often characterized as the father of history, was, I have read, constructed that way. He was writing some decades before the time of Hippocrates (*c.* 460 BCE–375 BCE) and his *Epidemics*, when oracles and omens were favoured predictors of the future, so one must bear this in mind when drawing on his insights.

For Herodotus, sources were categorized on three levels. The most reliable and useful were stories recorded in eyewitness accounts. Then came hearsay, based on stories derived from eyewitnesses. Finally came sources descriptive of official lines–expressions of politics and orthodoxy of the day, which he deemed the least reliable of sources! His reputation as a historian has waxed and waned–from charming but naive purveyor of other people's accounts to artful and intelligent overseer and shaper of sources, with the aim of creating a wider model and view of history. He was, it seems, attuned to a modern day anthropological and ethnographic approach to history, recorded through stories of culture and diversity, custom and practice, as much as through accounts of military and political events. From

this diversity of sources and stories, listened to and accumulated along his wide-ranging songline, he shaped his narrative, concerned with questions of who was telling what stories, where and in what context, and from what perspective. He did not focus on veracity of individual sources so much as on a kaleidoscope of truths and untruths being told and shaped to different ends, thus assembling an overview culled from multiple sources and communities of storytellers.

This historical analogy echoes in contemporary experiences of social media and its polyphony of stories and accounts: it speaks to how we, individually and as a society, shape and make sense of such stories; how, within the Internet-connected environment, we modulate and moderate these stories to serve personal ends; and how, in the parallel contemporary surge of artificial intelligence and software like ChatGPT, the computer is being used to assimilate, generate and propagate stories, challenging human ability and capacity to distinguish information from misinformation, and reason from unreason. As Herodotus believed, we are under no obligation to believe stories but do, nonetheless, need to shape our understandings from the patterns and contingencies they present and reflect.

This perspective has strong echoes, too, within health care professional practice. Listening to, capturing, recording and responding to a patient's story along the timeline of their care–documenting the observations, measurements, interpretations, decisions made, actions initiated and resultant outcomes–traverses social culture, academic discipline and professional practice. The clinician is akin to both historian and eyewitness participant in this encounter, working like Herodotus to piece together understanding from disparate sources and assembled collections of evidence and accounts that may at times be conflicting and dissonant. The narrative of these histories is drawn together and connected within records of care. And artificial intelligence will bring new capacity for entwinement there, in unpredictable ways, accomplishing many beneficial and desired outcomes. However, it also carries the risk of admixing its own, potentially detrimental, virtual caricatures of the scene into the storyline of care, shaping both machine and human action.

The science and art of professional practice intermingle. Clinical skills depend importantly on what Gillian Tett has termed 'anthro-vision'. This is the title of her 2021 book, which is further discussed in Chapter Eight (Vol. 2).[7] The term characterizes the focus of the anthropologist on making sense of and engaging with histories in the human context of individuals and

7 G. Tett, *Anthro-Vision: A New Way to See in Business and Life* (New York: Simon and Schuster, 2021).

their families and communities. Here, health and care become increasingly indivisible, and issues of personal trust and autonomy reign supreme.

There is a further relevant perspective about such records, running parallel to these historical and anthropological ones, concerning holism in science and shifting emphasis onto the whole as greater than the sum of its parts. In his 1953 BBC Reith Lectures, *Science and the Common Understanding*, the physicist Robert Oppenheimer (1904–67), who led the wartime Manhattan Project, discussed what he termed the 'malignant ends' arising from a systematic belief in the idea of total knowledge, where all truth is one truth, all potential can exist as actual, all community as one community, all experience compatible with all other.[8] He drew on the idea of complementarity of the particle and wave descriptions in quantum theory, showing there how richer understanding comes from holding these two seemingly incompatible ideas in mind at the same time, in order to 'get things right'. He extended this idea into the quest for understanding of the complexity of wider human knowledge and society.

In the concluding chapter, he writes:

> If we err today–and I think we do–it is in expecting too much of knowledge from the individual and too much of synthesis from the community. We tend to think of these communities, no less than of the larger brotherhood of man, as made up of individuals, as composed of them as an atom is of its ingredients. We think similarly of general laws and broad ideas as made up of the instances which illustrate them, and from an observation of which we may have learned them. Yet this is not the whole. The individual event, the act, goes far beyond the general law. It is a sort of intersection of many generalities, harmonizing them in one instance as they cannot be harmonized in general.[9]

This echoes with the nature of clinical practice in its marrying of knowledge about patients in general with care of the individual, and the challenge faced in capturing this reality faithfully and usefully in computer software. In the light of the intrinsic limitations of what we, as humans, know and can know, Oppenheimer goes on to make a case for open access to knowledge, describing it as providing 'unlocked doors and signs of welcome, [...] a mark of a freedom as fundamental as any'.[10] He quotes Bishop Thomas Sprat (1635–1713), writing in the 1680s about the scientific purposes of the newly established Royal Society, and talking there about the central importance

8 J. R. Oppenheimer, *Science and the Common Understanding* (Oxford: Oxford University Press, 1954).
9 Ibid., p. 103.
10 Ibid., p. 105.

of diversity and the joining of different points of view. He describes 'the open society, the unrestricted access to knowledge, the unplanned and uninhibited association of men for its furtherance' as 'what may make a vast, complex, ever growing, ever-changing, ever more specialized and expert technological world nevertheless a world of human community'.[11] In discussing how we should seek to accommodate and learn from incompatibilities and diversities he says that achieving balance of these is both a required goal and a process that defines who we are. The quest for balance is necessary to make progress and, at the same time, it is a process that defines what we should aim for–a connection between the balance we seek and how we seek it–a feedback between goals and methods, and between means and ends.

Once again, this echoes our struggles to deploy the computer for the benefit of health care in the Information Age, and the task we face in finding balance, continuity and governance of health care services for the future Information Society.

This seems an appropriate moment to emphasize complementarity more widely. Oppenheimer used complementarity of particle-wave theory as his example. James Clerk Maxwell (1831–79) wove together experiment and theory of electric charge and current, and magnetic pole and field, in his theory of electromagnetism. Much of what had been separate–motor and dynamo action–became one. Complementarities, sometimes elusive ones, pervade this book–knowledge and experience, observation and measurement, information and life, and health and social care. Health and social care as 'healthocarism'–a shame that that sounds so awful! The binary logic of truth and falsehood, and yes and no decisions, has been fundamental to how information systems function and how they broker the complementarities of our understandings of, and feelings about, the world.

I introduce here another trail-blazing series of Reith Lectures, also near the beginning of my songline. These were the very first Reith Lectures, delivered by the mathematician, philosopher and social activist, Bertrand Russell (1872–1970) in 1948–49. The two series, Oppenheimer's and Russell's, resonate strongly today, seventy-five years later, with where we find ourselves in the transition from Information Age to Information Society, and with the choices that we face in how we marry information technology with both individual and population health care.

Russell's title was *Authority and the Individual*, and he covered the topic under headings of social cohesion, human nature, government, individuality, conflict, control, initiative and ethics–all seen through contrasting individual

11 Ibid., p. 106.

and societal perspectives and motivations.[12] Russell was, as ever, incisive (if not always practical!) in his judgements:

> Broadly speaking, we have distinguished two main purposes of social activities: on the one hand, security and justice require centralized governmental control, which must extend to the creation of a world government if it is to be effective. Progress, on the contrary, requires the utmost scope for personal initiative that is compatible with social order.
>
> The method of securing as much as possible of both these aims is *devolution*. The world government must leave national governments free in everything not involved in the prevention of war; national governments, in their turn, must leave as much scope as possible to local authorities.
>
> [...] People do not always remember that politics, economics, and social organization generally, belong in the realm of means, not ends. Our political and social thinking is prone to what may be called the 'administrator's fallacy', by which I mean the habit of looking upon the society as a systematic whole, of a sort that is thought good if it is pleasant to contemplate as a model of order, a planned organism with parts neatly dove-tailed into each other. Society does not, or at least should not, exist to satisfy an external survey, but to bring a good life to the individuals who compose it. It is in the individuals, not in the whole, that ultimate value is to be sought. A good society is a means to a good life for those who compose it, not something having a separate kind of excellence on its own account.[13]

Information systems bring these same issues of individual autonomy and social cohesion, of global order and local devolution, of personal ethics and national and international law, under a new spotlight. They reveal and challenge us with complex technical, organizational and clinical issues, for which we must seek new balance, continuity and governance of care.

How do these diverse perspectives of Tett, as anthropologist, Oppenheimer, as scientist, and Russell, as philosopher and social reformer, connect with the world unfolding in the Information Age? What light do they throw on the human, scientific and ethically-challenging kaleidoscopic pattern of connections of the computer with the health care of individuals, communities, and societies, locally, nationally, and globally? Where do issues of balance, continuity and governance of health care services lie within these wider contexts of the individual and society?

12 B. Russell, *Authority and the Individual: The Reith Lectures for 1948–9* (London: Allen and Unwin, 1949).

13 Ibid., pp. 107–08 and 116.

One key message that recurs is that we must work practically at ground level, and that this process will both define and reflect who we are. First, we must look at the connections of information with health care.

Information and Health Care–A History of Connections

Narratives of life and death have found expression in beliefs, cultures and practices of society, and their clashes, from ancient and classical times, East and West. They are pieced together from documentary and archaeological record and interpreted by historians. They are preserved, supplemented with new discoveries and perspectives, studied, reshaped and passed down through recorded history. Such record is captivatingly present in Edward Gibbon's (1737–94) *magnum opus* history of the Roman Empire.[14]

In classical times, failing health, accident and disability were perceived as afflictions from the gods. They were mitigated by mystical and religious beliefs and practices, and sacrificial offerings. A systematic approach to health slowly gained sway, as recorded in the writings attributed to Hippocrates and Galen (*c.* 130 CE–210 CE). Accounts emerged of the carefully observed progression of ill health and interventions enacted, with experiences of bodily functions and correction of dysfunctions crystallizing as ideas of disease. Such concepts of the nature of health and illness evolved, finding expression in mythology, philosophy, arts and science. Over time, they were refined and gained wider explanatory context from later experience, new ways of thinking and growing bodies of knowledge. Medicine is a human invention. It started to emerge, in record, practice and discipline, in ancient and classical times, as recently pieced together with scholarly authority by the historian, Robin Lane Fox, in his book, *The Invention of Medicine*, which centres on the story of Hippocrates and his *Epidemics*.[15]

Philosophy, mathematics, logic and science evolved in sequence and in parallel. Measurements of space, weight and time, and reasoning with these, advanced for purposes of agriculture, commerce, construction and navigation. Medicine, ever a matter of life and death, stayed close to craft and religion, guarded by the priesthoods of successive eras. Folklore prevailed alongside belief and law of church and land. The idea of the body as a homeostatic and conscious organism dawned slowly, engaging philosophy,

14 E. Gibbon, *The History of the Decline and Fall of the Roman Empire* (London: Strahan and Cadell, 1788).

15 R. Lane Fox, *The Invention of Medicine: From Homer to Hippocrates* (London: Penguin Books, 2020).

mathematics and science in lengthy, earnest discourse and contention. Until the twentieth century, the interaction of measurement and science with the practice of medicine was mainly treated as irrelevant, an unwelcome intrusion. In the early stages of my songline, information technology was treated with much the same brand of ridicule, amusement and professional disdain in life science and medicine, as that afforded to the thermometer and stethoscope in their respective infancies.

And alongside all this, has evolved the story of information, as encompassed within the scope of this book. The story starts from earliest times, with human knowledge and the quest to classify books and documents and organize libraries. Over many centuries, religion, philosophy, logic and mathematics traded arguments about knowledge and its description in language. The terminology of this discourse evolved, as we sought to communicate within and among different disciplines and articulate and clarify differing positions and perspectives. This has often led to a restrictive appropriation of the use of words, to mean different things within diverse disciplines and contexts.

Models in mathematical form were used as expressions of the phenomena being measured or reasoned with. This enabled the rules of mathematics to be applied in abstract analysis, enabling the discovery of new knowledge. Formal logic evolved. Mathematics gave birth to theoretical foundations of computation and computer science. With the advent of the computer, mathematical models extended to more complex and comprehensive representations and reasoning. These mapped the observed and measured reality, expressed in words and numbers, to one expressed in the language of computation.

Information technology translated the world of knowledge, measurement and mathematical models to the world of the computer. Measurement technologies advanced and became ever more central engines of scientific advance. What was observed and measured, captured and reasoned with, as narrative and number, and analyzed with mathematics, extended into a world of codes and symbols. The computer focused first on calculation with numbers and then on processing of all manner of these data, captured and communicated from sensors and keyboards, stored in and accessed from databases, modelled and analyzed with program algorithms. Multiple descriptions of reality and its appearances lifted off and started their climb into and beyond the data stratosphere, into a universe of data and 'dataism'.

For example, consider the evolution of weather forecasting (a story of great success, from a very different world than health care).[16] From the feel

16 I have used many wide-ranging stories and examples throughout the book, to give context and perspective to what happened within health care in the Information

of seaweed hung on a door peg, a moistened finger in the air and observation of clouds; to weather stations on land and at sea, collecting and charting temperature, humidity, pressure and airflow; to the grouping and drawing together of these separate sets of data, by eye and mathematical fitting of curves, into contour maps used to display and reason about weather patterns; to mathematical models of the physics of the atmosphere, ever more granular and widely distributed sensors and systems of measurement, computer models and computations. Prediction of the trend and variability of weather was progressively tamed within newly discovered bounds of chaos and complexity theory. All rather a long way from useful models of biological systems, and their intrinsic and contextual variability. What works for the weather system cannot necessarily be expected to perform equivalently, and provide useful insight, for the systems of biology, medicine and health care.

Measurement devices and models are tools of science, designed and built by scientists and engineers of their times–some as trained professionals and others as gifted artisans. With arrival of the computer, engineering entered a new era of information engineering, underpinned by at first pragmatic, and then more principled, theoretical models of computation and data. Software tools evolved to support design and development of information systems, to manage ever-expanding amounts and complexity of data and ever-more powerful programs to process and analyze them. The rise of telecommunications engineering gave impetus to this advance, focused initially on electrical signals and their accurate transmission from a source device, through wires and junctions, to a destination. These systems evolved into networks of digitized information flow across the world, standardized progressively into a World Wide Web.

The idea of information as a science of order gained ground in the eighteenth century, from the thermodynamics of gases and steam engines

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Age and what is to come. Readers reviewing and advising me about earlier drafts of the book sometimes found them to be tangential and distracting from its core themes, and in part they are. They cover topics that have connected with and assisted me in making sense of experience accumulated along my personal songline. I have removed or abbreviated several of them. In real life, songlines do, though, tend to meander off track! Herodotus's multi-volume *Histories* is renowned for heading off track into 'rabbit holes' of story and anecdote, so I feel in good company! The writing of history and the creation of the future are both acts of imagination. I hope my storytelling is suitably and usefully imaginative! I have sought to retain the predominant flavour of an eyewitness account in the book and avoid *post hoc* rationalizations that might appear as a pretence that there was always a clear pathway ahead. When including such 'tangential' examples, I do, though, seek to show their relevance for illustration of the wide-ranging health care and information technology themes of the book.

and the physical concept of entropy. The idea of information as a science of signal gained ground from mid-twentieth-century theoretical analysis of the digitization and accurate transmission of electrical signals in telecommunications networks. The connection of these ideas with biology permeated scientific study of the nervous system and the propagation of the nerve action potential, and growing interest in the special nature of living systems that enabled them to sustain order and procreate, in apparent contradiction with known physical law. 'What is life?' and 'Why is life as it is?' became interesting questions connecting the physical and biological sciences. Over the ensuing decades, these ideas enmeshed with the elucidation of the mechanisms of cellular biology, their basis in genomics and bioenergetics, and the struggle to capture, organize and analyze the scale and complexity of data unfolding in these sciences. Information became a topic of central scientific interest, bridging computer science with life science and medicine. And with mathematics, physics and chemistry, as well, but more on that later!

The impact of evolving information technology on life science was closely paralleled in the science and engineering of clinical measurement and the diagnosis, treatment, monitoring, description, codification and classification of diseases and treatments. It spread more widely into the monitoring and analysis of the health and wellbeing of populations. The computer rapidly became a tool for the management of health care services. This paralleled its emerging role in commerce and industry, as a tool for the control of machinery and technical infrastructure, and the transaction and management of businesses. These innovations brought medicine towards a summit of connections of science with what was termed 'Industrial Age medicine' and its specialisms. Eric Topol characterized this as 'Shallow Medicine'![17]

And where we now stand, the computer has opened new frontiers of knowledge and posed new challenges for how we create, reason with and use that knowledge. It has transformed opportunities for how we connect with and depend on others in society and what we make and do for ourselves. However, all along, advances in capability to identify, prevent and combat disease have played out on a checkered and inequitable landscape of need for and provision of health care services. Balance, continuity and governance of services have proven increasingly difficult to afford and sustain. There is thus an increasingly pressing case for a coherent programme for reform, addressing fundamental issues of equity, quality and sustainability of health care systems and services, and caring relationships among citizens,

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

patients and professionals. Achieving this will require far greater coherence of supporting information systems than is presently in play.

We are learning experimentally, both excitingly and painfully, how the computer can assist us in the ways we create and share knowledge–how we can deploy it to help us apply and sustain the new insights and strengths it brings, while coping with and putting right the weaknesses and limitations it exposes and amplifies. Furthermore, as citizens and professionals, we must also consider the necessity of adapting our own roles, expectations and behaviours in this emerging world of the Information Society.

For from an economic perspective, we are increasingly challenged to interpret global expenditure estimated at eight trillion dollars each year on health services, and rising now towards four hundred and fifty billion dollars on information technology, with key policy priorities established half a century ago still remaining unmet. How should we respond to further estimations suggesting that our failure to get a sound grip on health care data has led to hundreds of billions of dollars of unnecessary additional annual cost, in repetitive, uncoordinated and ever-more expensive practices? And from a policy perspective, why have governments clutched repeatedly at empty promises, when investing in information technology for health care?

Information policy, more essential than ever to enable services to cope, has meandered wastefully through a landscape where remediable poor health of citizens persists, and continuity of health care services has become fragmented. The industrial age of medicine appears disconnected from the social determinants of health and wellbeing. The five giant evils of society described by William Beveridge (1879–1963) in 1942–want, disease, ignorance, squalor and idleness–were revisited in Michael Marmot's landmark reports of 2010 and 2020,[18] which documented the social determinants of health arising from inequalities and inequities of health and social care provision.[19]

The multiple dimensions of new technology and social change, that rose to a crescendo in the second half of the twentieth century, transformed society, shaking the foundations of education and professionalism, management and governance, and experience of health care services by both patients and professionals. They transformed norms and expectations.

18 M. Marmot, *Fair Society, Healthy Lives: The Marmot Review: Strategic Review of Health Inequalities in England Post-2010* (London: Marmot Review, 2010); M. Marmot, 'Health Equity in England: The Marmot Review 10 Years On', BMJ, 368 (2020), m693, https://doi.org/10.1136/bmj.m693

19 My childhood experience in a children's home, and later work in the voluntary sector and social housing movement, connected me closely with this reality. Marmot was an illustrious colleague as Head of the Department of Epidemiology at University College London (UCL), in my time as a Head of Department there.

The struggle to find balance of individual patient care and management of services for populations of patients, and the need for appropriate experimentation with the rapidly evolving, but serially immature, new technologies of information, were overridden by inappropriate, premature and widescale adoption. This was trumpeted and expected to perform, and depended upon to sprint before it could crawl, let alone walk. Giga-systems of information technology are not good at supporting incremental change, when they innovate inappropriately and disrupt without benefit, at giga-scale. They then create unaffordable waste and confusion, ultimately leading to destabilization and demotivation.

There have been many success stories, as well! Information technology in support of health care services has advanced spectacularly in its exploitation within the science and engineering of clinical measurement, treatment and pharmacy. But in the management of services, it has advanced in unfortunate ways. Central policy for health care information systems in the United Kingdom's National Health Service (NHS) proceeded in roughly quinquennial, electoral limit cycles of local delegation and central imposition, with little consistent and sustained focus on the need and capacity to experiment, learn and adapt. In these anarchic episodes, large monetary transactions between buyers and sellers equilibrated unhealthily with opportunism among those who sought to sell, consult and profit. Those who bought, ill-advisedly, and had to live with the consequences, lost out. Those who talked, wrote and consulted at a distance, came and went. Many who stuck with the task, on the ground, and sought to create a better future, by coping and improving, also paid a price. It is important to remember and learn from this period. As an eyewitness account of the times–and the people who lived through and experienced them–this book tells good and bad stories.

In that chaotic period, the adoption of information technology often proved a succession of Faustian bargains. Immature and rapidly-obsolete installed technology and methodologies interacted with distractions, confabulations and doom-mongering narratives surrounding the arrival of new technological waves. Serially unsuccessful attempts at imposing 'big idea', top-down innovations and reorganizations of services compounded the inevitable uncertainties associated with transitioning into the Information Age. They produced a destabilizing effect through the assertion of pretended knowledge and ability to predict and manage, while neglecting the greater imperative to cope and learn.

Information technology widened scientific vision to the extremes of the ultra-large and ultra-small. Humans tend to think big, but solutions to intractably complex big problems may sometimes only come, more simply, when the method is focused, more pragmatically, on the small–on the little

and incremental things that count. Expected largescale cost-benefits were not often achieved, and the costs and disruptions caused to services were excessive and severe. The resulting legacy of incompatible and progressively obsolete systems, and the data they martialled, made the necessary, but lacking, standardization ever more difficult to achieve.

Full circle, the revolution of the Internet and the refinement of tools and methods of information engineering have brought more rigorous and resilient technologies. These advancements are leading us into an era when information will become a utility, rising as a phoenix from a wide-ranging and battle-scarred landscape of accumulated obsolescence. Information viewed as a service, not a technology, that can be depended upon; that becomes a burden in daily life principally due to its *absence*, rather than to its *presence*. This vision emphasizes the importance of a dependable and incrementally sustainable flow of information, resembling a clean and sufficient water supply.

To achieve this emerging vision requires that we take a step back, to reimagine and reform health care information as a continuously evolving, citizen-centred utility and make new connections by looking beyond what currently is, under the bonnet, a piecemeal and fragmented landscape of information systems. Of course, as with the story of advice given to the motorist seeking directions on how to get to Dublin, it is not helpful to be told that one would have been better off not to start from here! We must, of course, start from here, and the key question is how to create a tractable and beneficial way forward, in the face of the combinations of undue trust and distrust that prevail in situations and times of transition and uncertainty. The way forward must cope with this challenge in all its dimensions, and not trample over or exacerbate it. It must start from small beginnings with things that can be achieved, envisioned within a practical framework that can be extended, adapted and generalized, as requirements naturally evolve. It must engender trust by delivering value at an affordable cost and with acceptable burden on current health care services, that will, necessarily, be adapting and evolving along the way. And it must build new environments and communities to create, sustain, operate, govern and own what is needed.

The challenge is huge–we may note how influential contemporary writers have viewed this scene. In his *Homo Deus: A Brief History of Tomorrow* (itself a good deal longer than Stephen Hawking's (1942–2018) *Brief History of Time*!),[20] Yuval Noah Harari divided human history into three

20 S. Hawking, *A Brief History of Time: From Big Bang to Black Holes* (London: Random House, 2009). Remarkably, time can now be measured with a strontium atomic

phases–conquering, giving meaning to and losing control of the world. The foreboding of the final chapter is captured in its title, 'Data Religion':

> The world is changing faster than ever before, and we are flooded by impossible amounts of data, of ideas, of promises and of threats. Humans relinquish authority to the free market, to crowd wisdom and to external algorithms partly because they cannot deal with the deluge of data. In the past, censorship worked by blocking the flow of information. In the 21st century, censorship works by flooding people with irrelevant information.[21]

His sense of loss of control is mirrored in the Guardian newspaper this week, as I write, in an interview with the novelist Kazuo Ishiguro.[22] This piece accompanied the publication of his latest short novel, *Klara and the Sun*, dreaming about a world of artificial intelligence and artificial friends, which I immediately read.[23] I love it that he says his novels, even this quite short work, typically take five years of deep contemplation and working out. The academic world has stretched itself rather too far, in seeking to entrain its outputs to Internet time!

Reflecting similar concern about loss of control, in February 2023 the fiction writer, Ray Nayler (author of the speculative novel *The Mountain in the Sea*), urged new legislative focus that is directed away from predicting the near-future for technology, to one imagining the worlds that emerge as a result. He imagines:

> 'Parliaments of the Future'–groups of technologists, social scientists, economists, legislators and perhaps even writers–who should game out the effect of emerging technological developments and [...] prepare framework legislation ready to ensure better protection of human and consumer rights, as well as civic freedoms. [...] It isn't that governments aren't trying to predict the future–they are. It is that these predictions aren't linked back to creating better legislation, lack transparency, and are over-reliant on the false promises of quantitative data and artificial

clock to a precision equivalent to less than one second in the age of the universe, but yet the nature of time remains a mystery!

21 Y. N. Harari, *Homo Deus: A Brief History of Tomorrow* (London: Random House, 2016), p. 396.

22 L. Allardice, 'Kazuo Ishiguro: AI, Gene-editing, Big Data... I Worry We Are Not in Control of These Things Anymore', *The Guardian* (20 February 2021) https://www.theguardian.com/books/2021/feb/20/kazuo-ishiguro-klara-and-the-sun-interview?CMP=Share_iOSApp_Other

23 K. Ishiguro, *Klara and the Sun* (New York: Knopf, 2021).

> intelligence. The future can't be 'solved for'. It isn't a mathematics problem. Predicting the impacts of change demands human creativity.[24]

In this spirit, Part Three (Vol. 2) of the book is couched in imaginative terms, thinking ahead to values, principles, scope, methods, and governance for creating and sustaining care information as a public domain utility.

An 80:20 Landscape View–The Structure of the Book

The storyline of the book traverses an extensive landscape along a lengthy personal songline, experienced during a uniquely formative era of both information technology and health care. Organizing and communicating such multi-dimensional subject matter is challenging. And as Erwin Schrödinger (1887–1961) surmised about his book, *What Is Life?*, perhaps foolishly so. The landscape surveyed is multidisciplinary, multiprofessional, multisectoral and multinational. The various stories and storytellers come from many times, places and walks of life. The conceptual and practical domains encompassed are, in themselves, huge, and impossible to cover in detail.

Thus, the book is what might potentially have been structured as several different books, directed at different audiences. Given the publishers' policy of making each chapter separately downloadable, and as readable as possible as a free-standing piece of writing, it might also be thought of as ten-and-a-half short books. This also acknowledges that few may wish, or find it possible or useful, to connect in both breadth and depth, throughout. A specialist may not find adequate detail of what interests them. A generalist may not find adequate coverage of all that concerns them. The material and stories the book brings together do, though, cover and connect through one personal career songline, and that has seemed a good reason to try to bring it all together in a single work.

I have sought to draw material from the many different landscapes that I have traversed, into an authentic, interesting and useful whole. My purpose has been directed towards showing the timeline and nature of the connections and disconnections that have been in play, and the impact they have had, and less towards encapsulating and grouping the detail according to what have become many, and increasingly fragmented, areas of health care endeavour. It is an 80:20 landscape view, which aims to cover key features of the wider scene, while acknowledging that as such it cannot

24 R. Nayler, 'Parliaments of the Future', *New Scientist*, 257.3427 (2023), 27.

offer a comprehensive or precisely definitive account. I therefore provide pointers to where greater detail can be found.

The connections and interrelationships of people, teams and ideas are a central feature of this history and my knowledge of them is heavily biased to the UK and its universities and health care services, and their related organizations in the public, private and voluntary sectors. Much of the UK landscape is recognizable elsewhere in the world, in similar form, and much of its domestic scene has played out alongside stories from other countries, internationally.

As ever, enduring features are remembered, celebrated and mythologized. But many failed or defeated endeavours, and successes that became obsolete (or otherwise disappeared out of sight), were also worthy of their place in the book. Many important stories will inevitably be absent, reflecting my personal lack of knowledge and awareness of them. The rapid evolution of new and incompatible technologies of the Information Age has swept over and buried lifetimes of effort, as did the transformation of society in the Industrial Revolution.

The book is structured to connect with the communities of many and disparate domains of academic discipline and professional practice, in context of their significance and enduring contribution to health care, and the inevitable imperative that they adapt and change over times ahead. It achieves this by encompassing perspectives of history before the computer, the experience of transition through the present-day Information Age and the joining together of contributions towards balance, continuity and governance of health care for the Information Society of tomorrow. As such, it addresses a multi-faceted and still evolving audience.

The book is also drawn together, in parallel, along the personal songline of its author, who has been closely involved in many of these communities since the advent of the computer. It uses extensive quotations from the stories of people encountered along the way, both in person and through their roles and writings. It lets them speak for themselves–it does not speak for them. As such, it is an eyewitness history of those times, and the book seeks to steer a straight course in describing many differently directed paths that have been encountered, experienced and navigated over time. In *The Art of War*–a text now much-used text in prestigious Master of Business Administration (MBA) courses on leadership–Sun Tzu (*c.* 544 BCE–496 BCE) wrote that 'Victory belongs to the man/ Who can master/ The stratagem of/ The crooked/ And the straight'.[25] Whether or not this songline has proved a victorious campaign (not really!), the book describes

25 J. Minford, trans., *Sun Tzu: The Art of War* (London: Penguin Classics, 2008), p. 43.

a personal journey through a landscape and, like walks in the countryside, interesting and fruitful experiences often lie tangentially, off the beaten track. Countryside walks meander and so does the storyline of the book, seeking authenticity and avoidance of *post hoc* rationalization. At the end of each chapter, I have reflected, in parenthesis, on general issues raised and challenges faced in introducing information technology to the domain on which the chapter has focused.

In terms of its intention, the book seeks to contribute towards a shared goal for the reformulation of health care, and a common ground of discipline and practice around which to achieve it. Coherent and trusted information will be central to this common ground. Throughout its pages, the book:

- asserts the importance of health care service governance and resource management that is maximally devolved towards the citizen;
- asserts the importance of knowledge that is openly shared, to create and sustain the common ground;
- asserts the importance of standardization of information systems as coordinated and regulated components of this common ground, centred on the shared requirements of the devolved communities of health care practice and connecting nationally and internationally with the disciplines and professions of health care that are needed to frame and address them;
- doubts that this quest can be expressed in the language of right and wrong answers, but rather through experiment and pursuit of practical goals, where complementary approaches can sometimes coexist to support and benefit shared endeavours.

Informatics must and will evolve as a central discipline of the communities, disciplines and professions of health care. It must grow in the context of the changing needs of both users and providers of services, through education, research and development, peer review and governance of services delivered, and through relationships with supporting businesses that provide information systems and services.

With all these considerations in mind, the structure of the book is a compromise that will, inevitably, not please or interest all. It is principally a songline and has been through three advancing drafts, with extensive peer review, both personal to the author, by numerous colleagues, and independently for the publisher, in reaching this published version. It is structured in three parts. Part One (Vol. 1) concerns what Alfred North Whitehead (1861–1947) called an adventure of ideas, this one being that which has powered the rise of computer science and technology and the

advance of life science and medicine as they moved into and through the Information Age. Part Two (Vol. 2) is about the ensuing transition of health care-related disciplines, professions and services, with its share of what Whitehead referred to as the anarchic pattern of such major transitions. Part Three (Vol. 2) imagines and sets out a programme for reform, drawing on Whitehead's characterization of how adventures of ideas guide transitions through anarchic times, towards a new order. This programme focuses on the creation of a coherent, citizen-centred care information utility, to support integrated health care systems and services, alongside citizen engagement in meeting their personal health care needs and those of people they care for.

A key interest of Part Three is in the changing nature of knowledge sharing and collaboration within and between public and private sectors domains, as increasingly evidenced in the growing influence of initiatives such as the Creative Commons and community-interest endeavours. In keeping with this philosophy, the book has been designed for open access electronic publication as well as print-on-demand hard copy. Each chapter seeks, as far as possible, to be a freestanding and self-contained component, that can be downloaded and read in that way, linked together in the book as a set of stories and reflections on connected themes. This requires that some material about people and their ideas and endeavours be repeated, to maintain continuity between chapters. Introductory sign-posting boxes seek to link and align the component chapters into a coherent whole. In keeping with the aim for self-contained chapters, page footnotes rather than book endnotes have been preferred, albeit that this inevitably sometimes disrupts the chapter flow. Some of the footnotes are used to anchor the themes being discussed in the chapter, to people and events featuring along my songline.

In aiming for an original and hopefully appealing and illuminating way to write about this wide-ranging material, which is both orderly and authentic, it seemed a good idea to start by recognizing the numerous connotations of the term information. This was the approach I took in an invited talk I gave at the Royal Society of Medicine (RSM) in London in 1991. I was asked to reflect there on a then much-discussed new phenomenon, that of 'information explosion', under the title: 'Coming to Terms with the Information Explosion in Clinical Medicine–Can Information Technology Help?' The audience was populated with illustrious professors of medicine of the era, some trading on reputation as the traditional rottweiler, but usually, in my experience, with noisy bark much worse than bite, and warm and generous people–assuming, of course, that one had prepared well!

It was risky–I was a marginal figure. A mathematician and physicist with an engineering PhD and experience of working in industry, subsequently immersed in computer science, physiology and medical physics research

and development, and later (due to the good fortune of having had a brave and forward-looking academic supervisor and subsequent sponsor), on the academic staff of the Department of Medicine of a medical school dating back now nine hundred years. I was an outsider in all these different but connected worlds and had ended up a professor in a central position at their intersection. Quite an unusual case, and imaginative medics are curious about those!

Although somewhat daunting in prospect, it turned out to be a satisfying and productive encounter for me, leading to invitations to attend and speak at events around the world. I had prepared by digging for two months into the literatures of physics, life science, medicine, engineering and computer science, for their narratives about information explosion. The unpolished and now rather dated notes I compiled for this talk are lodged as Appendix I in the archive of additional resources associated with the book, accessible from the Open Book Publishers' website listing for this book.[26]

In my research, I read through learned society perspectives cataloguing the growth of publications over time, and through critical reviews of the literatures of different subject domains, mined for their new content or lack thereof, and showing accelerating rise on both counts. It was amusing to discover that accelerating frequency with which the term 'information explosion' cropped up in papers catalogued in the Index Medicus over the preceding decade. I am sure there was not enough data to indicate that it was an exponential rise, and do not wish to offend any mathematician readers by describing it as such! It did, though, give me a good joke in showing a slide, albeit based on small numbers, suggesting that the information explosion was itself exploding!

Many proposals for reform were being suggested in this literature, including restricting an individual's published output to fifty publications during a career! Seeing some people's names over the years, attached to hundreds of strikingly similar publications (many of which have been long forgotten and seldom read in detail beyond a limited audience), such a restriction might arguably have helped! Albert Einstein (1879–1955) and Richard Feynman (1918–88) set an opposite example, nowadays far too risky, of publishing as infrequently as possible! (Theirs were brains and personalities that could get away with anything, of course.)

In the talk, I went on to discuss how information technology was supplementing and enriching the tools and methods of science, through mathematical modelling, signal processing and expert systems–now the domain of artificial intelligence. I described how, within the context of

26 Available at https://www.openbookpublishers.com/books/10.11647/obp.0335#resources

weather forecasting, a pattern of increasing accuracy and range of forecasts had been demonstrated, as measurement and computational models advanced synergistically and in parallel. I mentioned some areas where similar efforts to model systems and use them predictively were being made in life science and medicine. I identified some reasons why this was an especially uphill struggle in the diffuse, variable and highly context-dependent world of medicine and health care practice, and its related data.

Having commented on common usage of the term information and realizing that I might need to defend my interloper credentials a bit, I proceeded to talk about information and order as concepts fundamental to physics, emerging as the discipline came gradually to terms with the profound nature of the second law of thermodynamics and the elusive concept of entropy. How and why do physical systems move from states of order into states of disorder? How can description of these states, and transitions between them, be captured within an overarching theory. How do living systems survive for a while, and procreate, sustaining order and defying decline into disorder?

This is an interesting topic, yet arguably still rather esoteric in relation to matters of health care. I explore its relevance to the unfolding story of the book in Part Two. The 1991 RSM talk was not an occasion for discussing further what has sometimes been described as the most important equation in the world of science ($S=k\log\Omega$) or indeed the scientist Ludwig Boltzmann (1844–1906) whose grave is inscribed with it–a life sadly and, given this illustrious accolade, poignantly ended by suicide. But from these beginnings have grown new and progressively refined concepts of information, which have arrived, centre-stage, in scientific discourse.

In my presentation, I went on to talk about Claude Shannon (1916–2001) and his seminal work in what became known as information theory, coming to terms with digitization and communication of electrical signals.[27] In providing theoretical foundations of design for reliably error-free electronic communication, he led the way towards the new devices and technological infrastructure of the Information Age, on which the methods of physical and life sciences and medicine now depend. Advances in physics and chemistry of the earlier half century (which had culminated in the discovery of the double helix structure of DNA) combined with the growth of computer science and technology to bring new focus on and development of the bioinformatics-driven discipline of molecular biology.

I moved on next to the challenge faced by librarians in managing their rapidly accumulating collections of books and documents, where they

27 C. E. Shannon and W. Weaver, *The Mathematical Theory of Communication* (Urbana, IL: University of Illinois Press, 1949).

had coined the term 'information science' to describe efforts to tame their classification. I showed examples of the explosion of numbers of publications catalogued in the Index Medicus, in different sub-disciplines, and quoted from review articles of the time concerned about their quality. Cheekily, I reflected that the disorder evidenced might, to a physicist, suggest an era of ignorance explosion, rather than knowledge explosion! I had unearthed reviews suggesting that, in some areas, less than two percent of new papers contained new data or findings, but were, rather, repeating and reworking previous publications.[28]

In contrast, I then discussed information from the practical engineering standpoint of the design and programming of computer systems: the principles of data acquisition, communication, storage, retrieval, processing and display, and the associated hardware and software. In this context the term informatics had come to be used for 'the rational scientific treatment, notably by computer, needed to support knowledge and communications in technical, economic and social domains'. I recalled one of the first lectures on medical informatics that I had attended many years before, at St Thomas's Hospital in London. This was hosted by Walter Holland (1929–2018), the Professor of Epidemiology at that time, who was taking a close interest in information technology, and was delivered by Thomas Lincoln (1929–2016) from the RAND Corporation in California. He showed a slide that stuck in my mind, charting the numbers of clinical investigations, measurements and subclassifications of disease identified in treating patients with pneumonia, before and through the advent of the first antibiotics (sadly, slides he showed there have been lost from my archive). This showed that the number of investigations rose at an increasing rate before, and declined rapidly after, there was an effective treatment for these patients. The overarching message was that the less we know what to do, the more we tend to amass measurements and other information describing and reflecting that incapacity.

I showed a related slide from one of the first international encyclopaedias of medical informatics, edited by my eminent Dutch colleague of that time, Jan van Bemmel, charting the rapid increase in hospital investigations over a ten-year period, set against an unchanging baseline of numbers of hospital admissions. From another, but related perspective, I showed a slide created by my luminary sponsor John Dickinson (1927–2015), Professor of Medicine

28 Translated to 2014, 'a new paper is published every 41 secs. The 2% that is relevant to them would require practitioners to devote 21h per day every day to read it'. Quoted in R. E. Susskind and D. Susskind, *The Future of the Professions: How Technology Will Transform the Work of Human Experts* (Oxford: Oxford University Press, 2015), p. 48.

and Head of Department at St Bartholomew's Hospital (Bart's). This charted the increase in numbers of separately identified causal mechanisms in the regulation of human blood pressure, since discovery of the Cushing reflex a hundred years before (see Figure 1.2). These followed the timeline unravelling the story of essential hypertension, in which John remained a world authority until his death.

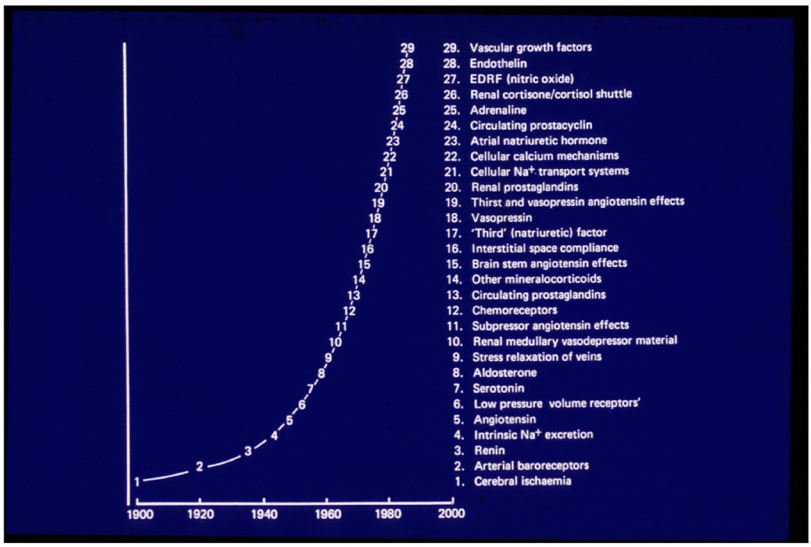

Fig. 1.2 John Dickinson's graph showing the growth of principal factors identified over a century as causative influences in the regulation of blood pressure in the human circulatory system, used in my 1991 Royal Society of Medicine talk. Image created by John Dickinson (*c.* 1990), CC BY-NC.

Turning to the professional issues encountered when dealing with such rapidly extending and ubiquitous sources of information, I showed slides illustrating the difficulties for clinical decision making that arise, the implications for overloaded content in curricula of medical education and the ways of continuing to learn about and access knowledge relevant to everyday practice. I touched on their implications for new relationships of patient and practitioner, governance of services, standardization and effectiveness of information systems and their ease of use. Finally, I suggested the importance of open information architecture, governed in the

public domain. There was a new imperative for harmonizing information across connected health care services, avoiding the cost and dysfunction of data silos. This quest, which interested and absorbed me from then on in my career, was crystallized in the establishment of the Creative Commons organization in 2001.

I have rehearsed the above-described talk in some detail as it has provided an initial template, nearly thirty years later, for thinking about how to organize the chapters of this book. Each chapter covers broad areas of discipline and practice. Each has historical context, contemporary relevance and significant implications for the future. Each has a relationship with the rise of information technology and its applications in health care services. I think of these chapters as stepping-stones along pathways of social and technical transition into and through the Information Age. I have stepped on many of these, along my songline, and the book is a story of how I have connected them. Each chapter theme has featured in my work and experience and shaped my understanding. Whitehead described such pathways as transitions of ideas, of ways of thinking and acting. He cautioned that they can be dangerous and risk undermining the foundations of society.

After this introductory chapter, Part One proceeds with Chapter Two on the theme of knowledge, beginning in ancient and classical times with knowledge thought of as an encyclopaedia–a circle of learning. It is a long chapter–arguably itself the content of a short book–exploring the development of ideas that underpin and provide context to health care of the Information Age. It connects perspectives from philosophy, logic and language with those of mathematics, natural science and computer science of the modern era. It traces the librarian's dilemma over the ages–where to place books and documents within their collections, and how to search them in pursuit of learning. The chapter then moves on to language as an expression of knowledge, and the many forms of such expression–spoken, written, artistic, mathematical and computational–and how they connect and contrast in different ways of reasoning with knowledge, and in their precision of expression. It touches on mathematical and computational disciplines that grew from the development of formal logic and the reformulation of the foundations of mathematics, in their transition from the nineteenth into the twentieth century, and now into the twenty-first-century world of machines and artificial intelligence. Moving on to the bemusing and complex world of medical language and terminology, the chapter illustrates the difficulties that have been faced in moving *corpora* of descriptive terminologies from pragmatic organizations into computable forms. Some notable pioneering initiatives and participants in these endeavours are profiled along the way.

Chapter Three (Vol. 1) is about observation and measurement and their connections with number, symbol, code, logic and ethics, traversing, over time, from cubits to bits and qubits. It starts from a historical perspective and links to the present-day scene in clinical measurement, exploring connections with science of the past century and information technology of the past half century. This leads to a discussion of data and records. The chapter considers both large- and small-scale devices. It links from the start of my songline in the 1950s, offering stories of people, devices and systems that underpin measurements in medicine and life science today. It traverses between worlds, where the computational capacity of yesterday's largest computer is now exceeded by devices built into a wristwatch or handheld devices. These devices monitor, communicate and advise about bodily systems and signs, and they exceed the computational power that shepherded the first voyage of humankind onto and back from the moon in 1969. This week, as I write, a high-definition video camera and computer system are memorializing and transmitting to us the automated arrival of a Mars lander on the Red Planet.

Chapter Four (Vol. 1) is about models as representations of reality. Models of different kinds–physical, mathematical and computational–and their use in different domains and for different purposes. Modelling and simulation as a third branch of science, alongside theory and experiment, enabling and supporting discovery, insight, understanding, reasoning, prediction and action. In the examples described, I focus on pioneers I have been taught by or collaborated with: my physics lecturer John Houghton (1931–2020), on weather and climate modelling (to give a perspective from a non-medical domain); my supporters and sponsors Arthur Guyton (1919–2003) and John Dickinson, on modelling of clinical physiology.[29] Further examples are drawn from later work that I have been privileged to see first-hand, as a reviewer of largescale research projects across the European Union: the Virtual Physiological Human project and the modelling and simulation of tumour dynamics (CHIC), led by Norbert Graf, in Germany, and Georgios Stamatakos, in Greece. Exploratory clinical and health care related applications of mathematical models are then introduced, as applied, for example, to analyzing and supporting clinical decisions, tracking and predicting the course of epidemics and guiding patient management.

29 There have been two reminders of John Houghton as I wrote this book. He died from Covid-19 infection in March 2020, and today, on 9 August 2021, as I write this note after listening to the United Nations (UN) global news conference launching the new report of the International Panel on Climate Change (IPCC), it was poignant to hear the report dedicated to his memory. I describe his contribution to climate modelling and leadership of the first UN IPCC report in Chapter Four.

Chapter Five (Vol. 1) focuses on information engineering and the design of information systems. It is often the engineer–positioned at the interface of science and society, between the commissioner and the user of the information system–who shapes and navigates the pathways leading to success or failure. I draw on Samuel Smiles's (1812–1904) 1884 book, *Men of Invention and Industry*, a wonderful account of engineering innovation through the English Industrial Revolution, to draw parallels with innovation in the information revolution of our age.[30] Stories drawn from shipbuilding and steam power illustrate the enduring character of such innovators and the manyfold challenges they face. The connection of steam engines with information engines resonates pleasingly with both science and society! Smiles campaigned with the Chartist movement for government reform, believing that progress would depend more on changing attitudes rather than laws, and on greater empowerment of citizens. This resonates with present day thoughts about the necessary reform and reinvention of health care.

The chapter connects the discussion of models and simulations in Chapter Four, with data models, information models and knowledge models of today, focusing on database and knowledge base systems. It connects varieties and groupings of data that are captured, processed, stored and retrieved, with the devices and systems employed. It considers how these have evolved from the village of my childhood, through school and university days, to my desktop today in the global village and the Cloud of computational resources with which it immediately connects. It highlights how characteristics and limitations of devices and evolving programming paradigms have channelled both theoretical and practical developments and determined their usefulness. It explores standardization of these methods and the transforming infrastructure of the Internet and World Wide Web.

The chapters in the first part of the book follow a common pattern, building from historical context and example and charting their changing scientific, technological and social contexts over time. To introduce Part Two, Chapter Six (Vol. 2) takes a step into another dimension, to consider where information itself, as an idea, now connects within life science and medicine. Information as somewhere between material and measurable entity and immaterial abstraction. The use of the term is now so widespread that it sometimes seems akin to a holy grail–a sought after but unattainable mystical essence of the natural world. The question 'What is Life?' and its connection with the nature of information as a scientific concept, has captivated luminary scientists who have written landmark books on this

30 S. Smiles, *Men of Invention and Industry* (London: Read Books, 2013).

theme. I examine an eclectic selection of such works, written from physics, life science, mathematics, computer science and cognitive neuroscience perspectives.

The anarchy of transition of health care services into and through the Information Age has correlated with the experimental coupling of new science and technology of living systems and health care, with new science and technology of information. The pace of advance in technology has impelled corresponding progress in medical science and health care. New technology leads to new data and new data leads to new technology: for instance, smart watches amassing non-coherent datasets monitoring chronic disease; chronic disease datasets tuning non-coherent and opaque artificial intelligence models for collecting, monitoring and interpreting smart watch data. Apart from signal noise and bias, there might prove to be something akin to self-referential feedback, here–computer models of information feeding as input to measurement, and measurement feeding as input to computer models of information. Feedback systems can be unstable. The health care data ecosystem is, perhaps, inevitably always going to be somewhat messily unstable.

In matters biological and clinical, if one looks for 'dysfunction' one will surely find something. Whether it matters is another matter. Deciding it matters when it truly does not, and vice versa, can matter a lot to all concerned, including those who pay, of course. We must be informed, wise and careful about such matters ('care full', maybe!). That is why we need professional and local people in the same loop, who are able, have time and are willing to empathize and care–how, where and when it matters for patients.

The Whitehead quotation heading Chapter Four warns of the risks incurred by intermixing putative abstract models with the real-world phenomena they depict. One wonders, perhaps provocatively, how far non-coherent information models underpinning policy and management for the Information Age of health care services have exacerbated the costly and burdensome anarchy of transition these services have been subjected to. In this, I am not in any way querying the importance of a coherent data ecosystem to underpin well-evidenced methods for diagnosis, treatment and management of disease. Quite the reverse: I am, rather, emphasizing concern about the harm and costly confusion that can arise from the non-coherence of such data.

Plunging then into the evolving world of health care, Chapter Seven (Vol. 2) goes on a long journey, covering in detail the seventy-five years that have connected it with information technology. Another whole book, perhaps! It highlights the associated transition in methods and organization of services, professions, education and research. It moves from health care

in the local context of village life that I experienced in childhood, to that experienced in global village life today. It introduces Horst Rittel (1930–90) and Melvin Webber's (1920–2006) ideas about the 'wicked problem' of social policymaking, in the context of the difficulties of design, implementation, operation and governance that have been faced in developing and sustaining information systems of the Information Age.

This transition has been described as turning the world of health care upside down, from the Industrial Age to an Information Age.[31] The then editor of the *British Medical Journal*, Richard Smith, addressed this future perspective in a landmark editorial in 1997. He showed a figure comprised of two triangles, one inverted above the other, depicting health care services turned upside down in the Information Age, from the industrial to the personal. In this figure, which I have redrawn for inclusion in the chapter (Figure 7.10), Industrial Age medicine is depicted as centred on the health care service providers, with citizens, as patients, largely dependent on decisions and actions of the professionals looking after them. By contrast, future Information Age medicine is depicted as centred on the patient and their needs and experience, with citizens achieving greater personal autonomy–making informed personal choices, participating in decisions about treatments and implicitly sharing more responsibility for how these turn out.

I have already introduced in this chapter Oppenheimer's Reith Lectures and his lucid reflections on the theme of complementarity. It is a theme that I build on in many places throughout the book. We may more fruitfully see these two perspectives of Smith's editorial as complementary, albeit that they are often positioned as conflicting. They are not half and half, as it were, zero sum games, with clear winners and losers, as the world turned upside down metaphor of the origins and outcome of the English civil war tends to imply.[32] As Oppenheimer emphasized, the whole can be greater than the sum of the complementary halves.

'Upside down' also carries the metaphor of up-down and down-up, a familiar lens through which we examine these matters: we talk of top-down and bottom-up approaches to problems. Any attempt to build a supportive framework or utility of health care information must recognize and accommodate complementary perspectives. This requires articulation

31 The phrase 'world turned upside down' was used by historians to describe changes in English society in the seventeenth century, in the chaotic transition from despotic rule to parliamentary government, through civil war between the armies of Roundheads and Cavaliers.

32 In fact, the geographical distribution of the Roundhead and Cavalier allegiances of that civil war resurfaced in the voting allegiances on Brexit!

of shared vision and the drawing together of complementary threads that contribute to the task of its implementation. I discuss ideas about the leadership for such an endeavour in Chapter Nine (Vol. 2). Health care itself is struggling for a new vision, as is health informatics, yet both continue to approach this struggle predominantly from a top-down perspective. Part Three of this book envisions a care information utility that supports the needs of the future Information Society. It addresses how we can and must learn how to identify and address these needs, by collaborating to imagine and implement this vision collectively, by working from the ground up, while also finding creative and imaginative solutions to the complementary top-down challenges of global standardization and cost-effective and affordable services.

With the arrival of new measurement and computational methods, from genome to population level informatics and machine intelligence, the Information Age has brought health care to another pivotal transition–between the Third and Fourth Industrial Age. This is the prospect of widescale machine learning and artificial intelligence. People who have pioneered key innovations along this pathway are introduced.

Moving on from the fragmented and worryingly unsustainable reality of health care systems today, Part Three of the book envisions a different path ahead; it describes how this path is already, in embryo, being developed in many parts of the world, across languages and jurisdictions, not from the top down but from below. It focuses on the idea of a coherent, person-centred care information utility, co-created by citizens and their supporting professionals, drawn together within collaborating local health care services and centred on care records that deploy computational methods and tooling that are standardized globally and locally customized. The utility would best be governed and shared, and the essentials made freely available, in the public domain. It is envisioned as an evolving common ground of collaborating health care organizations and companies, and the citizen, professional and academic communities that create and sustain it.

Chapter Eight looks at the form this utility might take, as a public domain ecosystem, and the values and principles required for creating and sustaining it. These rest on foundations of openness, sharing, governance and trust–an emphasis reminiscent of the advice given by the Chinese philosopher Confucius (*c.* 551 BCE–479 BCE) to his disciple, Tsze-Kung, on the three essentials for government: food, weapons, and trust. The first to sacrifice *in extremis* is the weapons and the one to hold on to until the end is trust, 'because without trust we cannot stand'.[33] The chapter emphasizes the

33 Analects, 12.7.

organic nature of such a utility, in analogy with the ecosystem of the natural world. It makes a parallel analogy with the monetary ecosystem, discussing the relevance for health care information policy of the lessons drawn by Mervyn King, when writing about the 2007–08 financial crisis.[34] These he attributed to an underlying 'crisis of ideas' reflected in the prevalence of 'hubris' and 'pretence of knowledge'. He called this the 'alchemy' of money. I compare his perspective with a similar alchemy of information.

The chapter charts the framing and implementation of information policy for health care over the past five decades, drawing again on people and stories encountered along my songline. I reflect on the unique character of some great innovators I have known and worked with, who have pioneered and laid foundations for transformational information infrastructure and services for health care, from small-scale and local, to large-scale utilities. They have all, in their different ways, been engineers. It is a tribute to such great clinical, technical and organizational engineers–operating at the interface of science and society–that they have demonstrated how wicked problems can, patiently, and sometimes necessarily impatiently, be tamed and overcome. The chapter then looks at contemporary trends in global village life, health care services, professionalism, education and research. From these, it seeks to envision the culture and principles needed to underpin a future public domain-anchored care information utility, identifying the issues affecting its implementation, sustainability and standardization.

The second half of Chapter Eight, numbered Eight and a Half (Vol. 2), for reasons I explain, is an account of the openEHR movement and, in lesser detail, that of OpenEyes, and how such initiatives originated and are forming as kernel components of future care information utility. These innovations are described to show that an embryonic utility already exists and is growing rapidly in archives of co-produced and shared clinical data models, software products and collaborating health care services and systems, worldwide. These initiatives have grown from the ground up, nucleated in the efforts of small teams of collaborating innovators, working with minimal funding and resources in comparison with the multi-billion, unsustainable sums that have been spent by governments, companies and health care organizations. Heavily funded endeavours that have been substantially funded in mutually non-coherent ways, arguably, conspired (in the word's sense of 'breathing together') to constrain and disrupt much creativity and progress in the domain.

The freely shared openEHR care record platform technology and its methodology are now central to products and services of a rapidly

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

expanding group of partnering companies and organizations in many different countries. The openEHR International community interest company now hosts a worldwide community of some one thousand clinical data modelers, working with common tools to define interoperable care record data structures–now the largest coherently curated, openly and freely shared knowledge base of such models in the world. openEHR has a growing constituency of health care organization adopters and is embodied in international standards for the field. It has been refined experimentally, iteratively and incrementally, and scaled across health economies, in multiple languages, over three decades. It has a growing footprint in the Nordic countries, Germany, Slovenia, Netherlands, Spain, South America, India, Australia, Russia, China, Japan, Italy… and now within the UK NHS, following several decades of fits and starts. It is argued that such a utility, and crucially, the way it is created and sustained, will be central to enabling the trusted and equitable citizen and professional relationships needed to underpin provision and support of citizen- and home-centred (or 'home first', as my colleague Sam Heard has characterized them) health care services in the future. openEHR started quite tentatively for me, as it came at a time of great flux in my life. It spun into a thread that has woven and connected my working life together to this day, now no longer its leader but often still its advisor and mentor.

OpenEyes, the brainchild and creation of my colleague at the Moorfields Eye Hospital in London, Bill Aylward, is an open-source software for eye care records. It has attracted a formidable team of active clinician designers and implementers, led in turn by the formidable polymath clinician, James Morgan, after Bill retired to a life sailing with his wife! Like openEHR, OpenEyes is lifting off, internationally, and today handles the care records for approaching fifty percent of eye care consultations in the UK, including for the whole of Scotland and Wales and some ten NHS Trusts in England. Both openEHR and OpenEyes are now managed by self-governing, self-funding community interest companies, providing access to their now considerable globally accessed and used Internet Protocol (IP), which is protected within not-for-profit organizations and made available under liberal Creative Commons, Apache and General Public Licenses (GPL).

Chapter Nine has been the most difficult to conceptualize. It concerns issues that are perhaps the most consequential to grasp and address–those of coherent and sustained implementation of information systems, at scale, in support of health care. That these remain urgent matters is evidenced by serial failure in tackling them, over decades. The principal motive in writing this book has been to document history and experience and give a future-facing perspective of how now to do better. The chapter is a work in progress, drawing together past, present and future perspectives, akin to a Dreaming

of the Dreamtime. It reflects on core challenges of implementation that are central to successful and scalable reform–from the start, I characterized the three top priorities of openEHR as implementation, implementation, implementation!

The chapter grapples with three essential threads of implementation. The first is about approach and method–that is *how* the care information utility can be created and sustained, connecting communities served with professional and academic work, and public and private enterprise and institutions. It highlights the importance of Creative Commons and operational governance that preserves the non-exclusive relationship of public with private enterprise. The story and cultural significance in the UK of common land, and its appropriation to new private interests through the eighteenth century and the Enclosure Acts, is visited as a parable for intellectual commons in the Information Age. It discusses the harm that restriction of intellectual property does in blocking innovation that tackles wicked problems, which requires connection and cooperation within diverse communities of practice.

In this respect, there are lessons to be drawn for health care from how antitrust concerns in the United States of America (USA) and the European Union (EU) are starting to inform the framing of protections needed to prevent socially harmful and exploitative tech industry monopoly. Big Tech, Big Data and 'Big' everything else are ringing alarm bells of concern. In these ways, the story of information and information systems is starting to connect more closely with the changing culture of national and corporate governance, internationally, and its increasing emphasis on environmental and social governance factors, as captured in the acronym, ESG.

The second thread of implementation is about endeavour, focusing on *who* will do the work of creating and sustaining the utility, and *where*. It considers the implementation endeavours needed and the teams of people who will be required to create and sustain a care information utility. It considers the qualities of environments where they can connect effectively with health care services, in a shared culture of learning by doing. This is about the teamwork needed to imagine, develop, lead and sustain the information systems of tomorrow, iteratively and incrementally. The chapter looks at the different qualities of leadership that pioneering endeavours along my songline have exemplified, and, for fun, ticks them off against the classic, much used text on leadership of Sun Tzu in *The Art of War*.[35] Commitment, insight and alliance are *sine qua non* attributes of communities that confront wicked problems, in combination with the most important

35 Minford, trans., *Sun Tzu*.

of all–staying power. Stubborn people often have extra staying power and thank goodness for all such people that I have been privileged to know, learn from and work with. Such communities are not well led by people who strut too far above them–they are sometimes best led from below, and sometimes most effectively when least visibly. The third thread of implementation is governance, and the chapter considers new requirements that the care information utility will pose.

Chapter Ten (Vol. 2) is a review of where we have reached in the transition to the Information Society of the future. It combines with a Postscript, offered as a preface to new personal songlines that are just starting to unfold, or those in mid-journey. Echoing Bon Jovi, the chapter builds on the theme of being halfway there! Human society defines itself by its values and how it adapts and changes. This is true for individual lives, challenged greatly in chaotic times, and for societies in transition. Wherever we travel as individuals and global villagers in the coming years, the story of health care services, health care systems and the information technology and utility they embody and utilize, will only be half of what determines their usefulness and fruitfulness. I recount, with her permission and approval, aspects of my wife's extraordinary personal struggle through critical illness, over a two-year period. Her survival and recovery, half about health care services she experienced–both good and bad–and half about her personal nature, struggle and resilience. The chapter reflects briefly on James Lovelock's (1919–2022) book, *Novacene*, which he published at age one hundred, as a guide and pattern for human civilization with the advent of hyperintelligent machines, and health care in future society with the advent of artificial intelligence.[36] A stimulating counterpoint is Ian McEwan's imaginative recent novel, *Machines Like Me*, about life lived alongside an extremely futuristic cyborg![37]

In the Postscript, my songline comes full circle and, in the spirit of T. S. Eliot's (1888–1965) *Little Gidding*, looks again at the 'unknown, remembered gate' that I first passed through into this field, some fifty years ago.[38] But with new eyes, having connected a full cycle around Shiyali Ramamrita Ranganathan's (1892–1972) circle of knowledge and completed an encyclopaedic personal circle of learning.

36 J. Lovelock, *Novacene: The Coming Age of Hyperintelligence* (Cambridge, MA: MIT Press, 2019).

37 I. McEwan, *Machines like Me* (Toronto: Knopf Canada, 2019).

38 T. S. Eliot, *Little Gidding* (London: Faber and Faber, 1943).

The following, supplementary materials can be found in the additional resources tab for the website listing of this book:[39]

Appendix I: Royal Society of Medicine Talk Notes, 1991

Appendix II: NHS Acts of Parliament, Policies and Organizations Relating to Information and Information Technology since 1946

Appendix III: Forty Years of Policy and Implementation in the UK NHS

Appendix IV: A Reflection on Health Informatics

Appendix V: A Wider Acknowledgement of Contributions

Appendix VI: Annexes to Chapter Eight and a Half–openEHR Documents of Record:

- Annex I: The Original openEHR Manifesto, 1999
- Annex II: Origins of openEHR
- Annex III: Transcript of Lecture about openEHR for Medinfo 2007, Brisbane
- Annex IV: openEHR History from 2002–18
- Annex V: openEHR Vision and Mission–Co-written with Thomas Beale, 2018

A 2020 Portrait View–People and Ideas

Throughout this book, I draw on material from many other books and reports and combine it with stories of many people and their ideas and contributions. I call this a 2020 portrait view, not just because of the date it was first being compiled and its focus on people, but also to convey a sense of balance. The stories of people relate to meetings and shared endeavours at many times throughout my fifty-year career songline. Some of the books are personal and reflective summations of their diverse authors' expert insights, accumulated and tested over long periods of time.

I have drawn substantially on a personal collection of such books that have influenced me and proved useful in connecting across disciplines,

39 Available at https://www.openbookpublishers.com/books/10.11647/obp.0335#resources

professions, and domains of health care, science and information. They have stood as navigational beacons, akin to the inuksuk signposts used as markers and guides by the Inuit communities of northern Canada. Inuksuks are rock cairns fixed at key and enduring points in the landscape and used as guideposts. For example, some are placed to be visible from afar in the seasonally changing landscape–alternating ice, snow and flood–to navigate on journeys through and along valleys and rivers below. I have a small model of an inuksuk on the shelf above my writing desk. Nowadays, few of us are, or can be, highly original thinkers. Our originality is increasingly expressed in how we use and combine ideas, resources and circumstances, to achieve interesting and useful things. In this quest, we all need our inuksuks. I call these special books, my 'inukbooks'!

An early inukbook was *The Songlines*, by the travel writer, Bruce Chatwin (1940–89); the inspiration for the characterization of my storyline, as recorded in this book.[40] He wrote there of the tradition of storytelling in the Aboriginal culture of central and northern Australia–legend woven around people, landscapes and journeys. The explorer and the storyteller alternate roles–an explorer moves along the songline, experiencing the changing landscape and meeting and listening to storytellers who attach their stories to the features of the place where they meet. Explorers sometimes stop in their journey, to become storytellers along the songlines of other explorers, who travel along the same or different intersecting lines to meet them, and then pass by. The stories told are records–data and narrative, commemoration and explanation–of the past and present, and provide a focus for the future. Having travelled quite extensively in former days, I am now much more of a stationary landmark!

In contrast with such enduring, inuksuk-like books, the exploding volume of published outputs in the Information Age has catalogued often ephemeral formative experiences of still largely anarchic domains of knowledge and endeavour, prone to large amounts of obfuscating noise. Reliable signposts are sorely needed through this confusing maze. At the time of writing (22 May 2021), *New Scientist* has two articles germane to this theme.

The title of the first is 'Machine Churning', a play on machine learning![41] It describes a review from the Cambridge Image Analysis Group (in the Department of Applied Mathematics and Theoretical Physics, University of Cambridge) of more than three hundred papers published between January and October of 2020, reporting applications of machine learning methods to

40 B. Chatwin, *The Songlines* (New York: Random House, 2012).

41 M. Roberts, 'Machine Churning', *New Scientist*, 250.3335 (2021), 23, https://doi.org/10.1016/S0262-4079(21)00873-3

diagnose Covid-19 from chest scan images and predict how patients will fare.[42] None of these was deemed of use in clinical settings. The authors describe this as a kind of publication bias that promotes inadequate experimental rigour and unreliable claims of success over careful experimentation–'churning' out of papers over the consolidation of learning. ROC (Receiver Operating Characteristic) sensitivity versus specificity charts provide a standard way to map and compare the performance of methods promoted in such a spectrum of publications. The collection of high-quality datasets with the necessary large numbers of data subjects that are typically required for the development of such methods, and then their prospective testing, is in itself a considerable challenge. Christian Leibig and colleagues followed this approach in their 2022 paper comparing the strengths of radiologists and an artificial intelligence (AI) method for breast cancer screening, as further discussed in Chapter Ten.[43] This scale of research, which is assuming greater importance as AI advances in capability, will be more readily achievable as the objectives of Part Three of this book start to bear fruit, establishing a coherent care information utility.

The second article is a book review of *Power to the Public: The Promise of Public Interest Technology*, which argues for greater government focus on meeting everyday needs of citizens, and catalogues how they have fallen down on this imperative in the transition to the Information Age.[44] The second and third parts of this book catalogue a similar pattern that has come about in health care and imagine new common ground on which we can achieve a better balance for the digital citizen and Information Society of the future.

To provide potentially many thousands of connected references for this book, would almost certainly prove an erroneous, easily misleading and quickly outdated exercise. Many of the inukbook references I have provided are, themselves, more narrowly focused and referenced than this book. Some date from over one hundred years ago but remain clear and relevant today. I have adopted this approach, also, because more specific and up-to-date connections are today quickly and potentially more sensitively made through keyword searches in easily accessible and extensive electronic reference works, such as the multi-disciplinary compilations in

42 M. Roberts et al., 'Common Pitfalls and Recommendations for Using Machine Learning to Detect and Prognosticate for COVID-19 Using Chest Radiographs and CT Scans', *Nature Machine Intelligence*, 3.3 (2021), 199–217.

43 C. Leibig, M. Brehmer, S. Bunk, D. Byng, K. Pinker and L. Umutlu,, 'Combining the Strengths of Radiologists and AI for Breast Cancer Screening: A Retrospective Analysis', *The Lancet Digital Health*, 4.7 (2022), e507–19.

44 T. D. McGuinness and H. Schank, *Power to the Public: The Promise of Public Interest Technology* (Princeton, NJ: Princeton University Press, 2021).

archives like Oxford Reference, to which I have access through university subscription, and the evolving and open access commons of Wikipedia, to which I personally subscribe. Readers can further view other resources and developments in the field using the additional resources tab on the website listing of this book.[45]

The organization of literature that encompasses and connects domains of knowledge became an increasingly complex edifice in the anarchic transition into the Information Age. I review its history in some detail, in Chapter Two. Wikipedia attracts some disdain, but it is a much utilized and improving experiment in the Creative Commons. Used carefully, it and other such online encyclopaedias of the Information Age provide increasingly valuable resources. This book has been constructed with Creative Commons licensed open-access publication in mind, and that principle, along with the widening public ownership of knowledge and related intellectual property, is a pathway along which information about, and supporting, health care will emerge as a sustainable care information utility for the future. Combining reports of data with the methods employed to analyze them, such that the analysis can be critically replicated by others, is increasingly important for the publication and communication of knowledge.[46]

Almost all the books that I have referenced come from my library at home, and there is one custom-built oak bookcase where I keep the many inukbooks that have interested and guided me most, at different times. It covers a wide range of themes: in philosophy, mathematics, physical sciences, life sciences, medicine and health care, economics, engineering, the arts, history, religion. I have sometimes allowed myself to be interested in too many things! These books are close at hand and often looked at or picked off the shelf, to read and refresh my memory. Some in the collection have more personal and sentimental value, such as books that helped my father in the 1930s, as he found his way on from an impoverished childhood, having lost both his parents from desertion and disease, and having left school at age fourteen. Writings of William Blake (1757–1827), Aldous Huxley (1894–1963), George Orwell (1903–50), and many more, are there, including an early edition of Huxley's *Brave New World*, published in 1932, and a first edition of Orwell's *1984* (published in 1948, when I was three years old–he died shortly after at University College Hospital, my alma

45 Available at https://www.openbookpublishers.com/books/10.11647/obp.0335#resources

46 Some years ago, I worked for a while on behalf of the British Library and the Wellcome Trust, to participate in and chair groups they established to consider and oversee developments contributing towards this end, including, initially, for the PubMed library resource in the UK.

mater of later years).[47] There was my early school-leaver Dad, eighty years ago, reading two authors prescient about the concerns of the Internet age of the 2020s! Huxley, concerned that human life would become trivialized and egotistical, surrounding itself and drowning in a sea of inconsequential information, and Orwell, concerned that the potential for malign official censorship would restrict access to information, to control and enchain society. These books remind me of all that I owe to my parents. I introduce several others of them, here, to give their flavour.

My mother's brother, my Uncle Geoffrey, a Casualty Surgeon at the Royal Northern Hospital and then the Whittington Hospital in North London, had a lifelong interest in history and astronomy. He was a member of the British Interplanetary Society and I have some of his early books about the solar system. He had collected some early printed volumes of the histories of Herodotus, but these have sadly decayed beyond repair. Also from him, I have an 1830 edition of the combined seventy-one chapters of Gibbon's *The History of the Decline and Fall of the Roman Empire* and an 1881, seventeenth edition of Joseph Haydn's (1786–1856) *Dictionary of Dates and Universal Information–Relating to All Ages and Nations*.[48]

Gibbon's *magnum opus* in my 1830 Galignani edition totals one thousand and three pages, with around one thousand two hundred words per page. This amounts to a creditably compact ten-megabyte account of history, spanning some one thousand five hundred years! In Haydn's nine hundred and nineteen pages of tiny typescript–packing in about four thousand words per page, and thus comprising about twenty-five megabytes of data or the equivalent of just a few jpeg images on our smartphones today. As recorded in his brief Preface to the 1841 first edition, Haydn set out 'to attempt the compression of the greatest body of general information that has ever appeared in a single volume, and to produce a Book of Reference whose extensive usefulness may render its possession material to every individual'.[49] There you have it: information selected and communicated for its general usefulness–not exactly the spirit of our age! Two ancient, thick and decaying, yet remarkable intact and readable, volumes on my shelf!

In 1945, Encyclopaedia Britannica published its 'new survey of universal knowledge' in the form of twenty-three volumes, alphabetized from A to Z and with a twenty-fourth volume comprising maps, indexes and lists of contributors. My parents bought this edition when they started their family and just after I was born. They are bulky–parallel columns of around

47 A. Huxley, *Brave New World* (n.p.: DigiCat, 2022); G. Orwell, *Nineteen Eighty-Four* (London: Hachette, 2021).

48 B. Vincent, *Haydn´s Dictionary of Dates* (Frankfurt: Salzwasser-Verlag, 2020).

49 N.p.

seventy-five lines and twenty words per line. The index to the maps extends to three hundred and eighty-nine pages, that of the twenty-three volumes of content to four hundred and ninety-seven pages, and the list of contributors to thirty-three pages. The instructions for how to use the indexes run to five pages. These hefty volumes are safely stored in our summerhouse. The pious incantation on the title page is 'Let knowledge grow from more to more and thus be human life enriched'.[50] A rough estimate says twenty-four thousand pages and (24000x75x20x5) around one hundred and fifty megabytes of data.

Grown, this body of knowledge certainly has! Wikipedia extends now to petabytes and Internet data sources extend by zettabytes each year! Maybe a DNA level of data storage minimization will reduce the sub-ocean, electricity-guzzling and heat-emitting Cloud data stores to the size of Gibbon's and Haydn's books, before long, as Internet-linked digital storage volumes continue their seemingly inexorable expansion! Maybe they will be archived on another planet that does not destabilize our environment on Earth! By way of sobering perspective, Chapter Six delves into a comparison of the capability and capacity of computer technology with that of the human brain and living cells, in its discussion of the landmark inukbooks of John von Neumann (1903–57) and Paul Davies.[51]

I have collected dictionaries on many subjects and the eight kilogram, two-volume 1971 Oxford English Dictionary has sometimes been helpful in pinning down the imprecise use of words and their misuse or hijacking within specialist jargons. This is hard to achieve in any domain, let alone when embarking on a work that intertwines experience along a songline through landscapes of health care and information technology.

Other historical works of Henry Hallam (1777–1859), Thomas Macaulay (1800–59), Karl Marx (1818–83), H. G. Wells (1866–1946) and Norman Davies are there on the shelves–the latter with his connection, for me, to Oxford and my wife Bożena's homeland of Poland and his special expertise in Central European history. I cannot claim to have read all of them but have browsed through and continue to benefit from knowing they are there. They sit alongside the writings of science laureates of the past century, especially in physics, and of modern-day writers. There is also an eclectic collection of novels that I have especially enjoyed, including those of Julian Barnes,

50 W. Yust, ed., *Encyclopaedia Britannica: A New Survey of Universal Knowledge* (Chicago, IL: University of Chicago Press, 1945).

51 J. von Neumann, *The Computer and the Brain*, Mrs. Hepsa Ely Silliman Memorial Lectures (London: Yale University Press, 1958); P. Davies, *The Demon in the Machine: How Hidden Webs of Information Are Solving the Mystery of Life* (Chicago, IL: University of Chicago Press, 2021).

whose life briefly brushed alongside mine at Magdalen College (University of Oxford) in the late 1960s and whose *A History of the World in 10½ Chapters*,[52] inspired my half chapter and the ten and a half chapters, here.

Another inukbook that I treasure, for personal reasons, is *Atoms in the Family* by Laura Fermi (1907–77), wife of the renowned physicist Enrico Fermi (1901–54), who was one of a generation thought to have damaged their health and died young as a result of exposure to harmful radiation during their experiments.[53] The book is the songline of her family life from the 1920s to the 1950s, featuring people and events at the centre of the unfolding of atomic and nuclear physics. It extends through to the Manhattan Project and the dropping of the atomic bomb on Hiroshima, which, she says, neither she nor other wives she was close to, had understood to be the work on which their physicist husbands were engaged.[54] It was from this closely connected community and era that the ENIAC computer emerged. Fermi was one of the great physicists of the time that saw the ascendancy of quantum mechanics. He shared the Nobel Prize in 1938 for his work on slow neutron nuclear reactions. Many lived through and were conditioned by the social and political strife that forced them to leave Europe and emigrate to America. This book was given to me by Elisabeth Ullmann, a physiology lecturer colleague at the Medical College of Bart's. She told me about key players of the age that she had known, such as Niels Bohr (1885–1962). I collaborated with her to introduce my work on simulation models of clinical physiology with John Dickinson, the then Professor of Medicine at Bart's, into her classes for medical undergraduates–a story I tell in Chapter Four.

Laura Fermi's songline was from the pre-war era and it intersected with that of Richard Feynman, the physicist who made the imaginative breakthrough leading to the theory of quantum electrodynamics, for which he was awarded the Nobel Prize, with Julian Schwinger (1918–94) and Shinichiro Tomonaga (1906–79), in 1965.[55] I have as complete a collection of

52 J. Barnes, *A History of the World in 10½ Chapters* (New York: Knopf, 1989).

53 L. Fermi, *Atoms in the Family: My Life with Enrico Fermi* (Chicago, IL: University of Chicago Press, 2014).

54 Among the Fermi family's closest friends were the Peierls family. Rudolf Peierls (1907–95) ended his career in the late 1960s as Head of Department and Professor of Theoretical Physics at the University of Oxford, where I attended his lectures. It is amusing to recall the fluency of such great figures of the time, who taught us, with such aplomb, things we now know not to have been true, and to recall us students, who sought to emulate them and were graded for our own dextrous aplomb in explaining the untruths that were truths of the day! I admire and am excited by physics to this day, but not sorry that I took a different path.

55 Enrico Fermi had joined the Los Alamos Manhattan Project in 1944 and, with other physicists of the era, played a key role in designing the atomic bomb. Feynman joined while still a graduate student at Princeton University. He

books in Feynman's name as I have been able to lay my hands on–his clear and illuminating style was a notable inspiration for me when discovering physics for the first time, at the University of Oxford. Feynman had an aversion to writing–many of these books comprised his ideas and notes compiled into book form by others. One of them, by Anthony Hey, is based on Feynman's highly original lecture notes for a California Institute of Technology (Caltech) course on computation. I worked alongside Tony Hey when he created and led the innovative UK e-Science Programme in the early 2000s.

Such has been the rapidity and impact of changing information technology at all levels of society, and extending throughout the world, that chaos along my songline was inevitable. Expensively misguided and sometimes disreputable stuff did happen. Another of my inukbooks, to which I have already referred several times, is Whitehead's *Adventures of Ideas*. As also quoted on the front page of Part Two of this book, he captures the chaos of such times very well:

> In every age of well-marked transition there is the pattern of habitual dumb practice and emotion which is passing, and there is the oncoming of a new complex habit. Between the two lies a zone of anarchy [...][56]

One wonders how he would have characterized the anarchic transition through the Information Age, with which his life scarcely overlapped. He was, though, a key figure, along with Russell, in the transition of mathematics and philosophy onto new foundations, around the turn of the twentieth century. This contribution was drawn together in their treatise, *Principia Mathematica*,[57] and progressed into ensuing decades of debate about the logical foundations of mathematics, blown open again by Kurt Gödel (1906–78). From this era, came ideas that laid the foundations of computer science, set down in the landmark contributions of the mathematicians John

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delighted in teasing the team by cracking the safes in which the results and designs were secreted each day, leaving mischievous notes to unnerve his colleagues when they opened them the next time. Joseph Rotblat (1908–2005), who pioneered radiation biophysics and was subsequently head of physics and a senior colleague at Bart's Medical College in London, had joined the project from the UK. Rotblat devoted much of his life, thereafter, to promoting understanding and cooperation among scientists, between East and West, through the Pugwash Conferences. Jointly with the Pugwash Conference, he was awarded the Nobel Peace Prize for this work in 1995.

56 Whitehead, *Adventures of Ideas*, p. 14.

57 A. N. Whitehead and B. Russell, *Principia Mathematica* (Cambridge, UK: Cambridge University Press, 1925–27).

von Neumann, Alan Turing (1912–54) and Alonzo Church (1903–95) in the 1930s, centred on the universal computer and theory of computation.

Russell and Whitehead wrote more widely about philosophy and social change. Following Whitehead's phrase, we might interpret a well-marked transition as one where there are well-delineated differences, before and after, and well-characterized causative factors at work, which illuminate our understanding of how and why change comes about. This understanding may not help a lot in characterizing and coping with change, when living through the anarchic zone he describes as lying in between. One could probably, if feeling so inclined, fill many books with examples of the kind of 'dumb practice and emotion' that Whitehead wrote about, many of them my own!

Too much musing and writing about imponderables can easily dominate too little thought and action about making and doing things iteratively and incrementally better. That was the slippery slope in antiquity that Gibbon cautioned against. It is best to write only when there is something useful to say, and not do so, or be incentivized to do so, otherwise. There has been hard-won progress and good practice, achieved by brave innovators, to stand against the opposing battalions of hubris and despondency that broadcast loudly in such times. Given the vagaries of national and institutional policy and allocation of resources in anarchic times of transition, success in making a useful difference as a pioneer can prove especially hard-won, and staying-power and good luck are key ingredients of the remembered storytellers. The inukbooks introduced throughout this book have been chosen to illustrate a diversity of stories that illuminate the anarchic transition of the past seventy-five years. It is a personal and eclectic selection.

Transition and Anarchy

We see and describe transition in terms of what happens and seek to understand and explain why. Change and transition are about past, present and future; about events occurring. We look for and make connections. All change over time is transition of one kind or another, sudden or gradual.

Today, the passage of time is tracked over unimaginable billions of years and fractions of seconds. Its subdivisions are variously described as eons, eras, periods, epochs and ages, to the present day. Cosmologists straddle imagination of time from 10 exp (-50) seconds to 10 exp (100) years, describing the past and expected future of the universe in terms of key transitions. They track time and energy in the universe from its unimaginably rapid and high energy creation and inflation, after the imagined Big Bang. This progression is marked in terms of radiation, particulate matter, stars, planets, galaxies

and black holes, projecting into equally unimaginable multitudinous eons of slow decay into low energy radiation and nothingness.

Geology spans from the formation of the earth to the present day, in billions of years. It tracks the sedimentary record of rocks, marked by many tens of stages of evolution of the earth, as it took shape and adapted in its orbit within the evolving solar system, flexed and buffeted from afar. Life scientists track the emergence of life on earth and its evolution, marked by transitions between simple and complex life forms, fuelled by the energy of the sun, constrained by underlying and emergent mathematical and physical patterns and properties. In these Covid years, we are focused on very short-term biological transitions, arising from movements and mutations of a virus and their consequences. Archaeologists map the emergence of human societies in different regions of the world, marked by tools, lifestyles and cultures. Historians describe and characterize the evolution and transition of human societies, marked by infinite contexts of stuff and stuff happening–good stuff and bad stuff–war, revolution, discovery, reformation, renaissance, enlightenment and industrialization. Sixty thousand years of Indigenous culture in Australia supplanted, under European influence, over just four hundred years.

Transition and anarchy are described in different ways in different contexts. In the physical world, maths and physics describe threshold phenomena, such as phase transitions, in terms of models of networks, forces and energies–from ice to water to steam, sometimes skipping phases. Heat energy is absorbed, exciting and destabilizing the water molecules in ice, breaking them from one kind of order and its prevailing forces and interactions (solid state) into another (liquid and then gas). The transitions in the reverse direction release energy as the energetic gaseous water molecules condense into liquid water and freeze into solid ice. Different forces operate and predominate at different ranges, to establish a new stable state or phase. Though precisely marked at scale, such phase transition is nonetheless chaotic at the molecular level.

The take-off of an airplane is a transition, as it lifts from the ground. Air flows at differential speed, above and below its aerofoil wings, and the Venturi effect characterizes the observed net upward lifting force. Thermodynamics describes this effect. It does not enlighten us, should we attempt, in vain, to understand what is going on by studying what happens to individual air molecules as the plane rushes through and perturbs them. In the natural world, cell division is a transition from a state of one to a state of two. Mitosis and meiosis proceed through waves of chaos in transition between well-marked states.

The forces in play, that drive transitions, may be extreme or subtle. The Chicxulub meteorite was a sudden extreme event, arriving out of the blue,

and the transition that followed extended across the physical and natural world in both immediate and long-term, irreversible changes. Transitions may occur suddenly, even when caused by slowly incremental change that has accumulated to a chaotic breaking point between an old and new order, as in an earthquake. For the animal kingdom, Stephen Jay Gould (1941–2002) described such rapid jumps and characterized them as a punctuated equilibrium.[58] The natural world defends itself, adapting to changes of season, climate and predator. It often seems okay until not okay, and then is very much not okay. The human body and mind, and their health and defences, are like that, too.

The terms anarchy and chaos describe lack of form and order. When we say the outcome of successive spins of a coin is a random process–50:50, heads or tails–we mean we do not know which way it will fall, but the two possibilities are equally likely. When we select a card at random from a pack of fifty-two, we do not know which of them will turn up–unless, of course, there is cardsharp practice in play! Random means essentially that we do not know–with 50:50 prior probability, if we want to predict, we might as well spin an (unbiased!) coin. In human affairs, a great deal is written and computed about situations like this (**e**xcessive **w**ords/**w**atts **a**bout **f**ifty-**f**ifty **l**ife **e**vents–a good acronym would be e-waffle!). There is upside and downside risk and utility in all of life's balances, and how we act to protect and influence them. Nassim Taleb's *The Black Swan*[59] and *Antifragile*[60] and Daniel Kahneman's *Thinking, Fast and Slow*[61] are books rich in insight about balance and transition, and human behaviour when faced with uncertainty.

Human society is in the throes of a long transition marked by the rise of information technology. We talk of transition twelve thousand years ago, from prehistoric times of hunting and gathering to settled agriculture; of ages characterized by stone, bronze and iron materials and tools; of eras deemed ancient, classical, medieval and modern. The modern world looks back over many centuries, to successive and interacting ages of renaissance in arts and culture, reformation of church and state, and enlightenment in philosophy and reason, that led into new ages of commerce, industry and science. The past hundred years of science and engineering transformed medical practice and seventy-five years of information technology has changed everything again. Much now unfolds in dramatically new ways,

58 S. J. Gould and N. Eldredge, 'Punctuated Equilibrium Comes of Age', *Nature*, 366.6452 (1993), 223–27, https://doi.org/10.1038/366223a0

59 N. N. Taleb, *The Black Swan: The Impact of the Highly Improbabl*e (London: Random House, 2007).

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

61 D. Kahneman, *Thinking, Fast and Slow* (New York: Macmillan, 2011).

year on year. The sequencing of the human genome took years of multicentre collaboration to assemble. The SARS virus was sequenced in a few weeks and the corona (Covid-19) virus sequencing, alongside routine human whole genome DNA sequencing, can now be completed within hours if not minutes. It is both an exhilarating and frenetic time.

My fifty-year career songline has moved through an oftentimes anarchic landscape. The stories I encountered and participated in reflect an amazing mixture of creativity, staying-power, luck, muddle and confusion. Given the uniqueness of the times, there was fortunate opportunity to meet and learn from heroic storytellers. And, unfortunately, sometimes to experience the beguiling but ultimately busted forays of hubristic mortals whose optimistic and confident predictions and promises were too readily believed by powerful ears, ill-equipped, ill-tuned or sometimes not interested, to discern pretence of knowledge. Diverse funding streams floated many computerized boats, and land-based admirals sent them to sea, where they were subsequently found unseaworthy or quickly obsolete. The wreckage left below the waves imperilled navigation of other boats, thereafter. The sinking of the massive ship, Vasa–now amazingly restored and preserved in the Vasa Museum in Stockholm–as it left harbour into a stiff breeze on its maiden voyage from Stockholm, is a memorable nautical parable of this sort of debacle.[62]

62 John Dickinson and I visited the Vasa on a trip to give talks at the nearby Karolinska University Hospital in Stockholm, nearly forty years ago. According to Wikipedia, 'The ship was built on the orders of the King of Sweden Gustavus Adolphus as part of the military expansion he initiated in a war with Poland-Lithuania (1621–1629). She was constructed at the navy yard in Stockholm under a contract with private entrepreneurs in 1626–1627 and armed primarily with bronze cannons cast in Stockholm specifically for the ship. Richly decorated as a symbol of the king's ambitions for Sweden and himself, upon completion she was one of the most powerfully armed vessels in the world. However, *Vasa* was dangerously unstable, with too much weight in the upper structure of the hull. Despite this lack of stability, she was ordered to sea and foundered only a few minutes after encountering a wind stronger than a breeze'. Wikipedia contributors, 'Vasa (ship)', *Wikipedia, The Free Encyclopedia* (9 June 2023), https://en.wikipedia.org/wiki/Vasa_(ship). Wikipedia has further interesting and illuminating details of this story, which resonate with unstable computer systems finding their way into everyday life. Take the NHS Covid App, for example–a doctor well known to me, who had been busy helping to cope with the flood of Covid admissions to their hospital, told me that staff had had to switch it off on their phones as its unreliable and unhelpful alerts risked the workforce becoming overwhelmed, because so many of them would have had to be sent home, unnecessarily. False positive alarms were a cacophony in the care home where my dad spent the last months of his life. What might we face from a non-coherent ensemble of unreliable alerts from AI-enabled smart phones monitoring illness?

At times it has felt as though the landscape unfolding was moving under foot–accelerated continental drift and frequent earthquakes, combined. Some explorers achieved iconic storyteller status and those stories have passed on into later decades. Others disappeared or gave up. It was all too easy to struggle up what turned out to be blind alleys, meeting storytellers who were stuck there, blocked from or unable to move forward onto a different, more prosperous path. Some had started with great energy, ambition and fluency, but had become exhausted and dispirited. Some were tied to technology and methods that had become quickly obsolete and unsustainable. Exploration of a problem may reveal previously unforeseen requirements that indicate or necessitate a completely different approach to it. New methods of working may require different skills, and reskilling requires willingness, aptitude, time and opportunity that may not be available. The information technology scene changed considerably, year on year, in the anarchic transition into and through the Information Age.

When thinking and writing of this more human and organizational chaos, I picked up another book, *In the Margins of Chaos*, describing relief work between the First and Second World Wars, led by an indomitable woman, Francesca Wilson (1888–1981).[63] She described the plight of refugees throughout Europe and the concerted efforts on many levels to help and support them. Her title is significant. It is hard to make a constructive and peaceful impact at the centre of a battle, but in the margins of the battle there is always opportunity, given courage and persistence. The book, given to me by friends of a friend of Francesca Wilson, and great friends of mine today, is one of my inukbook treasures. My mother worked with Francesca Wilson in running a centre situated behind Tibidabo in Barcelona, supporting refugees fleeing General Franco's advancing army, towards the end of the Spanish Civil War.

How, then, are we to characterize and understand the anarchy of transition into the Information Age? There can be no turning back, and it is a challenging and sobering time, the like of which King wrote of in his valedictory book about world financial crisis.[64] In his term 'pretence of knowledge', he was mirroring Friedrich Hayek (1899–1992) in his criticism of what he called 'scientism'. King reflected on what he called the crisis of ideas underlying recurring crises of the international monetary system. Whitehead, too, was given to sobering judgement about anarchic social change:

63 F. M. Wilson, *In the Margins of Chaos: Recollections of Relief Work in and between Three Wars* (New York: Macmillan, 1945).

64 King, *The End of Alchemy*.

> It is the first step in sociological wisdom, to recognize that the major advances in civilization are processes which all but wreck the societies in which they occur [...] Those societies which cannot combine reverence to their symbols with freedom of revision, must ultimately decay either from anarchy, or from the slow atrophy of a life stifled by useless shadows.[65]

The term *symbol* has special relevance when describing transition through the Information Age. Whitehead would have been fully cognizant of symbolic logic, although not of the coming era of computer science. Chapter Two tracks the evolution of mathematics and logic and the emergence of computer science, in representing, manipulating and reasoning with symbols–letters, words, numbers, codes, logical propositions and predicates. Logical truth became the touchstone of formal semantics, expressed and played out in terms of machine-based symbols. How powerful are these symbols? Can we, in Whitehead's terms, revere symbols that arise in and shape machine discourse, and are revised there, in ways we progressively no longer control or understand? Can we distinguish symbolism that arises in human culture and symbolism imprinted from machine culture, if one calls it that, just to emphasize the question? Are these boundaries whereby we can have our cake on one side of the transition and continue still to eat it on the other side? A divide is being crossed and we should listen to and reflect on these forebodings.

Charles Dickens (1812–70) wrote *A Tale of Two Cities* in describing the transition of the French Revolution and the Reign of Terror. It has these memorable and much quoted opening few lines: 'It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity'.[66] He might, might he not, have been writing about the Information Age! For me, the transition of the Information Age has been a tale of two villages–the rural hamlet where I grew up, from 1945, just as the UK NHS and the computer were being invented, and the global village in which I now live, in retirement. In the 2020s, I connect with both these villages. Between those times, a lot of both good and bad things have come and gone, and many good things remain. The transition is also a tale of science, before and after the rise of computer science and technology, in which all of science has developed ever more rapidly. And it is a transition with a social phenotype

65 A. N. Whitehead, *Symbolism, its Meaning and Effect* (New York: Macmillan, 1927), p. 88.

66 C. Dickens, *A Tale of Two Cities* (London: Chapman and Hall, 1868), p. 1.

of the pandemic–infectious unrest and political divisiveness played out in individually-targeted disinformation and nationally-targeted cyber-warfare.

I have lived, throughout my life and career, close to health and social care services in anarchic transition, linked with the rise of information technology. The technology transition is well-marked, but the human health care transition is not. The information revolution has starkly exposed disjoint perspectives on physical and mental health and social care, and how these services should be organized and managed.

From Physics to Biology

The science and technology of measurement that underpins our understanding and treatment of disease, and the promotion and safeguarding of health today, have accelerated along a runway of scientific advance over several hundred years. In the late nineteenth century, information emerged as a unifying concept for shaping and linking the physics of thermodynamics, entropy, statistical mechanics and order, increasing the scientific understanding of equilibrium and non-equilibrium physical systems.

In its rise during the second half of the twentieth century, information technology became inexorably rooted within scientific method, underpinning the capture and management of data from an ever-widening range and scale of observations and measurements. Information concepts also took root in the arts, in new paradigms for study of language and media. In science, measurement reached down and out over many tens of orders of magnitude towards 'zeptoscopic' granularity and 'zottascopic' giantism–prefixes of scale such as micro-, mega- and, even, giga- quickly became outdated! Science now peers at and grapples with Planck units, with blank incomprehension! And numbers characterizing the scale of the observable universe are similarly unimaginable.

New physics, building on the shoulders of earlier giants of electromagnetism, atomic physics, relativity and quantum theory, heralded new devices and experimental methods for chemistry, biology and medicine. Mathematicians, physicists and engineers pioneered computer science and the first electronic computers, which heralded the rise of pervasive information technology. In these ways, pioneering mathematics, science and engineering of the first half of the twentieth century powered biology, life science and medical science of the second half of the twentieth century.

This pattern of advance challenged understanding of living systems–did they somehow defy those same physical laws? The concept of information started to permeate more widely into electrical engineering and life science

of the mid-twentieth century. Concepts of epistemology and ontology fuelled philosophical debate about theory of knowledge and theory of mind. 'What is reality, life, truth ...?' is always a puzzled line of questioning, but philosophy is devoted to such puzzles, and it is good to seek clarity, even when not always useful! 'What is information?' has also raised its hand. Philosophy and mathematics, as with pure anything, seek Platonic distance from, while depending on, the nitty gritty of material reality, life and living. This is not a criticism–we need them.

As mentioned in the Preface, at the beginning of the Information Age, in 1944, Schrödinger published *What Is Life?* Reasoning from the physics of that time, he imagined, with remarkable prescience, some key aspects of the form and function of DNA. With modest and straightforward style, he laid an influential foundation for what developed over the coming decades into a story of immense detail, scale and complexity. In 2015, the biochemist, Nick Lane, a UCL colleague, wrote what read to me as another landmark book, to pose *The Vital Question–Why Is Life the Way It Is?*[67] It would have enthralled Schrödinger to read there the life stories of electrons and protons, operating in vast numbers across biological membranes within minute volumes, and at miniscule energy levels in comparison with those powering the semiconducting interfaces of the transistors at the heart of the electronic circuits of the computer, to constrain, channel and power living systems. Life harnesses and channels the energy of solar radiation to power and sustain itself. Cascades of electrons move along pathways of biochemical reactions, giving up energy and releasing protons that establish chemiosmotic potential gradients across cell membranes. These, in turn, provide energy required to fuel cellular processes. Critical of what he saw as overemphasis on the story of information, Lane added the story of bioenergetics, in proposing an answer to his question Why? I tell these stories in Chapter Six, alongside others bringing summative reflections about the nature and understanding of information and life.

From Mathematics to Informatics

In the first half of the twentieth century, new mathematical ideas, drawn together by Russell and Whitehead and further evolved from there, provided the foundations for computer science as they progressed into and through the 1930s. Mathematics advanced and connected more widely in

67 N. Lane, *The Vital Question: Energy, Evolution, and the Origins of Complex Life* (New York: W. W. Norton and Company, 2015). NB: the British edition is subtitled 'Why Is Life the Way It Is?' while the American edition is subtitled 'Energy, Evolution, and the Origins of Complex Life'.

science, through the continuous probing of topics like theory of number, set, network, symmetry and topology, and what they offer in clarifying physical, chemical and biological form and function. It has further connected with topics like the analysis of thresholds of transition in complex physical systems, the structure of complex hierarchies of data (such as genomics and proteomics data) and the largescale modelling of public health systems (such as those which guide the management of protection from epidemics). As human mathematicians battle the limits of what they can imagine and do in expanding the scope of their discipline, the computer is emerging as an essential tool in their pursuit of progress. In the not-too-distant future, software systems may bear the names of such renowned mathematicians as Erdős[68] and Ramsey,[69] with the creators of these systems acting as collaborators in their published endeavours! Will software start to win Fields Medals and Nobel Prizes, one wonders?

The range and virtuosity of mathematical methods has expanded and diffused rapidly across disciplines in the Information Age. In Chapter Six, where I explore ideas about the nature and relationship of information and life, I introduce my Ian Stewart inukbook that positions mathematics at the heart of understanding of the living world.[70] Mathematics, spoken of as both science and art, has defied definition. Some resorted to describing it circularly, and no doubt with tongue in cheek, as 'what mathematicians do'! Informatics took root in similarly wide-ranging contexts, also defying distinctive definition.[71] This all feels a bit like Nathan Bailey's supposed copout, in his *Dictionarium Britannicum* (1730), in describing a dog as 'an animal well-known'.[72] With increasing cross-fertilization, hybrid disciplines emerged, and their boundaries blurred–biomathematics, computational physics, medical informatics and so on.

Informatics evolved as a wider currency of scientific discourse, notably so in the reshaping of biology in the second half century. Molecular biology built on the physics and chemistry of crystallography, pioneered by father and son, William Henry Bragg (1862–1942) and William Lawrence Bragg (1890–1971) from the turn of the twentieth century. It led in the early 1950s to the discovery of the double helix structure of DNA. This had, it seems,

68 Paul Erdős (1913–66).

69 Frank Ramsey (1903–30).

70 I. Stewart, *Life's Other Secret: The New Mathematics of the Living World* (New York: John Wiley and Sons, 1998).

71 The celebrated physicist, John Wheeler (1911–2008), agreed about the indefinite nature of mathematics and mused further that, at the most basic level, everything is information–informatics being what informaticians do, perhaps! More on this theme in Chapter Three.

72 N. Bailey, *Dictionarium Britannicum* (London: T. Cox, 1730), n.p.

already been characterized by Schrödinger as a 'code-sequence'. The double helix was announced at the University of Cambridge in 1953, when the younger Bragg was head of physics there, as Director of the Cavendish Laboratory. His father had worked at UCL in the post-First World War years. Schrödinger connected with physics at Oxford, spending some time at Magdalen College, my alma mater. These ties to Oxford and UCL add connective warmth for me, in my story.

As with mathematics, informatics spread its wings. It was principally concerned with computation: methods for recording, processing and analyzing data in the engineering of information systems; methods for building representations or models of branches of knowledge, to assist reasoning about them, and for use in predicting their behaviour. Computational power and volumes of stored data grew extremely rapidly over decades. By the turn of the twenty-first century, bioinformatics had emerged, as characterized by my UCL colleague of that time, later the founding director of the European Bioinformatics Institute at Cambridge, Janet Thornton, as a core discipline of biology.

And *medical informatics* was consolidating itself as a discipline at the heart of medicine, as exemplified in the title of a conference held at the British Medical Association (Clinical Information–The Heart of Medicine, December 1994) addressed by the then Chief Medical Officer, Kenneth Calman. It extended further into health care where it was explored in the context of the delivery of services and interfaces with patients. This wider compass, characterized as *health informatics*, gained currency, as did *biomedical informatics* (both of which are often treated synonymously). *Bio-health informatics* also raised its standard, although I am not sure how many troops have rallied there. I will stick with health informatics, on which my first UCL lecturer appointee, Paul Taylor (now a UCL professor), and my Australian colleague, Evelyn Hovenga (like me, the first professor of health informatics in her country), write and communicate so well.

Over the decades traversed in the Information Age, the linkage of information and health care has evolved in fundamentally new directions. Methods of data capture, analysis, reasoning and communication have advanced, hand in hand. The skills and resources required for clinical practice, efficient and effective health care delivery, and self-care, have likewise evolved in parallel, and expanded. The advent of ever more powerful information technology, marked by the exponentially increasing rate of advance described by Moore's Law, has been fundamental. As Walther Ch. Zimmerli wrote for a Ciba Foundation Symposium in 1989, information technology is 'the one and only existing "horizontal

technology", a technology that pervades each and every part of social life and all the other technologies as well'.[73]

Emerging from and through all these anarchic forms and connections, health informatics is now more widely understood as playing a crucial role at the heart of health care. Fifty years ago, such thoughts were tolerated or puzzled over with a mixture of incomprehension, amusement and anger, and widely dismissed as pretentious, eccentric and irrelevant. Such is the perception and reception of adventurous new ideas and focus for reform. It is not unknown for clinical scientists close to Nobel Prize recognition, to be under pressure for a perceived lack of quality and progress of their work and publications. I have listened to one such person speaking in the series of annual clinical prize lectures at UCL.[74]

The transition of health care into the Information Age has challenged expectations, behaviours, and capacities: in education and professional roles, organization and financing of services, and their governance. It has seen many engineering and science-based industries come and go and others adapt, evolve, and extend to global reach. It has brought new focus on opportunities and requirements for every citizen to engage constructively and realistically with their personal health. New context of ethical dilemma, such as about personal privacy, preservation of life, and scarce and costly resource allocation, has arisen, while inequalities in health remain as a scourge on society, globally and more locally.

Health informatics, as the broad field that embodies the transition of health care into the Information Age, matters a great deal, has many aspirant owners and has achieved significant things, of which some have taken root. And it has often gone badly wrong. Most academic initiatives launched into the field have lasted just a few years, until their priming funds

73 Universität Bern. Akademische Kommission and Law Symposium on Human Genetic Information Science, *Human Genetic Information Science, Law and Ethics*, Ciba Foundation Symposium 149 (Chichester, NY: John Wiley and Sons, 1990), p. 94.

74 This was Stanley Prusiner, who unravelled the story of misshapen prion proteins–one wonders how quickly AlphaFold might now accelerate such discovery. Working at Penn State University, Prusiner was the first researcher to suspect that a misshaped protein, which does not contain genetic material that allows viruses and bacteria to reproduce themselves, could cause disease. The idea was controversial and dismissed by many in the scientific community, including colleagues who judged him unsuited for tenure in his post. Fortunately, he had influential colleagues like Britton Chance (1913–2010), who counselled in his support. Prusiner was awarded the 1997 Nobel Prize in Medicine or Physiology for his work in proposing an explanation for the cause of bovine spongiform encephalopathy (Mad Cow Disease) and its human equivalent, Creutzfeldt-Jakob disease. I well remember that lecture at UCL, describing his career.

ran out. Most pioneering health information systems in use have peaked and declined. Many national implementation initiatives have failed. All of this has cost a huge amount of money and involved much waste of effort and opportunity. And a great deal of learning has been lost along the way. It has made companies and careers and destroyed them. The story of health informatics parallels that of the transformation of society through the Industrial Revolution, starting several centuries before. Its scope is, though, more immediately and globally pervasive, and the anarchy it has brought is, in that sense, pandemic.

A Halfway View

In the extensive, anarchic and costly domain joining health care and information technology, admixtures of commercial, academic and professional issues and rivalries have become, and remain, controversial and strongly contended. Health informatics of the second half of the twentieth century set the scene for, and is now powering, health care systems of the first half of the twenty-first century. It is a transitional bridge between health care before and after the Information Age and this book is a view from halfway across that bridge, midstream in Whitehead's anarchic zone.

The term *pontiff* comes from the Latin for bridge. It conveys leadership in making and communicating connections. There are those that build bridges and those that travel and communicate across them. There are those that wish them into existence but themselves lack the expertise to design or build them–pontificators about impractical bridges. Practical grounding is essential when deciding what and where to build, and how to build, not just technically but also in terms of teams, organizations and communities of builders and users. This is necessary foundation for trust and cooperation, whereby combined efforts accumulate and augment one another, and are sustained.

Information technology has shown great promise in establishing and facilitating important new connections in science and society. It has in very many respects delivered on that promise and will surely continue to do so. It has also disturbed and disappointed, by letting loose a Pandora's box of unknowable connections and disconnections. These have been vectors of instability in economic and social life, loosening and weakening some human connections that have served society stably and well. The transition through the Information Age has become a communicator of fragmentation in society, as Whitehead's words about the anarchy of transition might, in retrospect, have foretold. This transition has not yet settled to a new order,

save, perhaps, for the sometimes rather trite observation that change is the nature of things.

Parenthesis–Audience

This introductory chapter began with E. M. Forster and 'only connect'. It closes here with a reflection on the book's connections with and relevance for the intended audience. Why would I attempt such work–both as a career and now as a book of record? This poses another question–the first one that my college friend, Duncan Gallie, asked when I told him of my plan to write the book. What is the audience it will address? Who would wish or need to read it? My off-the-cuff response was that I, myself, was one in the audience as I wanted to see if I could succeed in writing it and having it published, peer-reviewed, by a reputable publisher, believing that I had a unique and worthwhile story to tell. In a sense, writing the book has been an exercise in framing and creating its potential wider audience. How would what I wanted to record and express connect with the interests of others who might read it? Duncan is an eminent social scientist and historian and was at one time Foreign Secretary of the British Academy, and I was duly encouraged when he replied that this was a good reason to write it–albeit clearly not enough of a reason, of course!

The transition of health care from a time when the computer played no part in the science, professional practice and organization on which it draws, through the greater part of the subsequent decades when it was treated with airy disdain, to a time when it has emerged as central to health care, has been an astonishing and highly significant era. It has relevance and personal impact for multiple audiences, present and future, far larger than those who have time to engage with a book like this. The transition needs to be understood and communicated from a forward-looking perspective, and, adopting such a stance, this book addresses many of the audiences that are practically engaged in health care services, be it as inventors, developers, providers, users, researchers, educators, policy makers, administrators, managers or regulators.

In so doing, the book looks ahead to the coming decades of an imagined radical reinvention and reform of health care, focused on achieving and sustaining the best possible coherent, integrated and adaptable citizen- and home-centred supporting information systems and services. It tries to avoid superficial rationalizations and hubristic predictions of the future, that often prevail in times of uncertain change, leading to unwarranted confidence in the potency of preferred magic bullet 'solutions'. I believe that

is called 'optimism bias', but there is, of course, 'pessimism bias', as well, which should also be avoided.

The book seeks, rather, to connect constructively with the disciplines, professions and industries currently engaged in health care and health informatics, by presenting an eyewitness story of the ideas and communities of endeavour that have played out over time, in relevant contexts of their wider philosophical, scientific, engineering and societal contingencies. One way or another, information systems and services join them all together, and, when poorly construed and implemented, they can come to impede, fragment and disconnect component health care services from their shared purpose and goals.

As discussed in the Preface, the book focuses in large part on interdisciplinary and multiprofessional endeavours and communities, which are essential to a domain like health informatics. Members of such communities need to acquire and maintain mutual understanding of where fellow members are coming from, and this is a justification I offer for the breadth and depth of the book's coverage, chapter by chapter. Along the way, the building blocks of health informatics are visited, some in more detail than others, placed in context of the histories of both health care and information technology and how they have connected. Sources invoked from beyond the health care domain are used to illustrate their wider contingencies. Viable future reform may arise through connections made from way outside the current comfort zones of orthodoxy. It is necessary to explore widely beyond our current scope and reality of services to discover these.

The book also seeks to connect with citizens of the upcoming Information Society, regarding what health care services may look like and the changing roles and expectations incumbent on them, as well as on those implicit for the providers of services. Finally, the book seeks to connect with those who serve society more generally, in the politics of provision, management and administration of health care, on behalf of citizens.

In the final chapter of his recent book, *What We Owe the Future*, entitled 'What to do [in making the future]', the philosopher William MacAskill advises that we should focus on 'making plans [...] as if we were walking backwards [looking at the past and present] into unknown terrain'.[75] In this book, Part Three is centred on an imagined future reality of Information Society that we are backing into, anticipating a new audience that is being created along the way. My personal songline has involved participation in many of the interdisciplinary and multiprofessional endeavours that the

75 W. MacAskill, *What We Owe the Future* (New York: Basic Books, 2022), p. 224.

book describes. Making viable connections within such domains requires direct engagement and experiment within the different disciplines and practices involved, and judgement at their intersection and overlap. This truly is a matter of exploring and learning from 'what works' in practice. **Work**, as in **w**orkforce, **or**ganization and **k**nowledge! And to have things work**ing** together more widely brings the need to harmonize with **in**dustry and **g**overnance. If there were a letter **p** to qualify **work**, I would assign it to **p**ersonal, **p**ractical and **p**rofessional, much more than **p**olitical!

The book adopts a personal and conversational style, with the intention of being easily readable by a broad audience. However, it does often delve into detailed explanations of specialist knowledge, which may be less accessible, and thus of more limited interest and relevance, to some groups of the intended readership. Such readers may prefer to skip some sections and jump from chapter to chapter. To maintain the book's comprehensive overview and wide range of sources, keeping the length within hard-print publication limits, some relevant and supplementary content has been moved into the online additional resources.[76]

As mentioned, when discussing the book's structure, some might understandably prefer it to have been written as several books, not just one, each with a more narrowly defined scope and selectively focused discussion, in part to assert a more rational and abbreviated order for this anarchic domain. That is not my way; I prefer a book that challenges me to think more widely, and this is what I have aimed for, warts and all. By making the book open access, I wish it to be available to an audience of anyone, anywhere, who is curious about the subject. It is an open-ended invitation, which I encourage readers to draw from, incorporate their own insights, and build upon in their own reflections and endeavours. I hope it may help to create a new audience which continues to develop in its own way, making its own contributions to health care in the Information Society of tomorrow.

76 Available at https://www.openbookpublishers.com/books/10.11647/obp.0335#resources