

A ‘Digital Me’: Key to Implementation

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Introduction

In the primary health care setting, quite a substantial amount of information on patients is already available within various health-related computer systems [1]. This sort of data is the basic ingredient of so-called electronic health care records (EHRs). It provides a first step to digitised personal healthcare, in so far as the GPs are able to monitor routine aspects of the treatment and health records of their patients. Today, quite a few reasonably sophisticated data acquisition methods are available in the average GP’s surgery. Patients are already using simple devices to monitor their conditions and, to some extent, take control of the management of their own diseases. What is lacking is the ability of consultants, clinicians, nurses and doctors to be linked together to the wider healthcare system comprising both primary and secondary (hospital) environments, where the most challenging medical activities and procedures are implemented, often involving life or death decisions.

Insofar as patient empowerment must be at the centre of the dawning revolution, the current situation in primary healthcare is still far from adequate. Patients in general are still unable to access their own data, still less to interact with it and to form social networks with fellow sufferers. Internet-based IT is set to change this; in future, patient groups will be increasingly self-educating and will need to rely less on direct interactions with the hospital. At the same time, doctors are increasingly having to deal with ‘internet-savvy’ patients who today are able to find out more about their own condition than the GP administering to them. Ultimately, there is the wider issue of citizen empowerment, and the opportunities for commercial growth derived therefrom, reaching out through the Internet and high street pharmacists. The future citizen is likely to be able to marshal his or her own data and use it to make informed decisions to enhance their lifestyle, longevity, *inter alia*.

e-Medicine for a Digital Me: Key to implementation

E-medicine is set to facilitate all of this. To tackle health and well being on a personalised basis, we need to bring together and manage large-scale, heterogeneous, distributed, patient and citizen data to make a virtual human, just as Google maps draws on multi-resolution imagery to provide a detailed account of the Earth’s geography. Building on the wealth of personalised data, medical science is now constructing reliable, integrated, computer models at all levels from the molecular to the entire human and even population levels – this is what is referred to today by the Virtual Physiological Human, and eventually, perhaps, a Digital Me (Fig. 1). Through new agreements in terms of patient consent, much patient data are likely to become research data in the near future. Levels of security and privacy afforded by internet banking will be implemented to allow patients to manage their own data and store it “in the cloud”. That data can then be pulled down for all manner of health related purposes, from emergency healthcare decision making to lifestyle choices for the apparently healthy. The data itself will accumulate from a number of acquisition routes, ranging from the GP’s surgery through to increasing levels of sophistication in the hospital context [2, 3].

Gene sequencing and the associated omics capabilities are now at a stage where individuals can expect to acquire their entire genome within a matter of minutes. Information derived from the genome can be used to build personalised molecular models of proteins interacting with other proteins, DNA, RNA and, of course, drugs [4,5,6,7,8,9]. Imaging data, which provide a highly non-invasive route to exquisite three-dimensional representations of human organs and other structures, can also be used as the starting point for higher level – typically physiological – models of human pathology. And eventually, the two levels might be related via so-called genotype-phenotype mappings.

Drug design cannot continue to be done simply on the basis of attempting to design a single compound which targets one receptor or enzyme while ignoring the network of interactions of that protein with other biomolecules (including for example other proteins and nucleic acids such as DNA and RNA) with which it enjoys extensive interactions. Systems biology is the discipline which is concerned with teasing out the precise details of these often very extensive and complex interaction networks [10]. Ultimately, drug design must pay careful attention not only to very specific molecular interactions with one protein target, but also the way in which that interaction may impact, and be affected by, other interactions inside the network which are themselves altered not only by the presence of the drug but also by the consequence of the same or different genetic mutations.

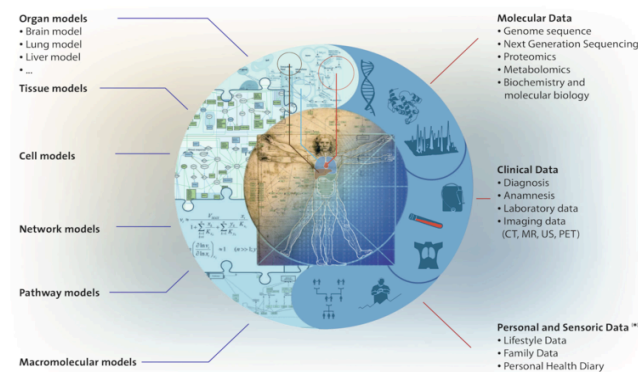


Figure 1. A ‘Digital Me’: from health to pathology [Courtesy of IT Future of Medicine Consortium]

E-infrastructure

Information technology is revolutionising medicine. We rely on advanced ICT infrastructures, not only to ease the administration of the day-to-day activities of the hospital, but also to aid the actual treatment of patients, through personalised, predictive simulation. The data contained in previously paper-based records can be integrated with data already in a digital form (such as imaging data) as well as the patient’s genetic profile, which is increasingly being generated as a matter of routine in the treatment of a number of conditions. This abundance of digital data also allows data mining and modelling techniques to be applied to data that would otherwise have lain dormant in filing cabinets. Such techniques can be used to spot correlations between cohorts of patients that would otherwise have gone unnoticed, and build patient specific models which assist the clinician in the better targeting of treatments to an individual. Models built from patient-derived data allow a clinician to assess the likely efficacy of a treatment on that patient before it is administered, potentially avoiding adverse outcomes and ineffective treatment regimes. Such model-based simulation techniques are now emerging from university research labs, and translation of such techniques from lab to routine is critical.

The implementation of such IT infrastructure, to handle the ‘data deluge’, is hampered by legitimate concerns over patient data security and confidentiality. The need to move data outside of a clinical domain means that data either need to be anonymised, so that it cannot be used to identify a patient, and/or data protection agreements need to be in place between the institutions accessing the data. However, the benefits of overcoming these hurdles are clear in terms of more effective treatments and fostering interdisciplinary research collaborations; thus many efforts are underway to do so. An international effort of relevance is the NIH-funded Informatics for Integrating Biology and the Bedside (i2b2) project, which aims to build an informatics infrastructure to support research by storing and integrating data from clinical practice, and making it available in anonymised form to researchers [11].

A new breed of clinicians

According to a new book ‘The Creative Destruction of Medicine’, 90% in large surveys of tens of thousands of doctors have said they are not comfortable or familiar with the use of genomic data in managing their patients. Many doctors are unwilling or reluctant to change the way they practice medicine. For example, although it might be more useful for sequencing and genomic research to freeze tumour samples, surgeons and pathologists most often store tissue in formalin, which tends to make meaningful

sequencing more difficult. None of this ought to be surprising, as the knowledge and training available today for the medical and clinical communities do not match the changing landscape of medical practice and personalised medicine to which we are now firmly headed. Still, patients trust their doctors the most with their data. So unless a new breed of physicians and clinicians is established, who are firmly grounded in the principles of biomedical modelling and its role in clinical decision-making, increasingly available patient information and medical/clinical data will simply gather dust. However, it is inevitable that, given a little time, clinical modellers will emerge to lead the revolution we are describing here. It is essential that such clinically trained people be in the vanguard of these new approaches or they will not succeed.

Ethical, legal and privacy perspectives

Armed with a wealth of information available at one's own fingertips through the click of a mouse button, global citizenry will be empowered as never before to address its own predicament – and to confront the unprecedented ethical problems that such vast amounts of information will inevitably also bring. Ethical, legal, and privacy implications of having one's data used for research will continue to be debated, until some regulatory body takes action or legal precedents are reached. It is important to remember it is still early days, and much of the regulatory procedure will become clear to the public, healthcare and IT providers as the technologies around personal genomics and clinical decision support are further explored. Still, one successful example is by Morris and co-workers who have shown that when patients are fully involved in a study and are aware of its value, they readily give consent for their data to be used [12]. The Scottish Health Informatics Platform defines the approach they adopt to data management as “proportionate governance”. Their approach is already being rolled out in Scotland and within some international health projects too.

Conclusion

It is manifest that medical science and its clinical applications can only be enhanced by the widespread but judicious use of information technology. This is already creating new domains requiring new forms of expertise – e-medicine and e-health. They are based on an ability to acquire and manage confidential personal data seamlessly across and throughout the healthcare system, and to use it in order to better treat individual patients. The data must be turned into useful information, often by combining it with a model and/or simulation, which helps the clinician to make decisions on treatment of the individual in front of him or her. Beyond these already compelling prospects for curing sick people, there is great potential for using computer-based tools to support clinical decision-making in the community at large, which will allow already knowledgeable patients to play a greater part in designing their own healthcare and lifestyles. Without a shadow of a doubt, medicine is transforming beyond recognition, and is set to become increasingly home-based.

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