Connecting & Collaborating - Healthcare for the 21stCentury

Grant P. Cumming

Honorary Senior Lecturer, University of Aberdeen
Honorary Professor, University of the Highlands and Islands
Consultant Obstetrician & Gynaecologist, NHS Grampian

1 Trondheim – a natural home for a workshop on health informatics

"Nature creates the stage upon which mankind acts"- words attributed to Kalle Sognnes here at the University of Trondheim as he concluded that the rock art in Norway was influenced by the geography, geology and topography of the area [1]. These words could equally well sum up the competitive edge that positioned Torleiv Maseng (of SINTEF, also in Trondheim) and his team in the late 1980's to win the competition with their work that was to set the standards for mobile telephony. Torleiv's team had to overcome the problem of the mountains affecting bandwidth as the technology moved from analogue to digital [2].

The "Lewis Chessmen" so named because they were found on the Isle of Lewis in 1831 are thought to have been made in Trondheim [3]. Chess has had a role in the advancement of Artificial Intelligence (AI) and has been called the "drosophila of AI" [4] with particular close associations with IBM computing [5].

2 The challenge to medicine from a changing society

The world is changing and changing quickly - not only physically with for example global warming but also socially. Social media has had a big part to play and the Internet has arguably increased collaboration, authenticity and transparency [6] - we all now live in glass houses whether we like it or not (our friends create data - and that data includes us) [7].

There has been a flattening of top down pyramidal hierarchical structures which has challenged traditional ways organisations have been structured [6]. This flattening has also challenged business models e.g. the record industry and publishing (books and newspapers). High profile companies who have not engaged have faced bankruptcy - Kodak being one example. Medical hierarchies are also being challenged and as medicine looks for new solutions to problems resulting from living in the 21st century (e.g. moving from the biomedical model to the bio psycho-social model of heath[8]) it cannot just add on new technologies to old ways of doing things, in other words redesigning for 21st century challenges using 19th century

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templates [9]. If medicine does, it should not be surprised if it fails, after all, if you pour new wine into old wine skins, the wine skins just burst [10].

3 The Internet of Things

The Internet has made it possible to get anything, anytime, anyplace, on any device, any network, for anyone making possible Kevin Ashton's vision of the Internet of things [11, 12]. The recent Pew report expects it to be thriving by 2025 [13]. The Internet of Things is becoming realized in the health domain. Already, movements such as the quantified self (the incorporation of technology to collect personal daily life data using wearable sensors), smart cities (a movement that utilizes Internet-enabled, broadband, wireless and digital equipment in the management by a city of their infrastructure systems for electricity, water supply, waste), and smart homes (a movement that uses automation technologies to provide home owners feedback information by monitoring many aspects of a home) are gaining momentum and further pushing adoption and development. We can therefore visualise the internet of things as a digital ecosystem, whereby technology is no longer a fixed architecture carrying out fixed functions. "Technology can now be seen as a system – a metabolism of things - executing things which can sense their environment and reconfigure actions to execute appropriately."[14]. We can now think of technology in terms of *cognition* e.g. smart machines/smart cities and smart homes.

4 Rate of Technological change

An analysis of the history of technology arguably shows that technological change is exponential, contrary to the common-sense "intuitive linear" view. We won't experience 100 years of progress in the 21st century – it will be more like 20,000 years of progress (at today's rate) [15]. The capabilities of many digital electronic devices are strongly linked to Moore's law in terms of processing speed, memory capacity, sensors and even the number and size of pixels in digital cameras.

In medicine this speed in progress raises questions of identity and personhood. As we get better and better replacing body parts, e.g. cochlear, retina, face transplants, questions of identity are raised and also what it is to be human [16]. If we keep replacing parts at what point will we have lost the original? - A modern reframing of Theseus's paradox. Even the mind is not immune from the possibilities of the Internet![17] One of the most technologically complex events at the Olympics for bionic athletes in Switzerland in 2016 will be the brain-computer interface race, where a competitor who is paralysed from the neck down will race in a computer simulation racing game using a headset that connects their mind to a computer [18].

5 Challenges facing delivery of Healthcare in the 21st Century

There is a consensus that current modes of health care delivery are unsustainable, in both the developed and developing world [19, 20]. From a global perspective, humanity faces profound questions about how our planet can sustain nine billion people by 2050. Current dietary choices and lifestyles are contributing to an unprecedented burden of chronic non-communicable diseases. Life expectancy has increased, and environmental and climate change pose additional new challenges. These factors taken together with a shortage of health professionals and information overload (both what a health professional needs to know and being able to keep current with the literature) contribute to the challenge of healthcare delivery on a global scale [21, 22].

6 Role of Information and Communication Technologies

In the 1990s, health information and communication technologies (ICTs) first offered promise to help mitigate against the problems facing the delivery of healthcare [23]. However, it required the cultural shifts that social media and mobile devices have catalysed since, together with the recognition that many healthcare systems are now at tipping point [19] to galvanize communities working in ICTs and health to integrate the Internet and related technologies into the delivery of healthcare [23]. The Vice President of the European Commission recognises that "Its time healthcare embraced the digital revolution"[24]. By 2025, the majority of the world's population will in one generation having gone from virtually no access to unfiltered information to accessing all of the world's information through a device that fits in the palm of your hand [25] – with each device having more computing power than those which put the first man on the moon [26]. Artificial Intelligence may help overcome the problems of information overload as evidenced by the evolution of IBM's computers Deep Thought, Deep Blue and Watson. In 1989, Deep Thought was beaten by Gary Kaparov at chess only for him to be beaten in 1997 by Deep Blue. In 2011, Watson competed in and beat the two greatest champions of the Jeopardy game show and the latest iteration - Watson, the Debater (2014) can access large bodies of information, extract relevant information, digest and reason on that information and understand the context and present it in natural language, with no human intervention?"[27]

7 Connecting and Collaborating

In twenty years, we have moved from the Web as a collection of linked documents using read only technologies, sometimes called Web 1.0, to the Web as a medium of information exchange, sometimes called the Social Web or Web 2.0, which incorporates both read and write technologies. Recently, many Web researchers and developers are beginning to talk of a Web not of linked documents, but of linked data, sometimes called Web 3.0 or the Semantic Web, in which the data within Web pages

can now be "read" and "understood" by machines [28]. In this brave new world**,** some may say that**,** Facebook defines who we are, Amazon defines what we want and Google defines what we think [29]. The digital age has opened up new niche markets and opportunities under "the long tail" [30] through algorithms and technology known as recommendation systems e.g. customers who bought this product also bought this. The wisdom of the crowd, together with the wisdom of the health professional utilising the power of the Internet opens up the possibility of applying the long tail of economics to the health domain where conditions that previously were not regarded as high priority become more on a level playing field in terms of profile, prevention, management and treatment options.

8 A new digital ecosystem: p4+C^n=e-IMT

The future of medicine is increasingly mediated through preventative, participatory, personalized, and predictive modes known as P4. Digital P4^{TM} Medicine uses a range of technologies from the fields of ICT, medical equipment, and pharmaceutical devices to deliver P4 medicine [31]. In 2003, Leroy Hood introduced the term P4, his vision was that it transform the practice of medicine, moving it from a largely reactive discipline (with an emphasis on sickness and treatment) to a proactive (prevention, self-caring) one [32]. The ambition is that patients will benefit from better diagnoses leading to individually targeted and thus more effective treatments as a consequence of new forms of active participation by patients and consumers in the collection of personal health data, such that a virtual data cloud of billions of health-relevant data points will surround each individual patient, thereby accelerating discovery science and simplifying treatment selection [32].

Underpinning the paradigm shift from a treatment, 'one size fits all' medical model to self-caring medicine employed across a variety of electronic platforms that utilise the Internet, mobile and TV (e-IMT) are collaborative, co-creative, co-design (C^n) principles that encompass an agile iterative methodology that aim to maximize engagement with the user [8]. Too many eHealth projects have assumed that adoption and engagement with the end-user would be automatic once the system was deployed. However, when the systems were deployed, adoption and engagement did not automatically follow and indeed did not happen [33].

9 Health Web Science and Medicine 2.0

Internet delivered healthcare, development, engineering, and how it is used needs therefore to be understood both at the micro level i.e., building and testing applications, and the macro level i.e., studying the use of the microsystem by many users interacting with one another and the emergent properties that arise [34]. This study comes under the overlapping and separate disciplines under the Medicine 2.0 and Health Web Science umbrellas [28, 35]. In essence Medicine 2.0 involves anything that uses the internet as a conduit for healthcare [36] and Health Web Science is a discipline which majors on studying, engineering and designing the web

to improve health outcomes [35]. If you were to understand the spread of diseases, one cannot do it without networks. If you want to understand the WWW structure, searchability and the Internet of Things one needs to invoke the Web's networks. If you want to understand digital health, one needs the overlapping and complementary disciplines of Health Web Science and Medicine 2.0.

10 Evidence Informed Medicine

Modern medical care has been influenced by two paradigms, evidence based medicine (EBM) and patient-centered medicine (PCM). They focus on different aspects of medical care and have little in common [37]. EBM tends to be disease orientated and doctor-centered rather than patient-centered [38]. EBM trials do not necessarily reflect what happens in practice and the trials may only involve a small percentage of people who meet the inclusion criteria. PCM recognizes the patient as the expert living with the condition who has a contribution to bring to the table [39, 40]. A patient-centered approach therefore recognizes that the patient is a source of data and knowledge and an integral part of the development team (co-development) when designing an intervention. In medicine there is often no correct treatment; the right treatment for a patient involves factors not often articulated or considered within the healthcare systems. For example, some patients prefer natural approaches while others prefer the latest technology, some patients are risk takers and others are conservative [41]. Furthermore, human agency is complex, nuanced and subject to a host of influences such as cultural and symbolic meanings, practical constraints and personal priorities and therefore the logic of care is non-linear and unpredictable [42]. In each of these dimensions, the degree to which the preference is held is a factor in settling on the correct treatment choice. The EBM paradigm is therefore shifting to evidence informed medicine and the formulation of personalized models of care. Notably, the personalized model of care is informed by, but not based on, the E of EBM [43]. There a shift to evidence informed medicine and an increasing recognition that mixed methods approaches are needed, i.e. those that involve both qualitative and quantitative methodologies in the evaluation of the digital delivery of healthcare [44, 45]. Indeed, increasingly, mixed methods design is being used to address the challenges of effective patient care and to understand the role of consumerism in promoting high quality healthcare services.

11 Behavioural Model

The effectiveness of Internet-based health interventions is connected with the adoption of the appropriate behavioural framework [46]. The behavioural model evolving in the North of Scotland is emerging from:

1. The importance of social networks in health e.g. obesity can arguably be 'spread' by person-to-person interaction through the normalization of obesogenic habits [47].

2. The" Social Physics" of Massachusetts Institute of Technology's Alex Pentland [48]which acknowledges the differential impact of strong and weak ties and the impact of rewards not only on the targeted individual but also their "buddies" in changing behaviour and the social fabric to sustain that change(http://www.youtube.com/watch?v=HMBl0ttu-Ow).

3. The Nobel prize winner psychologist Daniel Kahneman and his model of fast and slow thinking [49]. Kahneman presents our thinking process as consisting of two systems. System 1 (Thinking Fast) is unconscious, intuitive and effort-free and results in our behaviours. System 1 is influenced by peer to peer learning and the social environment .System 2 (Thinking Slow) is conscious, uses deductive reasoning and is hard of work. Most of our health information targets system 2 and has minimal impact on system 1. System 1 is the area that Alex Pentland's work suggests is amenable to change through strong and weak ties.

4. Richard Thaler and Cass Sunstein's Nudge theory [50] which argues that the use of positive reinforcement and indirect suggestions through non-forced compliance can influence the motives, incentives and decision making of individuals and groups.

5. The potential of Internet games to promote behavior change in prevention and treatment use suggests that "gamification" may improve the effectiveness of traditional health interventions to motivate behavior change and can thereby lead to better health outcomes [51].

In brief, the behavioural model contributes to the improvement of health outcomes by achieving behavioural change through the nudges of rewards not only of the targeted individual but also their buddies through the medium of social media including gamification. These nudges aim to target system 1 and by changing the culture that individual is in make sustainable changes in behaviour.

12 Big Data

Handling the quantity of "big data" generated from the Internet of Things through curation, visualisation and interpretation of data are fertile areas for innovation [28, 35]. Analysis of "big data" will be instrumental in bringing about the "healthcare singularity" [21] when the speed of medical innovation enables research findings to be put into clinical practice instantaneously (in theory). This finding-to-practice lag time has continued to decrease, linearly, with the current lag approximately 17 years from research finding to accepted clinical practice [21]. The Internet has already shown promise as both an instrument in reducing this lag time further and as a medium for new medical insight using "crowd wisdom". Looking for an association between Gaucher's disease and Parkinson's Disease using traditional research methodology took 6 years whereas using the Web took 8 months with similar results

[52]. PatientsLikeMe are sharing and distributing medical data and sharing their own research and publishing in journals. They recently correctly reported lithium's lack of efficacy in the treatment of Amyotrophic Lateral Sclerosis thereby reaching the same conclusion as subsequent randomized trials [53]. These two examples therefore suggest that data reported by patients over the internet may be useful for accelerating clinical discovery and evaluation.

The data from the Internet is turning prediction into an equation [7], and qualitative predictive models of human behaviour can be written. These models can be used to overcome the problem of cognitive bias and gain insight into health behaviours and conditions looking for the predictive power of patterns and possibly find new solutions [28, 35]. However caution must be highlighted – the data is so big that everything is significant and the scientific method no longer works. False correlations are commonplace and new ways to test the causality of connections are urgently required – correlations do not necessarily mean causation and to overfit is human [54].

13 Innovation and Evaluation

There is a growing awareness that Internet interventions work, but as yet, it is unclear for whom, for what behaviours, and for which medical conditions [46]. There is an increasing awareness that new methodologies in design and evaluation of Internet interventions are required. The fixed milestones of traditional research where a timeline of activity is planned and inflexible need to be evaluated alongside agile, iterative participatory action research. A change in thinking by the grant awarding bodies are also required to fund these new methodologies. The Digital Health Institute in Scotland is exploring this new landscape [55]. In many ways innovation is not the problem, there are many good pilots out there but because people work in silos no one knows about them. An infrastructure must be in place to allow ideas to be scaled up, scaled out and scaled in, and where necessary, stopped.

14 Conclusion

This paper is a call to action. Healthcare is broken and new solutions are needed for the problems facing 21st century medicine. The time to act is not yesterday, or tomorrow, but now. The challenges facing medicine are the same and also different from those we faced at the beginning of the 19th century. The biomedical model of germ theory has served us well – however it is now no longer enough. It's time healthcare embraced the digital revolution, and not only that, but healthcare also needs new infrastructure underpinned by the disciplines of Health Web Science and 2.0.

nature creates the stage upon which mankind acts - that time to act is now

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