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Formulating eHealth Utilizing an Ecological Understanding

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5.1 Introduction

Health care is a complex adaptive system, which requires an integrated and participatory approach to understand and improve the health of citizens (Rouse 2008). To address the complex societal challenges facing health-care delivery (Crisp 2010; WHO 2011) caused by ageing populations, globalization, and long-term/chronic conditions, a shift from the traditional reactive model to a proactive, patient-centric health-care model is advocated (Wanless 2002; WHO |World Health Statistics 2011). Furthermore in addition to the traditional biomedical model of delivering health care (principally targeting infectious diseases), psychological, social, environmental, and cultural factors are increasingly recognized to impact on human functioning in the context of disease and illness (McHattie et al. 2014). The future of health care therefore requires increasing effort directed toward improving personal choices regarding life risks (Keeney 2008) and requires the full engagement of people in their own health-care and lifestyle decisions (Wanless 2002; Crowley and Hunter 2005).

The biopsychosocial (BPS) model was theorized in 1977 as a “blueprint for research, a framework for teaching, and a design for action” for the “social, psychological, and behavioural dimensions of illness.” (Engel 1977) The implications of the BPS perspective have been described (Hickey 2013). These are:

1. The individual is the *only* person who can effect the behavioral change, though they might need some help, from family, friends, colleagues, or professional helpers.
2. In those cases where professional assistance seems needed, the blueprint for effective assistance is: (a) to help the individual understand the factors/circumstances that brought about the problem in the first place, (b) to help the individual identify and define the problem in specific terms; perhaps dismantle the problem into component, (c) to encourage a sense of competence and empowerment, and (d) to develop, with the individual, specific plans for replacing sub-optimal habits with habits that are more productive.

However, some argue that the model is open to interpretation and that the BSP model “is a vision and an approach to practice rather than an empirically verifiable theory” (Epstein and Borrell-Carrio 2005). As such, an ecological understanding of health, based on the reciprocal relationship between three interrelated dimensions involving: “the naming or identification of health statuses and conditions, health/illness as forms of capacity and capability, and health/illness as it is perceived by those who have it” (DeNora 2015) provides a way in which to consider the complexities of health. An ecological understanding of health considers health as multidimensional and temporal, influenced by intrinsic and extrinsic factors (DeNora 2015). In this approach, health is in a state of flux, it is constantly changing based upon the external influences upon the individual. By adopting an ecological understanding of health, medicine can become personalized to the individuals needs based on lived experience rather than a streamlined process based on biomarkers and predictive modeling (precision medicine).

Social media has provided a new way for patients to obtain and share information that enables a deeper understanding of their medical condition and treatment options (Eysenbach and Jadad 2001; Medicine 2.0 2008). Medical researchers, doctors, government policy makers, and others, are also making use of the Web, social media applications, and the large volumes of data produced. When applied to the process of utilizing information communication technologies (ICTs) to deliver health care, an ecological model of health may provide a lens, or frame of reference, through which to design, implement, interrogate, explore, and evaluate the effects of these interventions. It also provides a framework to observe how P4 medicine (P4 Medicine Institute) (personalized, participatory, preventative, and predictive) and in particular Digital P4 Medicine (Highlands Islands Enterprises 2012) impacts on health care and its delivery.

5.2 Major Concepts

As knowledge about individual variation in genomics, genetics, proteomics, epigenetics, and drug response increases; an evolution from a “one size fits all” model to precision medicine with personalized treatment

protocols is possible. The understanding of these complex relationships is being explored in the emerging fields of systems biology (P4 Medicine Institute) and Big Data analytics (Hansen et al. 2014; Shiao et al. 2015). In addition, the participation of citizens in health-related digital social networks (Denecke 2014b) means that information from these sites can be correlated with those from systems biology and insights gained for the health of that individual (Hood 2013). This digital participation of citizens in their health has contributed to the health professional–citizen relationship becoming an increasingly shared model of decision-making (Elwyn et al. 2012). Gender-specific medicine (Legato and Bilezikian 2009) and a life course approach to health (Schafer and Ferraro 2012) further tailor treatment plans to the end-user. The academic disciplines of Health Web Science (HWS) (Luciano et al. 2014) and Medicine 2.0 (Medicine 2008) with the development of Health Web Observatories (HWO) (The Web Science Trust 2016) provide an infrastructure to develop tools utilizing metadata for further personalization of medicine and to evaluate Internet provided health care within a P4 framework. Health care provided through the conduit of the Internet, that employs an effective behavioral model (Murray 2012), may have a pivotal role in changing health behaviors. However current evaluation and impact of Internet delivered health care is limited not only in cost utility and cost effectiveness (Torre-Díez et al. 2015; Bergmo 2015) but also in its scope in terms of feedback and interaction between the Health Web, health-care providers, and patients.

5.2.1 Preferable Health Outcomes

Providing health care in an increasingly patient-centered way can achieve preferred health outcomes (Hancock and Bezold 1993). These are the health outcomes, which are preferred by patients and involve a balance between medical evidence and the patients' wishes. This can be thought of as personalization of health care, which through dialogue takes the best medical evidence and information available and creates a management plan that fits with the patient's lifestyle and preferences. However, these preferable health outcomes may be a compromise on best medical evidence to accommodate the patient's wishes.

5.2.2 Gender-Specific Medicine

Gender-specific medicine is the study of how normal human biology, physiology, and diseases differ between men and women in terms of prevention, clinical signs, therapeutic approach, prognosis, and psychological and social impact (Legato and Bilezikian 2009). This field can contribute to the personalization of health care through recognizing that disease affects gender differently. Currently, the discourse on gender-specific medicine has not yet addressed transgender medicine.

5.2.3 Life Course Approach

A life course approach to health acknowledges the long-term effects of biological, behavioral, and social exposures during gestation, childhood, adolescence, and young adulthood on health and chronic disease in later life and across generations. It therefore recognizes the influence of genetics, epigenetics, gender, and lifestyle and environment on health and attempts to understand and predict health trajectories throughout the lifetime of individuals (Halfon and Hochstein 2002). Mitigating against potential health problems with early intervention including lifestyle/behavioral changes then becomes part of the P4 health ambition. The life course approach therefore allows the possibility of intervention before childhood adversity poses a health threat to successful aging (Schafer and Ferraro 2012).

5.2.4 Health Web Science and Medicine 2.0

HWS is a subdiscipline of Web Science (Luciano et al. 2013, 2014; Denecke 2015) that complements and overlaps with disciplines under the aegis of Medicine 2.0. HWS studies the role and impact of the Web on health and well-being and conversely the impact of health-related uses of the design of the Web structure and evolution that explicitly includes an alliance with nonmedical stakeholders. Medicine 2.0 or

next-generation medicine enabled by emerging technologies (Medicine 2.0 2014) on the other hand emphasizes anything that uses the Internet as a conduit to deliver health care.

5.2.5 Health Web Observatory

The Web Science Trust hosted by the University of Southampton is a charitable body, which supports the global development of Web Science (Web Observatory 2016). The Trust introduced the concept of a Web Observatory 2016 as a collection of data sources and data analytic tools that enable experimentation on the Web (Hall and Tiropanis 2012). Web Observatories work by the insertion of metadata into a website and using software to associate these sites. Examples of this may be the connection of disparate data sources to find out something new, or the targeting of a community or website to change some variable and assess its impact.

An HWO is a system that is envisioned to provide an infrastructure to ask and answer questions about the Health Web, the users of the Health Web, and the way that each affects each other within the domain of health-related uses, based upon a collection of metadata, disparate data sources, and Health websites (Fig. 5.1). It will be a key tool to informing the decision-making process to reach a preferred health outcome.

An HWO requires three capabilities. First, the ICT infrastructure that provides the capability to interrogate, curate, visualize, and make sense of health-related data from disparate databases. Second, the health professionals interface that provides (a) the capability to identify individuals who function as the main connectors in a health social network (b) be able to target these individuals with relevant health information, and (c) for health professionals to be able to assess the stage of health behavior change a person is in (Prochaska and Velicer 1997). Third, the individual's interface, required to provide the confidence and trust that the individual is not being manipulated for nefarious reasons and thus to be able to research and share information according to their personal values.

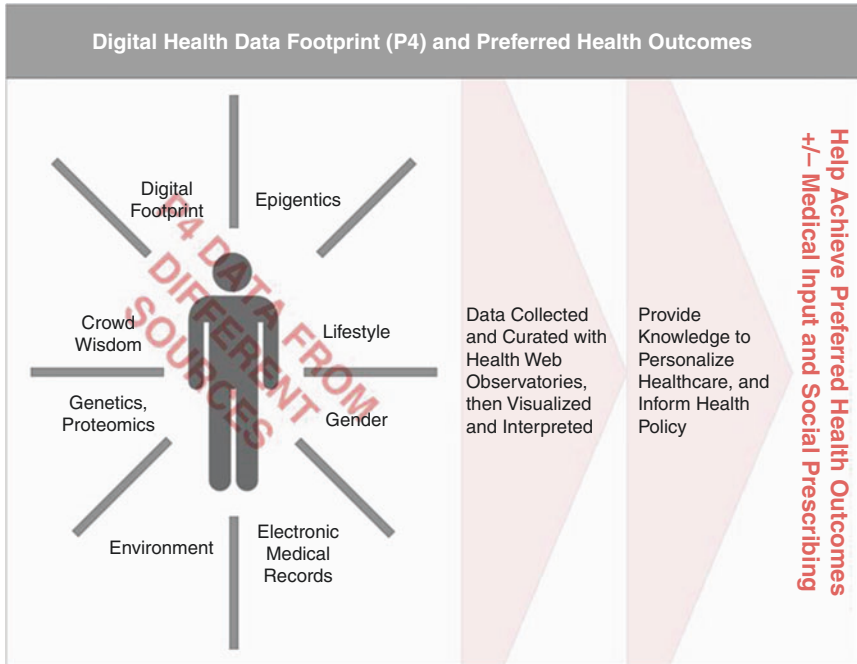


Fig. 5.1 Health Web Observatory

5.2.6 Metadata

Metadata is structured information that describes, explains, locates, or otherwise makes it easier to retrieve, use, or manage an information resource (NISO Press 2004). Metadata therefore allows navigation across data repositories to efficiently find, manage, and track information and allows the creation of associations and relationships between items and users across one or more repositories or related applications. The value of metadata lies in its ability to more efficiently classify and organize information, as well as to yield deeper insight into the actions taking place (M-Files 2013). In the HWO (Fig. 5.1), metadata will give insight into the many ways each citizen engages with the Health Web, for example, the path a citizen takes when clicking through a website, how long they stay on a page, and what content is selected in addition to

capabilities described in [Section 2.5](#). It will also address the question – does an online intervention change health policy as a result of community activism? Metadata therefore makes possible the individualization of health care to each personal circumstances.

5.2.7 A New Digital Framework: $P4 + C^n \times (i\text{-DMT}) = H$

The Internet has the potential not only to play an important positive role in facilitating interventions that can result in more health-promoting behaviors and better health trajectories (Kahana et al. 2014) but also can be envisioned as affecting health in its wider context (environments and policy). A formula can be constructed: $P4 + C^n \times (i\text{-DMT}) = H$ ([Fig. 5.2](#)) as a framework to consider the effect of digital interventions at the individual level from the perspective of either the citizen, health professional/policy maker, or at the population level. The equation therefore describes an HWO and gives a “value” of the state of health (H) at a point in time. This formula can be used as an evaluating tool to judge the quality of a health website or activity.

Here, P4 is how personalized, predictive, participatory, and preventive the application is. If the formula is visualized as a single action this may be a measure of how interactive the application is. C^n represents the various effectors on the systems, for example, how collaboratively the intervention was designed or how interactive the application is with multiple users. i-DMT are the technology platforms through which a citizen may be exposed to health care using the Internet as a conduit and is comprised of eHealth via “D” laptop/desktop computer, M-Health (mobile health) such as tablets and smartphones, and T-Health or exposure through the television. i-DMT can be viewed as a measure of accessibility to the information.

The challenge to the HWS community is to develop tools that measure H and inform which of the other component parts of an HWO need to be changed to close the difference between current health and a preferred health outcome. From this “gap analysis” a feedback loop is provided that informs future interventions and policy. The authors are developing an ecological model incorporating digital P4 principles, which can be captured and evaluated in the formula in [Fig. 5.2](#).



Fig. 5.2 Formulating health care

5.3 Exemplars from Elderly Citizen Use of the Internet for Health, Women's Health, and Sanitation

Web-enabled models with personalization of health care, citizen empowerment, and their potential influence on health behaviors support the argument that there is benefit to be gained from a move from more traditional medicine. The work from Case Western University emphasizes the benefits to be gained among older individuals while work from the UK will provide some reflections from the development of selected applications. In both communities the Internet is increasingly used for Health Information and associated activities. The underlying principles of the applications include a collaborative iterative approach to design within a P4 framework using an ecological approach.

5.3.1 Aging Work at Case Western Reserve University

The rapid growth of the older population globally has raised important questions about changing resources, lifestyles, and adaptations of older adults that can enhance health, psychological well-being, and longevity. Older adults of tomorrow want to take increasingly active roles in their health maintenance and health care. They engage in proactive adaptations that can serve to prevent normative stressors of aging (Kahana et al. 2014).

Research on the digital divide emphasizes underuse of computer technology by older adults (Peacock and Künemund 2007). Yet, older users of computer technology gain a major advantage by bridging the generation gap and becoming active members of an information society (Godfrey and Johnson 2009). In a health care context the Internet offers major access to both health information and health communication (Kahana and Kahana 2007). Use of computers has grown exponentially in recent years and the Web has helped facilitate proactive adaptations and initiative and assertiveness among elderly health-care consumers (Selwyn et al. 2003) and is likely to have contributed to more enlightened health beliefs in linking health-promoting life styles to avoidance of chronic illnesses, such as diabetes and cancer.

Longitudinal studies (Kahana et al. 2002; Kelley-Moore et al. 2006; Kahana et al. 2012, 2013) of successful aging in retirement communities and urban settings in the USA, afforded an opportunity to consider changing orientations and patterns of proactive behaviors of older adults. 1,000-retirement community-dwelling older adults were followed in annual face-to-face surveys and also conducted interviews with urban-dwelling elders in two large metropolitan areas. These elders were surveyed about use of the Web at different time points between 1995 and 2014. Internet use increased from 4.5% in the 1995 cohort to 40.5% in the 2008 survey. The findings indicate increasing comfort among elderly users of the Web. Indeed those who reported computer use generally did so on a daily, or at least weekly basis. It was found that older adults who use the Internet for health information and health communication are more confident in their interactions with physicians and their confidence bolsters their positive expectations regarding medical care. The elderly are not inclined to participate in Web-based support groups.

The growing reliance on cell phones has opened up many new opportunities to older adults regarding health monitoring and health-promoting activities. Smart phones offer an effective tool for promoting behavioral change, such as improving diets and increasing physical activity (Seçkin and Kahana 2015).

Older adults have traditionally been reluctant to speak up to their doctors and engage in self advocacy in obtaining health care (Kahana et al. 2014). Yet, active communication in health care and shared decision-making between patients and physicians can greatly benefit older patients (Kahana et al. 2011; Kreps and Maibach 2008). It was found that older adults who use the Internet for health information and health communication are more confident in their interactions with physicians and their confidence bolsters their positive expectations regarding medical care.

5.3.2 Nappies, Miscarriage, Toilets, and Menopause

It was found that preliminary evidence suggested that after providing information online about the use of disposable and reusable nappies that the Internet has the potential to change behaviors when (Miller et al. 2011)

people's beliefs were being nudged to enable them to see advantages in the use of reusable nappies. The persuasive factor was the reduction in landfill. In the formula in Fig. 5.2 the website would not have resulted in an optimal score as it was a read only website. However the information presented had been developed with the end-user and the website has now been redeveloped to provide information for the region.

The miscarriage website was designed in collaboration with end-users and using a modified patient preference design demonstrated the potential of a web-based intervention to reduce psychological morbidity following miscarriage (Klein et al. 2012) and therefore positively impacting on health outcomes. As it is only delivered on one platform it would not produce an optimal score in the formula than if the intervention was delivered on multiple platforms. Compared with the nappy example the website is participatory and preventative. Further work is required to ascertain whether or not it needs to be delivered on other platforms and research is being undertaken to see if a questionnaire can be developed to predict psychological morbidity to improve the predictive utility of the website.

A website for rating and finding public toilets was built after showing the need for better access to toilets in an online survey (Cumming et al. 2011). This has not been a success in terms of uptake despite positive feedback. A mobile app is currently being developed, which would enable access to public toilet information when the need arises. The website capability is limited by the fact that people need to plan ahead for their toilet requirements and does not allow for the unpredictability of the need to use the facilities. Thus an app would provide additional capability and the expectation would have a value closer to optimal in Fig. 5.2. Further work is required to address this question in practice.

www.menopausematters.co.uk is a patient-tailored, physician-led website which, although partly dependent for funding on pharmaceutical sponsorship, remains independent of the industry. The site aims to educate women and health professionals and to empower and enable women to be proactive in the management of their menopause promoting evidence-based practice and recommendation. The site was created in consultation with the end-user through feedback questionnaires. Through online surveys, the website obtains “snapshots” of Internet literate women's views on

all aspects of their menopause experiences and provide feedback to them and their health professionals in peer-reviewed journals and national/international conferences. Preliminary evidence has suggested the power of online storytelling to empower women to seek help for their vaginal atrophy and the information is used to educate health professionals to enquire directly about this symptom of the menopause thereby changing citizen behavior and health professional practice/policy. While www.menopausematters.co.uk allows health professionals and women to select expertly prepared information (Web 1.0) or interact with one another (Web 2.0) via the forum, it is limited with respect to personalization. It is envisaged that www.menopausematters.co.uk will work closely with www.managemymenopause.co.uk (Cumming et al. 2016). The main aims of www.managemymenopause.co.uk are to provide more personalized health care. www.managemymenopause.co.uk utilizes a patient questionnaire and three risk prediction tools to generate a tailored advice document that provides risk advice and information on lifestyle modification and pharmacological interventions. The website will “remember” a woman and can therefore tailor the information to the woman as she ages or as the information underpinning the management of menopause changes. Virtual clinics are becoming increasingly utilized within the United Kingdom National Health Service (NHS). A novel evolution of virtual clinics using digital technology to deliver and facilitate patient engagement with health provision is NHS Grampian’s No Delays (see Chapter 11). A menopause component is in the process of being designed.

5.4 Conclusions

An HWO and a new digital framework for evaluating and developing digital interventions is one of the responses to a growing consensus that current health models are unsustainable. Furthermore, medicine is also moving from a reactive to a proactive model of health care. Information and communication technologies (ICTs) utilizing the Internet are having an increasing footprint in the delivery of and personalization of health care with the convergence of social networks and precision medicine. Embracing a new digital framework within an ecological model of health,

it is suggested that medicine utilizing ICTs, which is personalized, predictive, participatory, and preventive (P4), has the potential to change health behaviors and health policy. The exemplars have demonstrated elements of digital P4 medicine and the use of a pragmatic formula for evaluating the intervention. Older adults who use the Internet for health information and health communication are more confident in their interactions with health professionals and their confidence bolsters their positive expectations regarding medical care. HWO aimed at curating metadata from websites and Web data have the potential to increase the utility of social networks, social machines, documentation, and online interventions. However, the challenge to the Web Science and Medicine 2.0 communities is to develop new tools to enable the triangulation of data to understand end-user interaction with the Web and thus identify new integrated strategies for preferable health outcomes.

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