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How Participatory Health Informatics Catalyzes One Digital Health

Kerstin Denecke[1], Octavio Rivera Romero[2,3], Mark Merolli[4,5], Talya Miron-Shatz[6,7], Elia Gabarron[8,9] Carolyn Petersen[10]

[1] Bern University of Applied Sciences, Bern, Switzerland
[2] Instituto de Ingeniería Informática (I3US), Universidad de Sevilla, Sevilla, Spain
[3] Electronic Technology Department, Universidad de Sevilla, Sevilla, Spain
[4] Department of Physiotherapy, School of Health Sciences, the University of Melbourne, Australia
[5] Centre for Digital Transformation of Health, The University of Melbourne, Australia
[6] Faculty of Business Administration, Ono Academic College, Israel
[7] Winton Centre for Risk and Evidence Communication, Cambridge University, England
[8] Norwegian Centre for E-health Research, University Hospital of North Norway, Tromsø, Norway
[9] Department of Education, ICT and Learning, Østfold University College, Halden, Norway
[10] Mayo Clinic, Rochester, Minnesota, United States of America

Summary

Objective: To identify links between Participatory Health Informatics (PHI) and the One Digital Health framework (ODH) and to show how PHI could be used as a catalyst or contributor to ODH.

Methods: We have analyzed the addressed topics within the ODH framework in previous IMIA Yearbook contributions from our working group during the last 10 years. We have matched main themes with the ODH's framework three perspectives (individual health and wellbeing, population and society, and ecosystem).

Results: PHI catalysts ODH individual health and wellbeing perspective by providing a more comprehensive view on human health, attitudes, and relations between human health and animal health. Integration of specific behavior change techniques or gamification strategies in digital solutions are effective to change behaviors which address the P5 paradigm. PHI supports the population and society perspective through the engagement of the various stakeholders in healthcare. At the same time, PHI might increase a risk for health inequities due to technologies inaccessible to all equally and challenges associated with this. PHI is a catalyst for the ecosystem perspective by contributing data into the digital health data ecosystem allowing for analysis of interrelations between the various data which in turn might provide links among all components of the healthcare ecosystem.

Conclusion: Our results suggest that PHI can and will involve topics relating to ODH. As the ODH concept crystalizes and becomes increasingly influential, its themes will permeate and become embedded in PHI even more. We look forward to these developments and co-evolution of the two frameworks.

Keywords

Participatory health informatics; one digital health; one health; social media

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1 Introduction

The One Health (OH) concept is based on the idea that health must be considered from a broader perspective, exceeding the individual and even society, and including all existing interconnections between humans, animals, plants, and the global ecological environment. OH defines an interdisciplinary approach to deal with human health, animal health, and the surrounding environment [1, 2]. It was first put forth in the 12 Manhattan Principles, a statement of an international, integrated, interdisciplinary approach to preventing communicable disease involving animal-human transmission [3]. This approach has gained the support of the World Health Organization, which has associated OH with sustainable development goals [4–6] .

Digital technology plays a crucial role in this interdisciplinary and holistic view defined by OH. The digital transformation has rapidly enhanced scientific knowledge development leading to improvements in the healthcare and wellbeing domain. One of the main causes of these improvements is the availability of large amounts of data. Data is considered the key component to develop new and improved healthcare and wellbeing services as the ones proposed in the 5P medicine (predictive, personalized, preventive, participatory and precision). However, these volumes of data are not available without active citizens' engagement and participation. Therefore, digital health research domains, particularly participatory health informatics (PHI), must be integrated into the OH approach. PHI is "a multidisciplinary field that is applied to medical conditions, uses information technology, and studies the effects of the use of tools. PHI provides resources and delivers tools supporting active participation, and focuses on individual-centered care, individual-centered self-management, and individual-centered decision making" [7]. One Digital Health (ODH) is a framework aimed at facilitating and improving collaboration among practitioners in OH and digital health communities. ODH integrates the technological research domains into the interdisciplinary research proposed by OH.

The objectives of the current work are to identify links between PHI and ODH, and to show how PHI could be used as a catalyst of or contributor to ODH.

2 Material and Methods

We consider as a starting point the unified framework [8] proposed by Benis *et al.* This framework is composed of three intertwined levels surrounding One Digital Health at the center: 1) an innermost level that includes One Health and Digital (keys to ODH), 2) a middle level that incorporates the ecosystem, population and society, and individual health and wellbeing (influential perspectives), and 3) an outermost level that adds the dimensions of the environment, human and veterinary healthcare, digital healthcare transformation 4.0, citizen engagement, and education. A technology ring interlaid between the perspectives and dimensions levels represents the role of technology as a catalyst for One Digital Health-ness. Adopting the ODH paradigm, industry 4.0-related technologies could be used to manage individuals' health data (including human and animal) and be integrated into environmental systems.

Members of our IMIA Participatory Health and Social Media Work Group (WG) have addressed topics that are mentioned in this framework in previous IMIA Yearbook of Medical Informatics (YB) contributions. In this paper, we are matching the addressed themes in contributions from our WG to the YB during the last 10 years with the ODH framework (Table 1). Based on this match, we provide examples on how social media and PHI can support the ODH's overall goal and discuss how social media and PHI could be the catalyst proposed in the framework.

Table 1 Considered YB papers with perspectives and catalyst factors of the ODH framework.

Year	Paper title	Perspective	Catalyst factors
2022	Social Media, Digital Health Literacy, and Digital Ethics in the Light of Health Equity [9]	Population and society	Digital health literacy as determinant impacting health equity
2021	Role of Participatory Health Informatics in Detecting and Managing Pandemics [10]	Individual health and wellbeing	Social media data as source of information to complement traditional disease surveillance data; and promotion of vaccination
2020	Ethical Considerations for Participatory Health through Social Media: Healthcare Workforce and Policy Maker Perspectives [11]	Population and society	Identification of challenges of PHI solutions for both patients and clinicians
2019	Artificial Intelligence for Participatory Health: Applications, Impact, and Future Implications [12]	Ecosystem	Identification of risk factors and population trends in diagnosis; Support in predicting patient's health issues
2018	Balancing Between Privacy and Patient Needs for Health Information in the Age of Participatory Health and Social Media: A Scoping Review [13]	Population and society	Identification of challenges of PHI solutions for both patients and clinicians
2017	Secondary Use of Recorded or Self-expressed Personal Data: Consumer Health Informatics and Education in the Era of Social Media and Health Apps [14]	Ecosystem	Impact of PHI big data on data collection in healthcare
2016	The Unintended Consequences of Social Media in Healthcare: New Problems and New Solutions [15]	Individual health and wellbeing	Integration of behavior change techniques and gamification in PHI solutions
2015	Ethical Issues of Social Media Usage in Healthcare [16]	Population and society	Social media as support of a range of forms of engagement
2014	Transforming Health Care Delivery Through Consumer Engagement, Health Data Transparency, and Patient-Generated Health Information [17]	Ecosystem	Impact of PHI big data on data collection in healthcare
2013	Social Media for the Promotion of Holistic Self-Participatory Care: An Evidence Based Approach [18]	Individual health and wellbeing	Acceptance of the PHI technologies as complementary mediums to achieving ODH

3 Findings and Discussion

YB contributions from our WG during the previous 10 years indicate that some topics were explicitly aligned with the ODH framework (*e.g.*, citizen engagement, digital health literacy) and others (*e.g.*, ethics, secondary data use) were embedded more generally throughout ODH keys, perspectives, and dimensions. We present analysis on topics with more concrete connections to ODH framework perspectives.

3.1 ODH Perspective: Individual Health and Wellbeing

PHI enables the ODH perspective of 'individual health and wellbeing' in multiple ways. A decade ago, members of the WG examined the increasing role social media were having on how individuals engaged with their own health and wellbeing in a shared decision-making (participatory health) paradigm [18]. PHI as underpinned by global movements such as the paradigm shifting 'ePatients' movement, is responsible for much of the acceptance of the Internet and social media as holistic complementary mediums to achieve OH [19]. Over the past decade, evidence-based frameworks have enabled us to view PHI with more rigor. For example, in our 2013 YB paper [18], the traditional 'health belief model' was described within a social media paradigm; and how various social media contribute to select beliefs and attitudes and help to predict behaviors. As another example, the SCENA model [20] (self-presentation, connection, exploration, narration, adaption) is also an evidence-based informatics model centering around the therapeutic affordances of social media that proposes ways in which social media may be used by individuals to support OH within a PHI framework (*e.g.*, activities like health information seeking, connection to others online).

One of the enduring challenges in PHI research continues to be a tension between what has traditionally been accepted as high quality evidence (*e.g.*, systematic reviews and clinical trials) and evidence generated by social media and other self-quantifying technologies. In the 2013 YB paper [18] it is suggested that evidence about health generated through social media analysis, or N=1 personal case-studies through collection of person-generated health data should not be ignored and increasingly be seen as complementary to traditional evidence-based research methods. Even more recent digital health research has voiced support for this, noting that evaluation of digital health intervention efficacy requires some room in how research is conducted and evaluated. Hence, a more contemporary attitude and approach to health informatics research evidence in this regard may support synthesis of new knowledge about human health to advance the ODH ideal.

The 2016 YB paper [15] shows how ODH is also supported by timely delivered services that integrate behavior change techniques in PHI solutions aiming at educating and promoting health to the population and society. As exemplified, public health organizations from around the globe have integrated behavior change techniques in their social media campaigns, and in timely developed chatbots during the COVID-19 pandemic aiming at improving health literacy, increasing global health security and reducing health-related misinformation [21]. The use of gamification has also proven to be effective to educate individuals to prevent conditions [22, 23], and also to improve their self-management skills [24], and therefore to play a key role in engaging citizens with their individual health and wellbeing.

PHI also supports the ODH framework through evidence-based knowledge on how to incorporate behavioral change techniques or gamification in digital health solutions at individual level. Our behavior is key for preventing, maintaining, managing and treating health conditions and disabilities [25]. Certain behaviors that increase the risk of developing or aggravating chronic, acute and infectious diseases could be modified through behavior change techniques [26], and/or gamification, defined as "the use of game design elements in non-game context" [27, 28]. PHI research shows that the integration of specific behavior change techniques or gamification strategies in digital solutions are effective to change behaviors that lead to a better individual health and wellbeing [23]. As exemplified, PHI research evidences that the integration of behavior change techniques "feedback and monitoring" and "goals and planning" in smartphones and activity trackers or gamification interventions have proven to be effective in increasing physical activity [29]; or the use of game elements is effective to engage children to establish healthy eating behavior [30]. Although these examples show how PHI research supports the ODH framework, more PHI research is needed to identify the best behavior change techniques and gamification strategies to prevent or improve specific health issues, to maintain the desired behavior effects over time, or to personalize behavior change techniques and/or gamification strategies in digital solutions for a better individual and global health.

The 2021 YB paper [10] shows that analyzing social media data provides an additional source of information to complement traditional disease surveillance data. Social media data can be used for disease surveillance, tracing or even predicting case numbers. Through social media not only for data on human and human health surveillance, tracing or predicting, is distributed, but also to do observations on the environment or on animals. Thus, it can provide a more comprehensive view on human health, attitudes and relations between human health and animal health. In this way, PHI supports ODH in the management of zoonotic diseases and in providing services to clusters of patients.

3.2 Perspective: Population and Society

In the 2015 YB paper [16] issues are discussed that are central to citizens' engagement in their health and healthcare, but are also foundational to the development and maturation of the ODH. The use of social media supports a range of forms of engagement – patient to healthcare provider, patient to clinical researcher, and patient to patient among them – and while human connection is a key aspect of these engagements, the effects of such connections on participants may be both positive and negative [16]. Peer-to-peer support, social networking communities, and data sharing platforms (*e.g.,* PatientsLikeMe) have the potential to

reduce barriers such as physical distance [31, 32] and access to care [33, 34], as well as to create a sense of community virtually. Such attributes may be crucial to the advancement of the ODH approach. Networking technologies also create other opportunities: they can be used to train older adults and their caregivers, can expand social connections among youth whose health prevents them from interacting with peers in person, can support crowdsourcing for ideas and resources, can be used to gather and transmit patient-reported outcomes data, can accelerate clinical trial recruitment, and can advance the patient-clinician relationship [16].

However, as discussed in our 2018 YB [13] and 2020 YB [11] contributions, these opportunities come with corresponding challenges for both patients and clinicians. Individuals may initially find that social media and networking platforms support their healthcare journey, but later experience harms such as harassment [35] or cyberbullying [36], encouragement of dangerous practices [37], or even health problems arising from excessive use of networking tools [38]. Clinicians may be subject to additional concerns, including the loss of license following activity that is deemed unprofessional [39], difficulty terminating social media engagement with patients [40], general disparagement of the profession leading to challenges in face-to-face relationships with patients [41], or violations of patient privacy and confidentiality expectations or legal requirements [42]. To succeed in terms of engagement with patients, ODH activities will need to include features that protect patients and clinicians from misbehavior enabled by the technology as well as features that facilitate meaningful engagement that advance positive health outcomes and general wellbeing.

Information accuracy is an important consideration within the ODH ecosystem, explored in the 2021 YB. Equally important is the prevention of the spread of misinformation that can easily spread through social media. Within the ODH approach social media can be used to establish and support a systemic and integrated understanding of the health and wellness of humans and animals in their common ecosystem, incorporating basic and transversal knowledge in educational programs for all levels and disciplines. Such programming must provide a knowledge base around health and its digitalization that allows differentiation of evidence-based information and fake news [10, 43]. The provision of learning opportunities to citizens so they can protect and take care of themselves when they share personal data on social networks is another important way in which social media and networking tools can support ODH.

Globally, there is increasing recognition of inequities regarding access to care and health outcomes, as well as growing efforts to address health disparities that result from health inequities [44, 45]. Such efforts include a broad range of approaches and tactics that, together, support the ODH framework. Social media, networking platforms, and PHI devices such as wearables can advance ODH where existing healthcare systems and infrastructure are already in place and where community involvement in problem elicitation and solution development are priorities. Informatics professionals have already envisioned a role and implementation strategies for citizen science as a way to address health inequities within ODH [46].

In the 2022 YB contribution [9], digital health literacy was highlighted as a key determinant impacting health equity. Whilst health literacy refers to how individuals access, interpret and use information about health, digital literacy may be viewed as how people access, interpret and use technologies to make light of information. When viewed together, we have digital health literacy [47]. Similar to what has previously been discussed in this paper, the very ideal of supporting individuals to be active shared decision-makers in their own health requires an inherent view of healthcare consumers as engaged, empowered, and equipped. This includes being digitally enabled [48]. Because individuals often use digital health tools on their own (*e.g.*, glucometers and fitness watches), it is easy to believe that at the heart of this is a reliance on health literacy, self-efficacy, and self-management skills [19]. These are important, but they occur within a greater context.

As proposed by our WG contributions, attention to digital health literacy in the age of social media and other PHI technologies means not only providing access to information, but the capability to use it effectively. This in turn increases empowerment [9]. To date, minimal studies have focused on low literacy groups, digital health literacy has infrequently been addressed in the development of digital health interventions, baseline assessment of digital health literacy is scantly performed, consumer involvement in intervention design has been limited, and accessibility is infrequently addressed [48]. Hence, strategies are needed to support target users of PHI technologies. Indeed, it has been recently claimed that, just as there are social determinants of health, there are also digital determinants of health.

More and more individuals choose to or are prompted to engage with patient portals, telehealth, online information sources, shared electronic health records, and are exposed to oceans of social media posts. This raises the question whether ODH can be truly enacted without digital health literacy being addressed. This is important as if not, it only serves to widen the healthcare equity gap [9]. To successfully integrate digital health into the core perspectives of population and society in ODH, digital health literacy needs to be given the attention it deserves. This requires attention to information processing ability, engagement in one's health, access and ability to engage with technology, motivation, sense of control, and personalization [49].

3.3 Perspective: Ecosystem

Big data has major implications for the ODH framework. As the 2014 and the 2017 YB papers [14, 17] have indicated, the revolution of big data – especially machine learning techniques – has had vast impacts on data collection in healthcare. It ranges from massive collection of aggregated data, to a quantified-self movement of gathering data from all sorts of personal behaviors that could relate to their health, ranging from social media usage to use of sensor devices. This new method of gathering information on one's health status has proven beneficial for risk factor identification and prevention of diseases, as well as creating interventions for behavioral change related to health. Yet, using this information without context on

individual patients' lives is an impediment to its full effectiveness. The context is where ODH fits in, and feeds back into health, as institutions and individuals can measure, monitor, and report on environmental aspects such as air pollution, pesticide use, and temperature, thereby potentially driving a personal, local, or even global change.

The 2014 YB paper [17] also introduced the concept of connectivism to health. It emphasizes the interaction between patients' personal health, the provider, scientific research, and other stakeholders. The notion of connectivism is largely related to ODH, a concept which encourages the use of technology to create a more holistic use of healthcare data.

The 2019 YB paper [12] on AI and big data foreshadowed the outbreak of COVID 19. Beyond emphasizing the importance of patients being "partners" in their own healthcare management, it acknowledged that, due to the vast amount of data that is required to integrate health information from a variety of sources, artificial intelligence has been employed to more deeply understand one's health profile. Complex algorithmic techniques enable tracking of sophisticated phenomena like disease outbreak spread and medication non-adherence. AI provides physicians with copious amounts of evidence ranging from drug safety concerns revealed in online health communities to family medical history. On a system's level, healthcare organizations can learn about risk factors and population trends in diagnosis for various conditions that cause the greatest health burden and whose treatment on the aggregate might require the most public resources. On the level of patients, AI applied to social media data provides useful information that might predict various health issues. While this paper was written before ODH was conceived, they mesh seamlessly. One thing to keep in mind though is that greater forces are at play. We go beyond the healthcare system to municipal and environmental agencies, engaging a whole different group of stakeholders.

Seen from the year 2022, the 2014 perspective, and even the one from 2019, appear narrow, and warrants including environmental data as well. One thing that hasn't changed is that the ability to seamlessly integrate healthcare information across all beings, ranging from humans to the natural environment, depends on gathering accurate data about the impact of the environment on humans, and vice versa. Given the variety of "environments" (including the internet, urban spaces, and farmland on which food is produced) which today influence human health, an understanding of the ways humans interact with the world around them is crucial for advancing health. Collecting data on these complex interrelations works best through techniques like big data which can harness large amounts of information with relatively short investment on the part of researchers.

Another aim that can be accomplished with ODH and PHI is smart environment platforms that provide information to smart homes to monitor and deliver personalized services to older adults. Doubtless, the integration of these platforms with animal health and environmental data could make them more accurate and effective.

4 Conclusion and Limitations

Our basis for exploring One Digital Health was the YB papers published during the past 10 years by our WG, which created several limitations. First, the submissions each covered a particular topic not always specific to ODH's scope. Second, information technology evolves rapidly, and articles written years ago do not reflect state-of-the-art current PHI practice. Third, ODH is both broad and novel, including aspects outside the scope of our WG (*e.g.*, the planet, veterinary healthcare), so our analysis does not address all aspects of ODH. In addition, the ability of PHI to drive change adds a fourth limitation. As early as 2014, we noted that comprehension of big data and its implications might be a barrier for its broad use, and the same is true of the ODH concept and the level of involvement it requires of citizens. Developing user-friendly methods of encouraging patient participation in their own health informatics, and in their environment health, can go a long way towards painting a more accurate and useful picture of the environment that affects one's health, digitally and practically.

Our results suggest that PHI can and will involve topics relating to ODH. From the perspective "individual health and well-being" PHI catalysts ODH by providing a more comprehensive view on human health, attitudes and relations between human health and animal health. Integration of specific behavior change techniques or gamification strategies in digital solutions are effective to change behaviors which address the P5 paradigm.

Regarding the perspective "population and society", PHI supports engagement of the various stakeholders in healthcare. At the same time, PHI might increase a risk for health inequities due to technologies inaccessible to all equally and challenges associated to this.

Related to the perspective "ecosystem", PHI is a catalyst in contributing data into the digital health data ecosystem allowing for analysis of interrelations between the various data which in turn might provide links among all components of the healthcare ecosystem.

As the ODH concept crystalizes and becomes increasingly influential, its themes will permeate and become embedded in PHI even more. We look forward to these developments and co-evolution of the two frameworks.

The boundaries of what is health, and more specifically - what is health data - are constantly being examined. The ODH framework broadens them to include animal health, and indeed climate and planet health as well. Where this may now seem too expansive, we can take the example of PHI, which used to sound futuristic, but now is an acceptable part of health data and practice. It might very well be that, in the 2030 YB, ODH will seem obvious and perhaps even lacking.

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Correspondence to:
Kerstin Denecke
Bern University of Applied Sciences
Institute for Medical Informatics
Quellgasse 21
2502 Biel/Bienne
Switzerland
E-mail: kerstin.denecke@bfh.ch
Tel: +41 32 321 67 94