Understanding patient-clinician relationships in participatory digital health practices

The collaborative use of person-generated health data

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Abstract. *From the technological perspective, person-generated health data (PGHD) is increasingly a topic for analysis in machine learning and artificial intelligence, however these are largely future-focussed computational strategies that are yet to include participatory perspectives on patient-clinician collaborations or shared decision-making today. As noted by Neff (2013), the "biggest challenge for the use of big data in health care is social, not technical", and that the "challenge now is figuring out how people, both patients and providers, will actually use data in practice". This article addresses the social dimensions of patient-clinician relationships and examines PGHD in the complex, collaborative process of chronic disease management, whilst taking into account the challenges and limitations of self-tracking processes and technologies.*

Participatory health is an approach that emphasizes patient engagement and personalized healthcare (Hood & Flores, 2012; Sagner et al., 2017) where patients are identified as co-pilots (Tang & Lansky, 2005) or partners (Holman & Lorig, 2000) for improved chronic disease management. Several patient-centric concepts and resultant frameworks (for implementation) have been put forward over the years, but there are no clear guidelines on ways/means to incorporate self-tracking processes or person-generated health data (PGHD) meaningfully into patient-clinician conversations for shared decision-making. Recent publications even state that there has been a perceived "reluctance to abandon timeworn theories and models" of health intervention (Patrick et al., 2016) and we examine this deeper here.

The changing dynamics of patient-clinician relationships

The relationship between patients and their healthcare professionals has been considered one of the 'most complex' relationships (Edwards & Elwyn, 2009), and been the subject of several studies over time. Ranging from aspects of patient-clinician communication, information-sharing and decision-making, there

are generally 4 broad relationship 'modes' identified as having evolved over the years: *Default, Paternalistic, Consumerist, and Mutualistic* (Roter & Hall, 2006; Scambler, 2008). In recent times, with the advent of patient-centric advocacy, the last form (of mutualism, leading through to notions of patient empowerment and shared decision-making) has emerged as the preferred mode (Charles et al., 1997) and is even considered the 'pinnacle' (Barry & Edgman-Levitan, 2012). This has been interpreted in numerous ways by slightly-differing concepts, some of which are described below *(Tables 1,2)* though it must be noted that most are yet to directly target or incorporate recent developments in ubiquitous personal health devices and self-tracking, or include specific methods to address them:

Table 1: Some examples of recent patient focussed concepts

Concept	Description / Definition
Patient-Centred Care	*"Respecting and responding to patients' wants, needs and preferences, so that patients can make choices in their care that best fit their individual circumstances"* (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001)
Patient-Centred Communication	*"Communication skills to elicit patients' true wishes and to recognise and respond to both their needs and their emotional concerns"* (Levinson, 2011)
Patient Experience	*"The sum of all interactions, shaped by an organization's culture, that influence patient perceptions, across the continuum of care"* (Wolf et al., 2014)
Patient-Reported Outcomes	*"Any reports coming directly from patients about how they function or feel in relation to a health condition and its therapy, without interpretation of the patient's responses by a clinician, or anyone else"* (Johnston et al., 2019)
Patient Activation	*"People's ability and willingness to take on the role of managing their health and health care."* (Hibbard & Cunningham, 2008)
Patient Engagement	*"Combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly"* (Domecq et al., 2014; James J, 2013)
Expert Patients	*"People who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases"* (Donaldson, 2003; Shaw & Baker, 2004)
e-Patients	*"Informed health consumers using the Internet to gather information about a medical condition of particular interest to them"* (Ferguson, 2007)

Similarly, in order to address the mutualistic patient-clinician relationship, we find several overlapping concepts, a few of which are outlined below (*Table 2*):

Table 2: Examples of concepts that address the patient-clinician relationship

Concept	Description / Definition
Doctor-Patient Communication	*"Creating a good interpersonal relationship, facilitating exchange of information, and including patients in decision making"* (Ha & Longnecker, 2010)
Physician-Patient Relation / Doctor-Patient Relationship	*"The 'medium' in which data are gathered, diagnoses and plans are made, compliance is accomplished, and healing, patient activation, and support are provided"* (Goold & Lipkin, 1999)
Shared Decision-Making	*"Enables a clinician and patient to participate jointly in making a health decision, having discussed the options and their benefits and harms, and having considered the patient's values, preferences and circumstances"* (Hoffmann et al., 2014)
Narrative Medicine	*"Medicine practiced with narrative competence - the ability to acknowledge, absorb, interpret and act on the stories and plights of others"* (Charon, 2001)

Many of these concepts and theories have been translated into frameworks and guidelines for implementation but on examining these metrics to assess their relevance or specificity to the process of making use of self-tracked health data, we find that most are yet to incorporate any strategies for the same. Even the ones that do partially acknowledge self-tracking and devices, such as the *Engagement Behavior Framework* (Tzeng & Pierson, 2017), or even those that address the process of shared decision-making, do not yet incorporate any detailed guidelines for dealing with PGHD. As Godolphin rightly states there is a "great gap between theory and practice", whilst noting that "a good level of SDM occurs 10% of the time" (Godolphin, 2009). To understand this theory-to-implementation disconnect deeper, we look at recent research that examines the process of patients and clinicians incorporating PGHD into their discussions or consultations.

Tensions identified during PGHD-sharing

Recent PGHD-centric empirical studies across Human-Computer Interaction (HCI), Computer-supported Cooperative Work (CSCW) and Health Sociology explore this emerging process of patients sharing their self-tracking data with healthcare professionals (Chung et al., 2016; Piras & Miele, 2017; Zhu et al., 2017). These qualitative studies continue to suggest that this data has the potential to empower chronic disease patients to better manage their conditions. In addition, they have uncovered some factors and issues at play when patients and clinicians incorporate PGHD into their discussions, even leading to a relatively high level of dissatisfaction. Some of these are summarized below (*Table 3*):

Table 3: Range of issues identified in PGHD sharing, classified by category

Category	Influencing Factors and/or Issues
Technological/Technical	*Synchronous versus asynchronous sharing,* *Co-located versus distributed sharing,* *Lack of infrastructural support for data integration,* *Commercial tools not designed to support sharing or collaboration,* *Data privacy and security concerns*
Social	*Clinician versus patient initiated tracking*
Organizational	*Time constraints*

Even though these studies conclude with future-focussed guidelines (by identifying design considerations for technologies, or specific solutions such as the need for tailored visualizations/interfaces for patient-clinician collaboration), there are no immediate strategies for meaningful use of PGHD currently-obtained by the vast array of available devices, particularly considering participatory health contexts. It is also noted that these studies do not reflect on the numerous patient-centric concepts or implementation frameworks developed in recent health informatics research that could be of relevance here, possibly indicative of a 'disconnect' between disciplines despite the rich multidisciplinary 'roots' of self-tracking, and self-trackers.

These barriers are understood as larger challenges requiring longer-term systemic strategies or interventions at the *'Technological, Social and Organizational'* levels, and as Piras and Miele (2017) insist, "it is necessary to shift the focus from the future to the present". Hence the focus here is on some immediate ongoing 'tensions' which are also identified by these studies, reflecting on the fact that even today (despite the pervasive and ubiquitous nature of such devices), the basic underlying perceptions and expectations of this data vary vastly between patients and clinicians. Some of these identified 'tensions' are listed below (*Table 4*):

Table 4: Some of the tensions identified in the PGHD sharing process between patients and clinicians

Tension Identified	Instance / Example
Misalignment of the clinician's and patient's agenda and expectations of the data	*"patients recording clinically irrelevant data, or not recording relevant data"*
Patients and/or clinicians overwhelmed by raw PGHD	*"too much data at once and not knowing how to process it"*
Issues around the reliability and accuracy of PGHD	*"unreliable or inaccurate data"*
Differing attitudes towards technology	*"electronic stuff is a lot easier to collect (but) harder to analyse"*

As seen, data-related sensemaking remain a significant hurdle, and specific guidance around resolving these initial tensions is still inadequate. Also, even though these studies address an initial/prerequisite step towards the meaningful use of PGHD (that of sharing the data with the intent to collaboratively use the same) they do not take into account the actual long-term usage itself, i.e. how do patients and clinicians individually and collectively make use of this new data and try interpret it, and how do they begin to incorporate their findings into the chronic disease management process itself.

Resolving 'tensions' through the collaborative use of PGHD

Meaning-making in health and medical contexts has traditionally been the domain of clinicians and healthcare professionals. However, due to the changing nature of patient-clinician relationships and the ubiquity of technological data-centric devices embedded (and capturing health data) outside the clinic and in everyday life, patients can now be seen as sources *and* experts of their self-tracked data. For improved decision-making (resulting from enhanced meaning-making), it is important to leverage the expertise of both patients and clinicians collectively and collaboratively, leading to practical means of 'negotiating' the tacit knowledge and subjective experience of both these 'experts', i.e. the lived experiential and contextual information (uncaptured by sensors or devices) that the patient brings to the table, as also the medical training, experience and knowledge of the clinician that is able to extract and contextualize the specific data relevant to understanding the chronic disease management process. This can also be seen aligned to parallels elsewhere in health research such as Negotiation (Maitland, 2011), Co-interpretation (Mentis et al., 2015) and Co-Design (Papoutsi et al., 2021) and there is the scope for studies in health informatics to examine these themes more closely, towards better participatory digital health platforms that adopt these self-tracking practices (and PGHD) more widely and effectively.

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