



Defining and Scoping Participatory Health Informatics: An eDelphi Study

Kerstin Denecke¹ Octavio Rivera Romero^{2,3} Carolyn Petersen⁴ Marge Benham-Hutchins⁵
Miguel Cabrer⁶ Shauna Davies⁷ Rebecca Grainger⁸ Rada Hussein⁹ Guillermo Lopez-Campos¹⁰
Fernando Martin-Sanchez¹¹ Mollie McKillop¹² Mark Merolli^{13,14} Talya Miron-Shatz¹⁵
Jesús Daniel Trigo¹⁶ Graham Wright¹⁷ Rolf Wynn¹⁸ Carol Hullin (Lucay Cossio)^{19,20,21}
Elia Gabarron^{22,23}

¹Bern University of Applied Sciences, Department Engineering and Computer Science, Institute for Medical Informatics, Bern, Switzerland

²Instituto de Ingeniería Informática (I3US), Universidad de Sevilla, Sevilla, Spain

³Department of Electronic Technology, Universidad de Sevilla, Sevilla, Spain

⁴Mayo Clinic, Rochester, Minnesota, United States

⁵College of Nursing and Health Sciences, Texas A&M University Corpus Christi, Texas, Corpus Christi, United States

⁶eHealth Expert and Idonia Founder, Mallorca, Spain

⁷Faculty of Nursing, University of Regina, Regina, SK, Canada

⁸Department of Medicine, University of Otago, Wellington, New Zealand

⁹Ludwig Boltzmann Institute for Digital Health and Prevention, Salzburg, Austria

¹⁰Wellcome-Wolfson Institute for Experimental Medicine, Queen's University Belfast, Belfast, United Kingdom

¹¹Digital Health Programme, Instituto de Salud Carlos III, Madrid, Spain

¹²IBM Corporation, New York, United States

¹³Department of Physiotherapy, School of Health Sciences, the University of Melbourne, Melbourne, Australia

¹⁴Centre for Digital Transformation of Health, The University of Melbourne, Melbourne, Australia

Address for correspondence Kerstin Denecke, Dr. rer. nat., Institute for Medical Informatics, Bern University of Applied Sciences, Quellgasse 21, 2502 Biel, Switzerland (e-mail: kerstin.denecke@bfh.ch).

¹⁵Faculty of Business Administration, Ono Academic College, Kiryat Ono, Israel

¹⁶Department of Electrical, Electronic and Communications Engineering, Public University of Navarra, Institute of Smart Cities (ISC), Navarra Institute for Health Research (IdiSNA), Pamplona, Spain

¹⁷Department of Information Systems, Rhodes University, Grahamstown, South Africa

¹⁸Department of Clinical Medicine, UiT The Arctic University of Norway, Tromsø, Norway

¹⁹Data Governance Manager, Victoria Legal Aid, Melbourne, Australia

²⁰College Economy & Business, The University of Tasmania, Tasmania, Australia

²¹Digital Innovation Centre for Latinoamerican Region, Temuco, Chile

²²Norwegian Centre for E-health Research, University Hospital of North Norway, Tromsø, Norway

²³Department of Education, ICT and Learning, Østfold University College, Halden, Norway

Methods Inf Med 2023;62:90–99.

Abstract

Keywords

- ▶ participatory health informatics
- ▶ Delphi study
- ▶ social media
- ▶ mHealth
- ▶ shared decision making

Background Health care has evolved to support the involvement of individuals in decision making by, for example, using mobile apps and wearables that may help empower people to actively participate in their treatment and health monitoring. While the term “participatory health informatics” (PHI) has emerged in literature to describe these activities, along with the use of social media for health purposes, the scope of the research field of PHI is not yet well defined.

Objective This article proposes a preliminary definition of PHI and defines the scope of the field.

Methods We used an adapted Delphi study design to gain consensus from participants on a definition developed from a previous review of literature. From the

received

July 22, 2022

accepted after revision

October 8, 2022

accepted manuscript online

February 14, 2023

article published online

March 14, 2023

DOI <https://doi.org/10.1055/a-2035-3008>.
ISSN 0026-1270.

© 2023. The Author(s).

This is an open access article published by Thieme under the terms of the Creative Commons Attribution-NonDerivative-NonCommercial-License, permitting copying and reproduction so long as the original work is given appropriate credit. Contents may not be used for commercial purposes, or adapted, remixed, transformed or built upon. (<https://creativecommons.org/licenses/by-nc-nd/4.0/>)

Georg Thieme Verlag KG, Rüdigerstraße 14, 70469 Stuttgart, Germany

literature we derived a set of attributes describing PHI as comprising 18 characteristics, 14 aims, and 4 relations. We invited researchers, health professionals, and health informaticians to score these characteristics and aims of PHI and their relations to other fields over three survey rounds. In the first round participants were able to offer additional attributes for voting.

Results The first round had 44 participants, with 28 participants participating in all three rounds. These 28 participants were gender-balanced and comprised participants from industry, academia, and health sectors from all continents. Consensus was reached on 16 characteristics, 9 aims, and 6 related fields.

Discussion The consensus reached on attributes of PHI describe PHI as a multidisciplinary field that uses information technology and delivers tools with a focus on individual-centered care. It studies various effects of the use of such tools and technology. Its aims address the individuals in the role of patients, but also the health of a society as a whole. There are relationships to the fields of health informatics, digital health, medical informatics, and consumer health informatics.

Conclusion We have proposed a preliminary definition, aims, and relationships of PHI based on literature and expert consensus. These can begin to be used to support development of research priorities and outcomes measurements.

Introduction

The World Health Organization (WHO) has recommended a series of strategies focusing on a person-centered approach that could help to provide and maintain universal, equitable, high-quality, and financially sustainable health care in the future.¹ One strategy includes integrating a person-oriented approach in health care services including specifically health education, shared decision making, self-management, and peer support and expert patient groups.¹

Information and communication technologies play a fundamental role in supporting a person-centered or participatory health approach, and shifting health care toward becoming proactive aligned with the concept of P5 medicine—a predictive, personalized, preventive, participatory, and precision discipline.² Participatory medicine has been defined as “a model of cooperative health care that seeks to achieve active involvement by patients, health care professionals, caregivers, and others across the continuum of care on all issues related to an individual’s health.”³ Patient participation in health care means being active in decision-making throughout the entire patient journey,⁴ for example, performing clinical or daily living skills in ambulatory settings. The rise of the Internet and social media has facilitated the participation of patients in health care: They can easily share their experiences in blogs and other social media, and can access experiences from others or information on health issues enabling them to make informed decisions. Patient participation also refers to participation in the context of research where people with relevant health conditions are actively involved in designing and conducting research to improve quality and relevance.⁵

The digital revolution is considered one driving factor of participatory health.⁶ In addition to tools that engage people with others in discussing and seeking peer advice on health, there are now tools available that, in principle, allow anyone to collect, store, manage, or analyze health information, with the potential for citizen-oriented changes in health care. Data collection and availability to patients, for example, through personal health tracking, personal sensing, and monitoring, are essential for participatory health.

While the practice of participatory health is becoming mainstream, there is currently a plethora of terms that describe these activities, often with no agreed-upon definition and poorly defined domains or activities and relationships between activities. For example, several terms that refer to the use of digital technologies for allowing participatory health are being used, such as “human-centered design” (an approach that involves the human perspective in all steps of the problem-solving process⁷), “cocreation” (referring to the service or technology design where consumers play a central role⁸), and “consumer health informatics” (a subbranch of health informatics that helps bridge the gap between individuals and health resources⁹). In the midst of this variety in terminology, a new term referring to a field that specifically focuses on patient engagement and participation through information technologies has emerged: participatory health informatics (PHI). The term PHI is being used, and has already been cited in academic publications.^{10–14} However, there is a lack of a formal consensus and definition of what PHI is. Formalizing a definition is necessary to move research forward to realize its potential.

Members of the International Medical Informatics Association (IMIA) Participatory Health and Social Media Working Group (PHSMWG, <https://imia-medinfo.org/wp/5089-2/>) first attempted to define PHI in a recent scoping review. This review explored the use of information technology or informatics in the context of PHI. In that review, PHI was framed as a multidisciplinary field closely related to participatory medicine.¹² Five top person-centered key themes related to PHI were identified: (1) patient empowerment and autonomy, (2) shared decision-making, (3) informed patient and health literacy, (4) collaboration (patient-provider relationship), and (5) disease management and self-management of health conditions. The suggested definition of PHI created was¹²: “*PHI is a multidisciplinary field that uses information technology as provided through the web, smartphones, or wearables to increase participation of individuals in their care process, and to enable them in self-care and decision-making. PHI deals with the resources, devices, and methods required to support active participation and engagement of the stakeholders. It has been applied in the context of various medical conditions requiring long-term disease management. The individual is placed in the center of decision-making processes, the care process, and/or the self-care or self-management process, and has to communicate with the care team. PHI delivers the tools—information, software, and community—for this work. PHI also studies the effects of the use of such tools on the patient, care process, or physician-patient relationship, including ethical issues.*”¹⁵ The goals to be achieved through PHI include maintaining health and well-being; improving the health care system; improving health outcomes; sharing experiences; achieving life goals; and self-education.”

With the present work, we take another important step toward our goal to formally define and scope PHI by finding consensus regarding aspects of PHI deemed relevant among researchers working in the area. More specifically, the research questions underlying this study are:

- What characterizes PHI?
- What are the aims of PHI?
- With which related fields (e.g., consumer health informatics, user-centered design, human factor research, mHealth, etc.) can PHI be associated?

To address these questions, we undertook an online Delphi consensus study to find expert consensus on these questions. To the best of our knowledge, this is the first study aiming at providing an international consensus on the scope of PHI.

Method: eDelphi Study

We followed a modified Delphi method¹⁶ instead of a traditional Delphi method¹⁷ to collate expert consultation and build consensus on a PHI definition. The traditional method has five or more rounds with the first being “a start point for discussion using open-ended questions.” The first round also aims to identify all items for later rounds. The first round of the modified Delphi method has voting questions, as the discussion points are preidentified.¹⁸ For

pragmatic reasons, we planned to conduct three rounds. We created first round items based on the previous PHI definition.¹² In addition to collecting opinions on these items, we elicited possible additional items for voting in the second round. In the second round, participants were able to adjust their opinions. In the third round, we framed a final consensus. We have followed the recommendations for Conducting and REporting of DElphi Studies (CREDES¹⁹). Ethical approval from the Ethics Committee of the Canton Berne, Switzerland, was obtained to conduct this study (Req-2021-01433).

The study was conducted between March and May 2022 and participants had 14 days to respond in each round. Reminders were sent after 1 week. Round 1 was available for completion until March 7. Round 2 was available for completion until April 11, and round 3 was open for completion from May 9 through May 23.

Development of the eDelphi Study Questionnaire

The definition of PHI from our previous work was split up into its components. We distinguished characteristics from aims and relations to other fields and each component was evaluated as an independent item in the eDelphi questionnaire. In the first Delphi round 18 characteristics, 14 aims, and 4 relations of PHI were included. We asked the participants to rate the relevance of each component for inclusion in the definition of PHI with response on a 5-point ordinal scale. The eDelphi questionnaire collected data to describe the Delphi participants including gender, education/background, years of experience in health informatics, sector currently working in, and continent where they work. Furthermore, we asked participants to offer additional items for each category (characteristic, aim, relation) with an open text response. The complete item list is provided in [►Supplementary Appendix A](#) (available in the online version).

The Delphi instrument was configured as an online questionnaire for each round and was created using Microsoft (MS) Forms. The usability and technical functionality of these questionnaires were tested using Google Chrome and IE Explorer browsers on a laptop (MS Windows 10), Safari browser on an iPad Air 2 (Mac OS 15), and Google Chrome browser on a Samsung Galaxy A51 smartphone (Android 12) before distribution. Each questionnaire was distributed by email that included a short link generated using the Microsoft Forms sharing functionality. Only people using the shared link were able to access the questionnaires. A brief report including the participant’s responses of the previous round and a representation of the percentages of scores for each question in the previous round was also included in the email to each participant in rounds 2 and 3. Each questionnaire was opened and accepted responses only for the defined period for the specific round, which was 14 days in duration. Questions were presented in the same order to each participant. Once the questionnaire was submitted, a result report of their responses was available for participants. Participants were identified by their email address in each questionnaire.

Expert Recruitment and Panel Size

Expert panels of Delphi studies comprise generally fewer than 50 participants, and most Delphi studies have included 20 to 30 respondents. We therefore sought to recruit 20 to 30 participants for the study from six continents (North America, South America, Europe, Africa, Asia, Australia and Oceania) balanced in gender, and encouraged participants from the health care sector and health informaticians to participate.

We recruited participants in the field of health informatics from the IMIA PHSMWG and from our peer networks. We define a participant as someone who works in the health informatics field in the domains of academia or research. The PHSMWG is IMIA's primary vehicle for stakeholder engagement in PHI and social media, and its membership is international, inclusive, and multidisciplinary. The IMIA PHSMWG engages members from the international health informatics community, across sectors, to identify, explore, collaborate, and disseminate research on the use of social media for participatory health. Of particular interest are the drivers of change, barriers, facilitators, and policies necessary for the application of the various social media categories in the health domain. To acknowledge the participation in this study, we offered coauthorship in this article to all participants who completed all three rounds of the study.

Data Analysis, Consensus Criteria, and Reporting

Components of the definition were assessed for relevance using a scale of 1 to 5 (1 = not important, 2 = slightly important, 3 = moderately important, 4 = important, and 5 = very important). Inclusion into the definition was requested as binary response (1 = include, 0 = remove). An item was included in the PHI definition if it reached consensus in the third round and the percentage of participants who assigned it a score of 4 or 5 was $\geq 75\%$. Therefore, dissent items were not included.

For finding consensus, we considered recommendations of von der Gracht¹⁸:

- Consensus measure: A consensus is reached when the interquartile range (IQR) of the all participants' responses on an item in the round is 1 or less. The IQR is usually found to be a suitable consensus indicator for 4- or 5-unit scales. Following this criteria, we defined "consensus (C)" for an item in a round when IQR of the responses is 1 or less and "dissent (D)" otherwise.
- Stability between rounds: Responses of an item in two consecutive rounds are considered stable when the median of these responses does not show a statistically significant difference between both rounds. To analyze this difference the Wilcoxon matched-pairs signed-ranks test is commonly used. Following this criteria, we classified each item in round 2 and round 3 into stable (Y) and unstable (N) depending on the Wilcoxon test results.

The missing responses in round 1 were not considered in the analysis. In rounds 2 and 3, the missing responses were changed by the score assigned by the participant in the previous round.

Free-text suggestions for characteristics or goals or related fields to be added have been reviewed independently by two persons (O.R., K.D.). Together they decided what to include in the next round and which items needed reformulation. Their consensus was reviewed by two other authors (E.G., C.P.). Regarding the related fields, expert's responses were reviewed and coded to identify proposed areas. Then, these areas were grouped and main disciplines to which they belong were identified. To reduce the respondent fatigue, only main disciplines were included to minimize the number of questions to be ranked by experts in the next rounds. No items were removed between rounds giving participants the chance to change their opinions and enabling stability calculation. However, we considered the comments from the participants to reformulate existing items when necessary.

→ **Supplementary Appendix B** (available in the online version) presents a summary of the CREDES reporting (items 8–16) recommendations including a reference to sections and pages of this article reporting them.

When the eDelphi study was completed, four of the coauthors (O.R., K.D., E.G., C.P.) drafted a first version of the article and shared it for further discussion with the members of the panel who participated in the three rounds of the eDelphi and explicitly claimed to be involved in the article.

Results

Characteristics of the Expert Panel

The initial expert panel had 44 people who responded to the first round questionnaire (→ **Table 1**). There were 33 participants in the second round and 28 in the third round. The final expert panel was gender-balanced (14 females and 14 males). Most of the participants in the final panel (19/28; 67.86%) had more than 10 years' experience in their fields. Several sectors were represented by the expert panel. Academia was the most represented sector (24 out of the 28 participants), followed by the health sector with 15 participants, and industry with 6 representatives. The panel was made up of a multidisciplinary team of participants belonging to different disciplines. Health informatics was the most frequent work discipline ($N=19$), followed by medicine ($N=8$), nursing ($N=5$), and other health sciences ($N=5$). The panel had participants from all continents; Europe was the most represented continent with 10 participants.

Consensus on Items

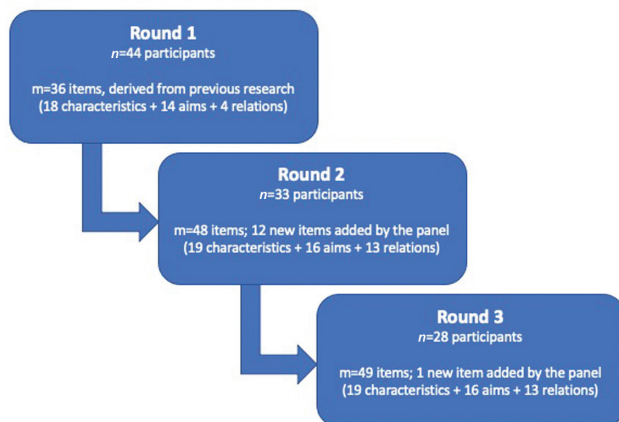
→ **Fig. 1** shows the total number of items that were assessed as well as the number of participants in each round.

Analysis of Characteristics

After the first round, in which 18 characteristics were assessed, item CH18 was removed and reformulated as an aim. Additionally, two new characteristics were added before conducting the second round (CH19 and CH20). Based on the participant's feedback, 4 items were reworded (CH3, CH4, CH10, and CH20). New and redefined items are shown in → **Supplementary Appendix C** (available in the online version). Consensus was reached on 16 of the 19 characteristics

Table 1 Summary of participants' characteristics

	Round 1	Round 2	Round 3
<i>N</i>	44	33	28
Gender			
Female	21 (47.73%)	15 (45.45%)	14 (50%)
Male	23 (52.27%)	18 (54.54%)	14 (50%)
Self-reported experience (y)			
< 5 y	7 (15.91%)	4 (12.12%)	4 (14.28%)
5–10 y	9 (20.45%)	5 (15.15%)	5 (17.86%)
> 10 y	28 (63.64%)	24 (72.73%)	19 (67.86%)
Sector			
Academia	37 (84.09%)	29 (87.88%)	24 (85.71%)
Health	20 (45.45%)	17 (51.51%)	15 (53.57%)
Industry	9 (20.45%)	7 (21.21%)	6 (21.43%)
Other	5 (11.36%)	4 (12.12%)	4 (14.28%)
Background			
Health informatics	31 (70.45%)	23 (69.7%)	19 (67.86%)
Medicine	14 (31.82%)	10 (30.30%)	8 (28.57%)
Nursing	7 (15.91%)	6 (18.18%)	5 (17.86%)
Other health science	5 (11.36%)	5 (15.15%)	5 (17.86%)
Computer science and engineering	8 (18.18%)	4 (12.12%)	4 (14.28%)
Psychology and behavioral sciences	3 (15.91%)	3 (9.09%)	3 (10.71%)
Other	3 (15.91%)	3 (9.09%)	3 (10.71%)
Physiotherapy	1 (2.27%)	1 (3.03%)	1 (3.57%)
Continent			
Europe	15 (34.09%)	11 (33.33%)	10 (35.71%)
Asia	7 (15.91%)	7 (21.21%)	6 (21.43%)
North America	8 (18.18%)	6 (18.18%)	5 (17.86%)
Australia and Oceania	9 (20.45%)	6 (18.18%)	4 (14.28%)
South America	5 (11.36%)	2 (6.06%)	2 (7.14%)
Africa	2 (4.54%)	2 (6.06%)	2 (7.14%)

**Fig. 1** Flowchart of the eDelphi process.

and participants agreed these 16 characteristics must be included in the PHI definition (CH1, CH2, CH3, CH4, CH5, CH6, CH7, CH8, CH9, CH10, CH12, CH13, CH14, CH15, CH16, CH17, and CH18). The participants' responses showed stability between rounds for 12 of these characteristics. Only CH3, CH4, CH13, and CH14 did not show stability between rounds (see results in ▶Table 2).

Analysis of Aims

The original questionnaire contained 14 aims. As mentioned before, a new item (AIM15) was created because of CH8 reformulation after the first round. Also, another new item (AIM16) was generated to address the participants' first round comments. AIM15 was split into two different items (AIM15 and AIM17) to address an expert's comment in the second round. Seven aims (AIM1, AIM6, AIM10, AIM12,

Table 2 Consensus and stability between rounds reached by each characteristic

Characteristics	Consent (C) / Dissent (D)	% of important or very important (rank 4 or 5) scores	Stability
Resources supporting active participation (CH3)	C	96.4	N
Assessing individual's technology acceptance (CH13)	C	96.4	N
Individual-centered care (CH6)	C	92.9	Y
Individual-centered self-management (CH7)	C	92.9	Y
Assessing individual's experience (CH12)	C	92.9	Y
Assessing individual's satisfaction (CH13)	C	92.9	N
Assessing usability (CH15)	C	92.9	Y
Assessing the appropriateness (CH17)	C	92.9	Y
Multidisciplinarity (CH1)	C	89.3	Y
Use of information technology (CH2)	C	89.3	Y
Effects of the use of tools (CH10)	C	89.3	Y
Assessing accessibility (CH16)	C	89.3	Y
Applied to medical conditions (CH4)	C	85.7	N
Individual-centered decision making (CH5)	C	85.7	Y
Delivery of tools (CH9)	C	78.6	Y
Assessing tool quality (CH18)	C	75.0	Y
Addressing ethical issues (CH11)	D	75.0	Y
User involvement in design (CH19)	D	75.0	Y
Community interactions (CH20)	D	64.3	Y

AIM14, AIM15, and AIM16) were reworded in response to experts' suggestions. The participants reached consensus on 14 of the 17 aims in the third round. Consensus was not reached for AIM4, AIM13, and AIM14. Because 9 of the 14 consent aims (AIM1, AIM2, AIM3, AIM5, AIM6, AIM7, AIM10, AIM12, and AIM15) were regarded as important or very important by more than 75% of the participants, these aims were included in the PHI definition. Two of these relevant aims did not show stability between the second and third rounds (see results in [Table 3](#)).

Analysis of Relationships

Four relationships were initially considered. Nine new relationships were added to address the participants' comments from the first round. No new items or rewording occurred in the following rounds. Nine of the 13 relationships reached consensus after the three rounds. Six of them (REL1, REL2, REL4, REL6, REL7, and REL12) were regarded as important or very important by the participants. These six relationships must be included in the PHI definition ([Table 4](#)).

Discussion

Principal Results

We performed a modified Delphi study with the objective of reaching consensus on a definition of PHI. Twenty-eight of the participants in health informatics participated in all three rounds of the eDelphi. The participants reached con-

sensus (more than 75% agreement) on 16 characteristics and 9 aims that must be included in the PHI definition, as well as on 6 main fields or subfields to which it relates.

Characteristics of PHI

Consensus was reached regarding 16 characteristics that should be included in the definition of PHI. The definition of PHI from this consensus is:

Definition of PHI

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. PHI also assesses accessibility, usability, individuals' technology acceptance, experience, and satisfaction, and tool appropriateness and quality.

Although consensus was reached on these 16 characteristics, 4 of the items did not show stability. Consideration of PHI as a field that delivers tools supporting active participation was one of the items that was unstable in

Table 3 Consensus and stability between rounds reached by each aim

Aims	Consent (C) / Dissent (D)	% of important or very important scores	Stability
Improve health outcomes (AIM8)	C	100	N
Increase participation in care process (AIM1)	C	89.3	Y
Maintain health and well-being (AIM5)	C	89.3	Y
Improve the health care system (AIM6)	C	89.3	N
Improve communications with health team (AIM15)	C	89.3	Y
Enable individuals in decision-making (AIM3)	C	85.7	Y
Improve the quality of health solutions (AIM7)	C	85.7	Y
Enable individuals in self-care (AIM2)	C	83.9	Y
Promote health equity (AIM12)	C	78.6	Y
Address individual's privacy (AIM13)	D	71.4	Y
Address individual's security (AIM14)	D	67.9	N
Improve health literacy (AIM16)	C	67.9	Y
Self-education (AIM11)	C	64.3	Y
Achieve life goals (AIM10)	C	60.7	Y
Improve communications with affected individuals (AIM17)	C	53.6	N
Share experience (AIM9)	C	42.9	Y
Awareness among general population (AIM4)	D	39.3	Y

Table 4 Consensus and stability between rounds reached by each relationship

Disciplines	Consent (C) / Dissent (D)	% of important or very important scores	Stability
Health informatics (REL12)	C	100	N
Digital health (REL6)	C	96.4	Y
Medical informatics (REL7)	C	89.3	Y
Consumer health informatics (REL1)	C	85.7	Y
mHealth (REL4)	C	82.1	Y
User-centered design (REL2)	C	78.6	Y
Health care innovations (REL10)	D	75.0	Y
Human factor research (REL3)	D	71.4	Y
Behavioral sciences (REL11)	D	67.9	Y
Precision medicine (REL5)	C	64.3	Y
Health psychology (REL8)	C	60.7	Y
Ethics (REL9)	D	46.4	Y
Legal informatics (REL13)	C	39.3	Y

the last round. The instability of this item could be explained by the fact that PHI delivers only some of the tools for supporting active participation. Other tools created by different stakeholders and with different objectives than health (such as the main social media sites) are also being used to increase participation. This highlights that participation in one's health may be seen at the

interface of health systems and social systems and therefore leads to uncertainty around the aspects of the definition. Alternatively, it can show that PHI is less about implementation than about research and evaluation. This also reflects the fact that the range of digital health interventions is broad, and the relevant various tools continue to evolve dynamically.²⁰

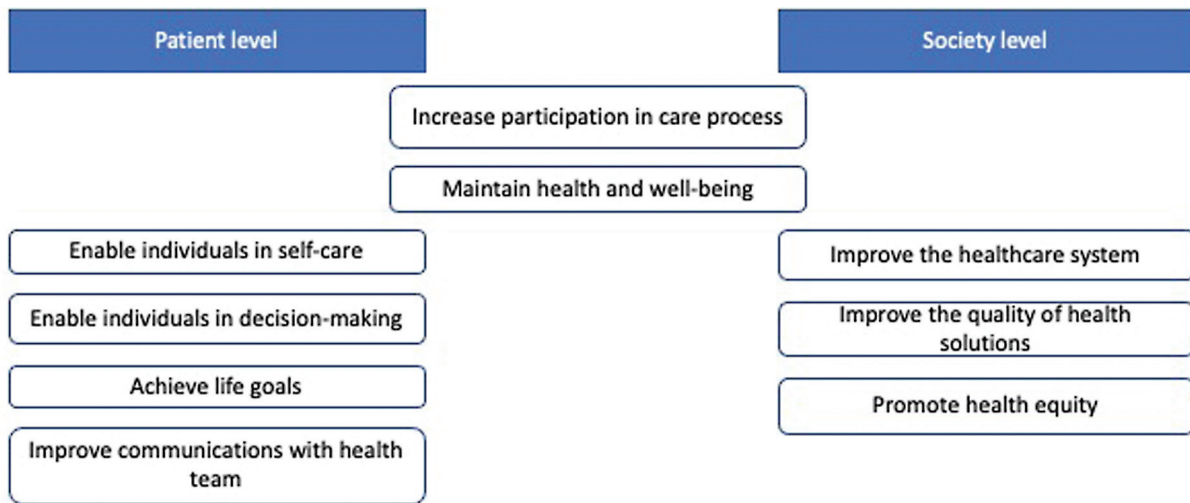


Fig. 2 Proposed aims of participatory health informatics (PHI). Aims can concern individual patients or the society. Aims “Increase participation in care process” and “Maintain health and well-being” are overlapping aims concerning both, patient level and society level.

There was a dissent on the characteristic CH19 referring to user involvement in design. A reason might be that the other characteristics were rather related to solutions instead of design of tools. Additionally, CH11 referring to ethical issues reached a dissent. This might be due to the composition of the panel who were mainly researchers with a background in health informatics. Another explanation might be that the characteristic is formulated too general or that ethical issues are still only considered to a limited extent in the development of PHI tools.

Assessing individuals’ technology acceptance and individuals’ satisfaction are also items that, although reaching consensus, did not show stability in the last round. Perhaps these functions are regarded as secondary to the actual practice of participatory health, and not primary purposes of it. For instance, the WHO developed a comprehensive guide that offers step-wise guidance to improve the quality and value of monitoring and evaluation for digital health interventions,^{21,22} and it describes additional opportunities that did not surface as key elements in this work.

Another item that did not show stability, despite eliciting a consensus, was regarding PHI being a field that applies to medical conditions. This instability could be due to the “unhealthy” connotation linked to the term “medical condition.” Although PHI is applied to diseases and disorders, it also focuses on the promotion of well-being and healthy lifestyles that can help to prevent, postpone, or reduce the risk of developing a medical condition. This goes along with the WHO strategy on digital health 2020–25: “Digital health will be valued and adopted if it: is accessible and supports equitable and universal access to quality health services; enhances the efficiency and sustainability of health systems in delivering quality, affordable and equitable care; and strengthens and scales up health promotion, disease prevention, diagnosis, management, rehabilitation and palliative care including before, during and after an epidemic or pandemic, in a system that respects the privacy and security of patient health information.”²³

Proposal on the Main Aims of PHI

The participants agreed that PHI has nine main aims: improving health outcomes, communications with health teams, the quality of health solutions, and the health care system; increasing participation in care processes; maintaining health and well-being; enabling individuals in self-care and in decision-making; and promoting health equity. PHI encompasses aims on a patient level and on a societal level, but also has overlapping aims covering patient and societal levels (→Fig. 2). Interestingly, even though PHI is individual-centered (see section “Characteristics of PHI”), there are aims on a societal level.

Two aims, improving health outcomes and improving the health care system, reached consensus but did not show stability in the last round. We hypothesize that these aims failed to achieve stability because while they are associated with PHI, they do not necessarily occur during PHI-based approaches and PHI-based initiatives do not necessarily seek to achieve these aims.

Consensus was not reached regarding some of the PHI goals that were identified in the scoping review,¹² including: improve health literacy, self-education, achieve life goals, improve communications with affected individuals, and share experiences. The participants dissented regarding previously identified PHI aims¹² including addressing individuals’ privacy and security, and increasing awareness among the general population. Addressing privacy and security is important in all health technologies, not exclusively for tools and technologies around PHI. This may explain why participants dissented.

Fields to Which PHI is Related

The participants agreed that PHI is related to six main disciplines (→Fig. 3). There are connections to the fields of health informatics,²⁴ digital health,²⁵ medical informatics,²⁶ consumer health informatics,²⁷ and mHealth.²⁸ The link between PHI and health informatics, however, did not show stability in the last round. We hypothesize that the

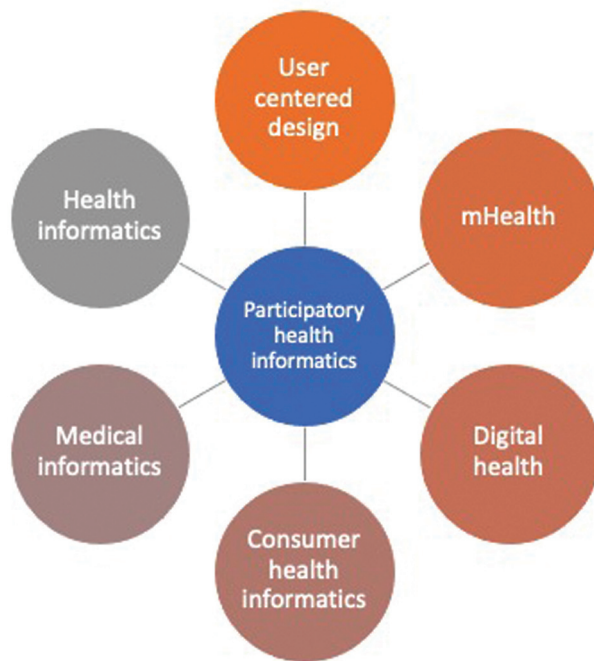


Fig. 3 Relations of participatory health informatics (PHI) to other fields.

inclusion of fields more specific than “health informatics” narrowed the participants’ thinking and resulted in a failure to acknowledge the broader term.

The participants dissented regarding PHI being related to other fields such as health care innovations, human factor research, behavioral sciences, and ethics. Given the participatory aspect, the lack of association may be related to a lack of user-centered design or the implication of legal issues. However, the participants did not reach consensus on this point. Another field that could be related is health psychology, which seeks to advance contributions of psychology to the understanding of health and illness through basic and clinical research, education, and service activities.²⁹ But participants did not reach consensus on PHI related to health psychology. They also failed to agree regarding the relationship of PHI with precision medicine.³⁰ It may be that we did not specify clearly what is considered to be a relationship, which might have resulted in cautious judgments.

Limitations

Although this eDelphi study has involved participants with extensive experience, is gender-balanced, and includes the perspective of participants from academia, medicine, and industry, the number of participants involved in the eDelphi decreased throughout the study. However, the 28 that were involved in the third and last round participated in all rounds. Most of the participants were members of the IMIA PHSMWG. We also acknowledge limited participation from participants from South America and Africa. In addition, because this effort sought to define a professional field, patients and citizens were not included among the partic-

ipants, which might have influenced the results. Furthermore, this work did not include sociologists or medical anthropologists, who might have offered different or additional interpretations of the data and the conclusions that the authors have drawn from it.

As we followed a modified Delphi method and stopped after three rounds, some items did not present stability in the last round. Future research could investigate if the items that did not show stability could do so in research involving additional rounds. The eDelphi study design prevented participants from interacting and discussing concepts collaboratively. Such interactions might help to clarify ideas. It may be that through such discussions our preliminary definition could have been additionally shaped.

Although our expert panel comprised a minimum of 28 participants, it is not possible to affirm the completeness of the definition. We might have missed characteristics or aims that were listed by the participants or aggregated some with other items that should be separate.

Conclusion

We have proposed a preliminary definition, aims, and relationships of PHI based on literature and expert consensus. These can begin to be used to support the development of research priorities and outcome measurements. Consensus has been reached regarding 16 characteristics, 9 aims, and 6 related fields that describe PHI. Future work should assess these characteristics, aims, and connections in more depth. The field of PHI is likely to evolve. Future developments could include further characteristics and/or aims, or spawn new research fields to which PHI relates. Our findings may be used to shape research topics related to PHI and to develop roadmaps for future research in the field of PHI including its relations to related fields.

Authors’ Contribution

Conceptualization: K.D., E.G., C.P.; Methodology: K.D., E.G., O.R.R., C.P.; Distribution of questionnaire: K.D.; Analysis of results: K.D., O.R.R.; Formal analysis and data curation: K.D., E.G., O.R.R., C.P.; Writing—original draft preparation: K.D., E.G., O.R.R., C.P.; Writing—review and editing: All authors; Answering Delphi questionnaire: T.M.-S., M.M., S.D., R.G., M.B.-H., R.W., F.M.-S., G.L.-C., M.G., J.D.T. G.W., R.H., M.M., C.H.

All authors have read and agreed to the published version of the manuscript.

Funding

O.R.-R. has received funding from the Universidad de Sevilla and the Ministerio de Universidades of the Spanish Government under the call “Recualificación del Sistema Español de Universidades” funded by European Union – NextGenerationEU.

Conflict of Interest

None declared.

Acknowledgment

We acknowledge the following persons for their participation in the eDelphi study: Wanda Pratt, Yulong Gu, Walter Paul Nchol, Chris Paton, Duc Minh Tran, Lisa Traboco, Peter Murray, Santiago de Matos Lima, Robab Abdolkhani, Mustafa Ghaderzadeh, Terry Hannan, Wendy Chapman, Mark Brommeyer, William Ed Hammond, Otto Rienhoff, Habibollah Pirnejad, Joia Nuñez, Kayo Waki, Christie L. Martin, Meriel Bladon, and Angelito Magno.

References

- World Health Organization. WHO Global Strategy on Integrated People-Centred Health Services 2016–2026. Geneva, Switzerland: World Health Organization; 2015
- Blobel B, Ruotsalainen P. Healthcare transformation towards personalized medicine - chances and challenges. *Stud Health Technol Inform* 2019;261:3–21
- Kantor D, Bright JR, Burtchell J. Perspectives from the patient and the healthcare professional in multiple sclerosis: social media and participatory medicine. *Neurol Ther* 2018;7(01):37–49
- Cahill J. Patient participation—a review of the literature. *J Clin Nurs* 1998;7(02):119–128
- Wright MT, Springett J, Kongats K. What Is Participatory Health Research? In: Wright MT, Kongats K, eds. *Participatory Health Research*. Cham, Switzerland: Springer International Publishing; 2018:3–15
- Martin-Sanchez F, Lopez-Campos G, Gray K. Biomedical informatics methods for personalized medicine and participatory health. In: *Methods in Biomedical Informatics*. Philadelphia, United States: Elsevier; 2014:347–394
- Melles M, Albayrak A, Goossens R. Innovating health care: key characteristics of human-centered design. *Int J Qual Health Care* 2021;33(Suppl 1):37–44
- Frow P, McColl-Kennedy JR, Payne A. Co-creation practices: their role in shaping a health care ecosystem. *Ind Mark Manage* 2016; 56:24–39
- Eysenbach G. Consumer health informatics. *BMJ* 2000;320 (7251):1713–1716
- Merolli M, Gray K, Martin-Sanchez F. TASoMe: validating a framework to generate evidence about health outcomes from social media use. *Stud Health Technol Inform* 2018; 247:606–610
- Denecke K, Gabarron E, Grainger R, et al. Artificial intelligence for participatory health: applications, impact, and future implications. *Yearb Med Inform* 2019;28(01):165–173
- Denecke K, Gabarron E, Petersen C, Merolli M. Defining participatory health informatics - a scoping review. *Inform Health Soc Care* 2021;46(03):234–243
- Wang K, Hambleton I, Linnander E, et al; ECHORN Writing Group. Toward reducing health information inequities in the Caribbean: our experience building a participatory health informatics project. *Ethn Dis* 2020;30(Suppl 1):193–202
- Gabarron E, Rivera-Romero O, Miron-Shatz T, Grainger R, Denecke K. Role of participatory health informatics in detecting and managing pandemics: literature review. *Yearb Med Inform* 2021;30(01):200–209
- Denecke K, Bamidis P, Bond C, et al. Ethical issues of social media usage in healthcare. *Yearb Med Inform* 2015;10(01):137–147
- McKenna HP. The Delphi technique: a worthwhile research approach for nursing? *J Adv Nurs* 1994;19(06):1221–1225
- Dalkey N, Helmer O. An experimental application of the DELPHI method to the use of experts. *Manage Sci* 1963;9:458–467
- von der Gracht HA. Consensus measurement in Delphi studies. *Technol Forecast Soc Change* 2012;79:1525–1536
- Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DELphi Studies (CREDES) in palliative care: recommendations based on a methodological systematic review. *Palliat Med* 2017;31(08):684–706
- WHO Guideline Recommendations on Digital Interventions for Health System Strengthening. Geneva, Switzerland: World Health Organization; 2019
- World Health Organization. *Monitoring and Evaluating Digital Health Interventions: A Practical Guide to Conducting Research and Assessment*. Geneva, Switzerland: World Health Organization; 2016
- Godinho MA, Ansari S, Guo GN, Liaw S-T. Toolkits for implementing and evaluating digital health: a systematic review of rigor and reporting. *J Am Med Inform Assoc* 2021;28(06):1298–1307
- World Health Organization. *Global Strategy on Digital Health 2020–2025*. Geneva, Switzerland: World Health Organization; 2021
- Bath PA. Health informatics: current issues and challenges. *J Inf Sci* 2008;34:501–518
- Lupton D. *Digital Health: Critical and Cross-Disciplinary Perspectives*. London, United Kingdom: Routledge; 2017
- Haux R. Medical informatics: past, present, future. *Int J Med Inform* 2010;79(09):599–610
- Houston TK, Chang BL, Brown S, Kukafka R. Consumer health informatics: a consensus description and commentary from American Medical Informatics Association members. *Proc AMIA Symp* 2001;•••:269–273
- Cameron JD, Ramaprasad A, Syn T. An ontology of and roadmap for mHealth research. *Int J Med Inform* 2017;100:16–25
- American Psychological Association. Society for Health Psychology. Accessed March 1, 2023 at: <https://www.apa.org/about/division/div38>
- U.S. Food and Drug. Precision Medicine. 2018. Accessed March 1, 2023 at: <https://www.fda.gov/medical-devices/in-vitro-diagnostics/precision-medicine>