

# User innovation rings the bell for new horizons in e-health: a bibliometric analysis

656

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## Abstract

**Purpose** – The study examines the amplifying role of users in the e-healthcare sector and holistically show its current state and potential. The paper aims at contributing to the scientific literature with a comprehensive review of the current state of the art on the application of user innovation (UI) in the e-healthcare sector, as a solid step for discussing the potential, trends, managerial gaps and future research avenues in this field. Despite the crucial importance of the topic and increasing attention toward it in the last few years, there is a lack of comprehensive scrutiny on different angles of involving users in health technology innovations so far.

**Design/methodology/approach** – This study combines two methods of bibliometric analysis and extensive content analysis of 169 journal articles on Scopus and Web of Science to unfold five research questions regarding the mechanisms of involving users, innovations characteristics and the role of users throughout the innovation process.

**Findings** – A clear result of the applied methodology is the profiling of users involved in e-health innovations in seven categories. The results of this study shed light on the current practice of not involving users in all the

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## Declarations

**Declaration of interest statement:** The authors declare that they have no conflict of interest.

**Ethics approval:** All procedures performed in studies involving human participants were in accordance with the ethical standards.

**Consent to participate:** We have read and understand the provided information and have had the opportunity to ask questions. We understand that our participation is voluntary and that we are free to withdraw at any time, without giving a reason and without cost.

**Consent for publication:** We give our consent for the publication of identifiable details, which can include photograph(s) and/or videos and/or case history and/or details within the text (“Material”) to be published in the “*European Journal of Innovation Management*”. Therefore, anyone can read material published in the Journal.

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stages of the innovation process of m-health, telemedicine, self-managing technologies, which is contrary to the best practices of the UI application.

**Research limitations/implications** – Collection of relevant studies due to lack of comprehensibility of the keywords.

**Practical implications** – The offered propositions can act as a roadmap to potential research opportunities as well as to organize such innovations from a managerial perspective in particular healthcare organization managers and the middle managers operating at R&D sectors and policymakers.

**Originality/value** – This study is the first of its kind that digs out the application of UI strategies such as user-centered design in the context of e-healthcare and provides a bibliometric and extensive content analysis of the studies conducted in this theme over the years.

**Keywords** Open innovation, Telemedicine, User innovation, Digital health, E-Healthcare, User-centered design, Digital transformation

**Paper type** Research paper

## 1. Introduction

The concept of e-health has dramatically extended the potential and scope of medical services and has promised to successfully address some of the pressing challenges in the healthcare market. The application of e-health has gained crucial importance due to the exponential growth of information and communication technologies (ICTs); the proven results of healthcare digitization, digitalization and digital transformation (Kraus *et al.*, 2021); as well as the increasing misbalances in the provision of health services worldwide, the escalating demand for medical services and the hope for e-healthcare to solve some of these issues (Scheffler *et al.*, 2018).

Looking at the key challenges in the healthcare industry described in the literature, such as the inelastic supply of professionals in this labor market (Figueroa *et al.*, 2019; Scheffler *et al.*, 2018) and the disproportion between healthcare demand and hospitals and medical facilities (Gagliardi *et al.*, 2021), the concept of user innovation (UI) might propose some answers. The present study considers the knowledge base and practices of applying UI strategies in the e-health sector that have recently been included in the research in a prominent place (Kraus *et al.*, 2021). The concept of UI has its roots in the pioneering research of von Hippel, who underlines the role of users as the main actors in the innovation process (von Hippel, 1976). Soon after this research, the theme of UI gained considerable attention in healthcare through the vigorous role of surgeons and medical practitioners in coming up with novel innovations to address various clinical problems (Füller, 2010; Lettl *et al.*, 2006; McNichol, 2012). Following the von Hippel (2009) theory, users develop new ideas with the motivation of benefiting by using them later in a product, and thanks to the increasing facility to do so with the advancement of ICT, firms started to involve users in a collaborative innovation process that creates win-win situations for users and producers (Amann *et al.*, 2016). Given the growing interest in the application of UI practices in healthcare, this study aims to contribute to the scientific literature with a comprehensive review of the current state of the art on the application of UI in the e-health sector as a solid step for discussing the potential, trends and future research avenues in this field. To the best of our knowledge, such a comprehensive review is scarce at present. The study is also timely because of the increasing number of new opportunities that UI has recently uncovered in many other sectors (Burger-Helmchen and Cohendet, 2011; Flowers *et al.*, 2010; Magnusson *et al.*, 2003) and the possibility of making a comparison with those arising from a diverse setting (healthcare), with varying stakeholders, unique business processes, broad applicability of ICT and a highly visible societal impact.

Specifically, this study answers five important research questions (RQs) in its quest to fill the gaps in the literature about UI in healthcare:

RQ1. *What* are the applications of UI in e-health?

RQ2. *Who* are the users involved in those applications?

RQ3. *Why* do users get engaged in UI in e-health?

RQ4. *When* do users participate in UI processes in e-health?

RQ5. *How* do users get involved in UI processes within e-health?

Pursuing a bottom-up understanding of UI application in e-health through the five RQs, this study reports the results from a bibliometric analysis to reveal the current advancements in this field and propose a research agenda accordingly. Based on the methods advanced by [Cobo et al. \(2011\)](#), the analysis was performed over a representative, high-quality sample of existing research consisting of publications from the Web of Science (WoS) and Scopus databases, using R software and its package Bibliometrix. In addition, we conducted a thorough content analysis to shed light on the users' involvement in the innovation process in e-health and gain deep insights into the roles that users are currently playing and those they could engage with in the future. This study might be of interest to researchers from innovation management and the healthcare industry because the results contribute to the understanding of the current research streams on the topic and provide practical insights on user involvement in such innovation interactions. In the discussion, we also offer a starting debate about the knowledge gap in the current literature.

## 2. Theoretical background

### 2.1 User innovation

The UI concept was first developed by [von Hippel \(1976\)](#) and stressed the crucial role users may play in business innovation processes. Later, von Hippel introduced the concept of lead users as those who feel the existing problems in products and markets much sooner than the rest of the users and have real-world experience to solve such problems ([von Hippel, 1986](#)). At that time, many published empirical studies provided support for these concepts because they showed the pervasiveness and importance of user-developed products in numerous technology-intensive industrial goods sectors ([Urban and von Hippel, 1988](#); [von Hippel, 2006](#)) and later even in some medium technologically intensive consumer goods sectors ([Lüthje et al., 2005](#)).

Further studies in this research line showed that users are the ones who benefit the most throughout the UI process in learning how to solve personal problems, gain reputation or pursue career prospects ([Battistella and Nonino, 2012](#); [Füller, 2010](#)). As a result, the role played by users in the innovation processes of organizations has changed drastically in the last decades ([Bogers et al., 2010](#); [Felin et al., 2017](#)). In this regard, the service sector has witnessed a tremendous involvement and collaboration between lead users and ordinary groups of users coming up with incremental and radical solutions ([Heiskanen and Matschoss, 2016](#); [Alves, 2013](#)). For instance, [Oliveira and von Hippel \(2011\)](#) found that 55 and 44% of computerized commercial and retail banking services, respectively, were primarily developed (and employed) by users.

Studies on the UI phenomenon have moved over the years from being focused on so-called innovating and lead users to a more collaborative approach of involvement called "co-creation," where the locus of innovation is distributed among various players ([Roberts et al., 2014](#), [Gustafsson et al., 2012](#)). The collaboration between users and organizations has gained much momentum with the exponential use of social networks and technology taking place on online platforms and mobile applications ([von Hippel, 2017](#)). Increasingly, various sectors, including healthcare, have started to employ participatory design and co-design approaches, which are known as some of the best UI practices to find creative ideas and functional solutions to develop the service design interactively ([Broberg and Edwards, 2012](#); [Donetto et al., 2015](#)). [Steen \(2011\)](#) defines co-design "as the attempt to facilitate users, researchers, designers and others [...] to cooperate creatively, so that they can jointly explore and envision ideas, make and discuss sketches, and tinker with mock-ups or prototypes" (p. 52).

Hence, organizations involve users from the very beginning of the innovation process, from the ideation phase to product development, commercialization and post-launch phases (Hienerth, 2006; Hoyer *et al.*, 2010; Magnusson *et al.*, 2003). In this vein, Tietz *et al.* (2005) discuss that innovation with/by users requires different collaborative tools, motivational triggers and preconditions at each specific phase of the innovation process. They suggest that the users take part in two stages of the innovation process—“idea generation” and “idea realization”—with the difference that in the former users confront needs and try to stimulate and develop concepts and in the latter users develop innovations and test them subsequently. In addition to idea generation and realization, some users even involve themselves in the innovation marketing (commercializing) (von Hippel, 2006; Hienerth, 2006). Nonetheless, there is not a defined methodology shaping user involvement, but there is a sequence of their processes. Users mostly rely on their local knowledge to exploit their existing capabilities and tangible assets and the communities of like-minded peers (Franke and Shah, 2003; Hienerth *et al.*, 2014; Lüthje *et al.*, 2005). Users tend to follow trial-and-error problem-solving by developing primary solutions, continuing with a test of those prototypes and ending with an assessment of the test results (Franke and Lüthje, 2020).

### *2.2 User innovation in healthcare over time*

UI has been extensively applied over the last decades in different healthcare contexts ranging from clinical experiments (Svensson and Hartmann, 2018) to natural language processing and sentiment analysis (Petersen *et al.*, 2020), passing through pharmaceuticals (Smits and Boon, 2008), mental healthcare (Schmidt *et al.*, 2021), cancer treatments (Poncette *et al.*, 2020) and orthopedics (Goldchmit *et al.*, 2021). Moving from an early stage, in which physicians and health professionals played the main role (Lettl, 2007; Lettl *et al.*, 2006, 2008), the end users, in particular patients and their non-medical caregivers, have become the core targets of the collaboration in the late stages of the innovation process (Biswas *et al.*, 2008; Habicht *et al.*, 2013).

At the beginning of the growth of UI in healthcare, inventor users were mainly physicians and surgeons, followed by medical staff who have a high level of expertise and experience in their field. These actors generated breakthrough ideas personally and within communities for technical equipment needs, diagnosis and cure of the disease, and surgeries. Health professionals are typically inventive users who are willing to participate from the beginning of the innovation process to the end by commercializing their innovations (Lettl, 2007; Lettl *et al.*, 2006).

The transformation underway in recent years from a disease orientation toward a more patient-centered one has highlighted the role of patients as end users of the healthcare system. As stated by Bul *et al.* (2020) the decisions made in healthcare should be tailored to specific end user needs, paying attention to their sociodemographic, cognitive, and health characteristics, as well as their skills and preferences. Røtnes and Dybvik Staalesen (2010) specify that the conventional characteristics defined by von Hippel (1986) do not exactly overlap with patient characteristics and their motivation to develop new solutions and concepts. In a patient-based innovation, users participate in the process by observing and fine-tuning the innovation phases with their experience instead of leading the innovation process. Yet, an alternative so-called patient-led view concentrates on the patients' needs and perceptions, calling for the prominent role of patients at the beginning of the innovation process itself in addition to the remaining phases throughout the development process (McNichol, 2012).

Note that even in a “patient-led” view, health professionals retain the leading role in the innovation process, whereas patients take part in the process of co-creation and co-design, interacting with health professionals in an iterative cycle. Participatory design is a widely applied concept in many settings, including prominently the healthcare sector. As stated, UI

is a powerful tool for opening the internal innovation processes toward more permeable innovation strategies, and being such, patients might become a contributor to innovations in the context of human medicine and its main point of interaction: healthcare. In the following sections, this study discusses some facets of the application of UI in healthcare, such as technology, clinics, and business, thereby triangulating the technical, functional and managerial dimensions of this important topic. Some critical remarks found in the literature are also briefly discussed at the end of the section for the sake of adopting a comprehensive and counterbalanced perspective of the application of UI in healthcare.

### *2.3 User innovation in healthcare – technology*

Since the early 2010s, most research in the healthcare sector has analyzed UI predominantly from a technological perspective dealing with aspects of e-health innovations, such as information flows, communication channels and technology systems (Sanderson, 2007). This may be due to the common belief that Norman (2013) describes as “fail often – fail fast,” which arises from the tension between technology and the evaluation of technologies over time. Thus, healthcare organizations also need to make constant adaptations or modifications rather than remaining focused on the current solution and waiting for the next radical innovation. Hence, ideas are co-created and tested with users to allow the business to cut losses and pivot to a better solution if something is not working.

Many studies have analyzed various types of technologies created by/with users in the healthcare sector. A large-scale study revealed that UI is applied extensively in medicine, but it is mostly used in the development of mobile applications (Bradonjic *et al.*, 2019). In this regard, UI has been applied in the m-health context and development of mobile applications for the self-management of healthcare issues (Gray *et al.*, 2020), reporting of health problems (Zaidi *et al.*, 2020) and education (Goldchmit *et al.*, 2021). With the fast adoption of technology and the use of cellphones, various health apps are designed and classified as medical devices. Nonetheless, Huckvale *et al.* (2015) and Lewis and Wyatt (2014) argue that the quality of many health apps does not meet the standard requirements and may hurt people's health by communicating incorrect data and feedback. Hence, app developers are encouraged to benefit from the involvement of users and co-create with them throughout the app design, development, implementation stages, as well as evaluation (van Velthoven *et al.*, 2018).

The poor design of health information technology may cause the product to fail because it cannot meet end user needs (Kellermann and Jones, 2013). Therefore, methods such as user-centered design (UCD) amplify m-health apps by making it possible for target end users (users and experts) to interact in different stages of the design process and take advantage of end-user suggestions (Schnall *et al.*, 2016). Telemedicine is another promising branch of modern healthcare closely related to innovation and users. Even though there is not yet a widespread application of UI in telemedicine, the concepts of co-design and co-creation have already been implemented in developing this branch of e-health (Leite and Hodgkinson, 2021).

### *2.4 User innovation in healthcare – clinical*

UI has gained considerable attention in the healthcare sector through the vigorous role of surgeons and medical practitioners, who have come up with radical and sophisticated innovation projects such as X-ray systems or surgery tools to address various clinical problems (Füller, 2010; Lettl *et al.*, 2006; McNichol, 2012). In purely clinical contexts, UI has been applied in several cases to diverse medical diseases such as cancer (Leach *et al.*, 2019), oncology treatments (Ben-Arye *et al.*, 2021) and mental diseases (Edbrooke-Childs *et al.*, 2019), to name a few. With the pervasiveness of e-health technologies, end users are involved in innovation processes for disclosing information needs (Biswas *et al.*, 2008; Walker and Clendon, 2016) and relieving communication difficulties between patients and health

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professionals (Marko-Holguin *et al.*, 2019; Niemelä *et al.*, 2019). In addition to chronic diseases, co-creation and co-design mechanisms target daily health issues and people's healthy lifestyles (Edbrooke-Childs *et al.*, 2019). Patients learn about symptoms and side effects of their treatments, and they perceive that being connected to other patients on virtual platforms is helpful to make medication decisions (Wicks *et al.*, 2010).

### 2.5 User innovation in healthcare – managerial

From the managerial point of view, UI has several applications, such as innovation of use, innovation in services, innovation in the configuration of existing technologies and innovation of novel technologies themselves (Weber, 2011). In health organizations, UI is considered to provide lower-cost service and to support mapping the patient's journey through the different health services and treatments to optimize the service pathways for delivering the proper care and enhancing convenience, quality and clinical safety (LaMonica *et al.*, 2021). Medical staff user innovators have the potential to identify critical factors for workplace time loss (Beaton *et al.*, 2021), in addition to their ability to better analyze patient treatment progress. The mechanism based on co-creation with users contributes to mitigating traditional problems within this context, such as the use of resources and individual responsibility (Iandolo *et al.*, 2013). Moreover, the co-creation facilitated by e-health technologies has been analyzed as a co-management approach to reduce costs for medical care in hospitals (Backman *et al.*, 2018). Empowering users has radically changed the way user and customer value is created and transferred; therefore, many organizations have consequently set out business concepts based on the recognition of these changes and the opportunities they bring about. By adopting technology solutions, health organizations and clinical services have started to empower users in contexts such as self-management treatments (Goldchmit *et al.*, 2021), healthcare education (Xu *et al.*, 2020), care for vulnerable users (Gill *et al.*, 2019) and developing peer-to-peer online communities (Amann and Rubinelli, 2017). Chen *et al.* (2014) suggest that e-health as a service innovation needs to consider a wide variety of users, including patients, service recipients and service providers, when it comes to the formation of commercially viable business concepts.

### 2.6 User innovation inappropriateness and critiques

The results of some studies regarding the application of UI in health care are at odds with previously discussed research through raising issues of appropriateness (Radaelli *et al.*, 2017). As stated by Silva (2017), health is a sensible socioeconomic issue that is prone to criticism when users with no medical education are involved. The assumption of the limited and even negligible value of the knowledge and expertise of users has also been supported by Bogers *et al.* (2010). Although these authors maintain skepticism about the potential of UI in healthcare due to user education, knowledge and expertise constraints, they nonetheless do not neglect their role in identifying the healthcare needs that could be addressed better, thus significantly reducing the scope of user involvement in the process of innovation.

However, only a handful of studies emphasized the business side of utilizing users in innovation development and the specifics of applying this model in healthcare (Oderanti *et al.*, 2021), so the existing research gap is widening by increasing the application of UI. Policies or regulations to moderate and control UI in healthcare are still lacking (Svensson and Hartmann, 2018). The literature does not provide a clear vision of the application of UI and the role of users in the e-health innovation processes, thus providing a research opportunity addressed in the present study to shed light on the innovation processes within the e-health sector with an eye on the roles that users play in this special setting. In doing so, this study encompasses a bibliometric analysis along with content analysis to structure the research streams of UI in e-health, the innovation specifics and the possible singularities of healthcare in comparison with other industries.

### 3. Methodology

The methods used in this study encompass different approaches to address the research questions. The procedures are summarized in [Table 1](#).

This research uses a science mapping approach to understand the topic foci of UI and its variations, such as co-creation, UCD, and co-design in e-health and health technology contexts. Moreover, a process-based perspective is adopted to understand the UI application in e-health, especially the roles that users typically play throughout the innovation process. It also identified and mapped the focal publications about user involvement in the innovation process of e-health innovations. This study offers a broad overview of the topic as an initial step for going deeper into the subtleties and exploring new horizons in these issues.

#### 3.1 Sample selection

The sample publications for conducting this study were selected using a Boolean search within the WoS and Scopus databases, because they contain a broad range of high-quality peer-reviewed journals with relevant and timely publications on previous e-health research efforts ([Ćwiklicki et al., 2020](#)). As suggested by [David and Han \(2004\)](#), the selection criteria centered on getting a representative sample of the existing literature while exceeding some threshold on rigor and correctness. On the restrictive side, books, book chapters, conference papers and publications not written in English were excluded from the sample. On the unrestrictive side, no exclusion was made on the grounds of field, year of publication or journal quartile. An important step in this type of bibliometric analysis is the appropriate selection of the keywords based on previous research, a process that was completed through the following procedure.

- (1) *General scope*: we applied 11 keywords including e-health, telemedicine, and digital health on the one side and end user, lead user, co-design, co-creation, and similar keywords on the other with the Boolean search string in the two databases separately.

This process yielded 218 results in WoS and 98 results in Scopus. The sum of 316 articles resulted in 280 articles, once duplicates were removed, in a single dataset containing information about author(s), language, year of publication, type of research, abstract, source title, keywords and cited references of the publications included in the search.

- (2) *Specific scope*: we examined the titles and abstracts of the 280 articles to exclude the out-of-scope articles based on a few specific inclusion/exclusion criteria.

Research question	Research methods used
(RQ1) <i>What</i> are the applications of UI in e-health?	Bibliometric analysis <ul style="list-style-type: none"> <li>- Co-keyword analysis</li> <li>- Strategic thematic map plotting</li> <li>- Thematic network of clusters</li> <li>- Historical development of thematic mapping</li> </ul>
(RQ2) <i>Who</i> are the users involved in those applications?	Content analysis and coding procedure (bottom-to-up approach covering the précised data set)
(RQ3) <i>Why</i> are users getting engaged in UI in e-health?	Content analysis and coding procedure (bottom-to-up approach covering the précised data set)
(RQ4) <i>When</i> do users participate in UI processes in e-health?	Content analysis and coding procedure (bottom-to-up approach covering the précised data set) based on the innovation process with users by <a href="#">Tietz et al. (2005)</a>
(RQ5) <i>How</i> do users get involved in UI processes within e-health?	

**Table 1.**  
Methodological approach to address the research questions of the study

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At this phase, the 280 records were examined carefully by going over the title and abstract of each publication to ensure the relevancy of their theme to our research aim. As a result, some out-of-scope entries were identified based on the application of exclusion criteria, such as (1) the use of e-health solutions (products, services and methods) by end users without user involvement as participants in the innovation process, (2) the application of technology in healthcare without any contribution to user engagement or co-creation in the process, (3) the consideration of user needs and values without letting them participate on their own in the process, (4) the mere investigation into user satisfaction and acceptance of health technologies and (5) the acknowledgment of technical issues associated with collaborative e-health environment (e.g. credentials security). This process down-scoped the final sample of publications to 169 records published in the WoS and Scopus databases, thus providing a high-quality, focused representation of the research done pertaining to the research questions addressed in this study.

### 3.2 Co-keyword analysis

As proposed by [Callon et al. \(1983\)](#), we applied a co-keyword analysis to discover semantic clusters of different topics based on the strength of the associations between the existing information in textual data with the aid of the R software and its package Bibliometrix. To do so, the author keywords from the sample publications were introduced as the inputs for the analysis. The dataset of author keywords was previously screened to avoid deviant results, such as those derived from using indexing keywords (instead of original author keywords) and heterogeneous spelling across databases and publications (e.g. e-health and ehealth, mhealth and m-health, mobile apps and mobile applications). In the next step, we determined the similarities between the items based on the frequencies of keyword co-occurrences. Using the techniques proposed by [Cobo et al. \(2011\)](#), we obtained the themes of studies based on a process of clustering in a way that the keywords that are strongly linked to each other are in the same conglomerates along the different periods, thus providing a longitudinal framework for tracing the evolution of the research topics. Then, using the visualization technique proposed by [Cobo et al. \(2011\)](#), a strategic thematic map was developed, plotting the themes into four quadrants of themes (conglomerates or clusters of keywords)—motor, transversal, niche and peripheral—according to their centrality and density rank values along two axes. Further details about the use of these techniques are provided in the results section.

### 3.3 Content analysis and coding

We scrutinized the whole set of the final sample of 169 publications and coded them according to (1) the type of users involved in the innovation process; (2) the innovation specifications in terms of the type of technology, tool, therapy and so on; and (3) the innovation process(es) that users get involved in. The four authors applied the content analysis and coding procedure separately, and any disagreement was resolved in iterative discussion sessions. More details about the content analysis are provided in the results section.

## 4. Results

The articles were published between 2001 and 2021 and reveal the growing interest in the topic in recent years. Notably, the topic received more attention after 2014 with the peak year in 2020. The smaller number of papers published in 2021 results from the fact that the data collection finished in March 2021, so only the first quarter of the year 2021 was covered in the sample. The *Journal of Internet Research* has the most published articles followed by *JMIR Mhealth* and *Uhealth* and the *International Journal of Medical Informatics*. The 169 articles were published in 94 different journals. Notably, the journals with a higher number of articles



according to the final selection—the most focused ones to UI in the e-health context—are predominantly medical journals. Despite having published many articles concerning user involvement and UI in the healthcare literature (Amann *et al.*, 2016; Broberg and Edwards, 2012; Nambisan and Nambisan, 2009), management journals dedicate little space to the application of UI and the related concepts within the e-health and health technology sectors.

#### 4.1 Keywords

Figure 1 displays the keyword tree map with the 50 most frequently used keywords. The rectangle size represents the recurrence of keywords in terms of frequency, and the correspondence by color represents the degree of correlation among keywords. Notably, the most relevant keywords are telemedicine followed by m-health and e-health. Telemedicine and e-health are occasionally used interchangeably; however, telemedicine is driven by medical professionals, whereas e-health is conducted mainly by non-professional users (Della Mea, 2001). E-health is related to keywords such as self-management, co-design, mental health and patient preference. Likewise, telemedicine is associated with medical professional issues, such as primary health care, multidisciplinary, cultural characteristics and help-seeking behavior.

Although e-health and telemedicine are the two most frequently used keywords, they have become less popular over the years. Digital health is gaining momentum in recent years, replacing e-health and m-health keywords, which resonates with a broader view at the time of digitization, digitalization and digital transformation (see Figure 2).

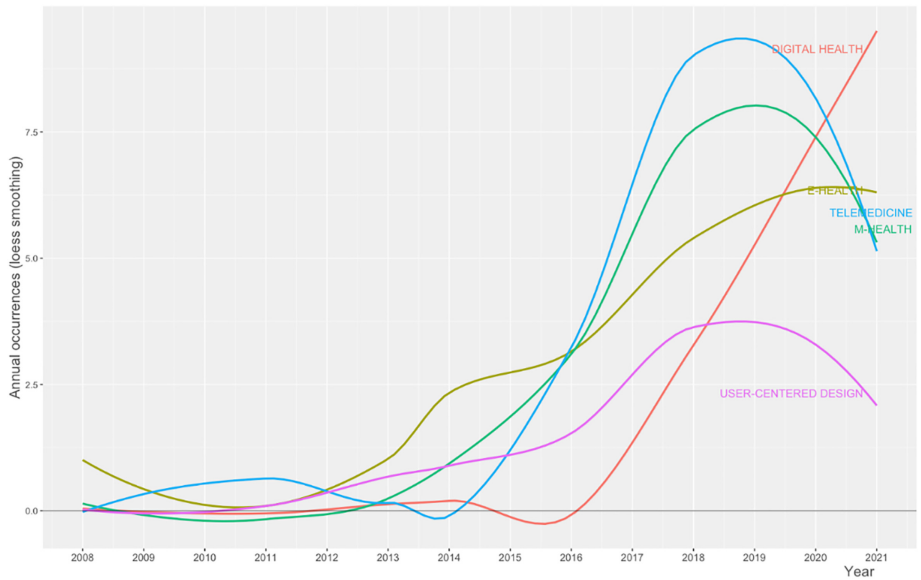
#### 4.2 Themes

The initial analysis based on the most frequently used 50 keywords for the tree map was subsequently extended to include the 250 most frequently used keywords. This broader scope enabled deepening the analysis for the definition of thematic maps and thematic networks. These conceptual tools aid in shedding light on the structure of keyword co-occurrence using network analysis, where a keyword is a node and the co-occurrence of two keywords is an edge of the network. The network is configured according to a two-step procedure. First, the literature is organized into sets of strongly linked keywords that form semantic clusters or themes, and the label of each theme is chosen based on the strongest keyword within each set. Second, the links among themes are derived; as a result, a general view of the literature organized into themes and their connections is produced. Contrary to the keyword tree map, in which the unit of analysis is an individual keyword, this further analysis takes a cluster of keywords forming a theme as the starting point. The application of this analysis resulted in a thematic network consisting of 11 themes: m-health, telemedicine, e-health, self-management, rehabilitation, Internet, adolescent, trust, human factors, self-monitoring and application software.

These themes are classified using the network analysis from which they are derived on two axes of network centrality and network density. The former refers to the level to which a theme bridges the gap to other themes in the literature, and the latter refers to the proportion of existing connections over all possible connections within a theme subnetwork. Centrality is consequently an indicator of a theme's relevance to link different subsets of the literature, whereas density indicates whether the subset of the literature that the theme represents is well developed. Following Cobo *et al.* (2011), a two-dimensional thematic map was developed by plotting the themes into four quadrants according to their centrality and density rank values (Figure 3).

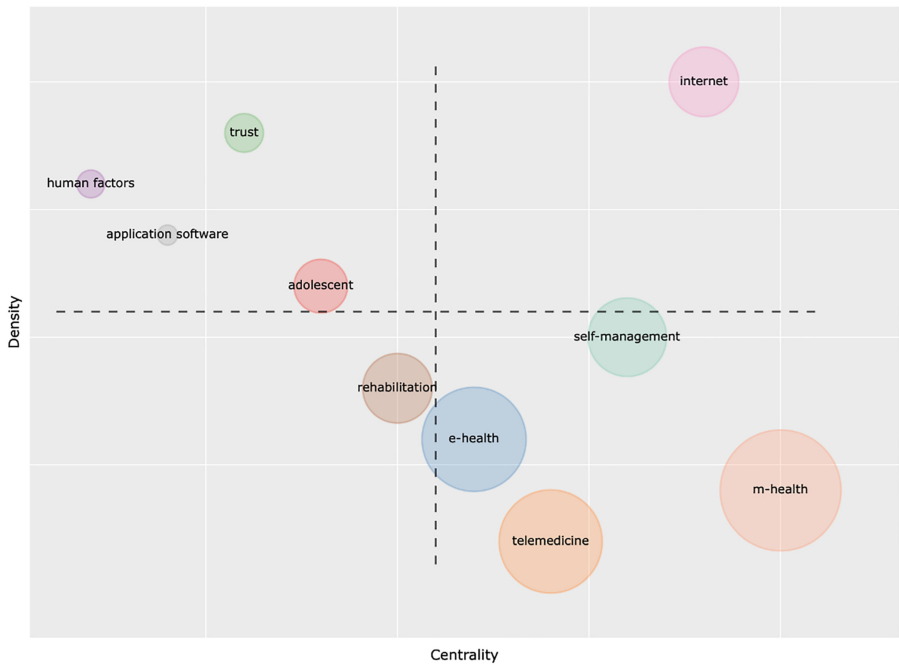
The upper-right quadrant includes the *motor themes* as those that present strong centrality and high density. These are well-developed themes that are important for the structuring of the research field. According to the results, there is only one motor theme: the





**Figure 2.**  
Evolution of the top  
five most used words

Internet. Note that this theme is the main node of a cluster that includes other keywords mostly related to ICT (e.g. smartphone and cell phone, app trial) and to mental health topics



**Figure 3.**  
Thematic map

such as depressive and anxiety disorders, as well as to user testing and trial of e-health and m-health.

The lower-right quadrant contains the *transversal themes* considered as general and basic themes. These are themes with a strong centrality and low density, thus representing important yet underdeveloped themes such as e-health, telemedicine, m-health and self-management. This finding is not surprising because e-health and telemedicine concepts are at the heart of our topic and are broad concepts. Notably, the m-health theme is the biggest cluster and most central node. Zooming into this cluster, other central nodes, such as digital health and UCD, appear. The remaining self-management theme is the smallest one in this quadrant of basic and transversal themes.

The upper-left quadrant encompasses the *niche themes*. These are well-developed but specialized themes that do not link significantly to other themes within the literature. These themes are marginally important for the progress of the field generally, although they may remain of interest for highly specialized settings such as adolescent, trust, application software and human factors. During the period between 2005 and 2021, the niche themes consist of adolescence, trust, application software and the human factor.

The lower-left quadrant includes the *peripheral themes*. This comprises emerging and declining themes, characterized by low density (underdeveloped) and low centrality (marginal). Rehabilitation is the one and only peripheral theme in this period.

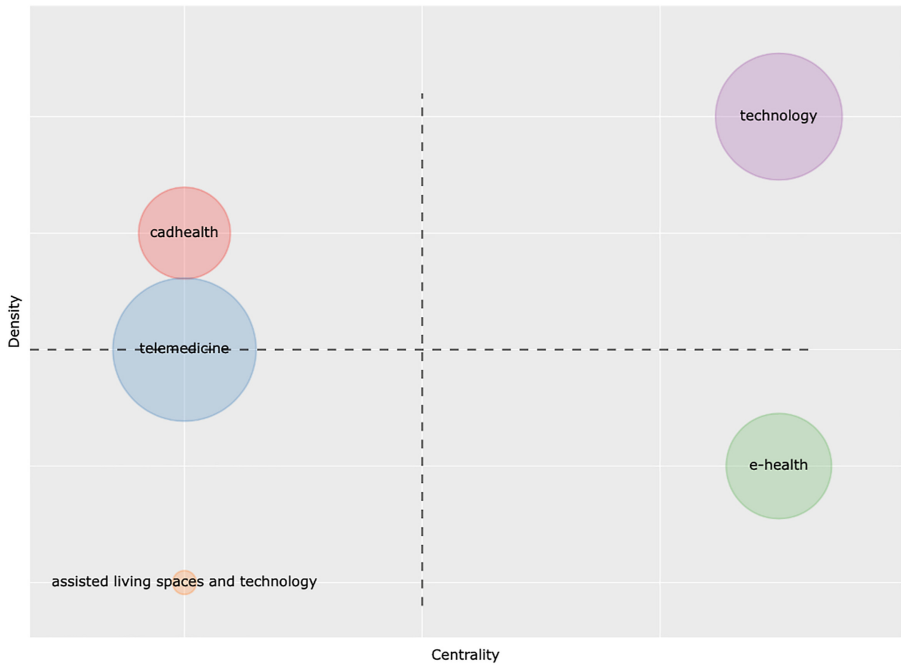
#### 4.3 Evolution of themes

A picture of the evolution and trends in the literature was derived by splitting the sample period into two sub-periods: 2005–2012 and 2013–2021. According to the results, during 2005–2012, there were only five clusters, and the motor theme was technology (Figure 4).

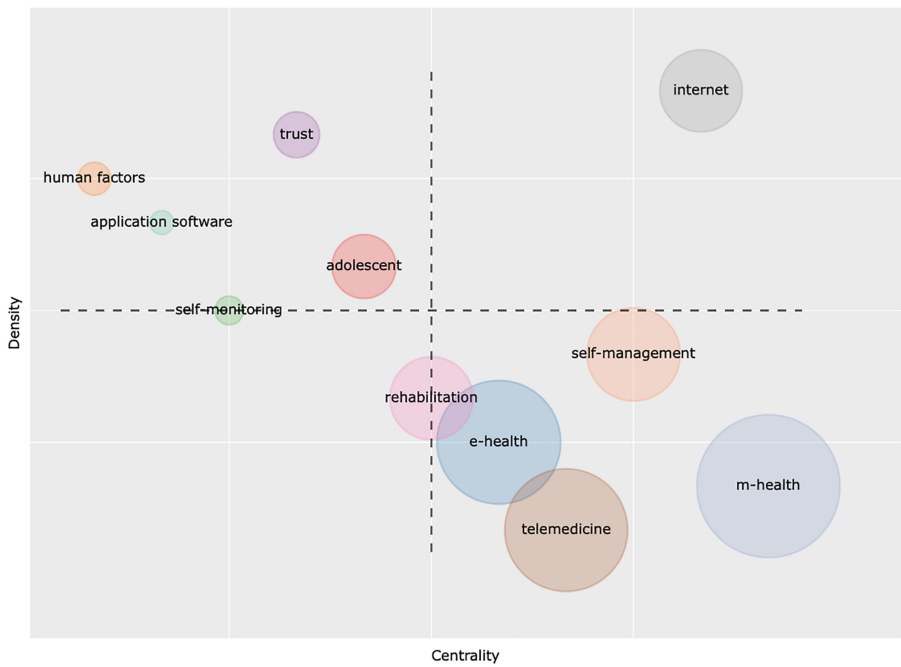
More interesting, during this first period, the clusters were isolated from each other. One possible reason is the small attention received by this topic during the 2005–2012 period. During the second period (2013–2021) the number of clusters and the links among them increased considerably, and the Internet replaced technology as the motor theme (Figure 5). The vast adoption of the Internet has led to novel methods of co-design and co-creation on various Internet platforms and resolved the difficulties of poor and incomplete communication and information transfer between clinicians and patients (Fico *et al.*, 2020).

Basic and transversal themes go from one theme in the first period to four themes in the second period, with e-health as a theme persistent over the two periods mainly due to its broad scope. Concerning the themes that emerged in the second period, telemedicine occupies a prominent path to seek solutions for the difficulties of face-to-face interactions between health professionals and patients in different settings (Leite and Hodgkinson, 2021; Thomas *et al.*, 2017). One application of telemedicine is telehealth as a new technology in the healthcare sector, which allows the monitoring of the daily health status of patients (Timmerman *et al.*, 2016). Recently, the COVID-19 pandemic has massively proved the effectiveness of telehealth technology (Bate *et al.*, 2021).

M-health is another transversal theme that was not a topic of interest during the first period. However, it achieved remarkable attention later as to become the most prominent theme in the second period. M-health is a setting in which mobile applications could benefit from UCD and co-design models based on the participation of end users at different stages of the design process and continuing exploitation of end user feedback. In this regard, the interaction between end users of health services guiding based on their needs and experiences, and human–computer interaction experts providing expertise to the interface design, is a common practice in m-health (Cornet *et al.*, 2020; Giunti *et al.*, 2018a, b; Bendixen *et al.*, 2017).



**Figure 4.**  
Thematic map  
(2005–2012)



**Figure 5.**  
Thematic map  
(2013–2021)

Digital health is another basic and transversal theme, along with m-health, that is linked together frequently because both are used a lot together in many real-world situations. The last basic and transversal theme is self-management, which moves from a peripheral theme in the first period to a basic and transversal one in the second period, even positioned at the border of getting a motor theme status. Research on self-management is related to aspects such as the co-design of smartphone apps with users for disease self-management and the provision of real-time information (Xu *et al.*, 2020). The studies focus on co-creating and co-managing the online personalized programs and solutions to leverage the self-management of physical and behavioral symptoms associated with different diseases (Leach *et al.*, 2019; Michalak *et al.*, 2019). Among the top applications in this theme, there are some female-related issues, such as maternal health (Evans *et al.*, 2019; Lackie *et al.*, 2021).

There are four niche (specialized) themes that are internally well developed but are isolated from the other themes and have marginal importance in the development of the scientific field. Adolescent, trust, human factors and application software appeared as the niche themes in the literature. There was another niche theme in the first period that later disappeared in the second one, called cadhealth, which is a system aimed at enabling knowledge and work practice transfer among clinicians across geographical, regional and workplace boundaries for effective clinical decision support in e-health (Tawfik *et al.*, 2012). Nevertheless, cadhealth vanished among the niche themes in the second period and adolescent, trust, human factors and application software remained the most focused ones.

The study of trust is related to safety and truthfulness considerations among users while co-creating and co-designing some technological solutions. It mainly concentrates on ethical issues and awareness about user needs and preferences (Beul *et al.*, 2012; Solem *et al.*, 2020; Schmidt *et al.*, 2021; Stinson *et al.*, 2014). Research on the biggest theme in this niche quadrant concerned how adolescents deal with the use of UCD methods and e-health interventions in young adult physical and mental disorders with an emphasis on empowering them and addressing their specific needs (Coyne *et al.*, 2016; McCann *et al.*, 2018). The theme of human factors encompasses concepts such as human-centered design or human-system interactions in which humans refer to users of e-health systems (McCann *et al.*, 2018; Theis *et al.*, 2018). Finally, application software ID another defined niche theme, despite having overlaps with the theme m-health, because it expands the literature to the topics related to the design characteristics of special apps such as user-friendliness (Giunti *et al.*, 2018b; Panatto *et al.*, 2016).

The last quadrant of peripheral themes included only rehabilitation over the two periods. Among the common applications within this theme stand out the provision of self-care exercises and therapies for patients; the transition from hospital care to home care, specifically in geriatrics; and the use of computer-aided health services for older people (Giroux *et al.*, 2019; Korpershoek *et al.*, 2020; Backman *et al.*, 2018; Bendixen *et al.*, 2017). The studies focused on rehabilitation were so significantly developed throughout the second period that they were close to the border of the basic and transversal themes quadrant. In the first period, the theme assisted living spaces and technology appeared but gradually disappeared and vanished over the years.

#### 4.4 Content analysis

The results from the systematic content review of the 169 sample publications made it possible to deepen the results from the co-keyword analysis with a specific picture of the role that users play in the above-mentioned applications and themes. We tried to answer the questions about *who* the users are, *why* they get involved, *when* they participate and *how* they do so.

4.4.1 *Who the users are.* UI as a strategy for innovation development relies on the experience of some users to bring insights and source ideas about getting a better alignment with the real needs of potential customers (Keinz *et al.*, 2012). Contrary to many industries and markets, users of e-health innovations in a medical setting are nonetheless a much more diverse group of people going well beyond the target stakeholder: the patients. Thus, UI strategy for new product and service development is applied differently in this special setting and a critical and insightful question is who the users participating in UI are in e-health innovations. The results of coding the users involved in the 169 sample publications show that they fall into one of the following seven categories:

- (1) Patients or persons related to a specific disease in different stages such as under-treatment patients, cured patients, screened patients or patients in remedy (Leite and Hodgkinson, 2021; Schmidt *et al.*, 2021; Quintana *et al.*, 2020).
- (2) Risk groups or segments of people at risk of suffering a disease such as children, elders or women, to cite a few (Lackie *et al.*, 2021; Perestelo-Perez *et al.*, 2020).
- (3) Healthcare specialists such as clinicians, lab staff, health professionals or doctors (Berry *et al.*, 2020; Lee and Kim, 2020).
- (4) Caregivers include professional as well as family and non-professional ones (Couture *et al.*, 2018; Latulippe *et al.*, 2020).
- (5) Academics range from researchers, professors, teaching staff and university students (Ferri *et al.*, 2020a).
- (6) Nongovernmental organizations (NGOs) and government instances as interested parties in health-related issues (Makeham, 2020).
- (7) Digital service providers such as application developers, interface designers, artificial intelligence technicians or data scientists (Peiris-John *et al.*, 2020; Ray *et al.*, 2019).

Reorganizing the classified group of users into an overarching theme, three major actors evolve: patients (actual patients or potential patients in terms of risk groups), experts (healthcare specialists, academics and technicians) and caregivers (people in contact with the patients regularly).

4.4.2 *Why users participate.* User participation in innovations is partially driven by the self-interest of having some encountered problems fixed and ready to be used subsequently once the innovation has been implemented. Practically, to better understand the reasons for user involvement requires analyzing the characteristics of the resulting innovations. With this purpose, this study codified those characteristics as part of the content analysis carried out on the 169 sample publications. The results revealed three critical reasons that cut across the themes identified in the co-keyword analysis and bridged them according to clear patterns in e-health innovations: self-care (Gray *et al.*, 2020), remote care (Zaidi *et al.*, 2020) and health education (Goldchmit *et al.*, 2021).

The self-care reason lies at the intersection of self-management, m-health, rehabilitation and adolescence (see Figure 3). Some examples in the literature are the self-management treatment of diseases (Morrison *et al.*, 2015; Bendixen *et al.*, 2017; Morita *et al.*, 2019), the support of rehabilitation and post-recovery processes (Lavalley *et al.*, 2019; Backman *et al.*, 2018), and the tracking of chronic diseases such as diabetes, HIV, or mental health problems, to name a few (Tonkin *et al.*, 2017; Marent *et al.*, 2018; Gill *et al.*, 2019; Fonda *et al.*, 2010).

The remote care reason cuts across the themes of m-health, telemedicine, software applications and human factors. Some of the most distinguished innovations are self-administered digital tools for elder mistreatment screening, e-health tools for caregivers

responsible for elder persons, digital health tools to improve clinical trial–informed decision-making and SMS text messaging tools for two-way communication between patients and health professionals (Latulippe *et al.*, 2020; Fleisher *et al.*, 2020; Abujarad *et al.*, 2021). Interestingly, this reason has two facets: one for care provision and caregivers and another for healthcare and health professionals.

Finally, the health education reason is related to the themes of e-health, the Internet and trust. Such innovations include massive open online courses (MOOCs), patient educational materials and information databases (Ferri *et al.*, 2020b; Badiu *et al.*, 2017; Dai *et al.*, 2019; Cheng *et al.*, 2020; Marko-Holguin *et al.*, 2019).

*4.4.3 When users participate.* The content analysis involved coding each publication according to the phases of the innovation process in which the users participated. Taking the process model advanced by Tietz *et al.* (2005), user participation falls into two stages and six phases: (1) idea generation (encountered problem, concept derivation, concept development) and (2) idea realization (information gathering, development, testing). In many cases, users may participate in a few phases of the innovation process or in only one of them.

Three out of the six possible phases concentrate the bulk of user involvement in the process of e-health innovations. The most frequent innovation process phases in which users participate are concept development within the idea-generation stage and information gathering and testing within the idea realization stage. Concept development comes at the very end of the idea-generation stage, being the third step in the chained process of innovation.

An interesting example from the literature is a UI project aimed at collecting patterns of use of e-health solutions based on a design thinking method in which the users participate in all the phases of a usual innovation process, with the notable exception of the first one, which is the initial definition of the need or understanding the problem (Daniëls *et al.*, 2019). Another UI project based on a UCD method involved users in the concept-derivation phase instead of going back to the identification of needs by trying to understand the e-behavior of the target group (Gill *et al.*, 2019). These examples are simply an illustration of the trend for e-health innovators to involve users only in projects in which the needs have been previously identified by the innovating organization on its own.

*4.4.4 How users participate.* In addition to when users participate, it is also crucial to understand how they do so. Bearing in mind the six phases, an interesting result is that 12% of the sample publications analyzed user participation only in the testing phase of the innovation process without involving them in previous phases, whereas the co-creation literature warns about the likely disappointment of users when they are simply employed for testing purposes at the end of the process (Weber, 2011). About 16% of the sample publications studied user participation in the information-gathering phase either in isolation (8%) or in combination with other phases (8%). In such publications, users mostly get involved through surveys, interviews and reviews with the aid of digital tools to gain insights into end user perspectives on the concept without truly engaging them throughout the innovation process (Peiris-John *et al.*, 2020; Chehade *et al.*, 2020; Minen *et al.*, 2020).

Turning the attention toward the handful of exceptions in which the users are extensively involved in the innovation process, the practice of hackathon events emerges as an advantageous manner to understand the unmet needs of patients and health professionals from the beginning to the end of the innovation process (Poncette *et al.*, 2020). In these few studies (about 4%), patients and health professionals have engaged actively in the quest for finding the best possible health outcomes through a careful exploration of their needs and ends, continuing with the development of the ideas generated and ending with the successful adoption and use of the resulting new technologies (Grant *et al.*, 2020; Wannheden and Revenäs, 2020).



## 5. Discussion and implications

By applying a bibliometric and a content analysis of the selected articles, this study described the main foci of the e-healthcare sector in terms of user innovation. It could be reckoned as the ultimate and most comprehensive research on the topic given the large scope and the research questions addressed. This study scrutinizes the innovative ideas, the various groups of users involved in the process of innovation, the resulting innovation characteristics and user roles in the different stages of the innovation process premised on a UI strategy. The overriding aim of this study is to inspect the different angles of the UI strategy and its applications, such as co-creation, co-design and so on, within the ever-increasing sector of e-healthcare. [Table 2](#) provides a snapshot of the key findings from bibliometric and content analysis. Its purpose is to provide a comprehensive analysis of the main benefits for e-health projects in using users for innovation management, taking advantage of UI best practices.

### 5.1 Discussion of findings

The descriptive results and the thematic maps show that there was not considerable interest in the topic of UI before 2012. The applications of UI (known as themes in this study) within the e-healthcare sector have changed drastically over the years and have achieved more significance within the last few years. In searching to answer the *what* question of this study, the results revealed that advancement of ICT technologies facilitated the process of innovating with users, enabling them to play a central role in generating, developing and testing novel health ideas through e-health channels, m-health, self-managing applications and telemedicine technology. Users have played a less critical role in resolving the ethical and trustworthiness issues of co-created innovations, such as data security, probably due to the complex nature of these concerns. Additionally, the humanistic factors in methods such as UCD and co-design (e.g. in designing a mobile application) remain nascent. The objectives of co-creating health solutions and treatments vary across the spectrum of different target end users.

Extending the inquiry to *who* and *why* showed that a remarkable percentage of user participation in innovation processes aims at finding self-care solutions (for those we can consider as individuals). It corresponds to the increasing need of applying m-health to track and treat long-lasting diseases, rehabilitation, recovery processes and chronic diseases in a manner that enables the patients themselves (eventually with the aid of their caregivers) be able to self-manage the procedures as much as possible and release the resulting time and effort devoted by health professionals to alternative health and medical priorities. We found partial examples for UI in P2P (patient-to-patient) use cases, but the topic remains insufficiently researched in the context of UI. Patients (specifically those with chronic and special diseases), followed by health specialists and specific risk groups (specifically elders and women), are among the groups of users who seek to find and fine-tune self-care solutions and treatments to boost patient quality of life, staying in control of their own care process and get empowered to actively contribute to their treatment. Involving users aims also at innovating remote-care solutions, which deal with the provision of care by health professionals without requiring direct contact or physical presence, thus benefiting patients, caregivers, and health professionals, as well as digital providers. Remote care can resolve communication barriers and improves patient monitoring in situations such as the experienced COVID-19 pandemic crisis. It supplies health providers with real-time data of hard-to-reach patients, creates valuable insights into the needs of special groups of targeted users, and improves communication and consultancy quality.

Among the remote-care applications, telehealth technology, mobile apps, remote-sensing systems, robots and natural language processing (NLP) technology have doubled down. A wider group of end users get involved in innovating remote-care solutions, particularly health specialists, patients and their family caregivers, and digital service providers. Health

RQs	A summary of results from the bibliometric and content analysis
<b>(RQ1)</b> <i>What</i> are the applications of UI in e-health?	<p><i>Time span 2005–2012</i>            Motor themes: Technology            Transversal themes: E-health            Niche themes: Cadhealth            Peripheral themes: Telemedicine  <i>Time span 2013–2021</i>            Motor themes: Internet            Transversal themes: E-health, telemedicine, M-health, self-management            Niche themes: Adolescent, trust, human factors, application software            Peripheral themes: Rehabilitation</p>
<b>(RQ2)</b> <i>Who</i> are the users involved in those applications?	<p>(1) Patients or persons related to a specific disease, (2) Risk groups or segments of people at risk of suffering a disease, (3) Healthcare specialists, (4) Caregivers, (5) Academics, (6) Non-governmental organizations and government, (7) Digital service providers</p>
<b>(RQ3)</b> <i>Why</i> are users getting engaged in UI in e-health?	<p>(1) Self-care solutions (e.g. co-designed apps), (2) Remote care (e.g. digital health, text messaging tools, self-administered tools, health education (e.g. Massive open online courses (MOOC))</p>
<b>(RQ4)</b> <i>When</i> do users participate in UI processes in e-health?	<p>Users get involved in the second stage of the innovation process: Idea realisation (specifically in information gathering and testing)            Fewer studies concentrate on involving users in the first stage of the innovation process—idea generation—within which is mostly in the conceptual development phase</p>
<b>(RQ5)</b> <i>How</i> do users get involved in UI processes within e-health?	<p>20% of studies articles show users take part in a single phase of the innovation process which is mostly information gathering and testing the innovations            75% of studied articles analyze users' role in two or three phases of the innovation process (without any clear sequence of innovation phases)            4% of articles concentrate on the involvement of the users throughout the whole innovation process in both idea generation and realization</p>

**Table 2.**  
 Snapshot of the key  
 findings from  
 bibliometric and  
 content analysis

education is another reason for various end users to co-create e-health innovations to develop solutions to improve people's knowledge and digital health literacy and remove the digital divide among diverse targets. This application of UI in the e-healthcare sector has broadened the focus on other target end users—academics and NGOs and health organizations—in addition to the aforementioned users.

To answer the fourth and fifth research questions regarding the *when* and *how*, we went over the selected articles to identify in which innovation process stages and phases users get involved. The findings indicate that the user involvement in e-health innovations begin too late—mostly in the idea-realization stage rather than the idea-generation stage—in disconformity with UI theory, which points to the identification of needs as one of its major applications through the acknowledgment and understanding of the problems encountered by users (Franke and von Hippel, 2003). Indeed, UI scholars posit that users should be involved from the early stages of the innovation process because innovation is more likely to happen when users get the chance to specify their requirements and express their needs from the very beginning (Alam, 2006; Urban and von Hippel, 1988; von Hippel, 1986). The reasons behind this imbalance across the two stages may lie in the extensive use in the sample publications of co-design and participatory design methods, which are naturally biased toward idea realization.

A deeper motive may be because the time-consuming, expensive and complex development of health technologies makes health organizations and service providers reluctant to involve users in the ideation stage. Unfortunately, the late involvement of users may produce a lack of embeddedness of user needs in the innovation and the resulting failure of the product/service offer (Salomo *et al.*, 2003; Pitta and Franzak, 1996). Dividing the two innovation-process stages proposed by Tietz *et al.* (2005) into different phases revealed in most of the reviewed articles that users are involved in single or a limited phase of innovation processes, specifically concept development in the idea-generation stage and information gathering along with the testing phases in the idea-realization stage. A small fraction of studies focuses on the involvement of the users throughout the whole innovation process in the idea-generation and realization stages.

The phases in which users get involved do not follow a clear-cut sequence; however, they typically remain active either in the first stage or the second stage and rarely happen to be engaged in separate phases associated with two stages. The involvement of users in a single phase of the innovation process accounts for 20% of the sample publications in which users do not consequently participate throughout the innovation process. This finding is again in conflict with the co-creation literature, which prescribes broad participation because user needs may change throughout the process of innovation; consequently, keeping them vigorously involved could strengthen the concept through to the end (Donath, 1992; Füller *et al.*, 2006; Moore, 1987). A related issue is that users predominantly participate in UI projects as invitees rather than proactive initiators of the innovation process. It seems clear that if health organizations and care providers are not ready to give users an early role or an extensive one throughout the different phases of the innovation process, they are even less willing to let them initiate the whole process spontaneously. This is again an issue in e-health innovations because the inflows of knowledge are severely restricted in this manner.

### 5.2 Research implications

The results from the present study have research implications for the advancement of user innovation and the related fields of open innovation and digital transformation. Existing studies have explored user innovation in many settings, ranging from industrial to consumer products, from manufacturing to service industries and from for-profit to not-for-profit organizations. Still, most of them analyze a relatively simple innovation project with clear objectives in which the users are typically well defined. Our findings are, on the contrary,

derived from a much more complex setting in which the users and the purposes are notably diverse, as is the case of healthcare. In this context, increasing users to take on varied roles and address sensible issues seems to produce essential deviations from the prescriptive recommendations based on user innovation theory. Indeed, we found end users' late, passive, partial and distant involvement in the initiation and different stages and phases of the innovation process in healthcare. It remains to learn what the reasons for these deviations are from those found in other settings. Some underlying dimensions, such as the number of users, the diversity of users, the variety of goals pursued, the expert knowledge involved or the tacitness of knowledge, might be explanatory factors for those differences. Future studies might try to answer some of these questions to systematize the latent variables that make user innovation theory applicable differently in varying settings. For example, in this vein, whether diverse end users in the e-health sector could play various roles in the co-creation process as conceptualizers, designers, testers, supporters and marketers (Nambisan and Nambisan, 2008) is an interesting research proposition. Future research could highlight if different groups of users such as patients or professionals played specific roles throughout the innovation process.

User and open innovation are related fields that share the assumption that distributed knowledge makes permeable and collaborative innovations better alternatives to those derived from the traditional, closed, vertical-integrated innovation model (Baldwin and von Hippel, 2011). Although there are many differences between user and open innovation paradigms, such as the level of analysis, the motivations to innovate, the appropriability regimes or the behavioral assumptions, they appear as convergent research programs toward a distributed innovation model (Bogers and West, 2012). Interestingly, our findings on user innovation in the particular setting of healthcare showed some similarities with the open innovation perspective.

The tight control that healthcare organizations maintain over the innovation process is more typical of open innovation prescriptions than user innovation ones. This is also the case with the multiplicity of users that we have identified, including firms (service providers), universities and research centers (academics), and even other organizations (government and NGOs), which are typical sources of inbound innovation widely recognized in the open innovation literature (Keupp and Gassmann, 2009; Laursen and Salter, 2006). It is interesting to note that the healthcare setting proved to be an appropriate scope to explore the possibilities of integrating the user and open innovation perspectives into an overarching framework, as recently called for by Alexy *et al.* (2020). The bibliometric and content analysis carried out in this study contributes to the discovery of a good thematic in which this kind of theoretical integration seems especially suitable.

The emerging topics concerning digital transformation represent a final related field to which to connect our findings. Digital technologies affect everything in business and society, including healthcare, as the publications reviewed in this study show (Hanelt *et al.*, 2020). The triangle consisting of business, society and technology is especially rich in the healthcare context, which provides a unique combination of firms, organizations, customers, suppliers and regulators for the study of digital transformation in diverse applications such as m-health, telemedicine, or e-health, as our research found. Future studies might follow interesting avenues for investigating user and open innovations, considering, for example, the kind of digital technology involved—cloud computing, big data, artificial intelligence, robotics and so on—or the digital purpose aimed—digitization, digitalization or digital transformation (Schneider and Kokshagina, 2021).

### 5.3 Managerial implications

Along with the research implications, these study findings are helpful for healthcare organization managers. Despite a repeated emphasis on involving users through the whole

stages of the innovation process, we observed that users in e-health get involved in the innovation process in a scattered manner. Healthcare organization managers should consider the active participation of end users from identifying needs and soliciting new ideas all through to the product/service design, prototyping and testing. There is an urgent need for research for such a specific (user-wise) collaboration at all the stages of the innovation process and the creation of a clear and easy-to-follow process that could be applied by not only “user innovation management” experienced leaders. This recommendation raises some flags for the vague and yet undefined innovation process when using user innovation strategies. Given that an after-the-fact check to evaluate user satisfaction may lead to user disappointment, managers may also pursue an early involvement of users in the innovation process and keep the users involved up to the last stages. The latter assumption calls for more understanding and research on user disappointment in e-health projects and endeavors when users had not been involved earlier. Hence, managers and health professionals must consider that users cannot participate in silos in the process of healthcare and e-healthcare innovations, and they require a holistic view to meet users’ needs.

Another valuable prescription for managers is to seek ways to get users more deeply involved (and actively engaged) in the innovation process and overcome the paradox seemingly resulting from the reviewed publications. Users in this very sector can no longer watch from the sidelines thus paying attention to their specific needs and characteristics are of crucial importance. On the one hand, we have highly motivated users to contribute to the innovations because they or their relatives suffer from a disease or are caregivers. On the other hand, health organizations and digital providers assign a passive, distant and late role as user innovators to those eager users. Implementing digital and openly accessing tools such as open-source e-platforms to attract specific users to participate in diverse UI projects in healthcare could be helpful in that regard. Noteworthy, the active participation of users would be at stake if the health solution fails to meet the socio-demographic characteristics, preferences and special requirements of the users (Bradonjic *et al.*, 2019).

#### *5.4 Policy implications*

No one policy regulation and legislation on a country level have introduced user innovation as an official and legitimate stakeholder so far. On the contrary, decision-makers tend to underestimate user innovation (Bradonjic *et al.*, 2019). Users are mostly used in testing medicines and possibly healthcare services before those have been introduced to public access as this study demonstrated. This may lead to a waste of time and sources to bring forth the health solutions that could not meet the real-time needs of millions of users out there. Emphasized also by Bul *et al.* (2020), formulating open-access policies would raise awareness toward current digital solutions and provide potential gaps and lags in the sector for passionate users ready to innovate and collaborate. All these arguments lead to the urgent collaboration of user innovation researchers and healthcare professionals to work together to build a legal basis to support and motivate the voice of users in the context of innovation.

In this regard, the regulation over data is particularly crucial. In an increasingly data-driven innovation context in healthcare (Madsen, 2014; Wehde, 2019), some legislative regimes such as that imposed in the European Union countries with the General Data Protection Regulation (GDPR) could need some amendments for healthcare innovation and user innovation to take place more easily in the name of general interest. For example, some special rules could be applied regarding privacy restrictions when a user gets the status of user innovator in an e-health innovation project for a smooth flow of information among the different parties involved—resulting in this way in a more comprehensive, early and deeper involvement of user innovators in the innovation process, as suggested by this study findings.

## 6. Conclusion

User innovation and users, in general, have become a vital contributor in the field of e-health since the 2000s, especially noticeable with technology advances and implementations of B2C- and C2C-designed technologies at a user level. As a result, from the conducted bibliometric and content analysis on the research done during the starting point of research on users involved in e-health in 2001 until 2021, some clear patterns and knowledge gaps have been identified. The main purpose and thus a potential contribution of this study is the full-picture analysis on these users: *who* they are; *why* they participate; *when, how* and possibly *whether* e-health could gain more benefit from them. We categorized all possible user involvement in innovation in the field of e-health into seven groups after a thorough profiling analysis: (1) patients or persons related to a specific disease, (2) risk groups or segments of people at risk of suffering a disease, (3) healthcare specialists, (4) caregivers, (5) academics, (6) NGOs and government and (7) digital service providers. Our analysis revealed the profile of engaged users combined this revelation with some insights on when and how they are involved in user-innovation initiatives. Doing so, the study does provide suggestions on how innovators/government/medical organizations and R&D organizations can find, engage and collaborate with users for e-health matters. With this categorization of the existing profiles of users since the new millennium, we contribute to the question of who the users participating in e-health are. This has potentially a two-fold value: (1) to the practice by giving a clear location of where to find and engage users (contributing and motivated lead users) and (2) to the theory by calling for further research on how these different types of users could be managed in terms of the specifics of user and open innovation applied in e-health.

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