Digital transformation in patient organizations: an exploratory study

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Submitted to: Journal of Medical Internet Research
on: May 30, 2024

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Abstract

Background: Patient organizations (POs) are an integral part of the healthcare landscape, serving as advocates and support systems for patients and their families. As the digitalization of healthcare accelerates, POs are challenged to adapt their diverse roles to digital formats. However, the extent and impact of POs' digital adaptation remains underexplored.

Objective: The aim of this study was to examine the digital transformation processes within POs. We examined what kind of digital activities and processes are being implemented, who is involved in respective tasks, what challenges are encountered, and which attitudes towards the POs digitalization exist.

Methods: The study was carried out by the multi-center interdisciplinary research network PANDORA. We adopted a qualitative, explorative approach conducting n=37 semi-structured interviews and n=2 focus groups with representatives and members of POs in Germany. Results were obtained through a deductive-inductive approach based on Kuckartz's qualitative content analysis. Methods and results were reported in accordance with the Consolidated Criteria for Reporting Qualitative Research.

Results: POs primarily apply basic digital tools to engage in communication, health education, and information dissemination. Some also develop specific mobile applications and collect health data through patient registries. Volunteers cover a considerable part of the workload. Sometimes, POs collaborate with external partners such as health professionals or other nonprofit organizations. Many interviewees also referred to the importance of involving members in digitalization efforts to better meet their needs. However, they described the actual practices used to involved members in (e.g.) developing digital services as limited, passive or implicit. When evaluating digital transformation processes, representatives and members of POs frequently expressed generally positive attitudes and acknowledged its potential to improve accessibility of support services, management efficiency, and outreach. Still, resource constraints, the complexity of digital initiatives, and accessibility issues for certain demographic groups, especially the elderly, were frequently mentioned as challenges. Several interviewees highlighted POs' increasing responsibility to support their members' digital competencies and digital health literacy.

Conclusions: POs are actively involved in the digital transformation of health services. To navigate challenges and to further shape and sustain digital activities and processes, POs may benefit from governance frameworks, i.e., a clear plan for with whom, how, and with which objectives digital projects are being realized. Support from public, scientific, and policy institutions to enhance the process through training, mentorship, and fostering collaborative networks seems warranted.

(JMIR Preprints 30/05/2024:62750)
DOI: https://doi.org/10.2196/preprints.62750

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Abstract

Background: Patient organizations (POs) are an integral part of the healthcare landscape, serving as advocates and support systems for patients and their families. As the digitalization of healthcare accelerates, POs are challenged to adapt their diverse roles to digital formats. However, the extent and impact of POs' digital adaptation remains underexplored.
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Conclusion: POs are actively involved in the digital transformation of health services**.** To navigate challenges and to further shape and sustain digital activities and processes, POs may benefit from governance frameworks, i.e., a clear plan for with whom, how, and with which objectives digital projects are being realized. Support from public, scientific, and policy institutions to enhance the process through training, mentorship, and fostering collaborative networks seems warranted.

Keywords

Patient organization, patient support, digitalization, digital transformation, health research

Introduction

The digital transformation of healthcare is an ongoing process in which health-related services such as types of care, diagnostic methods, and health information are being digitalized [1–3]. The degree of digitalization varies considerably between different health organizations and health sectors, and this gap has widened during the pandemic. This is due to, inter alia, the available resources and organizational structures, the degree of digital literacy of those responsible for implementing digitalization, and attitudes towards digital services (e.g., [4,5]). Some institutional actors within the health system, such as health insurances, ask individuals to contribute to the digital transformation and to develop their own digital literacy. To make this possible, those institutional actors need to provide the necessary resources and define the appropriate levels of contribution and literacy [3]. Overall, the digital transformation requires more collective efforts across the healthcare sector to counter the uneven degrees of digital transformation [5].

Alongside primary care services, patient organizations (POs) are now recognized as key health advocates, providing vital support to patients, people with chronic conditions, and their families. While varying in size and scope, POs all aim to empower individuals to better manage their condition, e.g., by providing health information and self-management resources [6,7]. Previous research shows POs as representing patient voices in health care and health policy-making by developing new forms of collaboration [8,9] [10] and as research facilitators and partners [11,12]. In fact, for countries such as the UK, the Netherlands, Sweden, and Germany, POs are now one of the central contributors to health research, e.g., when their members contribute to the planning and implementation of study projects. The main domain in which this takes place is rare disease research [13,14].

Considering their roles and tasks, POs face the need to join in the digital transformation of society, and the medical field specifically [15]. With this, POs are also subject to the challenges that come with shifting towards digitalized work processes, e.g. the search for appropriate resources. PO-specific challenges – particularly regarding scarce administrative and financial resources and the proportion of vulnerable and elderly people who seek help from POs [16–18] – add to these demands. For example, POs need to engage in collaboration with other stakeholders to ensure sufficient resources for their digital transformation [19].This in turn leads to challenges for POs in their internal and external governance processes, including their ethical dimensions (e.g., [19–21]): POs need to be transparent vis-à-vis their partners and their members, they need to balance their members' interests and autonomy with collective responsibilities, e.g., in research advances, and they need to handle rapidly increasing amounts of patient data. In addition, POs attach importance to professionalization, e.g., in terms of creating professional management and organizational structures by digital tools.

To assist POs in shaping their own digital transformation, a better understanding of current practices, opportunities, and potential barriers is needed. Unfortunately, insights into how POs operate are largely lacking [12], particularly in relation to digital transformation. With the present study, we explored the current state of German POs' digital transformation. We looked at the digitalization projects that POs implement, what government structures they use, and which actors they involve. We also assessed the extent of POs' members involvement in the POs' digital transformation and the attitudes of POs' representatives and members towards their organization's digitalization efforts.

Methods

Study design and context

This study was conducted as part of the multicenter research network PANDORA ("Patient-centered digitalization: An ethical analysis of the role of patient organizations as actors in the context of digitalization in health-related research and care"). PANDORA investigates how POs contribute to the digital health transformation, shape their own digital practices, and address the challenges they face therein [22]. For this study, the three study sites pursued distinct, though related objectives within the same overarching research questions defined by the aim of PANDORA. Through semi-structured interviews and focus groups digitalization practices in POs were explored. An exploratory design was chosen, as these practices have rarely been investigated so far. We use the Consolidated criteria for reporting qualitative research (COREQ) to report our methodology (see Multimedia Appendix 1) [23].

Target group

To gain in-depth insight into the digital transformation in POs, we invited representatives and members of POs in Germany to participate in this study. Except for the recruitment, no prior relationships with the target group existed prior to the study. We defined representatives as those persons who work full-time, part-time, or voluntarily for a PO and are involved in leadership roles. Being affected by a chronic illness and/or disability was not a requirement to be recognized as a PO representative. PO members are individuals affected by the disease or disability the PO they are registered with advocates for. It was inconsequential whether they were involved in the POs' work, as long as it was not in a leadership role. We did not include professionals, such as medical staff or clinical researchers. Regarding the sampling procedure, we aimed to include PO representatives and PO members in equal shares. We also aimed to approach numerous POs (see below) to increase diversity regarding place, size, and thematic focus. Each study site recruited until these criteria were sufficiently satisfied and no new topics were mentioned by the interviewees.

Recruitment strategy

We first conducted a manual online search and a comprehensive review of German POs' umbrella organizations and their member organizations. We then merged these findings into a single list of German POs. During this process, we screened the POs websites for mentioning involvement in digital activities. POs that did not meet our criteria were excluded. The final list contained a total of n=96 organizations. We then initiated a purposive recruitment process at each study center. This included sending invitations by email, making follow-up calls if there was no response to the initial approach, forwarding the invitation to PO members via the POs' channels of communication, and approaching PO members directly via the PANDORA advisory board. Study center 1 contacted n=15 POs, study center 2 contacted n=21 POs and study center 3 contacted n=39 POs.

Data collection

Qualitative data collection from October 2022 to April 2023 was conducted mainly through individual telephone interviews and complemented by two online focus groups with PO representatives – the latter to increase practicability for the interviewees (SWa, SK, HJvGS). All female and male junior and senior research fellows had a background in public health or medical ethics. They developed and pre-tested semi-structured interview guidelines, including detailed feedback on topics and wording from the PANDORA patient advisory board. While the interview guidelines varied slightly in their exact questions per study site, each included three broad sections: 1) general aspects related to the level and relevance of digitalization in the respective PO; 2) perceived opportunities and challenges of digital technologies, for example by referring to the respective digital tools previously developed by the PO (e.g., the aforementioned app or registry); And 3) the digital transformation of the German healthcare system (Multimedia Appendix 2). At the beginning of the interviews, for which only the researcher and the participant(s) were present, we provided general information on the researchers' role in the study without mentioning any specific researcher characteristics. We did not carry out repeat interviews and used field notes to further structure the interviews.

Data analysis

Each audio file from the interviews and focus groups was transcribed, pseudonymized and then exported for analysis in MAXQDA (1989-2023, VERBI Software. Consult. Sozialforschung GmbH, Berlin, Deutschland). To generate our findings, we conducted a qualitative content analysis based on the steps described by Kuckartz [24]: 1) We deductively derived initial main categories for analysis based on our interview guidelines, and agreed on these categories among the co-authors. 2) We coded four out of 39 manuscripts (approximately 10%) to test the suitability of the main categories. 3) We compared the results of this test phase and further developed and refined the coding system until the main authors agreed (SWa, SK, HJvGS, JL) – see the results section for an overview of the main- and subcategories. 4) We analyzed all remaining manuscripts with the final version of the codebook (SWa, SK, HJvGS). Here we used consensual coding, i.e., the main person coding discussed any uncertainties with one of the co-authors based on the definitions established for each category in the codebook. 5) Once the process of applying the main codes to all manuscripts was complete, we inductively derived sub-categories within each main category by screening each code within the main categories to further concretize the content. 6) We added frequencies to each sub-category – based on the individual mentions of each aspect – to gain an overview of the weight of each aspect mentioned by our participants.

Our study adheres to the Declaration of Helsinki and ethical approval was obtained from the ethics committees of each study center (project 1: 11/6/22 (University Medical Center Göttingen) & 2022-20 (University of Applied Sciences Hamburg) project 2: 10395_BO_K_2022; project 3: 11/6/22).

Results

Participant characteristics

We interviewed a total of n=46 participants (n=26 female, n=20 male) who were either a member (n=26) or a representative, i.e. staff (n=20) of a Patient Organization. The mean duration of interviews was 71 minutes and focus groups lasted for 124 minutes. The majority of our interviewees were 45-59 years old (n=17), followed by n=15 participants in the ≥60 years age group. Interviewees often stated to have completed secondary (n=7) or tertiary (n=32) education, which equals a high school or university degree respectively. The Patient Organizations – most of them acting at a national level – involved were diverse in size, with n=2 acting as umbrella organizations.

Table 1. Characteristics of participants

Characteristic		N	%
Age group			
	18-29 years	4	8,7
	30-44 years	10	21,7
	45-59 years	17	36,9
	≥60 years	15	32,6
Sex			
	Male	20	43,4
	Female	26	56,5
	Other	-	-
Educational level			
	Primary education	1	2,2
	Secondary education	7	15,2
	Vocational training	6	13
	Tertiary education	32	69,6
Status in Patient Organization			
	Member	26	56,5
	Staff / representative	20	43,4
Size of interviewees' Patient Organization (members)			
	<100	1	5,3
	100-500	3	15,8
	501-1,000	3	15,8
	1,001 – 10,000	5	26,3
	10,001 – 100,000	2	10,6
	>100,000	3	15,8
	n.a. (umbrella organization)	2	10,6
Scope of interviewees' Patient Organization			
	Regional	1	4,5
	National	21	95,5
	International	-	-

Main themes that were addressed included digital activities, actors involved in POs digital transformation, participatory approaches to the digital transformation, current attitudes towards POs' digital efforts. Overall, POs engage in a range of digital activities with distinct aims, rely on and engage in collaboration with volunteers and other institutions to cover the workload, and face considerable technical, conceptual, and motivational hurdles along the way.

Digital activities of POs

Digital communication and management

To communicate with their members and the wider public, POs mostly use basic communication tools ranging from emails and websites to social media platforms and in-app communication features (sub-theme 1.1, see Table 1). Platforms such as Facebook, Instagram and YouTube allow them, for example, to reach a younger and wider audience to spread information about the various health/disease topics POs deal with. Although PO members use such social media apps among themselves, WhatsApp for instance does not constitute an official channel of communication according to PO. Rather, it is used by members on their own initiative and responsibility. POs also use digital communication tools to their advantage. One prominent example for this are digital or hybrid meetings that serve to supplement or even replace in-person meetings to overcome contact restrictions (especially during the Covid-19 pandemic), to accommodate disabilities of POs members, and, again, to appeal to a wider audience from distinct, i.e. more distant places. In addition, POs employ digital technologies to adapt their administrative and management work, such as digital membership databases and collaborative project management software.

Digital health education

The increasingly digitalized world entails a new responsibility of POs as digital health educators (sub-theme 1.2). As repeatedly stated by our interviewees, many PO members have difficulties to effectively search for and apply health information and/or to use available digital tools to their advantage. Thus, POs educate their members in the use of digital technologies as part of their goal to support their members' disease management, improve their digital health literacy, and empower them to take part in the digitalized world.

Digital health research

Besides providing digital communication and health education, some POs even start to develop digital technologies, such as mobile health apps and data registries (sub-theme 1.3) either on their own or in cooperation with other stakeholders, such as public research institutes and private companies. Through data registries, POs collect health data from their members to facilitate medical and health services research. Remarkably, some of them also apply these registries to conduct their own research projects.

Actors involved in planning and implementing POs' digital activities

POs as independent actors

POs advance their digital transformation by collaborating both with internal and external stakeholders and partners. PO representatives are primarily responsible for planning and implementing digital initiatives (sub-theme 2.1). It also happens that individual organizations rely on regional or national associations of POs – i.e. umbrella organizations – that develop technologies for them. For example, the national association of German Rheumatism Association developed an app that each partner of that umbrella organization on the regional level can make use of.

Support from volunteers and external partners

Furthermore, due to a lack of know-how within the POs themselves, interviewees frequently mentioned that they establish collaborations with volunteers among their members as well as external partners. Within their own ranks, POs rely on members that – based on their professional background or private interest – have expertise in digital service development and delivery (sub-theme 2.2). This support ranges from assisting with short-term tasks to taking full responsibility for certain activities, such as managing the PO's social media channels. External partners are needed to develop digital services that are specific for the PO (sub-theme 2.3). Examples include the development of an app by which the members can communicate with each other, the design of a new PO website, and the provision of technical infrastructure for instance to establish patient registries. External partners are also involved in developing health information for the POs' digital formats. Health professionals, mainly physicians, are asked to provide feedback as a sounding board.

Public and private financial assistance

According to some of our interviewees, POs struggle to seek and maintain appropriate financial resources for planning and implementing the various digital services, projects, etc. In their search for financial support, they apply for external funding from health care insurances and political actors. Also, some POs seek funding from pharmaceutical companies (sub-theme 2.3).

Participation of PO members in digital projects

Motivations to establish and sustain participation

In general, PO members repeatedly indicated to be willing to participate in their POs' digital initiatives (sub-theme 3.1). They cited the benefits they gain from the digital technologies being developed and the feeling that their involvement is making a difference as the main reasons for their involvement. PO representatives stated that member participation is necessary to be able to consider the needs and preferences that users have regarding digital products, i.e., their members. In contrast to the many positive perceptions and willingness vis-à-vis participation, interviewees referred to concrete examples of established participation approaches rather rarely, indicating a gap between aims/willingness and practice.

Types and intensity of participation

PO members and representatives indicated rather unanimously that active participation should already take place early in the planning and implementation of the products. Yet, in contrast, it was highlighted several times that currently member participation stays rather passive, e.g., by participating in a member survey. Some representatives mentioned that they do offer members the opportunity to contribute in a more active way, e.g., by serving on an advisory board for the development of a patient registry (sub-theme 3.2). Unfortunately, members indicated that they were not aware of such opportunities to participate. This meshes with representatives, who said that members involved in such digitalization efforts tend to be those who already volunteer within their PO.

Requirements for participating

Because of this struggle to achieve 'true', i.e. active and ongoing participation of members in the various digital transformation efforts, our interviewees pointed at the need to improve the prerequisites and conditions for this: To do achieve this, PO members repeatedly emphasized that digital projects should be set up in such ways that participation is neither too time-consuming nor too demanding, e.g., in terms of specific professional or technical knowledge. This was considered crucial for the motivation of members to get involved (sub-theme 3.3). The importance of getting members involved is added to by the observation that members can bring specific expertise to digitalization projects because of their professional backgrounds.

Table 2: Main themes and sub-themes mentioned by research participants

Main theme	Sub-theme	Example quote
1. PO’s digital activities	1.1 digital communication and management	We now have a membership management system, which is also a program where you can fill in all the member data, including account data and so on. We can now also see online who is affected. [1-14-4]
	1.2 digital health education	I know from the PO that they had many offers, especially during the pandemic, where doctors or therapists gave a short lecture on some topic, and where you had the opportunity to submit questions in advance, which were then discussed via the computer. [2-4-17]
	1.3 digital health research	I think we are opening up many things with the register that can go more in the direction of digitalization of care. (...) So we actually developed this as a hybrid of outpatient clinic, software and register software. This means that the doctor can see everything you enter directly. And also graphically (...) it looks a bit as if it had at least once swum past Apple. [1-2-4]
2. PO’s digital (collaboration) actors	2.1 POs as independent actors	This means that I drive forward all digitization projects within the organization, for example the connection of a new CM system, which was a very large project, or the relaunch of a new website (...). I work full-time in our organization and collaborate with many volunteers in the digitalization department. [1-1-2]
	2.2 support from volunteers and external partners	Our homepage is now maintained voluntarily by a member. Whether that's good or bad, I'll leave that for now. Our Instagram is also managed by a member. Neither of them are on the board. The fact that [it] exists at all was also [their own initiative]. [1-10-36]
	2.3 public and private financial assistance	The pharmaceutical company even approached us and offered us this sponsoring membership, and for us it is simply a blessing that we can cover our fixed costs (...) with it. [3-2-66]
3. Involvement of PO members	3.1 motivations to establish and sustain participation	It is actually the case that digitization processes should actually be driven from the bottom up. [2-9-95]
	3.2 types and intensity of participation	(...) It's not always easy, there's a lot of tokenism at both national and international level that you involve patients because there may be funding criteria that require it or because it looks good. And that they are not actually taken seriously. (...) Of course, we are also involved from time to time when it comes to consultation or consultative processes (...). [2-5-96]
	3.3 Requirements	So what can ultimately diminish the motivation to participate is if you keep making suggestions that are ultimately not taken into

Attitudes towards digitalization in POs

Our participants generally viewed the shift towards more digital communication and increasing use of digital tools positively. However, certain aspects elicited mixed responses, including criticisms regarding how POs are digitally transforming their work.

Digitalization in POs as...

- *Accelerating management, outreach, and communication* (sub-theme 4.1)
Participants mentioned several examples of successful digital initiatives. POs' websites and, sometimes, social media channels are now a key outreach element to reach out to a wider public and attract new, i.e. younger members. Moreover, patient registries have been established and digital formats for face-to-face interaction and exchange were introduced during the COVID-19 pandemic. Several representatives also highlighted how digital tools help to handle daily and/or regular tasks related to administration and management. Participants also mentioned the ability to network at a national or even European level through digital tools, for example by connecting with abroad sister organizations and research institutes that the PO had not previously worked with. Some also mentioned that costs can be reduced by moving from analogue to digital formats.

- *Simplifying access to PO support services* (sub-theme 4.2)
Many participants described digital tools as helpful and convenient. PO representatives saw video conferencing software as particularly valuable for simplifying communication or facilitating events. In particular, representatives and members alike appreciated the opportunity to improve access for those who cannot attend PO meetings or events in person, e.g., due to a physical impairment.

- *Supporting health research for people with chronic and rare diseases* (sub-theme 4.3)
Many participants found patient registries particularly beneficial and promising. Registries were seen to advance health research the development of new treatments. Valuing the potential benefit for themselves, but also for others affected, several PO members indicated that they would generally be willing to provide their data for use in such a patient registry.

- *Ineffective, costly, and time-consuming activities* (sub-theme 4.4)
Despite these various positive aspects, especially PO representatives reported it as costly, requiring significant personal and financial resources and know-how to implement the projects. This included, but was not limited to, large-scale projects, such as patient registries and mobile apps for which these resources were not readily available. These challenges were seen as particularly significant for smaller, less resourced POs. Some PO representatives as well as members referred to unsuccessful or failed digital projects – although they reported failures less frequently compared to the successes. For example, one participant noted that the PO's social media channels were not effective enough in reaching a wider audience. Another mentioned a chat forum that was discontinued after a while due to lack of use. A last example is the discontinuance of a patient registry at a smaller PO, due to a lack of resources and know-how.

- *Challenging personal interaction and access* (sub-theme 4.5)
Representatives and members alike stated that the value of in-person meetings cannot be fully captured by digital alternatives. Despite perceived advantages, digital technologies were mainly seen as supplement, rather than replacement. In addition, many stated that digital formats are less accessible to the elderly PO members or those with medical conditions impairing cognition.

Participants stated that these persons may lack access to important information. They lack the literacy to work with digital tools, have physical difficulties using digital equipment, or have concerns regarding the use of digital technologies in general.

- Additional efforts needed: planning, training, risk management (sub-theme 4.6)
Both representatives and members emphasized that POs need to make additional efforts to succeed in their digital transformation. Several participants stressed the importance of training members to use digital technologies effectively. Furthermore, they emphasized the importance of digital services meeting members' preferences, providing clear benefits, and being user-friendly. Another key issue our participants brought up is data privacy, e.g., of the data stored within patient registries or gathered by the use of digital tools such as mobile apps. Here, our participants considered comprehensive privacy policies important and necessary.

- Encouraging ambivalence / fostering undecidedness (sub-theme 4.7)
Several of our participants expressed difficulties evaluating the consequences of digital technologies. They are generally uncertain weighing benefits against potential risks. This was exacerbated, as the digital tools had often only recently been implemented by the POs. Others acknowledge that while digital workflows and communication may be feasible and useful in POs, they involve a significant amount of work and financial resources, which are both scarce for POs. Furthermore, some representatives pointed out that while digital transformation within the organization is generally positive, this might not be the case for everyone involved in the process. Specifically, they perceived older PO members as being more reluctant to embrace digitalization in the PO, resulting in low motivation level, skepticism or even resistance. Again, some indicated that the benefits would eventually outweigh the potential drawbacks.

Discussion

This interdisciplinary interview study explored how German POs enact their digital transformation, who is involved in this process, and how PO representatives and members evaluate past and current efforts. The aim was to provide empirical evidence on the 'ways of working' of one of the most important institutional actors in health care and research. While digital transformation is seen as promising and potentially transformative for the delivery of care and research, practical insights into this process, its requirements, and the challenges for POs are largely lacking.

Principle findings

Our findings show that, firstly, POs often have established 'basic' digital information and communication formats, i.e., websites, social media channels, and video conferencing. Although less common, some POs are also engaged in digitally collecting health data for research and have started to transform their administration to digital formats. Secondly, POs rely heavily on internal support and external collaboration to develop and sustain these digital activities. Our participants often referred to volunteer members and collaboration with external public and private partners to cover the necessary workload and resources. Thirdly, while active involvement of members, e.g., in the design of digital tools, was considered desirable by all participants, it participation is not a 'routine' in POs, relying much on sufficient motivation of those involved. Fourthly, the digital transformation in health care comes with a new task for POs: improving digital (health) literacy of their members. Finally, PO representatives and members highlighted that the digital transformation brings the hope to reach a wider audience and attract younger people. However, advantages of the digital transformation of health care may only be realized if several barriers can be overcome. These include, most obviously, a lack of financial resources, the need for digital training for staff and volunteers, and a productive dealing with the reduction of face-to-face communication,

Roles and tasks of POs

Until today, there has been limited research on the roles and tasks of POs in general and in relation to digital transformation especially. Our findings contribute to the evidence base in several ways. For example, according to van Bovenkamp et al. [10], POs seek and depend on collaboration with external stakeholders for a variety of reasons, not least to secure material and immaterial resources, which are often limited, especially in smaller organizations [15]. However, our PO representatives and members were somewhat ambivalent about this fact. On the one hand, POs collaborate in the planning and implementation of digital activities relatively intensively, involving many volunteers (i.e., PO members) and, less frequently, sister organizations such as the national and regional associations. On the other hand, collaboration with external partners, such as pharmaceutical companies or health insurance, was often described as hampered. It was perceived as that it does not serve ‘true’ collaboration purposes, such as jointly developing a new digital service. Rather, collaboration is meant to secure needed resources or to outsource work to external partners given limited own capacities and skills. According to van Bovenkamp et al. [10] , POs however need to foster actual collaboration to promote their role in the health care system.

While Claus et al. [11] state that POs could help to recruit patients for research studies, we found little evidence that POs are indeed using their digital resources for this purpose [12]. Our findings show that POs are using a wide variety of more basic digital tools, mainly for purposes of communication. Those tools include websites, social media, digital events, resulting of the POs internal digitalization efforts. In comparison, the development and use of more elaborate digital tools, such as mobile apps or patient data registries, is less common. A lack of resources, both in terms of finances and skill set, is one important reason for this. Considering the relative novelty of the digital tools and the lack of experience and expertise within the POs to use these tools, a robust digital governance framework is necessary to further advance the digital transformation in POs [3]. Such a governance framework would serve the POs as a guideline in the development and maintenance of their digital activities and services to ensure compliance with their core aims and values.

Involvement of members and lay persons

Our findings highlight a consensus among many PO members and representatives regarding the value of participatory approaches to enhance the usability of digital services. This is consistent with the reported general benefits of stakeholder engagement in the development of digital health tools, highlighting the critical role of this approach [25–27].

The interviews also revealed a strong willingness among members to engage in digital initiatives, while relatively few reported actual participatory approaches. Some studies, though not specific to the PO context, point to organizational capacity constraints, including time and financial resources, which hinder a more thorough use of participatory approaches [27,28]. Further examining such challenges in the context of POs can provide valuable insights for bridging the gap between intentions to participate and actual engagement.

To tap into the full range of perspectives and skills of PO’s members, organizations need to design engagement methods, as our interview data point to the design of such approaches as a potential pivot point for increasing engagement. For example, participants highlighted the importance of clear benefits, manageable requirements, and early engagement as determinants of participation decisions. POs may consider these aspects when planning participatory approaches, as they have also been identified as key participatory design principles for stakeholder engagement in other digital health projects [29,30].

Further, participatory approaches used in POs' digital initiatives seem to focus predominantly on the initial stages of engagement, such as surveys and user testing. The prevalence of these methods in the PO landscape may be due to their relative organizational simplicity and lower demands on participants. More active, collaborative forms such as advisory boards were less frequently mentioned. This echoes a trend found in two reviews, which identified such collaborations in the participatory development of digital health tools, but comparatively more frequently reported forms of participation that tended towards more passive engagement [28,30]. In terms of the PO context, this may prompt further consideration of the applicability of active participation or the potential reluctance of members to take on more control and responsibility.

Building on our findings, future research should explore POs' members' willingness to engage in their PO's projects, their specific needs and expectations, and organizational capacity to support and sustain (active) participation. Such studies could guide the design and implementation of participatory approaches in POs' digital initiatives, or even establish frameworks to align member expectations with organizational realities.

Ethical aspects related to digital transformation within POs

Our findings also highlight the ethical complexities that come with the digital transformation. POs are confronted with a wide range of ethical considerations regarding their digital projects and services as well as the processes of developing and maintaining them. Topics like digital literacy, accessibility of digital tools, and data security ([31–33]) are highly relevant for the POs' digital transformation processes.

Our findings show the importance of accessibility to the digital services POs provide for their members. Interestingly, digitalizing services can lead both to enhanced and diminished accessibility of the services in question. For an inclusionary approach, POs need to identify the respective groups that will and will not most likely benefit by the digital transformation. One group that was seen as potentially disadvantaged were older members, since they might lose the connection to the activities of the PO. This may be due to a lack of resources, to insufficient digital literacy, or to preferences for analogue formats. Yet, use of digital tools may also increase accessibility of POs services. For example, one group for which digital tools increase accessibility are persons unable to attend in-person meetings due to their ailment or disability. Thus, there is ambivalence concerning accessibility, meaning that POs' have to carefully weigh their options and try to forge a path that includes all their members.

A just allocation of scarce resources and the collaboration with external partners was also considered important. Previous research has found that POs rely heavily on third party funding, but that there is a lack of transparent information about potential conflicts of interest [18]. POs are challenged with the task to secure enough resources, to allow them to develop and maintain their digital activities, while remaining independent of undue influences. Their political and economic independence is especially important to maintain integrity and trustworthiness. Here again, careful consideration is needed when choosing an external partner and to safeguard the PO’s independence. However, such considerations might be hampered by a lack of choices.

Persons in POs contributing to digitalization projects may easily find themselves in attitudinal and judgmental conflicts when weighing the positive and negative sides of those projects. This stresses the need for an ethical governance framework for POs’ digital transformation.

Strengths and limitations

We were able to include participants from more than 23 individual patient organizations, each with different target groups and issues in the field of health and medicine, and thus also cover a certain degree of geographical diversity. We believe that this may have helped to increase the diversity of perspectives on the digital transformation of POs, while at the same time clearly identifying which of the practices, actors, and attitudes are most prominent. However, as digitalization activities vary consideribly between POs, there could be a greater differentiation of these and the actors involved according to the size of a PO, the topics dealth with, and the level of digitalization within the respective organizations. Regarding our methodology, it should be noted that, given our limited personnel resources, we did not return interview transcripts and the eventual findings to the participants for comments. Our study can be a starting point for further such analyses.

Conclusion

German POs are currently investing considerable resources to engage in digital transformation processes in health care. They engage in rather sophisticated projects, such as setting up patient registries or providing digital learning platforms (apps), and involve a wide range of professional and non-professional stakeholders/individuals. These efforts and collaborations call for the need of POs to establish more comprehensive ethical governance frameworks to clarify the goals of digitalization, what is needed to achieve them, and how to engage with different stakeholders, including a clear role and motivation for their members to participate. Public institutions could help POs with the multiple tasks and requirements, e.g., by training and providing mentors who could work with POs to develop a digital transformation plan and/or by facilitating networking and sharing among POs.

Acknowledgements

We thank all of our interviewees for their time and dedication to participating in this study. We are grateful for the feedback during the planning and revision of this study provided by our patient advisory board: Miriam Schlangen, Thomas Duda, Wiebke Papenthin, Thorsten Freikamp, Heidemarie Haase. We thank the German Federal Ministry of Education and Research for funding the PANDORA research project.

Conflict of interest

None declared.

Author contributions

SWa, SK, HJvGs and JL planned the study. SWa, SK, HJvGS and JL collected and analysed the data. SWa and JL wrote the first draft. SK and HJvGS provided extensive feedback and revised the draft. CW, SWo, MLD and MAS provided critical input for the draft. All authors read the final version of the manuscript.

Funding

This study was conducted as part of the PANDORA research project, funded by the German Federal Ministry of Education and Research (BMBF); research grant ID: 01GP2115A-C.

Multimedia Appendix

Multimedia Appendix 1: COREQ checklist

Multimedia Appendix 2: Overview of interview and focus group questions

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Abbreviations

PO: Patient Organization

PANDORA: Patient-centered digitalization: An ethical analysis of the role of patient organizations as actors in the context of digitalization in health-related research and care

Supplementary Files

Multimedia Appendixes

COREQ checklist.
URL: http://asset.jmir.pub/assets/232a325e16ad9389b6a88cecfce9e52e.pdf

Overview of questions.
URL: http://asset.jmir.pub/assets/e27ea707d662b7abcc70ec85b2b3340a.pdf

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Transformation.