Users' Involvement in Digital Health Collaborative Projects

Purpose

This research analyses the roles of users in innovative digital health collaborative projects from the perspective of the user by considering three dimensions: their motivation, project activities and the support of the partnership for their effective involvement.

Design/methodology/approach

We unravelled profiles of users by using a Q-methodological analysis of 24 statements and 44 service users. The statements for the three dimensions were designed according to previous models of stakeholder identification and customer participation in new product management.

Findings

We obtained two profiles that advocate active participation of users, though with a different degree of involvement. One of them supports the role of users as 'advisors' of users' preferences and needs, and the other indicates a higher involvement of users as 'co-creators' of the innovation, with the same contribution and responsibility as the other partners.

Originality

Previous research has analysed user involvement in digital health, as part of wider research on factors leading to the success and adoption of innovations. Moreover, previous research has analysed user involvement in innovation projects, but without differentiating between projects carried out by an individual organization and those conducted by a partnership. This research contributes to filling this gap by revealing

users' expectations about their involvement and how they think they will fit in with the dynamics of collaborative projects.

Introduction

Healthcare systems are under pressure to respond to changing population needs, integrating services inside (primary and hospital services) and outside the healthcare system (e.g. social services), and improving their efficiency (Medeiros and Schwierz, 2015; Figueroa et al., 2019; Garattiny et al., 2023; Gifford et al., 2023), user experience and quality (Kruk et al., 2018; Figueroa et al., 2019; Shrank et al., 2021; Garattiny et al., 2023). To respond to these challenges, digital health initiatives have been shown to be a factor in the improvement of the population's health (Lewis et al., 2012; Majeed and Khan, 2019; Duffy et al., 2022). ICT-based health promotion improves living standards, quality of healthcare, and patients' knowledge about the treatment and illness (Haluza and Jungwirth, 2015; Duffy, 2022). Indeed, digital health innovations such as telemedicine can help to address mismatches between the supply and demand of healthcare providers caused by increased access of the population to healthcare services (Kvedar et al., 2014). However, despite the general agreement about the relevance of digital health in the future of healthcare systems, digital health innovations do not usually reach the implementation stage (Zanaboni and Wootton, 2012; LeFevre et al., 2021).

The inclusion of the point of view of the users in the development of the innovation could reduce implementation barriers as it increases the perceived usefulness and ease of use of the innovation (Gagnon et al., 2012; Jang-Jaccard et al., 2014; Urueña et al., 2016; LeFevre et al., 2021). This is why we analysed users' perspectives about their involvement in digital health collaborative projects, and defined their roles in those projects, considering (1) the motivation for their involvement, (2) the activities they think they should carry out, and (3) the support of the partnership that is needed for effective user involvement.

We focused on projects developed by partnerships of public and private organizations, since these have been encouraged to develop digital health initiatives due to the combinations of knowledge and resources from different areas (e.g. medical and technological) needed for digital health initiatives (Vayena et al., 2018). Moreover, previous research has analysed user involvement in digital health and innovation projects, as part of wider research on factors leading to the success and adoption of innovations (Bjørkquist et al., 2015; Ghulam and Robinson, 2006; Glomsås et al., 2020), but without differentiating between projects carried out by an individual organization and those conducted by a partnership (Fang, 2008; Nambisan and Baron, 2010; Cui and Wu, 2016). This research contributes to filling this gap by revealing users' expectations about their involvement and how they think they will fit in with the dynamics of collaborative projects.

The rest of the paper is organised as follows. First, the background and theoretical framework are provided, then the methodology and research design are explained, and in the fourth section the results are presented. Finally, a discussion is provided in the last section.

Background

Users Participation in Co-creation Projects

In current highly complex societies, external knowledge is an essential input for projects to obtain a high innovation performance and strategic competitive advantage (Chen et al., 2009; Quintane et al., 2011), but knowledge is widespread and organizations must integrate it fast (Chesbrough, 2003). To face this challenge, organizations seek to establish collaborations to obtain external resources, improve the innovativeness of the new product, enhance decision-making and reduce costs (Morgan et al., 2018). The creation of networks of heterogeneous collaborating partners/stakeholders is therefore seen as important to obtain and integrate resources, and increases the performance of the innovation strategies (Faems et al., 2005; Urueña et al., 2016).

Users play a crucial role in the search for collaboration (Prokop et al., 2019). Users can provide unique information about their preferences, and their valuable and original ideas might help to increase users' acceptance, improve new product outcomes, and obtain process innovations (Cui and Wu, 2016; Mahr et al., 2014). However, to obtain the benefits of user participation, organizations need high levels of absorptive capacity (Cohen and Levinthal, 1990), otherwise they cannot properly acquire, transform, assimilate and exploit users' external knowledge (Morgan et al., 2018; Zahra and George, 2002). Organizations need to consider the activities users carry out and their responsibilities in the project in order to avoid a misalignment with the organizational learning approach that can cause ineffective collaboration (Cui and Wu, 2016).

The development of new ICTs has opened up the possibility for new interaction opportunities with users in order to create value (e.g., online communities), by improving user knowledge of organizations, user trust and by supporting collaboration (Kroh et al., 2018; Piller et al., 2005). Indeed, technological breakthroughs present opportunities for organizations to co-create with users (Payne et al., 2008). In this context, relations between organizations and users in innovation projects have also evolved: from organizations that takes care of users' needs and preferences without their involvement to collaboration with the users in which the user may even lead the innovation process (Desouza et al., 2008). For instance, user-innovators are more likely to lead new trends and ideas in the market, and are highly incentivized to innovate (Hippel et al., 2011).

Identifying and working together with these user-innovators is one means of achieving effective innovation (Cooper, 2019). This approach means that companies/partnerships should not confront them. They may even need to reorganize in order to give support to users during every stage of their project (Hippel et al., 2011). It could be considered the maximum level of user involvement in co-creation projects: users carry out all the activities by themselves with the assets provided by the organizations. However, this new role of users could also be a challenge for organizations because they would need strong strategic flexibility (Cui and Wu, 2016) and the organizations do not fully control the innovation process (Desouza et al., 2008). Indeed, Storey and Larbig (2018) found that high levels of customer involvement in innovation service projects may cause some resistance from project partners to user input.

Regarding the motivations of users to participate, previous research has found a wide variety, such as personal benefits (Kristensson et al., 2008), knowledge acquisition (Fernandes and Remelhe, 2016) or the possibility of making service decisions that will benefit themselves or other users (Sjödin and Kristensson, 2012). The motivations that drive users to participate may differ across industries, and so may the motivation of organizations that involve users, because of the differences in their needs.

Co-creation in Healthcare System ICT Projects

In most cases, user involvement regarding digital health innovation processes has been analysed as part of wider research on factors leading to the success and adoption of innovations. However, how to involve users has received limited attention, despite it being one of the keys for successful innovation.

Ghulam and Robinson (2006) found that users are more involved in testing and trial phases, but also participate in concept definition and design phases. Similarly, Ghasemzadeh et al. (2022) have demonstrated that users typically engage in few or just one phase, with the testing phase being the most common, followed by the concept development and data collection phases. In contrast, Glomsås et al., (2020) have revealed that users wanted more involvement, more information in all parts of the process, better response to their feedback on projects, and the possibility of seeing the benefits of the technology.

Regarding users' motivations to be involved in digital health innovation projects, Ghasemzadeh et al. (2022) found that users are motivated to participate due to the self-interest in seeing their problems fixed through the innovation. On the other hand, Bjørkquist et al. (2015) reveal that the most important role of the users for the project is as a source of information and to increase the legitimacy of the innovation.

The misalignment between users' motivations and their willingness to participate, and how they are engaged, can lead to failure. Baines et al. (2022) have demonstrated that the failure to involve users in digital health innovation may stem from their limited participation in the early stages of projects, the retention of power by researchers and developers, and concerns related to data privacy, security, and trust.

This background shows the demand for a higher involvement by users in the development of digital health innovations and the need for more transparency and communication with the users involved in order to achieve efficient involvement.

Theoretical Framework

As discussed above, value is created among multiple actors interacting and exchanging in networks (Vargo and Lusch, 2008). In these networks the users can play a different role to their predetermined role in the design and provision of a service (Vargo *et al.*, 2020). Different approaches have been used regarding the possible roles of stakeholders. Mitchell et al., (1997) and Wagner Mainardes et al. (2012) created a general classification of stakeholders according to the priority of their claims for the organizations. Achterkamp and Vos (2008) argue that stakeholder classifications should be adjusted to the situation where they are applied in order to be more useful, as do innovation projects (Callan et al. 2006; Turner 2006; Vos and Achterkamp 2006). Other research focuses on analysing the roles of one stakeholder, the users, in new product development (Blazevic and Lievens, 2008; Cui and Wu, 2016; Nambisan, 2002). Nambisan (2002) based the classification of customers on their use as a source of knowledge and their possibilities regarding participation in new product development (design and development or testing and support). Blazevic and Lievens (2008) develop a similar characterization of the roles of customers. However, their approach is related to the passive or active role of consumers as a source of information and the type of relationship with the organization (unidirectional or bidirectional). Fang (2008) evaluates the impact on two variables and two possible roles of customers: as a source of information, and co-developers in new product innovativeness and speed to market. Cui and Wu (2016) evaluate these roles in new product performance, adding to this classification the possibility of user innovators who take on responsibility in the innovation process with the support of the firms, and thus the role of organizations in each circumstance.

Taking these models as a reference, we evaluated the role that individual users think they should have in collaborative healthcare innovation projects, considering three dimensions that define the role of users in these projects: 1) activities conducted by users in the innovation process, 2) the support of the partnership for the involvement of users, and 3) motivations for user involvement. The main consideration of all the classifications is the contribution of users. Hence, we included the activities they carried out in the project as one dimension. We also included the support of the partnership as a dimension because it reflects the extent to which the partnership is open to the participation of users and the activities they carry out during the process. Most of the classifications described above include how the organizations should deal with each type of user, with different approaches: the phase of a project in which users can participate (Achterkamp and Vos, 2008), the tasks the organization should do for the effective involvement of users (Nambisan, 2002) and the role/responsibility of the organization in the innovation development (Cui and Wu, 2016). The last dimension, motivations for user involvement, has been included from the user's perspective in the Nambisan (2002) model and from the organization's perspective in Cui and Wu (2016). We decided to include the motivations as a dimension because if the motivations for the involvement of users are not aligned with their activities in the project and the support of the partnership, users' expectations won't be achieved and their involvement will be ineffective. Moreover, this dimension is more important in digital health innovation projects because the lack of user incentives for the adoption of the innovation can also affect their participation in the project.

In order to define the different perspectives of users regarding their involvement, we used Q-methodology to carry out the research because it allows us to establish relationships within and between the three dimensions.

Methodology and Sample

Q-methodology was developed by Stephenson (1953) to collect and analyse the subjectivity of the individual's perception on an issue. This methodology allows us to group individuals together, not variables, according to common attitudes, beliefs and perspectives (Brown, 1980). From these groups, it is possible to draw general conclusions about the viewpoints of the individuals in an inductive way. Indeed, the purpose of this methodology is to analyse the individual's perception of an issue, not to extrapolate the results.

The Q-methodology began by designing a sample of statements (Q-sample) that are representative of the issues studied (concourse). Then, a diverse sample of individuals (P-sample) that could be representative of the different points of view in the issue studied was selected for conducting the Q-sort. Before conducting the Q-sort, the respondents received an explanation regarding the research project and Q-methodology, and how their information would be used. Next, the respondents signed a consent form, and received the statements (which were presented through the online tool Q Method Software). The respondents had to sort these statements in a quasi-normal distribution with seven array positions (from -3 to 3, see Appendix I). The researcher was present to help the respondent whenever needed. The resulting sorting of statements from each respondent is called a Q-sort. The distribution of the Q-sort can be forced (the number of statements with the same value is restricted) or unforced. In this research, the respondents gave a value for each statement in a forced distribution, because an unforced distribution is not more reliable and may suffer from the Barnum effect (Block, 1961). Once all responses (Q-sorts) were obtained, a factor analysis was performed to form groups of respondents with the same patterns of opinions and beliefs, and which represented the ranking of statements. The factor analysis was performed with Ken-Q software.

The Q-sample

Table I shows the statements from the Q-sample classified by dimensions and the level of involvement. We included 24 statements based on the background previously described. Statements at the bottom of Table I represent a lower level of involvement, where users have a passive involvement, and those at the top show a higher level of involvement as leaders of the innovation process.

The first of these dimensions is the motivation to participate, which can be considered by looking at the needs and the supposed capabilities and knowledge of the users. The motivation and capability that represent the highest level of involvement is represented in statements 1 and 2 that cover the possibility of a user innovator (Desouza et al., 2008). In the next level of involvement, if users have a high level of involvement in the partnership, they should feel a strong sense of partnership and be considered like another partner (statement 3) (Nambisan and Baron, 2010) and their perspective should be of overall importance in the project (statement 4). Their mere inclusion therefore to show their preferences and ensure user orientation of the innovation (statements 5 and 6) has been related with the lowest level of participation (Cui and Wu, 2016), but we decided to consider a lower level of participation. Innovation in healthcare systems must comply with high standards of proven usefulness and safety which might encourage users to participate just to check their compliance (statement 7). Moreover, lots of these innovations are lacking proper support from users, so it is possible to have an interest in involving them only to give legitimacy to the innovation (statement 8).

[Table I. Statements by dimension]

The second dimension is related to the activities of users in the project. Users might think they shouldn’t participate at all (statement 16), be passive participants and only be informed of the innovation (statement 15) or be active participants. There are different levels of user activities and responsibilities in an innovation project: providing information about their preferences and needs (Cui and Wu, 2016; Vos and Achterkamp; 2006), working together with partners on the project solution with shared responsibilities (Cui and Wu, 2016; Nambisan, 2002) and being the users who design and direct the project (Cui and Wu, 2016). We have separated the possibility of users being the main voice in the design of the project (statement 10) from their actually directing the innovation process (statement 9) because the latter is related to a coordination and leadership capability in a project that may not be related to only having the knowledge to design the process.

The last dimension is the support from the partnership that also defines the level of user freedom in their participation in the project. The Q-set considers statements ranging from a closed project where the partnership only informs the users (statement 24) or gives a reactive response to user's contributions (statement 23) to a partnership that does not control the process and just provides resources and advises users so they can carry out the innovation project (statements 17 and 18). This classification is similar to the roles for an organization in a collaborative project (Desouza et al. (2008) and the role of the organizations for customer involvement as innovators (CIN) in the Cui and Wu model (2016).

In order to ensure that the statements were understandable and correctly represented possible user participation in a project, a pilot study was carried out in Belgium with users with similar characteristics as those in the P-sample.

The P-sample

[Table II. P-sample sorted by country and respondents' background]

We used a non-probabilistic purposive sampling because we wanted to obtain a sample of users with experience in these types of projects that can enrich the perspectives about user participation, not a representative sample. Users of digital health tools can be service users of the healthcare services or professionals providing these services. They can participate in the projects as individual users or by representing users' organizations. We selected individuals that participate as individual users in digital health innovation projects in the healthcare system. The projects cover a wide range of digital health innovations for process and product innovation through the use of tracking devices, wearables, apps, suggestions systems, artificial intelligence and big data among others (See Appendix IV).

The projects were selected according to the following requirements: they were finished, included formally established collaborations between public and private stakeholders in the healthcare sector, had gone through a trial phase, and had users participating in the project with a higher participation than just being informed about the innovation. Some of these projects had a private organization as a coordinator and others had a public sector organization. Multiple organizations were typically involved in the selected projects (e.g. hospitals, primary care centres, technology organizations, research centres, etc.). Sixteen projects in five different countries of the European Union were eventually selected (see Appendix IV)

To contact the users, the coordinators of the projects were consulted about possible candidates who had been involved in the projects, and they provided the contact information about the respondents. Next, the users were asked for their participation through email or phone after a short explanation of the project. Those users who agreed to participate were interviewed in person. The respondents did not receive any kind of compensation for their participation. The selected users had different professional backgrounds in the selected projects, but were all selected because of their roles as users (and not because they represented the organization as a whole). No users with health conditions (patients) were included as the privacy requirements of the projects in which users participated did not allow the coordinators to provide their contact information. User representatives, such as patient organizations, were available but were not included in the sample as this research focuses on users with direct individual involvement in the projects.

Results

Seven factors were extracted from the correlation matrix of the responses by using centroid factor extraction, the most common method in Q-methodology research (Brown, 1980). Table III show six common criteria for the selection of the factors (Brown, 1980; Watts and Stenner, 2012). All factors have an eigenvalue higher than 1, so all of them comply with the Kaiser-Gutmann criterion. The first four factors have more than two factor loadings (f_{xy}) that exceed the limit. However, the highest square factor loading of factor 3 does not explain more than half of the common variance. Moreover, factors 3 and 4 do not comply with Humphrey's Rule (the crossproduct of the two highest factor loadings is higher than twice the standard error). In addition, the inclusion of factors 3 and 4 for the factor rotation does not give consistent results, so we only retained the first two factors for rotation. Indeed, the solution should only include the necessary factors to make the viewpoints on the issue interpretable (Brown, 1980; Wastts and Stenner, 2012).

[Table III. Factor extraction criteria]

Factors 1 and 2 were extracted and rotated using the varimax method and the respondents for each factor were selected using a significance level of 0.05 (See Appendix II). The rotated factors explained 34% of the variance (Factor 1 and Factor 2 explain 18% and 16% respectively) and the correlation between them is 0.5293. It is a medium correlation that could be explained by respondents' support for both factors in the relatively 'active' participation of all the users in our sample.

Factor 1 is endorsed by more respondents in the sample than Factor 2, 19 and 14 respondents respectively, a normal result in factor analysis. There are differences in the sample between the professional backgrounds of the respondents in each factor (See Table IV). Regarding healthcare system users, most physicians in the sample support factor 1, and nursing staff do not prevail in any factor. On the other hand, there are more respondents in the sample from social services aligned with factor 2 than factor 1. We do not find any differences in the users according to socio-demographical conditions such as gender that endorse these factors (See Table IV).

[Table IV. Composition of factors by respondents' background]

General Description of the Discourses

Each factor gives a different ranking for the statements, which shapes a discourse about user involvement endorsed by the respondents of the factor. Both discourses advocate an active participation of users due to their unique perspective as users. However, there is a difference in the intensity of involvement. Respondents from Discourse 1 believed that the importance of user participation is to ensure the satisfaction of future users so that they have to participate as advisors in the partnership. These users advise partners about their preferences and user orientation of the innovation. On the other hand, respondents from Discourse 2 endorse the idea of co-creation. They consider that project users and partners should contribute equally to the project and the users in the partnership should participate from the moment the project is designed and thus in the decision-making throughout the project.

Discourse 1: Users as Advisors

Discourse 1 shows the role of users as advisors in innovation projects. Indeed, respondents grouped in this discourse believe that users should not leave the development of innovation to others (s:16, v:-2) and that users should not just listen to what the other partners in the partnership have to say (s:15, v-3), but should instead advise the partnership on how they could increase user satisfaction (s:13, v:2).

According to this discourse, users are motivated to participate in the innovation process because of the different viewpoints they can contribute to the partnership (s:4, v:3). Their practical experience with using similar services provides the partners with knowledge about quality standards and demands that need to be met. This is why users involved in this discourse expect to be consulted by the partnership, so the partners can obtain more information about their preferences (s:14, v:1). The partnership should therefore also enable the involved users to see how the innovation works in reality (s:22, v:2) in order to improve their feedback and ensure that the innovation is user-oriented (s:6, v:1). Moreover, users should be well-informed to increase acceptation of the innovation (s:24, v:2). Statements 24 and 22 reflect the importance of transparency for the collaboration of user respondents in this discourse.

Statement 6 shows that testing the user orientation of the innovation is important, although its value shows that it is not the main concern of users. The same is true for statement 5, which shows how important it is for the users to “indicate what they perceive as an exquisite end product” (s:5, v:1) even though it may not be the main reason to be included. These statements do in any case present users’ roles as advisors and the other motivations and tasks are valued lower by the respondents in this discourse.

The respondents in this discourse also expect the partnership to ensure joint decision-making between the involved users and the partners (s:20, v:1). However, they do not think that users are capable of developing and organizing service delivery (s:2, v:-2) and they are unable to define problems and solutions better than the partners (s:10, v:-1). For these respondents, users should not set and guard the direction for the innovation process (s:9, v:-1). The ranking of these last statements indicates that, even when the respondents expect joint decision-making, they do not believe in extensive empowerment of users or co-creation of innovation with the other partners. Indeed, they think there may be other ways to create relevant innovations (s:11, v:-1).

Discourse 2: Users as Co-creators

Respondents grouped in Discourse 2 also advocate the active participation of users but with more direct involvement than those whose answers are included in Discourse 1. They support the role of users as co-creators of the innovation, with a similar activity and responsibilities as the other partners in the project. Indeed, these respondents disagree strongly with excluding users from development of the innovation (s:16, v:-3), or a passive participation limited to listening to the partners (s:15, v:-2) or protecting user rights (s:7, v:-1). The strong support for co-creation of this discourse is shown in the high value of statement 11. This discourse states that equal contributions by users and other partners (co-creation) is the only way to create relevant innovations (s:11, v:3).

The motivation for this support of equal participation is that the alternative views the users have are useful for other partners (s:4, v:2). This discourse points out that users and other partners should jointly define the problem and the solution (s:12, v:2) because both are better defined by users (s:10, v:1). Furthermore, the partnership should align the objectives of users and partners (s:19, v:1) and should ensure there is joint decision-making in the project (s:20, v:1). However, the low values given to statements 19 and 20 do not show the alignment of objectives and joint decision-making as huge priorities. Other tasks of the partnership are more important for the respondents in this discourse, such as transparency towards the involved users regarding how the innovation works (s:22, v:2), and informing users in order to enhance the acceptation of the innovation (s:24, v:1).

However, the respondents in this discourse do not believe that users know best how to develop and organize service delivery (s:2, v:-1). These differences between users and partners' views and capabilities may be the reason why the respondents in this discourse see the need for collaboration as a unique way to achieve outstanding innovation. Indeed, this discourse does not advocate users taking care of users' issues by themselves (s:1, v:-

2) and questions the possibility of collaboration where the partnership just gives resources to develop users' ideas (s:17, v:-1).

Discussion

This paper has analysed the role of users in collaborative projects for digital health innovations. Their motivations, activities in the project and the support of the partnership for their involvement have been evaluated by applying Q-methodology to a sample of individual users who participate in digital health innovation projects.

Two user roles were found. The first group of users preferred to be actively involved in the innovation process, but without a very intensive level of user involvement. These users were satisfied with an advisory role, and were not looking for co-creative contributions to the innovation process. The latter characteristic of this user group is however very differently rated by the second group of users. In fact, statement 11 (i.e. ‘equal contributions of users and other partners is the only way to create relevant innovations’) is the highest rated statement for the second user group, while it is negatively rated in the first user group. The second user group also wanted to be actively involved during the innovation process. In contrast to the first user group, this user group expected users and partners to jointly define the problem and the solution, as real ‘co-creators’.

Our analysis displays a rather nuanced depiction of user involvement. Both of the user groups expect to be actively involved, but the level of user involvement is slightly different (an advisory role as opposed to a co-creation role). We did not find any evidence of a distinct user group that includes passive users who do not want to actively participate in the innovation process (i.e. just receive information, give support or provide information), as some theoretical models predict (Blazevic and Lievens, 2008; Nambisan, 2002; Vos and Achterkamp, 2006). Neither did we find support for the possibility that users want to lead the innovation process (Cui and Wu, 2016; Desouza et al., 2008). The users in our cases clearly do not identify themselves with these two extremes.

Both roles match Nambisan's idea (2002) of a customer as a co-creator who participates in the design and development of an innovation. However, users participating as advisors are involved to ensure the user-orientation of the innovation, and to provide information about their preferences. In contrast to the CIS described by Cui and Wu (2016), these users would be partly involved in decision-making to some extent, moving them away from the passive role. Users as co-creators reflects the need for equal participation of users and partners in the project, which not only means an exchange of responsibilities (Cui and Wu, 2016) but also an equal contribution. Although users want to have similar participation to the partners, we do not find that 'being considered a partner' is a strong motivation to participate. This does not support the relationship between the sense of partnership and the level of contribution indicated by Nambisan and Baron (2010).

The motivations of users to participate are closely linked with the barriers found in the adoption of digital health technologies. The importance discovered regarding communication between the partnership and users could be explained by the lack of information about digital health innovation being a barrier for its adoption (Harst et al., 2020; Jang-Jaccard et al., 2014), and the active involvement of users requires more information exchange to be successful (Nambisan, 2002). Indeed, seeing how innovation works in reality is also a motivation for users to participate, and to learn about the innovation, which will eventually be used by them (Nambisan, 2002), and is necessary for the users to come up with new ideas (Kristensson et al., 2008).

Limitations and Further Research

This research has found two roles that users have in digital health innovation projects, and which gives a lot of insight into the types of user involvement that are present in collaborative innovation projects. However, the kind of participation that is best for the success of the innovations studied was not explored. Future research should analyse projects with or without the participation of both roles of users to see if it increases the success rate in the implementation of projects and how it affects the output of these projects (e.g., quality, usability and acceptation rates of the digital health innovation developed).

The roles found in this study show differences in the degree of involvement that users want to have in these projects. However, the sample used in this research does not include patients with specific medical conditions, so part of the viewpoints of these users may not have been considered. Patients may have a different perspective than other users as they have to deal with the uncertainty of their medical condition and the effects of their treatments, and may require higher privacy requirements. So, their goal in these projects may be different. Future research could analyse whether they share the same viewpoints as the ones discovered in this study.

We have found differences in the backgrounds of respondents in each discourse sample that point to differences in the opinions of physicians, social workers and other staff. Q-methodology does not allow us to explain the cause of these patterns. The same thing occurs with the heterogeneity of the projects. In this research we have included a wide range of digital health projects from different countries which have allowed us to capture all the perceptions about the user role in these projects. However, it also limits the explanation of the cause of these roles and the possible differences between selected countries. There are indeed differences between the characteristics of each health care system which were not all captured in this research. Further research, therefore, could extrapolate these results to link the discourses with users' backgrounds, and the type of project and country in order to facilitate managerial decisions.

Conclusion

This study contributes to the research on collaborative projects for the development of digital health innovations by showing the viewpoints of users on their involvement. According to this research, users want active participation in these projects but with different levels of involvement. Some users want to participate as co-creators together with the rest of the partnership and others want to be involved as external advisors to give their knowledge as consumers. Previous research has already studied multiple factors that affect digital health innovation, but the way users are involved has generally been overlooked by previous literature, and this research gives a deeper understanding of how to involve users and overcome the user-related barriers that often cause these projects to fail to be implemented.

Considering the two uncovered roles, partnerships who want to carry out a digital health innovation project have to seriously consider the involvement of users in the project as an active part in the process. Partnerships have to evaluate the participation of possible user candidates as their motivation for involvement may be as both co-creators, on the one hand, who contribute throughout the project in the decision-making process and, on the other hand, as advisors who provide knowledge about user preferences regarding the innovation. The partnership thus has to promote or limit their participation according to the user characteristics. The number of users acting as advisors in a partnership could be relatively higher than those acting as co-creators, but it may be necessary to have users involved with the two roles described. Users participating as co-creators participate in the design of the project and its decision-making process, ensuring the user-orientation of the project. However, more users as advisors may be needed to ensure enough user knowledge and increase the usability of the digital health innovation.

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Appendix I. Q-sort Structure

[Figure 1. Composition of factors by respondents’ background]

Appendix II. Rotated matrix and respondents by discourse and country

[Appendix II. Rotated matrix and respondents by discourse and country]

Appendix III. Value of statements by discourse

[Appendix III. Rotated matrix and respondents by discourse and country]

Appendix IV. Digital health innovation projects

[Appendix IV. Digital health innovation projects]

Users' Involvement in Digital Health Collaborative Projects

Tables

Table I. Statements by dimension

		Motivations		Activities		Support from the partnership
↑ Level of Involvement	1	Users should tackle user issues themselves instead of waiting for others to do it	9	Users should set and guard the direction for the innovation process	17	The main role of the partnership is provide the resources to develop proposals of the users
	2	Users know best how to develop and organize service delivery	10	Users can best define problems and solutions	18	The partnership should maximally give room to the involved users to develop their own proposals for the innovation
	3	Involved users especially want to be recognized as partners	11	Equal contributions of users and other partners is the only way to create relevant innovations	19	The partnership should primarily align the different goals of the involved users and the other partners
	4	Users should be involved because they can have alternative views, useful for the other partners	12	Users and the other partners should jointly define the problem and the solution	20	A crucial task of the partnership is to ensure joint decision making between the involved users and the other partners
	5	Users want to be involved primarily to indicate what they perceive as an exquisite end product	13	Involved users have to advise the partnership about how to increase user satisfaction	21	The principal concern of the partnership is letting involved users voice what quality they expect from the innovation
	6	Involved users should above all check how user-oriented the innovation is	14	Just like a company asking its customers about its products, the partnership needs to consult the users about their preferences	22	The partnership should enable the involved users to see how the innovation works in reality
	7	Users are especially involved to check whether the rights of those they represent are guaranteed	15	The majority of users is there predominantly to listen to what the partners have to say	23	The partnership actors are there to make sure that the input of the users and other actors certainly does not go against the regulative framework (e.g., legislation)
	8	Users should be involved primarily to create support for the innovation	16	Users best leave development of innovations to others	24	The users should be well-informed by the partnership because the innovation can then be easily accepted

Country		Background		Gender	
Belgium	9	Nursing Staff	10	Male	15
Denmark	7	Social Worker	10	Female	29
Estonia	2	Physician	19	Total	44
Netherlands	10	Other*	5		
Spain	16	Total	44		
Total	44				

*Pharmacy staff (2), ICT staff (2) and Technician of Health-care system (1)

Table II. P-sample sorted by country and respondents' background

Table III. Factor extraction criteria

	F. 1	F. 2	F. 3	F. 4	F. 5	F. 6	F. 7
Eigenvalues	11.782	3.218	2.591	2.651	2.304	1.803	1.733
% Explained Variance	27	7	6	6	5	4	4
Cumulative % Exp. Var.	27	34	40	46	51	55	59
$f_{xy} > 0.40$*	32	4	3	5	1	1	1
Max. f_{xy}^2	0.700	0.422	0.246	0.320	0.291	0.223	0.186
$h_x^2/2$**	0.371	0.408	0.378	0.287	0.339	0.308	0.322
Humphrey's Rule	0.688	0.504	0.228	0.232	0.204	0.168	0.15

Number of factor loadings > 1.96(1/square-root(24)), a significance level of 0.05

**h_x^2 = common variance calculate as the sum of the square f_{xy} of the Q-sort x

Table IV. Composition of factors by respondents' background and gender

Background	Factor 1	Factor 2	None	Total	N
Nursing Staff	10.0%	30.0%	60.0%	100%	10
Social Worker	20.0%	60.0%	20.0%	100%	10
Physician	63.2%	26.3%	10.5%	100%	19
Other	80.0%	0.0%	20.0%	100%	5
Male	46.6%	26.7%	26.7%	100%	15
Female	41.4%	34.5%	24.1%	100%	29
Total	43.2%	31.8%	25.0%	100%	44

Appendix II. Rotated matrix and respondents by discourse and country

Part.No.	Factor 1	Factor 2	Disc.	Project Number	Country	Background	Gender
1	0.8093*	0.3359	1	13	Spain	Other	F
2	0.5685*	-0.0498	1	14	Spain	Physician	M
3	0.4081	0.2484	1	1	Belgium	Physician	M
4	0.4391	0.4068	1	13	Spain	Physician	F
5	0.444	0.4086	1	9	Netherlands	Social worker	F
6	0.482	-0.0813	1	2	Belgium	Other	M
7	0.6993*	0.2742	1	15	Spain	Physician	M
8	0.5956*	0.5886	1	10	Netherlands	Physician	M
9	0.4028	0.2222	1	3	Belgium	Social worker	M
10	0.4321	0.4314	1	13	Spain	Physician	F
11	0.6*	0.3078	1	15	Spain	Physician	F
12	0.6063*	-0.0271	1	16	Spain	Physician	F
13	0.7363*	0.0968	1	15	Spain	Physician	F
14	0.4492	0.2276	1	6	Denmark	Nursing staff	F
15	0.595*	0.0422	1	16	Spain	Physician	F
16	0.7167*	0.1631	1	14	Spain	Other	F
17	0.5463*	0.5097	1	14	Spain	Other	F
18	0.6*	0.2653	1	13	Spain	Physician	F
19	0.5257*	0.2036	1	1	Belgium	Physician	M
20	0.146	0.5989*	2	9	Netherlands	Social worker	F
21	0.1802	0.4283	2	7	Denmark	Social worker	F
22	-0.2453	0.6574*	2	4	Belgium	Physician	M
23	0.2662	0.5572*	2	7	Denmark	Social worker	F
24	0.1761	0.735*	2	7	Denmark	Social worker	F
25	0.1355	0.62*	2	4	Belgium	Physician	M
26	0.1344	0.6997*	2	10	Netherlands	Physician	M
27	0.0335	0.5012	2	6	Denmark	Nursing staff	F
28	-0.0794	0.4876	2	12	Netherlands	Nursing staff	F
29	0.0702	0.5403*	2	5	Estonia	Physician	M
30	0.3557	0.5706*	2	5	Estonia	Nursing staff	F
31	0.2951	0.4055	2	13	Spain	Physician	F
32	0.4139	0.563*	2	8	Denmark	Social worker	F
33	0.4415	0.6201*	2	16	Spain	Social worker	F
34	0.3721	0.1875	None	9	Netherlands	Social worker	M
35	0.3578	0.3684	None	9	Netherlands	Social worker	F
36	-0.054	0.1465	None	4	Belgium	Physician	M
37	-0.343	0.1458	None	11	Netherlands	Nursing staff	F
38	-0.0292	0.3353	None	11	Netherlands	Nursing staff	F
39	0.3822	0.3798	None	13	Spain	Nursing staff	F
40	0.1944	-0.0121	None	13	Spain	Physician	M
41	0.3422	0.235	None	3	Belgium	Nursing staff	F
42	0.2108	0.3261	None	3	Belgium	Other	M
43	0.2856	-0.0499	None	6	Denmark	Nursing staff	F
44	0.2313	0.1379	None	12	Netherlands	Nursing staff	F
% Exp. Var.	18	16		Total % Exp. Var.		34	

Note: All Respondents of Discourses 1 and 2 are flagged with a significance level of 0.05; Those with * were also flagged with a significance level of 0.01. F: Female, M: Male

Appendix III. Value of statements by discourse

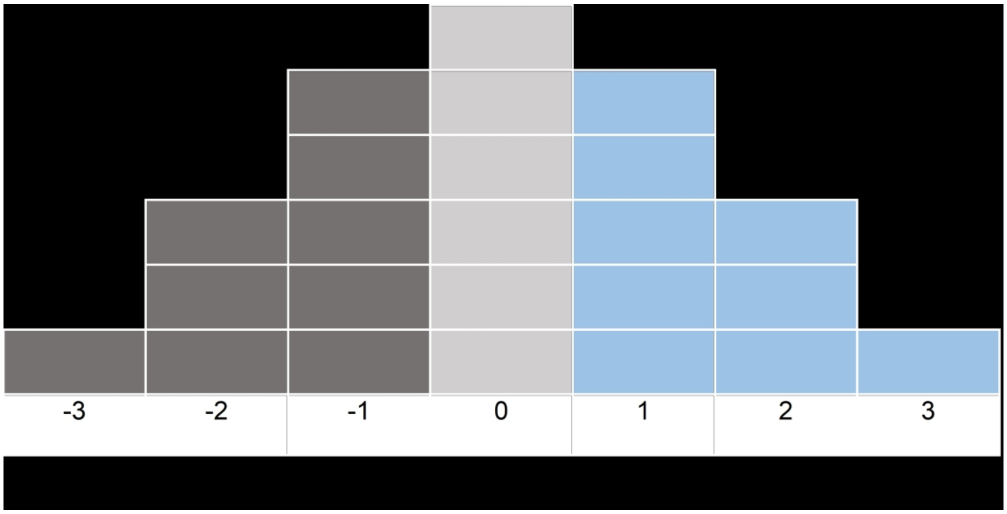
N	Statements	D. 1	D.2	C/D
1	Users should tackle user issues themselves instead of waiting for others to do it	0	-2	D
2	Users know best how to develop and organize service delivery	-2	-1	C
3	Involved users especially want to be recognized as partners	-2	-2	-
4	Users should be involved because they can have alternative views, useful for the other partners	3	2	-
5	Users want to be involved primarily to indicate what they perceive as an exquisite end product	1	-1	D
6	Involved users should above all check how user-oriented the innovation is	1	0	D
7	Users are especially involved to check whether the rights of those they represent are guaranteed	0	-1	D
8	Users should be involved primarily to create support for the innovation	0	0	C
9	Users should set and guard the direction for the innovation process	-1	0	D
10	Users can best define problems and solutions	-1	1	D
11	Equal contributions of users and other partners (co-creation) is the only way to create relevant innovations	-1	3	D
12	Users and the other partners should jointly define the problem and the solution	0	2	D
13	Involved users have to advise the partnership about how to increase user satisfaction	2	0	D
14	Just like a company asking its customers about its products, the partnership needs to consult the users about their preferences	1	0	D
15	The majority of users is there predominantly to listen to what the partners have to say	-3	-2	C
16	Users best leave development of innovations to others	-2	-3	D
17	The main role of the partnership is provide the resources to develop proposals of the users	-1	-1	D
18	The partnership should maximally give room to the involved users to develop their own proposals for the innovation	0	0	C
19	The partnership should primarily align the different goals of the involved users and the other partners	0	1	-
20	A crucial task of the partnership is to ensure joint decision making between the involved users and the other partners	1	1	C
21	The principal concern of the partnership is letting involved users voice what quality they expect from the innovation	-1	1	D
22	The partnership should enable the involved users to see how the innovation works in reality	2	2	C
23	The partnership actors are there to make sure that the input of the users and other actors certainly does not go against the regulative framework (e.g., legislation)	1	-1	D
24	The users should be well-informed by the partnership because the innovation can then be easily accepted	2	1	D

Note: C: Consensus statement with a level of significance of 0.01; D: Distinguishing statement for both factors with a level of significance of 0.01

Appendix IV. Digital health innovation projects

N	Country	Description of the project	N. of respondents
1	Belgium	A collaborative effort involving universities, private health organizations, national and regional government agencies, Red Cross organizations, knowledge institutions, ICT suppliers, and individual healthcare professionals to develop, validate, and distribute evidence-based healthcare guidelines for healthcare providers.	2
2		A collaborative initiative involving government agencies, ministerial offices, hospital networks, regional governments, private healthcare suppliers, insurance organizations, and user associations, to establish a national portal website that offers comprehensive information and services to all citizens.	1
3		A collaborative endeavor between a public nursing home (local government), private construction firms, consulting companies, nurses, and patients to implement various technologies in the nursing home setting, such as wearables, smart cameras, and more.	3
4		A collaborative effort involving private nursing organizations and federations, ministerial offices, national government agencies, hospital networks, individual general practitioners (GPs), and multiple private health organizations to develop a patient information sharing tool for GPs and home care organizations.	3
5	Estonia	Voice command app to guide health care providers, created through a collaboration between a ministry, public health insurance authority, colleges, network of healthcare providers, ICT companies, several health care organizations	2
6	Denmark	A smartphone application for capturing patient-reported outcomes, developed in cooperation between a public hospital, an ICT company, and healthcare professionals.	3
7		An e-learning program focusing on dysphagia, established through a partnership between a regional government, municipalities, public hospitals, an ICT company, and representatives of healthcare professionals.	3
8		A smartphone application designed to communicate bone scan results to osteoporosis patients, developed through a cooperative effort involving a public hospital, a university, ICT and healthcare service companies, patient associations, and healthcare professionals.	1
9	Netherlands	A digital platform aimed at promoting neighborhood collaborations between clients and consultants, developed through a partnership between a municipality, a private healthcare provider, neighborhood teams, and citizens.	4
10		An information and communication technology (ICT) platform that streamlines the sharing of health data among partners and patients, established through a partnership between a municipality, a public hospital, and various private healthcare organizations.	2
11		Monitoring technologies implemented in a nursing home, developed through a partnership involving a semi-private association, a software developer, and a patient organization.	2
12		An innovative "smart diaper" designed for the elderly, developed through a collaborative effort between a semi-private association, an ICT company, and a consulting firm.	2

13	**Spain**	A web-based application for computerized cognitive-behavior therapy (CCBT) that has been developed through the partnership of public hospitals and healthcare services, a public research institute, a private technology center, and a diverse group of healthcare professionals, including psychiatrists, psychologists, physicians, and more.	7
14		An electronic prescription system, patient appointment system, and an automated storage and dispensing robot, developed through a cooperative effort involving multiple public hospitals, private ICT companies, various patient organizations, and a university.	3
15		Artificial intelligence (AI) employed for diagnosing uncooperative patients, developed through a partnership between public hospitals, ICT and telecom companies, and physicians.	3
16		Information and communication technology (ICT) tools for home health management of chronic patients, developed through a collaborative effort involving a public hospital or health service, regional government, ICT companies, consulting firms, various private enterprises, universities, healthcare professionals, and patients.	3



Q-sort Structure

2374x1203mm (38 x 38 DPI)