

# Participatory Development of Rehabilitation Technologies – Chimera or Future Standard?

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**Abstract.** Today, there is widespread agreement that innovative rehabilitation technologies should ideally be developed with the participation of future users. However, there are still considerable uncertainties regarding the methodology of such participatory technology development and regarding the required depth of participation in the development process. The latter is closely related to the empowerment of those affected to participate and the know-how of the technology experts on participatory technology development. The self-help organisations of chronically ill and people with disability are an important actor to further advancing the necessary conceptual development process in the participatory development of rehabilitation technologies.

## Partizipative Entwicklung von Rehabilitationstechnologien – Chimäre oder zukünftiger Standard?

**Zusammenfassung.** Heute herrscht weitgehende Einigkeit, dass innovative Rehabilitationstechnologien idealerweise unter Mitwirkung der künftigen Nutzerinnen und Nutzer entwickelt werden sollten. Allerdings gibt es noch erhebliche Unsicherheiten hinsichtlich der Methodik einer solchen partizipativen Technologieentwicklung und hinsichtlich der erforderlichen Beteiligungstiefe im Entwicklungsprozess. Letztere steht in einem engen Zusammenhang mit dem Empowerment der Betroffenen zur Mitwirkung und dem Know-how der Technologieexpertinnen und -experten zur partizipativen Technologieentwicklung. Die Selbsthilfeorganisationen chronisch kranker und behinderter Menschen sind ein wichtiger Akteur\*innen, um den notwendigen konzeptionellen Weiterentwicklungsprozess bei der partizipativen Entwicklung von Rehabilitationstechnologien weiter voran zu treiben.

## 1 Introduction

According to the well-known definition of the WHO, rehabilitation comprises the coordinated use of medical, social, occupational, educational and technical measures as well as measures to influence the physical and social environment in order to improve function, to achieve the greatest possible self-activity, to participate as far as possible in all areas of life, so that the concerned person becomes as free as possible in shaping his or her life (WHO 1981).

This definition makes it clear that the use of rehabilitation technologies is an integral part of the concept of rehabilitation but that this concept also refers to the participation and free shaping of the life of the concerned person.

It is, therefore, obvious that rehabilitation technologies should also be developed in a participatory manner. This is even truer given that the time available to treatment providers today is becoming increasingly limited. Therefore, rehabilitation technologies must contribute in particular to providing patients with the intensive therapy they need (Hafen et al. 2000; Spiess and Colombo 2017).

For rehabilitation technologies to be designed in a user-friendly way, their development should already take place together with users. Although there is a broad consensus on this objective, there still seem to be many deficits in the implementation of rehabilitation technologies. Who should be involved at which points of the development process, and how? Is there a desire for participation and what advantages can be achieved through participation in the development process?

These questions will be examined in the following.

## 2 Current Status and Challenges

### 2.1 Methodological Issues

The basic concept of participatory technology development is not new. It is based on the assumption that the target group better accepts a technology if it meets their needs. The target group should already be involved in product development and testing to meet this requirement (Cieslik et al. 2012; Friedhof 2017). However, it is already unclear on what methodological basis this involvement should take place. More pragmatically oriented approaches refer to the organization of workshops with affected persons or their participation in advisory boards of institutions and companies developing rehabilitation technologies. In some cases, however, it is also argued that the methodology of qualitative social research should be applied. Then, the formation of focus groups or participant observations is suggested (Jahnel and Schüz 2020; Matiouk 2019).

There are also disparate ideas as to which outcomes should be evaluated regarding the participation of those affected in the development of technology. On the one hand, the effectiveness of the technology itself is conceivable. However, it is also possible to question whether participatory technology development, in particular, leads to users using the technology sustainably and regularly (Henne 2019). It should therefore be noted that there is yet no fixed methodology for how user participation should be planned and implemented in the process from the emergence of the technology idea to the market launch of the technology. So far, much seems to be decided on a situational basis by those involved.

A further point of departure in technology development concerns the determination of whether the user should be discussed in an as differentiated manner as possible according to the concrete impairment scenarios or whether the aim should be to strive for a universal design in order to avoid the stigmatizing effect of special solutions (Cieslik et al. 2012).

The questions raised show that it makes sense to make participation methodology a participatory decision-making process under certain circumstances. Workshops with stakeholders, an advisory board accompanying the project, interviews with stakeholders in a focus group or the observation of the discourse of stakeholders on needs and application experiences are to be understood as options that are always available in the process of technology development and whose use must be decided in each case. These decisions should already be made in a participatory manner.

## **2.2 Lack of Prior Knowledge on the Part of Those Affected**

In participatory development of rehabilitation technologies, the difficulty often arises that, although people affected have generally acquired specific competencies with technologies, this does not automatically equate to technological know-how or general technical experience. This then raises the question of whether they can develop technologies in a participatory manner. In participatory technology development, there is indeed, on the one hand, the danger of being overwhelmed, and on the other hand, the danger of misinterpretations in communication, both on the part of the technology experts and on the part of those affected (Cieslik et al. 2012; Grates and Krön 2016). For this reason, approximation processes are necessary. On the one hand, this approach can be achieved simply by explaining the fundamentals and modes of action of the technology in question and the fundamentals and modes of action of technological alternatives in a way that is understandable to laypersons.

For technology experts, this poses the challenge that sound communicative and didactic knowledge is required in order to be able to impart the necessary knowledge. Attention must also be paid to ensuring accessibility (Cieslik et al. 2012). Thus, training courses for technology experts are a prerequisite for adequately transferring know-how to technological laypersons.

Another possible approach in this context is to interview potential participants from the field of application of the technology in question.

For example, assistants, physiotherapists, nurses, employees in workshops, etc., can be asked for an initial assessment of the relevant problem. The involvement of such professionals primarily involves the user's perspective but not necessarily the affected person's perspective. In some cases, attempts are also made to establish stable working relationships with the target group by means of living labs or hubs (Prilla et al. 2012). Interdisciplinarity, i.e., the combination of stakeholder competence and technological competence, is very difficult to achieve through isolated cooperation. Fixed cooperation contexts are required.

## **2.3 Depth of Participation**

In the development of rehabilitation technologies, there is always one area characterized by the need to apply mainly complex technical know-how, while there are other areas, such as usability, where the user perspective is of crucial importance.

This means that the involvement of users in technology development is perceived as rather remote at some stages of the process, while the participation of affected parties seems indispensable at other stages.

Consequently, technology development can be conceived as a continuum of decisions in which expertise and stakeholder competence are sometimes more and sometimes less important. Therefore, from the point of view of participation, a decision must always be made about the depth of participation (Keeley et al. 2019). However, the depth of participation depends not only on the relevance of expertise and stakeholder competence for the issues to be clarified but also on the resources of the people to be involved.

In the field of participatory research, it was found that the material resources, the time and scheduling possibilities of the target group, and the accessibility of the process are decisive. On the other hand, the mental and cognitive abilities of the target group to be involved are important (Cieslik et al. 2012).

As has already been pointed out, it is important to ask what resources other people involved in the development process have at their disposal for organizing participation, preparing specialist knowledge in a way that is understandable to laypersons etc.

It is a great challenge for all those involved to determine the adequate depth of participation objectively and rationally and not to let constraints, time pressure or the practicability of the procedure become the guiding principle of technology development (Panek and Zagler 2015). A frequent shortcoming of participation is that it occurs only after the product has already been conceived. There is a tendency for non-participation before that. In some cases, it is even argued that the accent of efforts should deliberately be on empowering those affected. Innovation is only possible if people with impairments are supported to question the reality of what has happened before and to participate in technology development from the outset (Köppen, Schmidt, and Tiefenthaler 2020).

## 2.4 Requirements for Technology Developers

The world of technology is characterized by specific circles of experts, their linguistic style, their habitus and a world view based on this (Habermas 1969; Hafen et al. 2000).

Unless technicians have affected competence due to an impairment, they depend on so-called everyday theories for dealing with an impairment in the reality of life.

Therefore, a participatory approach to the development of rehabilitation technologies requires, first of all, that one's own presuppositions and preconceptions are consciously reflected upon (Maaß et al. 2016).

Often, singular personal experiences or socially shaped ideas shape the view of the acting persons on the life of people with impairments.

This must be disclosed. Otherwise, there is a risk that such assumptions will be transferred without reflection to the persons involved or the target group of the technology development.

Even in this phase, i.e. at the beginning of a technology development process, an exchange with those affected makes sense.

Furthermore, it is of course, important that knowledge about the methodology of participatory development of rehabilitation technologies and the conditions of success of participation is available and that the motivation is given to realize the most significant possible depth of participation continuously. It can be helpful to draw on experience from similar projects on a comparable technology and/or a comparable target group or a comparable rehabilitation measure (Maaß et al. 2016).

A further major challenge for the experts from the field of technology is to find participants who are affected by the respective development project. It is common to choose the path of approaching people from the experts' personal environment. It often appears to be the ideal way to approach employees of the company or research institution who have a corresponding impairment.

This may be particularly obvious for the self-reflection phase at the beginning of the process. Overall, however, the problem of such involvement is that the respective experiences are only singular and that, there is a bias of loyalty of the involved persons to the technology development team (Maaß et al. 2016). Genuine criticism of the process or of the inadequate consideration of the perspective of those affected can thus be considerably impeded.

Market research is often used to obtain an overview of user expectations. However, their methods cannot organise ongoing interaction characterized by trust. It should, therefore, be noted that, on the part of the technology experts, knowledge is also required about how the collective experiences and preferences of those affected by the respective target group can be gained or where processes can be identified that can be involved in a respective development project.

Finally, it should be pointed out that the technology development process with all its sub-decisions should be documented as precisely as possible so that the people involved in the decisions know exactly which input is needed for which purpose. Furthermore, the documentation also serves as a control framework to make the consistency of the participation and the decision to be made in each case about the depth of participation transparent.

**Interim conclusion:** Today, there is widespread agreement on the goal of developing rehabilitation technologies as participative as possible. From a methodological point of view, however, there are still considerable uncertainties with regard to implementation. Knowledge deficits and a lack of empowerment on the part of those affected, but also on the part of technology experts, continue to make participation projects a pioneering task.

### **3 Potentials of Self-Help Organizations for Chronically Ill and Disabled People**

A large number of people with impairments have joined forces in the self-help organizations of chronically ill and disabled people in Germany. Fortunately, such organizations exist for most impairment types, and their membership extends throughout Germany. There are also networks in the international area (Danner, Nachtigäller, and Renner 2009; Danner 2016).

The self-help principle is characterized by the mutual exchange between those affected on all issues dealing with the respective illness or disability. One focus of the

exchange thus concerns rehabilitation, particularly the use of rehabilitation technologies in everyday life. In addition to the exchange on the use of such technologies, the dissemination of information and counselling work for those affected is a core task of self-help.

Regarding the participatory development of rehabilitation technologies, the self-help organizations of chronically ill and disabled people thus have great potential in many respects.

### **3.1 Contact Person to Recruit Contributors for the Technology Developers**

For the developers of rehabilitation technologies, the self-help organizations of chronically ill and disabled people are ideal contacts for finding affected persons who would like to participate in the development work in the long term.

On the one hand, those responsible in the organizations have an overview of the people who can be approached and their competencies. On the other hand, those responsible for the organizations also have an overview of the unique features that must be considered to cover the target group adequately. Differences in the stage of the disease, in the degree of impairment, differences depending on whether the person has a job, what age, and what gender they are, can be relevant for technology development. Thus, early cooperation with self-help organizations also offers the opportunity to ensure the representativeness of the affected person's perspective in the development process.

In addition, the self-help principle is characterized by the exchange of experiences of those affected. Thus, an aggregation of affected persons' experiences occurs in the self-help groups and committees of the self-help organizations. Therefore, if self-help representatives are integrated into the development of rehabilitation technologies, then the individual's experiences and the collective experiences of a large community of similarly affected persons can be helpful.

### **3.2 Monitoring Body to Ensure the Necessary Depth of Participation**

Self-help organizations for chronically ill and disabled people are nowadays confronted with many requests for cooperation. This sharpens the awareness of those responsible in the organizations to whether a request for participation is based on a well-founded motivation for participation or whether it is only intended to create a good atmosphere around the product.

This critical view of requests is also necessary when looking inward. Especially, the particularly committed members of self-help organizations are often involved in many work contexts and have no time to waste. It is, therefore, seen as a nuisance rather than an honour to be asked to participate in projects that are not really about any real relevance to the technology development decisions to be made (Danner and Meierjürgen 2015).

For this reason, those responsible for the self-help organizations will critically examine requests for participation with regard to the intended depth of participation before people are approached and placed in the respective projects.

Here again, the fact that experience is aggregated in self-help organizations comes into play. In this way, the participation experiences in other, possibly past, projects form the benchmark for participation in future projects. Good and bad practices can

be identified, and a learning system for developing participation standards can emerge.

### **3.3 Building up the Knowledge of those Affected by Technology Issues**

As already explained, the exchange of information on the use of rehabilitation technologies is a core component of self-help work. It is true that this exchange does not automatically lead to technical know-how or even to the ability to survey technological innovations as an alternative to current practice.

It can be assumed that the exchange self-help always helps to establish and strengthen the interest of those involved in further development and innovation. Furthermore, it has been a well-established part of self-help organizations for many decades to provide qualification offers for their members or to create new offers. This is a good basis for expanding the knowledge of rehabilitation technologies among interested self-help representatives via training, for conveying competencies in communication with technology experts, and for conveying good practice examples on participation models and on the search for an adequate depth of participation.

The interaction of those active in self-help in a complex knowledge society is increasingly characterized by the emergence of special expertise depending on the interests and competencies of those active. This can concern questions of digitization, questions of affected-oriented telephone counselling, or questions of participation in political bodies.

Therefore, it cannot be ruled out that specific expertise on the development of rehabilitation technologies will emerge, which could then be used not only for participatory technology development but also, for example, for counselling work in self-help. Ultimately, such technology experts from self-help organizations would then be ideal mediators for communication between technicians and those affected by concrete development projects.

### **3.4 Representation of Interests**

Part of the self-help principle is not only the exchange among those affected in the same way on how to deal with chronic diseases and disabilities and the development of counselling and qualification offers. Part of the work of self-help organizations is, of course, also the joint representation of interests. "Nothing about us without us!" is not only the core statement of the UN Convention on the Rights of Persons with Disabilities but also the mandate for action set by the self-help organizations themselves for the representation of interests.

This, of course, includes technology development and especially the development of rehabilitation technologies. Therefore, it is up to the organizations to also and especially increasingly demand participatory technology development in the future.

It is true that the field of participation research has experienced an upswing in recent years. However, it is now important not only to play on the lofty heights of scientific discourse but also to anchor participation methodologically in concrete technology development projects.

Here, the social sciences are called upon to bring more clarity into the methodological arsenal and to develop clear criteria for evaluating the participation of those affected in the development of rehabilitation technologies.

Part of the political demands of the self-help organizations must also be that the requirement of participation becomes a condition for the funding of development projects and that self-help organizations also receive the necessary funds to implement the qualification measures mentioned, as well as the placement of affected persons in development projects.

However, effective representation of the interests of self-help organizations in the field of participatory development of rehabilitation technologies also presupposes that corresponding will-forming processes are established and implemented in the self-help organizations.

For example, the question of whether the focus of innovative rehabilitation technologies should be on universal design or on the highest possible degree of specification for special needs must be discussed in the self-help community.

Many potentials of self-help are still unused for the clarification of such questions.

## 4 Conclusion

Whether the participatory development of rehabilitation technologies can be underpinned with clearly, defined standards in the future or whether the "Nothing about us without us!" will always remain a chimera is not foreseeable. However, the self-help organizations of chronically ill and disabled people are an actor that can advance the undoubtedly necessary further development process in many respects.

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