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## Participatory Development of a Virtual Reality Exercise Program for People with Chronic Pain

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### Abstract

**Background:** By describing how a participatory process led to changes in the design of a study of a virtual reality (VR)-guided exercise and mindfulness intervention tailored to people with chronic musculoskeletal pain, this article makes the case for including end user at an early stage when planning research within this field.

**Methods:** A multidisciplinary panel including end-user representatives, researcher, clinicians, and VR developers participated in a 1-day workshop to design a randomized study and a VR-guided intervention.

**Results:** Through the participatory process, changes were made to the original study design with respect to experimental design, duration, content of VR interventions and mode of delivery.

**Conclusion:** This case exemplifies the importance of including end-user participants in the early phases of planning VR interventions for people with chronic pain.

**Keywords:** End-user participation, VR games development, Chronic pain

### Introduction

**F**IBROMYALGIA IS A CONDITION of generalized pain, where central pain sensitization is considered an important part of the pathology.<sup>1</sup> Multimodal physical exercise is the management intervention with the highest level of evidence, but mindfulness may also have positive effects.<sup>2,3</sup> However, patients with fibromyalgia frequently report pain during and after exercise and low adherence.<sup>2-4</sup>

Virtual reality (VR) is an important medium for the remote delivery of personalized immersive interventions.<sup>5</sup> Gamifications are integral in most VR exergames and may promote adherence to exercise. In addition, VR has a pain reducing effect with possible mechanisms being distraction from pain, cognitive inhibition of ascending pain pathways, and neuroplastic modulation through repeated activities.<sup>6-9</sup>

There are no specific guidelines for the development of VR interventions in health. However, the National Institute for

Health and Care Excellence emphasizes the importance of end-user participation in the development of technological interventions.<sup>10</sup> End-user participation in the development of VR interventions has, however, not been widely discussed or implemented.<sup>6,11,12</sup>

To emphasize the importance of facilitating a participatory process at an early stage when conducting research within this field, we describe how a participatory process led to changes in the development of the study design and VR intervention in a study to assess a VR-guided exercise and mindfulness intervention targeting people with chronic musculoskeletal pain.

### Proceedings

This study is part of a larger project, *VR-algia*, which received funding from the Regional Research Fund—Inland Norway (Grant No.: 328461). The initial project description

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outlined a randomized control trial with parallel arms comparing a VR-guided exercise and mindfulness intervention with a group-based physical intervention in people with chronic pain, with change in functioning as the primary outcome. Furthermore, it established that both the research design and the VR-intervention would be finalized through a participatory process.

In this scope, to facilitate in-depth end-user and stakeholder participation, a multistakeholder workshop was held at the offices of a VR games developer (Fynd Reality AS) at Hamar, Norway. The project was approved by the local research committee and data protection office.

#### Participants

The stakeholder panel consisted of:

- *End-user representatives*: Three female end-user representatives aged 40–55 years with training in patient/public involvement in research, two with prior experience of VR for entertainment.
- *Clinical representatives*: Three clinicians with long-term experience of rehabilitation.
- *Technology developers*: Representatives from VR games/simulation developers.
- *Researchers*: Researchers within the field of public health, rheumatology, technology development, VR, and user involvement.

#### Participatory process

The workshop started with presentations of guidelines to user participation (H.P.), VR exercise and mindfulness games available (G.C.), the FYND VR platform on which the intervention could be developed, and limitations of funding and time frame (S.A.P.).

The participants were then split into groups of three to four participants, each group included an end-user representative. The groups were asked to discuss the following questions:

- Patient recruitment: Where should the VR-guided exercise take place?
- Data collection/outcomes: How can we measure the effect of VR-guided exercise?
- Intervention: What type of VR-guided exercises may be suitable for people with fibromyalgia?

After group discussions, the whole group convened to finalize the study design and planned interventions. Any disagreements were resolved through discussions until a unanimous decision was made.

#### Results

Table 1 summarizes key revisions made to the initial study design and intervention.

#### Revision of study design/outcome

The group was skeptical to the feasibility of VR-guided physical activity and mindfulness exercises in the patient group, and the study was, therefore, framed as a feasibility study. A cross-over design was decided on with a supervised intervention in VR and on a television screen. Heart rate was chosen as the primary outcome to assess the level of physical activity, whereas self-reported questionnaire assessed the level of relaxation after mindfulness.

#### Revision of intervention

End users insisted that the planned exercise intervention should be short, that sound and visual stimuli should be minimized, and that the VR scenario should be without unpredictable events. The panel agreed that if the VR-guided intervention proved feasible to the group, a larger study examining the long-term effects in patient function and pain would be designed.

TABLE 1. SUMMARY OF CHANGES IN STUDY PROTOCOL FOLLOWING END-USER PARTICIPATION

<i>Planned method preparticipation</i>	<i>Implemented methods postparticipation</i>
<b>Patient recruitment</b> Recruit 30 persons for home exercises	Recruit 30 patients for supervised exercises
<b>Data collection</b> Two-armed parallel group randomized controlled trial	Two-armed randomized trial with cross-over design. Each individual was exposed to one session of VR-guided exercise and mindfulness AND one session of exercise and mindfulness shown on television screen
Group exercises as comparator	Comparator was identical program shown on television screen
Decentralized data collection	Supervised data collection at study center
<b>Outcome definition</b> Primary outcome: change in function Secondary outcome: change in pain, patient acceptability, and adverse events	Primary outcome: feasibility of exercise assessed by heart rate, and self-reported relaxation to assess feasibility of mindfulness sessions
<b>Intervention</b> 10- to 20-minute interventions for both exercise and mindfulness administered at home during the course of 3 months compared with group intervention at study center Off-the-shelf VR exercise program	After a 5- to 10-minute warm up, short 5-minute interventions for exercise and then mindfulness were administered by VR and on television screen to each participant Custom-made VR exercise intervention with reduced visual and sound stimuli

VR, virtual reality.

## DEVELOPMENT OF VR EXERCISE

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## Discussion

We described how a participatory process changed a planned study with respect to experimental design, parameters and content of the VR intervention, and outcome variables collected. Interestingly, end users wish for a less complex and stimulating VR experience contrasts with the general trend of VR games for health that lean more heavily into gamification elements and virtual rewards.<sup>13</sup>

A participatory approach to health research is described by Northway et al. Key features of the approach are the shifting of power from researcher to end users, inclusion of marginalized groups, and the production of knowledge that is useful in the life of end users.<sup>14</sup> The role of the researcher in a participatory process may be that of both a participant and a facilitator.<sup>14</sup> The participation of researcher ensured that the study retained scientific quality, but shortening the intervention meant that a therapeutic exercise dose could not be reached due to the brevity of the intervention, and the study was reframed as a feasibility study.

The collaboration with end users increases the likelihood that the knowledge produced by the study will be useful by this group. In this study, we had described user participation in the initial project description and could, therefore, adapt study design according to end-user input, this may not be possible if the end users are involved late in the project planning.

In conclusion, the case described exemplifies how end-user participation at an early stage is highly valuable in developing a study assessing a VR intervention for people with chronic pain. The process resulted in substantial changes in the study design and VR-guided intervention, compared with the initial researcher-led project plan.

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## Authors' Contributions

S.A.P. contributed to conceptualization, funding acquisition, formal analysis, methodology, writing, and approval of the article. G.C., S.L., and H.P. were involved in conceptualization, funding acquisition, participation in data collection, writing, and approval of the article. O.E.F. participated in design, collaborated with end users, and participated in data collection, writing, and approval of the article. L.R. was involved in conceptualization, funding acquisition, participation in and organization of data collection, writing, and approval of the article.

## Author Disclosure Statement

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