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Exploring the subjective experience of researchers and co-researchers with lived experience of psychosis high risk states: a qualitative analysis within a participatory research process

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involved in a participatory research project.

Methods In this study with a combined participatory and qualitative research approach, we used a reflexive thematic analysis approach to systematically analyse open reflection reports from researchers and co-researchers with lived experience of psychosis high risk states, who took part in a participatory research project (VOICE). All participants ($n = 12$) were asked to anonymously write reflection reports on their subjective experience of participatory research. There were no formal or content-related instructions for writing the reflection reports. Reflection reports provided by eight participants were qualitatively analysed.

Results Three themes were identified from the analysis of the reflection reports. First "When uncertainty becomes a unifying element – reflecting on expectations and roles". Second "Fostering community growth: creating an environment for collaborative teamwork as well as new and creative directions". Third "Exploring personal and scientific achievements of the project". At the outset of the research project, the researchers' focus was on expectations and reflections on their role within the project, accompanied by a feeling of uncertainty. Subsequently, a sense of community developed within a favourable study framework. Finally, attention focused on research project outcomes and personal achievements within the project.

Conclusion The analysis of the anonymous reflection reports on a participatory research project indicates that there was a positive collaboration between participants with and without lived experience of psychosis high risk states, wherein they were able to interact on an equal footing. Participants reported an experience of equal cooperation and gained relevant personal insights from project participation. Although we do not have clear evidence of experiences of power imbalances or perceived hierarchies based on the analysed reports, these cannot be ruled out and have to be addressed in future research.

Keywords Participatory research, Lived experience, Ultra-high risk for psychosis, Psychosis high risk, Service user involvement, Qualitative research

Introduction

In recent years, public and patient involvement and engagement (PPIE), partly overlapping in terms and definitions such as "service user involvement" or "participatory research", has become increasingly important in various areas of research [1–3]. PPIE has the potential to democratize research processes and to introduce a shift of power and ownership towards those affected by health issues as well as the "lay" public more generally [4, 5]. Individuals with lived experience can be involved in different activities and phases in research processes, from prioritizing research topics to dissemination of results [6]. By including those affected by health issues as experts by experience, research designs and quality can be improved and innovation can be driven to create solutions that make a difference for those affected [7, 8].

Consistent with this, PPIE has also become more prevalent in psychiatry. Furthermore, the Lancet Commission on ending stigma and discrimination in mental health stated that the inclusion of people with lived experience of mental health conditions in all project stages of anti-stigma programmes is a key component of their effectiveness [9]. Participatory research thus also represents a crucial element of initiatives that aim to reduce stigma associated with mental health problems. The growing emphasis on the importance of involving people with lived experience in psychiatric research is also reflected in the fact that funding applications increasingly require plans to involve those affected [10, 11].

Individuals living with different psychiatric disorders, e.g., mood disorders, substance use disorders, and psychotic disorders, have already been included in participatory research projects in recent years [12–17]. Given the growing body of research on early detection and early intervention in psychosis, efforts to actively involve individuals with psychosis high risk states can also be found [18, 19]. A set of criteria for the identification of individuals at "ultra-high risk for psychosis" (UHR) has been developed and operationalised and allow to detect an increased risk for psychosis in help-seeking individuals with distress [20, 21]. With respect to intensity or frequency of occurrence, distressing experiences below the threshold of manifest psychotic symptoms with impaired functioning in the past 12 months are defined as "attenuated psychotic symptoms" (APS) or "brief limited psychotic symptoms" (BLIPS) [21]. To promote patient and public involvement and engagement of individuals identified as being at ultra-high risk for psychosis (UHR), the participatory research project "VOICE - Patient and Public Involvement and Engagement with People at Ultra-High Risk for Psychosis (UHR)" was conducted (in submission) [22]. The project aimed to reflect on terminology, current diagnostic and treatment guidelines, and to identify unmet needs together with people with lived UHR experience. Further, guidelines and best-practices for researchers to effectively involve and engage people with lived UHR experience were co-creatively developed [23].

Continuous evaluation and assessment of participants' experiences is important in clinical and especially in novel research approaches, such as participatory projects [24–26]. It allows to better understand how the engagement of experts by experience influences researchers and people with lived experience bidirectionally and could provide information on the extent to which engagement impacts the research process [6, 27]. Evaluation can be carried out using quantitative or qualitative methods. While quantitative methods allow objective measurements of variables and outcomes, in certain areas they can neglect the context and depth of participants' experiences and limit the capture of participants' perspectives [28]. Qualitative research approaches enable a deeper and more nuanced understanding of the subjective experience of experts by experience and researchers in a participatory research framework. Furthermore, combining a qualitative and a participatory research approach was found to broaden the range of perspectives, target 'harder-to-reach' populations and bridge across potential boundaries [29].

To our best knowledge, this is the first qualitative study analysing reflection reports of researchers with and without lived UHR experience working together in a participatory research project. In this study, a reflexive thematic analysis approach was used to answer the research question: How did researchers and co-researchers with lived experience of psychosis high risk states subjectively experience their involvement in a participatory research project?

Methods

Study design

The present qualitative study is part of the "VOICE - Patient and Public Involvement and Engagement with People at Ultra-High Risk for Psychosis (UHR)" project. The primary objective of the VOICE project was to reflect on UHR terminology, current diagnostic and treatment guidelines, as well as to identify unmet needs together with people at psychosis high risk states and mental health professionals. Twelve participants, including six psychiatrists or psychiatric residents experienced in treatment of people with psychotic disorders or UHR and six co-researchers with lived experience of psychosis high risk states, attended the workshops. The co-creation research project included four full-day workshops: one to define a framework and three with a thematic focus, namely the concept of UHR, terminology, diagnostic assessments, and treatment. The workshops were held in a working space in a seminar hotel in Vienna (i.e., outside of a clinical setting) and were moderated by a facilitator experienced in participatory research. The workshop content was open-ended. It followed the outcomes and discussion points of each workshop. Each workshop included an information session on specific UHR topics at the beginning, one-to-one or small group interactions, co-creation of content on specific topics in small groups and group discussions with all researchers. The manuscript reporting the results of the VOICE study based on the unmet needs of those affected was still in submission at the time of publication of this paper [22].

During one of the workshops, all 12 project participants were asked to provide open written anonymous reflections about their experiences within the VOICE project. There were no formal or content-related instructions for writing the reflection reports.

In this qualitative study, we systematically analysed these reflection reports using a reflexive thematic analysis approach [30–32] to answer the research question "How did the researchers and co-researchers subjectively experience the participatory research project and their involvement in it?". The qualitative analysis was performed after all VOICE workshops had been completed. Written informed consent was obtained from all participants. According to the local ethics committee of the Medical University of Vienna and in line with others such as the UK Health Research Authority policy framework for health and social care [33], no ethics vote was necessary since individuals with lived experience were involved as active co-researchers and not subjects of the study in the common medical research sense according to the declaration of Helsinki.

Table 1 Overview of study participant characteristics of the VOICE study (*n* = 12). To ensure complete anonymization, all participants in the VOICE study are listed here collectively

Gender	**female: *n* = 8 (67%)** **male: *n* = 4 (33%)**
Age (years)	M = 31.45 years (SD = 9.07)
Lived UHR experience	*n* = 6 (50%)
Occupational Background	employed at the university: *n* = 6 (50%) employed in the public sector: *n* = 3 (25%) unemployed: *n* = 2 (17%) employed, not specified: *n* = 1 (8%)

Study participants

Co-researchers with recent or lifetime lived UHR experience were recruited at the early psychosis outpatient clinic at the Clinical Division of Social Psychiatry, Department of Psychiatry and Psychotherapy at the Medical University of Vienna. UHR state was assessed using the Comprehensive Assessment of At Risk Mental State (CAARMS) defined per operationalized criteria [34]. Inclusion criteria of co-researchers were defined as follows: (a) lifetime history of UHR, (b) availability for study participation, (c) at least 18 years old. Exclusion criteria were: (a) recent suicidal behaviour or suicidality, (b) lifetime history of manifest psychotic episode. Recruitment was conducted by two researchers from the early intervention outpatient clinic. Overall, twelve researchers participated in the VOICE study, consisting of six resident and consultant psychiatrists and six experts by experience with lived UHR experience (see Table 1). All participants of the VOICE project (*n* = 12) were asked to write anonymous reflection reports on their experience of participating in the study, which was provided by eight participants.

Data collection and analysis

Of twelve participants, eight provided anonymous written open reflection reports (eight of twelve = 66.67%). The average word count was 383 words per report. These reflection reports were provided by psychiatrists as well as experts by experience with lived UHR experience (see Table 1 for further details). Since the aim of this study was to deepen our understanding of the subjective experience of being involved in a participatory research project in general, no distinction was made in the analysis between reports from psychiatrists and experts by experience. The reports were anonymously collected and analysed. By offering the possibility for anonymous reflection reports, we wanted to give all participants the opportunity to report any perceptions including negative aspects, e.g., power imbalances or hierarchies within the project process. Nevertheless, for some reports it was possible to deduce from the text whether it was written by a mental health professional or a co-researcher with lived UHR experience. The qualitative analysis was performed after all workshops had been completed. Most authors of this qualitative analysis participated in the VOICE study. For this reason, the reports were collected anonymously and authors who did not participate in the VOICE study were included in the analysis to broaden the perspective.

Reflection reports were analysed using a reflexive thematic analysis, a flexible and data-driven approach to uncover patterns, meanings, and themes in textual data [30–32]. After an initial familiarisation with the data, an open coding process was conducted independently by two researchers (MT, AR). Following repeated discussions within the study group, a tentative coding framework was developed. All reflection reports were coded using this preliminary coding construct. Based on these codes, tentative themes were developed. These themes underwent a refinement process involving consultation with a third researcher (BH). The themes were also reviewed by other study group members (clinical experts as well as experts by experience with lived experience of psychosis high risk states). This inclusive approach bolstered the methodological rigor of our analysis and ensured a comprehensive and multi-perspective interpretation of the reflection reports. Throughout the analysis, we maintained a reflexive stance, acknowledging our individual perspective on the data (see Supplements for reflexive statements). For the purpose of this publication, the quotations have been translated from German into English (see Supplements for the citations used in German).

Results

Three themes were identified in the reflection reports via our analysis. The first theme deals with reflections on expectations prior to the study, accompanied by a feeling of uncertainty as well as thoughts about the individual role in the study context. The second theme describes the experience of the development of a sense of community, associated with an exchange that deviated from the traditional doctor-patient interaction within a favourably experienced study framework. The third theme deals with the perceived outcomes of the project. Some excerpts from the original reports have been quoted elsewhere without further analysis [22].

Theme 1: When uncertainty becomes a unifying element – reflecting on expectations and roles

The first theme captures a commonly expressed feeling of uncertainty at the beginning of the project, which formed an initial connection between the participants. At this point, the participants also reflected on their individual strengths and their possible role in the project. For most of the participants, it was initially unclear what exactly was in store for them. This uncertainty was accompanied by feelings of tension and insecurity but also curiosity and positive anticipation. Consideration was also given to whether the roles could actually be discarded.

> *"The closer the first appointment got, the more nervous I became. After all, I had no idea who would be there, what we would talk about, and how I could productively contribute to the workshop." [P4].*
> *"Is it possible to talk to each other and forget who you are without forgetting what you have experienced? Okay. That sounds so drastic. No one has to forget who they are. But maybe push it aside a little, break up the rigid division of roles a little, because you could learn something from each other." [P7].*

It was a new situation for clinical researchers and co-researchers with lived experience alike. The uncertainty, which was experienced equally by all participants, created a sense of connection and equality, fostering exchange on an equal footing:

> *"The initial feeling of not knowing 100% what to expect, felt almost a bit irritating to me at first, yet subsequently increasingly unifying, as all participants seemed to feel similarly." [P6].*
> *"Initially, I was excited and curious about how a project of this kind would work. It soon became clear that the experts, patients and moderators were on an equal footing." [P1].*

However, this initial stage also brought forth the reflection on the differing individual baseline situations. This included the question which of the participants' own experiences (and lessons learned) were brought into the project. In addition, the participants reflected on their own strengths they had available for the project.

> *"The only thing I could participate with was my experience of my situation. I had no idea of terms, symptoms, treatments … I only knew what I felt and how to roughly put it into words." [P4].*
> *"And there we were, 12 people who did and didn't know each other. 12 experts, each in their own field. 12 experienced people with different experiences." [P2].*

Theme 2: Fostering community growth: creating an environment for collaborative teamwork as well as new and creative directions

The second theme describes how participants experienced the development of individuals from different backgrounds into a research community/team with common goals. This was accompanied by a different type of exchange than the traditional doctor-patient interaction within a favourably experienced study setting that was seen as positive and helpful for the purposes of the project.

> *"The setting of the workshops shattered/disrupted the sometimes hierarchical doctor-patient relationship." [P1].*

Starting with shared visions and ideas, this resulted in a process in which different topics were addressed within the group and collectively developed solutions put forward.

> *"The path was worked out and defined together. The anticipation and euphoria of working together in the upcoming workshops on the defined topics and ideas was clearly perceptible." [P5].*
> *"Together we were able to expand on individual ideas, understand problems better and simply be so much more creative. The small groups were also so pleasant because there were even fewer of us, and everyone really had space to talk and ask questions." [P4].*

The creative work in the group was emphasized as promoting innovation. During this process, most people experienced a change or broadening of their perspective.

> *"...old familiar topics raised and discussed, and yet they appear in a completely new light as a result of being worked through in the group." [P3].*

The group work was accompanied by a feeling of motivation and anticipation of upcoming further tasks. Open communication and exchange on an equal footing characterised the whole project and were experienced as positive, respectful, motivating and conducive to the research process. This atmosphere was experienced as beneficial to the exchange as well as the research process and formed the basis for elaborating the results.

> *"The insights this collaboration has provided are clearly due to the format of exchange on an equal footing between stakeholders and experts." [P8].*
> *"It quickly became clear that the experts, patients and moderators were on an equal footing." [P1].*
> *"I was surprised how well it worked at the second workshop, that everyone was able to put aside their roles for a while, at least a little, and that we always discussed and listened to each other as equals." [P7].*

Especially the setting and the course of the workshops, with professionally guided moderation by a supervisor experienced in participatory research and project design, working in small groups and the possibility for individual reflection were positively highlighted by participants and described as beneficial for the research process. Overall, the framework created within the project was experienced as a "safe space".

Theme 3: Exploring personal and scientific achievements of the project

Participants reported gaining insights, through participation in the project, that could either be used to advance the scientific field in general or to achieve personal development.

> *"As part of the project, aspects of diagnostics, terminology and treatment were critically scrutinized, and new initiatives were created to make the topic more accessible to the general public." [P1].*
> *"With the end of the workshops, however, new tasks are arising again, namely, to publish our findings, to present the project at congresses as well as to launch planned goals of the workshops such as the VOICE - homepage or the Instagram account." [P6].*

The reports of the personal insights gained from the collaboration can also be differentiated according to the role of the participant. Experts with lived experience of psychosis high risk states emphasized the positive exchange with each other, but also with psychiatric experts.

> *"On the one hand, the project enabled an insightful exchange with doctors about their experiences and views on the subject of psychosis, and on the other hand, it also provided the opportunity to exchange ideas and listen to other people affected." [P1].*
> *"Talking about it with others who have experienced similar things can be very liberating and also give hope." [P7].*

However, similar results were formulated independently from the understanding of one's own role. Many highlighted gaining of a different perspective as a sustainably enriching experience. Many described a personal gain in knowledge and thus an expansion of their individual understanding of the subject matter. Some people referred to dealing with their own symptoms in the sense of a better understanding of them. Others described the influence of the project experience on their own clinical activities.

> *"...my view on the subject of "psychotic-like symptoms or psychosis" changed significantly". [P1]*
> *"...While also expanding my knowledge and approach regarding the treatment of patients." [P6].*

Discussion

In this study, we qualitatively analysed reflection reports written by participants of a participatory research project comprising mental health professionals experienced in the diagnosis and treatment of psychosis and psychosis high risk states and experts by experience with lived experience of psychosis high risk states, using a reflexive thematic analysis approach.

Our first reported theme covers reflections on expectations, individual roles, and a feeling of uncertainty regarding participation in the project. This uncertainty, which most participants experienced regardless of their background, created an initial connection within the research group. The fact that all participants of this study – clinical researchers as well as experts by experience – took part in a participatory research project for the very first time, might have influenced these experiences. This might have contributed to the establishment of equitable interaction and collaboration from the beginning of the project. Significant discrepancies in prior experiences with knowledge of participatory research practices might have had a divisive and disruptive effect on team dynamics, especially at the beginning of the study. There are at least some indications in the reports that there was uncertainty as to whether sufficient contributions could be made to the study and concerns about a lack of expertise prior to the first meeting. Future participatory research projects should bear this in mind and either create an equal baseline knowledge or address this issue specifically e.g., by providing detailed information about the planned study procedure and requirements sufficiently in advance. Reports of challenging impacts on service users include a lack of preparation and training resulting in a feeling of being unable to contribute in group situations [35]. Other barriers described in participatory research involving people with lived experience of psychosis include difficulties in shifting power between researchers and service users was well as mental health stigma [12]. The analysis of the reports in this study yielded no evidence for the above-mentioned barriers. Nevertheless, future studies should consider these potential challenges, e.g., by assessing the attitudes of participating researchers regarding role allocation, incorporating supervisors experienced in participatory research, and designing contingency plans in the event of overwhelming experiences.

The second theme focuses on the development of a sense of community within a conducive setting. The established setting was repeatedly described as beneficial, safe, with an atmosphere of equality, all of which were considered helpful for the research process. One comment indicated that the work in the large group was less inviting to active participation than the co-operation in smaller groups. The project core team (including experts by experience and mental health professionals in equal numbers) made numerous efforts to design the setting beforehand, i.e., detailed structure of the workshops including the provision of a theoretical background on relevant UHR topics, inclusion of a skilled moderator experienced with participatory research and group works. Considering the results of this study, an orientation towards the guideline that emerged from the VOICE study seems recommendable [23]. One report focused on the traditional doctor/patient role and the associated power imbalance in general. Although it was emphasised that these were not experienced during the project, there are indications that there might have been some scepticism beforehand as to whether the traditional roles in collaboration could be overcome. Given existing critical reports about the "real-life" difficulties and power hierarchies in participatory projects involving people with lived experience of psychosis [36], repeated, honest reflections, targeted demand and survey and ongoing evaluation could contribute to optimization and quality improvement of further participatory research projects. Although the analysis of our reports does not provide clear evidence of power imbalances or perceived hierarchical structures, these cannot be entirely ruled out given to this study's methodology.

The third theme deals with the question of the outcomes of the project. Independently of each other – and without explicit instruction to do so – the participants reflected on possible outcomes of their research activities as part of the study and the personal benefits they gained from it. Co-researchers highlighted the opportunity of exchange with others who have had similar lived experiences as a positive part of the study. Furthermore, an increase in knowledge and an expansion of the individual perspective and understanding of symptoms were reported as benefits of project participation. Similar reports can be found on the impact of service user involvement at a personal level, including gains in knowledge, improved well-being, self-esteem and confidence [27, 35]. Furthermore, studies reporting on subjective experiences of research participation of people with psychotic disorders showed largely positive findings [15, 37]. Another survey on the experiences of people with lived experience of mental health conditions who were actively involved in anti-stigma programmes demonstrated that this inclusion can also contribute to the individual recovery process [9].

When conducting participatory research with people with lived experience of mental health conditions, researchers have to be sensitive towards stigma and discrimination often experienced by people with mental health conditions [12]. Bearing this in mind, it should be emphasized that conclusions about the extent of contribution should not be derived from the lack of individual naming as authors of co-researchers with lived experience in this manuscript. Within the VOICE project, individual preferences of co-researchers with lived experience regarding explicit naming as authors were respected.

Several limitations of this study must be addressed. The reflection reports were written without any formal or content-related instructions in advance. On the one hand, this represents a strength as the participants were able to freely reflect on content important to them without any external influences or specific demands. On the other hand, there is a lack of information in certain areas, such as points of criticism or suggestions for improvement for future participatory research projects. However, an analysis of quantitative feedback data by Hinterbuchinger et al. showed a high level of satisfaction among the project participants [22]. The fact that the requested reflection reports were not submitted by all, but by two thirds of the participants should be noted as another limiting factor. The reasons why not everyone submitted a report are not known. It cannot be ruled out that the participants who did not write a report were critical or dissatisfied with the project process. However, as mentioned above, quantitative analysis showed a high level of satisfaction among all project participants [22]. Further participatory research projects are needed to qualitatively examine certain aspects of participation, e.g., by using focus groups or semi-structured in-depth interviews to cover additional areas of interest including areas for improvement, potential dissatisfactions, difficulties in the collaboration, and experiences of hierarchy or power imbalances. Future studies should specifically address and separately analyse the perspectives of researchers and co-researchers to gain insights into overlaps and differences.

Recent literature described the challenge of lacking consensus about what effective participation in research should look like, and how such processes can be developed and sustained. While case studies exploring PPIE in research and service delivery exist, little conclusive evidence about a "gold standard" to implement PPIE in research design and practice is available. Differences in PPIE models and motivations do not make things any easier, pragmatic motives that aim to improve research processes and outputs contrast with ideological motives aiming to address power imbalances and democratic representation [38, 39]. Arnstein's critique of participatory involvement without a genuine redistribution of power [40] is in line with other, more recent, voices [41] who criticise limited forms of participatory involvement, such as the inclusion of people with lived experience on steering committees without any real shift in power relations.

In order to address the aforementioned criticisms and challenges, our project employed a series of strategies and principles. These included the consideration and implementation of existing guidelines on participatory involvement [42–44]. To mitigate the potential for power imbalances, targeted measures were implemented: These included ensuring an equal number of individuals with lived experience and psychiatrists on the core team, with equal veto and decision-making rights from the project's beginning, opportunity for anonymous feedback after every workshop for all participants and several more [22, 23]. Based on the analysis of the reflection reports, it can be assumed that the participatory process was experienced as beneficial and balanced concerning hierarchies and power relations. However, as mentioned above, there are certain limitations, and existing power or hierarchical imbalances that were not explicitly addressed and reported cannot be ruled out.

Conclusions

Researchers and co-researchers with lived experience of psychosis high risk states working together within a participatory research project experienced equal cooperation and gained positive personal insights. Overall, there are indications that participatory collaboration was experienced as positive by participants of this participatory research project. Available reports do not give evidence of subjective perceptions of power imbalances and hierarchies, however, these cannot be ruled out. This is the first qualitative study systematically analysing reflection reports of researchers with and without lived UHR experience working together in a participatory research project with a reflexive thematic analysis approach providing a foundation for subsequent research that further addresses specific challenges associated with participatory research and service user involvement, i.e., hierarchical imbalances or power imbalances. The combination of a qualitative and participatory research approach can bridge existing boundaries and provide a more comprehensive perspective of subjective experiences of those involved.

Abbreviations

PPIE	Public and Patient Involvement and Engagement
UHR	Ultra-High Risk for Psychosis
APS	Attenuated Psychotic Symptoms
BLIPS	Brief Limited Psychotic Symptoms

Supplementary Information

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Supplementary Material 1

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Author contributions

Author MT and BH contributed to the concept and design of the work, acquisition, analysis and interpretation of the data and have drafted and substantively revised the work. Author AR contributed to the analysis and interpretation of the data and have drafted and substantively revised the work. Author NM contributed to the concept and design of the work, acquisition and interpretation of the data and substantively revised the work. Author AK contributed to the design of the work, interpretation of the data and have substantively revised the work. Author REK contributed to the concept of the work, acquisition and interpretation of the data and substantively revised the work. Author FF, JSB, ZL and the VOICE CONSORTIUM contributed to the acquisition and interpretation of the work and substantively revised the work. All authors read and approved the final manuscript.

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Data availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

The authors confirm that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees for human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. According to the local ethics committee of the Medical University of Vienna, no ethics vote was necessary since individuals with lived experience were involved as active co-researchers and were not subjects of the study in the common medical research sense according to the declaration of Helsinki. Participants were aware and informed that the project was done within a research study of the Medical University of Vienna and that publication of results was planned by the authors. Written informed consent was obtained from all participants.

Consent for publication

Written informed consent was obtained from all participants.

Conflict of interest

The projects VOICE (FA763C0801) and VOICE+ (FA763C0802) (PI: Barbara Hinterbuchinger) were funded by the Ludwig Boltzmann Gesellschaft (LBG), Open Innovation in Science Center (OIS center) (https://lbg.ac.at). The other authors declare that they have no competing interests.

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