

# PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT (PPIE): FUNDING, FACILITATING AND EVALUATING PARTICIPATORY RESEARCH APPROACHES IN AUSTRIA

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## ABSTRACT

The LBG OIS Center established a new Patient and Public Involvement and Engagement (PPIE) Implementation program aiming at 'active involving' public members in research across different phases of the research cycle – from setting the agenda to disseminating results – and its governance. The program offers funding and facilitation of these PPIE activities. The first PPIE pilot call was launched in Autumn 2020. It supports researchers in Austria with up to EUR 60.000 in order to implement their PPIE activities. In addition, the program offers support in the form of consultation, training, knowledge exchange and networking opportunities. One important characteristic of the selection process is the composition of the expert panel, bringing together transdisciplinary expertise from different areas (scientific experts, patients, and students). The expert panel recommended 11 out of 25 PPIE projects for funding (success rate 44%). 45% of the applicants participated in the support offers prior to the call and 52% in the continuing support offer after the call had been closed. Based on our online surveys, overall, participants were very satisfied with the support offers. Learnings of the first call address the eligibility of applicants. In the selection meeting, we found that different understandings of 'active involvement' were negotiated among experts. However, this was not a problem due to the open and collaborative atmosphere and mutual learning opportunity for experts. The panel suggested opening the call to non-research bodies, which indicates small changes in the application format – e.g. video and text-based applications in German and English. Despite of small adaptations in the second PPIE Pilot Call 2021, it seems that the funding instrument was appropriate and reflects a low-threshold offering for researchers introducing public involvement activities in their work.

## BACKGROUND

Patient and public involvement and engagement (PPIE) in research is an important driver for societal impact of science and its capability to

develop new solutions for existing challenges (Greenhalgh et al. 2019). One of the main drivers is the United Kingdom, which introduced PPIE in the national research agenda and research funding (National Institut of Health Research 2021): research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them (Hayes, Buckland, and Tarpey 2012). Such approaches to engaging the public in research have increasingly come into the focus of national and international policy actors often framed as citizen science, public engagement, and public involvement in policy documents (Hecker et al. 2019; Bundesministerium für Verkehr 2016; Bundesministerium für Wissenschaft 2015; European Commission 2014). Hecker et al. (2019) explored the conceptualization of citizen science and found that policy documents attribute educational benefits to citizen science by fostering scientific literacy, individual learning, and skill development, as well as by facilitating environmental stewardship.

In a recent analysis of 34 reviews, Ocloo and colleagues (2021) explored barriers and enablers of patient and public involvement in health-related research. The authors identified adequate funding and resources, the lack of training opportunities for the public and professionals, and the lack of general support structures, such as emotional, practical and financial support as key barriers among others. Health researchers also emphasized the emotional component of working with PPIE, which is both rewarding and burdensome, and requires practical as well as social support (Boylan et al. 2019). Further, researchers' positive attitude and experience towards PPIE are key factors in the successful implementation of public involvement activities in research (Boylan et al. 2019, Nathan et al. 2006, Thompon et al. 2009, Ocloo et al. 2021).

The situation is similar in Austria. Here, too, there is a gap in the implementation of such participatory approaches among researchers and a lack of instruments for funding such approaches in the Austrian research landscape. Challenges of implementing PPIE practices address the lack of awareness and knowledge about the PPIE concept in the local scientific communities, the lack of appreciation of the value of involving patients as 'experts by experience' and fear of violating research ethics if PPIE activities are carried out without formal ethical approval (Kaisler et al. 2021). To overcome these challenges, the Ludwig Boltzmann Ge-

sellschaft (LBG) Open Innovation in Science (OIS) Center established the PPIE Implementation Program in 2020. It intends to fill the gap and institutionalize support for public involvement activities in Austria. The PPIE Implementation Program is funded by the National Research Foundation for Technology and Development. The PPIE Implementation Program is embedded in a wider 'open innovation in science' framework fostering collaboration among different stakeholder groups to enable transdisciplinary collaboration. This requires an open mind-set and open research practice which allows for thinking beyond the research discipline and academic framework in order to generate scientific insights and translate them into innovations (Beck et al. 2020).

## CO-DEVELOPMENT OF THE PPIE IMPLEMENTATION PROGRAM

To systematically introduce public involvement at LBG and in Austrian research institutions, we co-developed the PPIE 'How to' Guide for Researchers (Kaisler & Missbach 2019) aiming to support researchers in implementing public involvement activities in their research. In a series of five co-creative workshops, citizens, patient advocates and LBG researchers co-created principles of PPIE in research and project steering structures, self-assessment checklists, and monitoring of PPIE activities in research projects (Kaisler & Missbach 2020). In the last workshop, we discussed potential funding models with all stakeholder groups based on the PPIE 'How to' Guide for Researchers. The discussion covered three topics with the aim of co-creating action plans to establish a public involvement focus at LBG:

1. funding structures to implement public involvement activities,
2. support structures to facilitate implementation,
3. and the evaluation of public involvement activities.

The output led to a nationwide PPIE Implementation Program funding and facilitating public involvement activities in research launched in Autumn 2020.

## PPIE IMPLEMENTATION PROGRAM

The PPIE Implementation Program ([ppie.lbg.ac.at](http://ppie.lbg.ac.at)) aims to support 'active involvement' (Hayes, Buckland, and Tarpey 2012) of public members in research activities across different phases of the research cycle – from setting the agenda to interpreting data – and its governance. It supports public involvement activities with up to EUR 60.000 over a project period of 6-12 months implemented at Austrian research organizations and universities. Private and public Austrian research organizations were eligible for funding. Eligible costs included honorarium for public members, other direct costs, travel costs for public members and researchers, and 20% overhead costs. Personnel costs for researchers and research equipment were not eligible. Applicants were asked to submit a three-page application describing the societal impact, implementation plan, considered methods, and expected learnings of the PPIE activities. The first PPIE Pilot Call opened in September 2020 (total funding volume EUR 600.000) and accompanied support offers on the administrative and methodological implementation of the project idea prior to submission in

form of individual consultations and webinars. A second PPIE pilot call was planned in September 2021 (total funding volume EUR 600.000).

In addition, and at the core of the program, we aim to build at LBG OIS Center an institutionalized support for PPIE projects located within LBG as well as at Austrian research institutions. This was supported with staff representing 1,5 full-time equivalents. This includes individual consultation and training opportunities in PPIE related topics and participatory methods, such as webinars and co-creation workshops with different stakeholder groups, as well as creating learning opportunities through a peer network. The peer network aimed to establish a PPIE community and embed public involvement in the Austrian research landscape and beyond. The support offers were available without charge for researchers and public members in Austria and assessed after each event with a questionnaire tailored to each support offer. Moreover, the PPIE Implementation Program – the funding instrument and support offers – will be externally evaluated.

As part of the Program evaluation, the evaluation of the funded PPIE projects and activities include views from all stakeholders that participated in the PPIE activities (researchers and members of the public). The projects' evaluation questionnaire addresses the following dimensions: quality of involvement, learnings from activities, future and sustainability of activities, scientific and societal impact of activities on individual and organizational level, implementation of activities, and satisfaction with the PPIE activities. The project evaluation is conducted once after the end of the project period.

## TRANSDISCIPLINARY EXPERT EVALUATION PANEL

Based on previous experience of involving experts by experience (e.g., patients and citizens) in project steering and governance – for example, people with lived experience in a field of mental health (Kaisler & Paul 2019) – we established an independent and international expert panel including members of the public for assessing the PPIE funding applications. The expert panel aimed to assess and select the high-quality applications. It consisted of two scientific experts in the field of public involvement, a patient in the field of health, and two students with basic scientific background (16-30 years). We established characteristics for each group of experts (scientists, patient, students), which consisted of mandatory skills (e.g., fluent English for all experts, or lived experience in case of the patient) and desirable skills (e.g., experience in committee work for all non-scientific experts). To align the experts to the goal of the call, we organized a briefing meeting introducing the scope of the call, the assessment criteria and gave the experts the opportunity to get to know each other and to explain their respective relation to participatory science.

The transdisciplinary expert panel assessed the project proposals individually based on four criteria: quality of involvement, societal impact, implementation plan, and feasibility within the given time frame. The assessment focused on the participatory approach and its quality of involvement (Hayes, Buckland, and Tarpey 2012) rather than the scientific approach. After individual online assessments, the expert panel discussed outstanding PPIE project proposals in a selection meeting and recommended the highest rated projects for funding to the LBG Management Board.

In the selection meeting, we were able to observe good and respectful cooperation in which the experts were responsive to each other's perspectives and concerns. These different perspectives led to discussions

about 'high-quality' involvement activities and a consensus among the participating experts.

## RESULTS OF THE FIRST PPIE PILOT CALL 2020

A total of 29 applications (62% female and 38% male applicants) were submitted from 15 different research institutions in Austria. Thereof four applications were not eligible for funding. More than half of the applications were submitted from other federal states than Vienna. In line with the scope of the call, most of the applications were thematically related to health sciences. The PPIE Pilot Call 2020 primarily addressed scientists in early career stages (24% PhD students and 41% PostDocs) from universities (34%), research organizations (28%), university of applied sciences (14%), private universities (7%), and public agencies (7%).

The expert panel recommended 11 of 25 eligible proposals for funding (81% female, 19% male) with a total amount of EUR 505.193. The success rate of female applicants increased (81%) compared to the application stage (62%). The successful projects addressed the following areas: medicine (46%), social sciences (45%) and psychology (9%). 46% PostDoc researchers, 27% PhD students, 18% professors, and 9% research administrators were granted. Their project ideas describe many different participatory approaches, such as co-creative workshops with stakeholders and members of the public (37%), the establishment of project steering and advisory boards including patients (27%), the co-development of questionnaires and research activities (27%), and involving patients as co-researchers in the research team (9%).

The expert panel decided not to use the entire funding volume of the call because some proposals did not convey the desired quality of involvement. More than half of the projects (55%) used support and consultation prior to the submission, thereof 60% succeeded in funding. In comparison, 45% did not take advantage of consultation, but still succeeded in funding. Preliminary results from the evaluation of the sup-

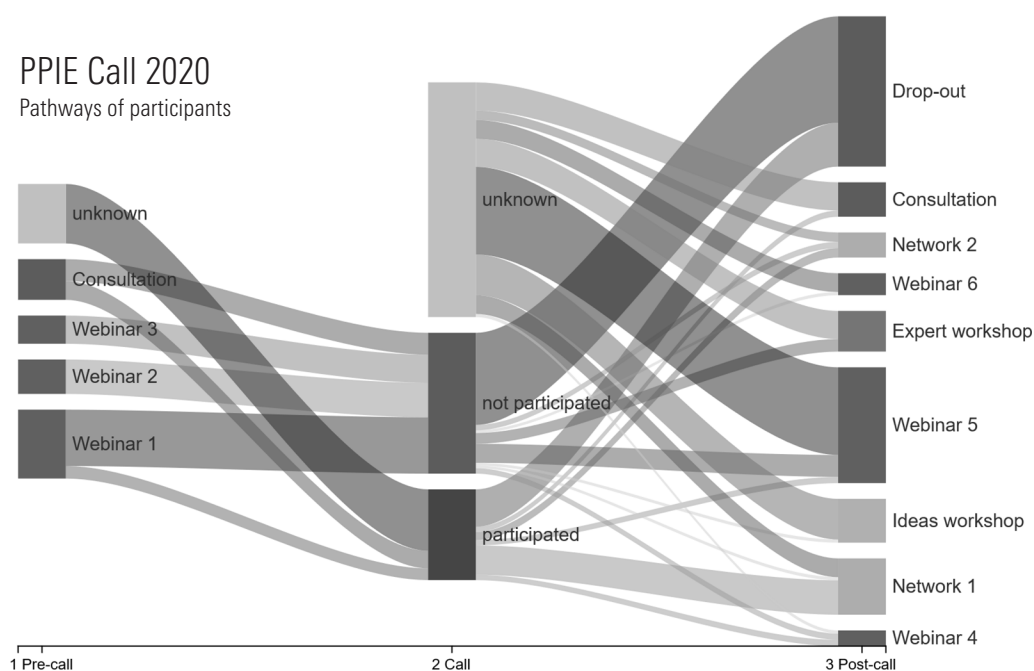
port offers indicate that the project leaders were satisfied with both, the funding instrument and support offers, and they expressed their interest in learning from the other peers.

## EVALUATION OF SUPPORT OFFERS

The PPIE support offers aimed at building a second pillar alongside the funding instrument. The support offers provided low-threshold opportunities to get familiar with the topic and consult project ideas with the experienced researchers working with participatory methods. It is therefore primarily aimed at researchers, although other stakeholders were also welcomed to participate and take part in some of the offered activities (e.g., idea workshop with stakeholders). For this purpose, the PPIE Implementation Program offered a series of different activities to support the introduction and implementation of PPIE to researchers and to inform about important aspects or existing solutions regarding PPIE. Here, we analyze the eleven activities (including the PPIE Pilot Call 2020) that were conducted from September 2020 until June 2021. These activities vary from face-to-face consultation (n=18), webinars (n=6), idea workshop (n=1), PPIE Pilot Call 2020 (n=1), expert workshop (n=1) and network meetings (n=2). Due to the Covid-19 pandemic all activities were held online.

In total, we documented 248 interactions since the start of the program within this timeframe. An interaction is defined as: a person showed intention to participate in one of the support offers, such as by registering or by making an appointment. Therefore, a person may have several interactions. In 197 cases (79%) the interaction resulted in the participation of a person in an activity of the support offers.

The webinars accounted for the most interactions as the webinars were most frequently offered and had the lowest barrier to participate. On average, we had 23 interactions per webinar compared to around 15 in the other formats (consultation and pilot call excluded). Nevertheless, the attendance rate of the webinars was the lowest (66%, see Table 1) compared to the other activities.



**Caption Figure 1.** Pathways of participants' attending different support offers.

Figure 1 shows the initial and following interactions of participants in different support offers. It indicates that the webinars raised awareness about other PPIE support offers but had limited influence on submissions to the PPIE Pilot Call 2020. While about one third of the first webinar's participants also attend later activities, only a fraction of them applied for the PPIE call. The two content-related webinars (2 and 3) did not result in any further applications in the PPIE Call. This indicates that the webinar format did not attract potential applicants to the call. However, it generated broader attention for the support offers as well as further interactions in other activities. About half of the consultations (average duration about 60 minutes) prior to the call resulted in an application. It seems that this format – providing individual feedback to projects ideas – was more effective in terms of attracting researchers to apply. Further, more than half of the applicants also attended in a later activity of the support offers. This indicates that the funding instrument generated commitment to the support offers in the first round of the PPIE Pilot Call. A large proportion (Fig. 1 'unknown' column) of the participation in the call and other support activities did not result from prior interactions with the PPIE Implementation Program. These unknown participants may have been recruited via social media, newsletters, and information on topic-related platforms as well as word-of-mouth dissemination of information in the field. This is especially valid for capability building in the PPIE community in Austria. Based on the distribution of disciplines and topics submitted, we conclude that we have reached different participatory approaches in health research.

**Table 1** Evaluation of participants' satisfaction with different support offers.

	Webinar	Network	Consultation	Expert WS	Idea WS	Total
Total number of activities	6	2	18	1	1	28
Number of participants	91 (137)	26 (30)	24 (24)	13 (15)	14 (14)	168 (220)
Attendance rate	66,42%	86,67%	100,00%	86,67%	100,00%	76,36%
Number of survey respondents	17	7	7	11	10	52
Overall satisfaction event (1-5)	4,68	5,00	5,00	4,91	4,60	4,70
Satisfaction with learnings (1-5)	4,47	4,25	4,71	4,66	3,97	4,38

*Note:* Numbers in brackets indicate total number of registered participants for the activity. We used a 5-point Likert scale to assess the satisfaction of participants (1 not satisfied to 5 very satisfied). WS = workshop.

Table 1 shows the different activities of the support offers describing the attendance rate and the satisfaction of the participants. To adapt our support offers to the needs of the community and to improve the implementation, a small questionnaire ("participation check") was sent to participants after each activity. The participation check surveyed how comfortable the participants felt with the event, how well it was implemented and whether they were satisfied with the takeaways from the event. As the activities were conducted online due to the Covid-19 pandemic, the participation check was also conducted online, even though this may have had a negative impact on the response rate. For this reason, we have significantly shortened the questionnaire for the webinars, which has improved the response rates to some degree, although we lost some interesting information.

In total the 248 interactions led to a reach of 163 individual persons. On an individual level, 31 registered individuals (19%) never participated in any of the support offers, while 87 individuals (53%) participated in one and 45 individuals (28%) in two or more offered activities. Of these 45 individuals, 20 were identified as regular users who participated three or more times in the support offers. It remains open why 19% of users did not attend the activities.

The analysis shows that the group of no-shows was mainly interested in the webinar format. 42% of the no-shows worked at foreign research institutions and were consequently not eligible for the PPIE Call. Among the group of regular participants only 5% (n=1) were associated with a foreign research institution. The group of regular participants also made particular use of the PPIE consultation or tended to take part in more advanced formats such as the network meetings and the expert workshops. This highlights the importance of the funding instrument to encourage the rather fragmented community of different disciplines and participatory approaches to interact on a regular basis.

The webinars were designed as a low-threshold format and consequently generated the least commitment. Nevertheless, the webinars enabled the highest mobilization among people, while activities with a higher threshold (expert workshop, network meeting) required more incentives to participate. In the case of the PPIE Implementation Program, the prospect of funding may have played a role. In general, the different support offers led to a more diverse audience with different needs being addressed by the program.

These findings indicate that the overall satisfaction of the participants across all activities was high, ranging between the scores four and five on a scale from 1-5 ('not at all satisfied' to 'very satisfied'). While satisfaction with the webinars was somewhat lower, the consultations and the peer network seem to be particularly well received. The open field in the questionnaires highlighted that the respondents appreciated the offer and their relevance. Respondents positively underlined that the webinars gave a short overview of the areas and that the topics were of interest. However, the respondents mentioned that less time was dedicated to networking with other participants which was frequently emphasized as impediment.

To bridge this gap, we offered two interactive settings in addition to the network meetings, i.e. the expert workshops and the idea work-

shops. The overall satisfaction in these two formats was high. The respondents in the open fields emphasized that they were well suited for joint learning and cooperation opportunities as well as to gain knowledge from different perspectives.

Despite the very positive feedback in the open fields, the ideas workshop scored lowest in both overall satisfaction and takeaways. This shows the weakness of the survey design lacking information about motives and backgrounds of the participants. In case of the ideas workshop, the majority of participants were patients or citizens, which might evaluate the questions more critically than scientists who are more familiar with such surveys.

The consultation received the highest ratings in terms of both satisfaction and takeaways. Both in the survey and as feedback during the consultation, respondents emphasized the unique position of this offer in the field and its relevance for developing a participatory approach in research projects. This offer was less supportive of the networking of individuals in the field but was extremely effective in providing knowledge about the call and participatory research approaches. For the PPIE team, it was also a direct opportunity to learn about barriers and opportunities in the field and, if necessary, to follow-up with a tailored support offer (e.g., topic for expert workshop).

## LEARNINGS AND CONCLUSION

With the PPIE Implementation Program, we aimed to introduce patient and public involvement in the Austrian research landscape as well as a new research-funding instrument by involving members of the public in the development of the activities, assessment of the project proposals and the overall evaluation of the program.

In the consultation sessions we experienced difficulties from applicants to describe their participatory approach. This often resulted in describing the scientific approach instead and left the expert panel with open questions in their assessment of applications. For this reason, we are adapting the application documents in the second call and expand the consulting activities. The latter is also important as non-research bodies, e.g., patient organizations and non-governmental organizations, are eligible for funding in the second call, which was recommended by the expert panel. Non-research institutions may need more support in preparing their applications, as they are usually less familiar with applying for funding. Therefore, we will make the application more accessible for public members by allowing applications in German in justified cases and introducing a video format additionally to the text-based application.

In the selection meeting of the transdisciplinary panel, we found that – despite the briefing – different understandings of active participation were negotiated. However, this was not a problem due to the open and collaborative atmosphere and mutual learning opportunity for experts. This shows the importance of creating an atmosphere where all participants can get involved, provide facilitation, and allocate enough time for discussions. Experts reported a high workload assessing all 25 applications in detail. We underestimated the effort required for less trained experts during the assessment. In the second call, we will allocate a maximum of ten applications for each expert for individual assessment.

Regarding the evaluation of the support offer, we learned that the questionnaire was not suitable for drawing conclusions on the PPIE Implementation Program and target group. At first, we decided to exclude

personal data such as gender or institutional background etc. ensuring anonymity to the respondents and keeping the survey as short as possible. Also, we did not perceive these data as relevant for the evaluation of the activities. While this provides general feedback on the activity, it reduced our possibilities to evaluate the single activity connected to the PPIE Implementation Program as we lack knowledge about the respondents' perspective and the reasons why they participated. Therefore, in the second PPIE Pilot Call 2021, we revised the 'Participation Check' based on the experience gained so far including demographic data about participants, and feedback on the format. Nevertheless, there are some lessons we can draw from the participation check so far – especially in combination with the responses in the open fields. The evaluation of the support offers indicated that a pure focus on dissemination events (like webinars) is not sufficient to foster capacity building in community. It seems that there is a need for formats in which people work together and thereby come into direct contact, such as co-creative settings to jointly find solutions for the problems of others.

The different support offers were identified as strength of the PPIE Implementation Program, well perceived in the PPIE community and positively evaluated by the participants. However, the cross-linking between the different activities should be improved to increase the share of repeated participations and thus improve networking effects.

Despite the need for small adaptations in the second PPIE Pilot Call 2021, it seems that the funding instrument was appropriate and reflects a low threshold offering for researchers introducing public and patient involvement activities in their work. The PPIE Implementation Program is a first step towards establishing high quality public and patient involvement in research and an institutionalized PPIE support structure.

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