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Patient advisory boards as strategic partners for patient safety – participatory development of practical recommendations for action from the PEPS project

Patient safety is one of the central quality objectives of all healthcare systems. Despite extensive measures, many preventable adverse events continue to occur (Kumah, 2025; Slawomirski et al., 2017; World Health Organization, 2021). In Germany, too, a significant proportion of inpatients are affected by preventable events (Friebel et al., 2021; Schrappe, 2019). Therefore, approaches to improving patient safety must be continuously developed and supplemented with innovative, strategic perspectives – especially in cooperation with all stakeholders in healthcare (Brust et al., 2024). One lever that has been largely underestimated to date is the involvement of patients and their representatives at the organisational level. While participation in immediate care steps is already recognised as effective (Berger et al., 2014), the possibilities of organisational participation formats such as patient advisory boards (PABs) for safety processes have not been sufficiently researched and utilised (Ocloo & Matthews, 2016). PBRs combine collective experience with a systemic outside perspective and can reveal blind spots, communication barriers and acceptance problems in safety measures (Coulter & Oldham, 2016; Engler et al., 2024). In Germany, legal requirements and certification requirements create a basis for patient participation (SGB V, § 140f/g) (Federal Ministry of Justice, n.d.). Nevertheless, the practical integration of PBR in this country often remains inadequate: healthcare facilities do not always know how to effectively integrate PBR; patient representatives sometimes lack in-depth knowledge of safety concepts, participatory involvement or communication methods (Davis et al., 2007; Koch et al., 2024; Newman et al., 2021).

Summary

Patient safety is a central goal of modern healthcare systems, yet many preventable events continue to occur. One approach that is underutilised is the involvement of patient advisory boards (PABs) at the organisational level, which provide important impetus for safety processes through their experience and external perspective. In four sub-studies of the PEPS project, needs were assessed, international approaches were reviewed, a training programme ("Partners for Patient Safety", P4PS) was developed, and its acceptance and feasibility were evaluated. The results show that PABs are usually involved in an informative or consultative capacity, but require expertise in patient safety, communication, and quality management. The P4PS programme demonstrates feasibility and effectiveness, showing that training can transform the role of patient representatives – from pure experience to multi-skilled consulting that combines the real world with system logic.

Based on the results and a participatory strategy dialogue, practical recommendations for action were developed together with project participants for healthcare facilities, PBRs and system actors. The central demand is the binding integration of PBRs into safety-relevant processes, supported by resources, clear roles and joint training. In this way, patient participation can be developed from a symbolic to a strategic partnership.

Keywords

Health education, recommendations for action, patient advisory boards, patient participation, patient safety

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International role models show that targeted training for patient representatives and clinical staff can strengthen this partnership and establish structural dialogue formats (Abelson et al., 2024; Cox et al., 2022; Greenhalgh et al., 2019; Romme et al., 2024). However, Germany has so far lacked both a systematic needs assessment and evaluated offerings tailored to the local context.

Against this background, our research project aimed to strengthen the integration of PBR to promote patient safety in German healthcare facilities. To this end, needs were assessed, international publications were reviewed, and a multimodal training programme was developed and piloted. However, our focus in this publication is on synthesising the findings and deriving practical recommendations for action in order to promote transfer into healthcare practice.

Methodology

The PEPS-3 project (Implementation of patient involvement for the strategic promotion of patient safety: A feasibility evaluation using the example of patient advisory boards in clinical institutions in Germany) was carried out in several interrelated sub-studies, which are summarised below (see Figure 1). The project involved patient advisory boards and representatives of oncological healthcare facilities in Germany (Fig. 1).

Substudy 1: Needs and requirements analysis

A modified Delphi method was used to achieve professional consensus on the relevant needs of PBRs and healthcare facilities with regard to patient safety (Brust et al., 2025; Levitt et al., 2018; Nasa et al., 2021; Spranger et al., 2022). First, qualitative online interviews wereconducted tasks, roles, knowledge, influencing factors and desired educational formats. In the second round of interviews, these were summarised in order to reach consensus on content, competencies and involvement.

Overview of the research process and the sub-studies (SS) of the project

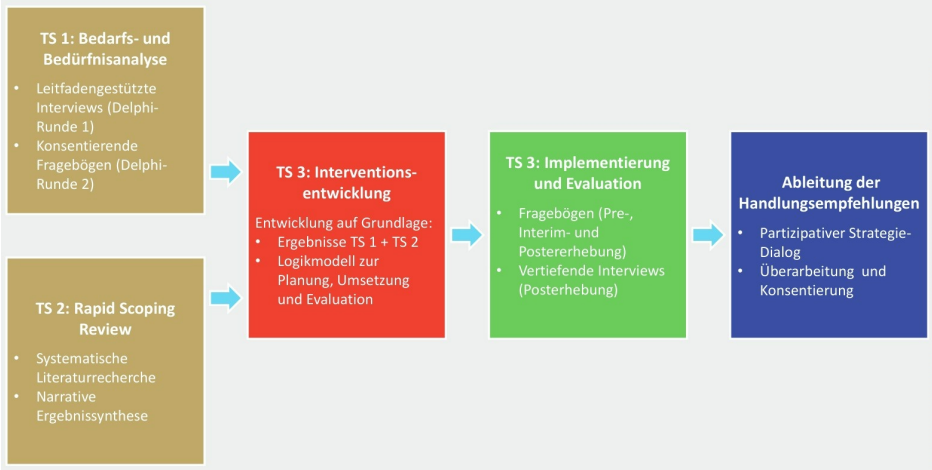


Fig. 1: **Overview of the research process and the sub-studies (SS) of the project. Own representation.**

Substudy 2: Rapid scoping literature review

At the same time, a literature review was conducted to identify exemplary international teaching approaches and materials for PBR qualification in patient safety (Rramani Dervishi et al., 2025). Relevant information on the target group, content, format, setting and learning outcomes was extracted and the methodological quality was evaluated (Hong et al., 2018; Pace et al., 2012).

Substudy 3: Participatory development of the training programme

Building on sub-studies 1 and 2, a training programme was developed (Blum et al., 2025). Its orientation was defined using the logic model (Goeschel et al., 2012; W. K. Kellogg Foundation, 2004) and learning objectives relating to patient safety, PBR involvement and communication were operationalised along established taxonomies (Bloom et al., 1956; Krathwohl, 2002). The target group was members of existing or developing PBRs as well as employees and managers of healthcare facilities.

Substudy 4: Mixed-methods evaluation of acceptance and effectiveness

The evaluation used a quasi-experimental, exploratory mixed-methods design (Brust et al., 2025; Creswell, 2015; Creswell et al., 2011). Quantitative online questionnaires assessed feasibility, acceptance, implementation and competencies (Kien et al., 2021; Weiner et al., 2017). Semi-structured interviews after completion enabled an in-depth interpretation of the results and the identification of factors promoting and inhibiting the implementation and optimisation of the programme.

Derivation of recommendations for action

The final derivation of recommendations for action for greater organisational involvement of patients and their representatives in patient safety-related care processes aimed to promote the transfer of our results into practice and the conditions for improved PBR involvement (Zscheppang et al., 2025). To this end, a participatory approach in the form

of a strategy dialogue was chosen, which involved participants from different institutions and thus took into account institutionally varying perspectives and contextual factors. Three participants were recruited for this purpose: a PBR member, a member of a healthcare institution and an external patient representative who had previously been involved in the project in an advisory capacity. In preparation for the dialogue, the participants received a layman's summary of key project results to provide a common basis of information. In addition, key guiding questions and preliminary considerations were provided to facilitate reflection and discussion and to focus on deriving practical recommendations. Further questions were also provided to structure the actual dialogue. The key questions and preliminary considerations provided are shown in Table 1.

The key questions and preliminary considerations focused, among other things, on the objectives of the recommendations for action, which addressees and actors should be involved, and which results and experiences need to be taken into account. Further questions dealt, for example, with how recommendations can be made understandable and practical, which barriers need to be considered in implementation, and whether there are any unintended exclusions of topics or target groups.

The exchange with the participants took place in the form of a one-hour virtual meeting via the Zoom video conferencing platform. All perspectives and assessments expressed on the feasibility, relevance and prioritisation of potential recommendations for action were discussed and documented. The participants were actively involved in weighting and shaping the recommendations. This corresponds to the stage model of participation in co-determination and partnership (Arnstein, 1969; Wright et al., 2007). This gave them a significant influence on the formulation of the content and enabled them to play a key role in shaping the recommendations for action.

The documented statements were systematised by the research team and converted into formulated recommendations. The external patient representative was then involved. She reviewed the recommendations and provided suggestions for changes and revisions . Finally, this version of the recommendations for action was forwarded to the participants for final correction and approval. After consultation on any changes, the final recommendations for action were drawn up.

Leitfragen und Vorüberlegungen des Projektteams	
Leitfragen	**Vorüberlegungen**
Was soll durch die Handlungsempfehlungen erreicht werden?	• Unterstützung von Gesundheitseinrichtungen bei dem systematischen Aufbau sowie der strukturierten Entwicklung und Implementierung von PBR zur Einbindung in Versorgungsprozesse • Unterstützung von Gesundheitseinrichtungen und PBR bei der zielgerichteten Weiterentwicklung von PBR und deren Einbindung in Qualitäts- und Sicherheitsmaßnahmen - Klärung von Erwartungen, Zielen, Funktionen und Rollen sowie Kommunikationsprozessen - Arten und Umsetzung der Einbindung - Implementierung konsistenter Aus- und Fortbildungsmöglichkeiten
Wer soll die Empfehlungen mitgestalten und warum?	• Vertretende der PBR (Patientenperspektive) & Gesundheitseinrichtungen (Klinikperspektive) • Externe Patientenvertreterin (externe Perspektive; Überprüfung auf Laienverständlichkeit) • Forschungsteam (wissenschaftliche Perspektive; Gesamtüberblick)
Welche Ergebnisse und Informationen sollen berücksichtigt werden?	• Vorrangig Ergebnisse der Bedarfs- und Bedürfnisanalyse (TS 1) und der Evaluation (TS 4) - Dokument mit Kurzzusammenfassungen der Ergebnisse • Eigene Erfahrungen und Kenntnisse der Mitwirkenden
Für wen sind die Empfehlungen gedacht? Wer sind die Adressaten?	• (Universitäts-) Kliniken in Deutschland - Personal mit Führungs- oder Leitungsfunktion, z. B. Direktorium, Qualitäts- und Risikomanagement, Pflegedienstleitung, Ärztliche Leitung - Personal mit koordinierender Funktion, z. B. Schnittstellen zwischen PBR und Klinik • Potenzielle und aktive Mitglieder aus PBR, z. B. im Sinne der Patienten-/ Selbsthilfevertretung • Systemebene (z. B. Gesellschaften, Verbände, Akkreditierungs-/Zertifizierungsstellen, Institutionen zur Qualitätssicherung)

Table 1: **Key questions and preliminary considerations of the project team for the development of recommendations for action to promote organisational patient involvement in safety-critical care processes. PBR – Patient Advisory Board, TS – Sub-study. Own representation.**

Ethical aspects and participation

The overall study was registered in advance (DRKS; ID: DRKS00034733) and approved by the Ethics Committee of the Medical Faculty of the University of Bonn (Ref. No.: 2024-236-BO). Before participating, all participants were provided with comprehensive information and gave their consent. Data collection and processing were carried out in accordance with the Declaration of Helsinki, the General Data Protection Regulation (GDPR) and the Federal Data Protection Act (BDSG).

Results

Key findings

The sub-studies (SS) provided a comprehensive picture of the situation, needs and practical approaches to strengthening PBR in the area of patient safety:

The needs analysis (TS 1) revealed a current discrepancy between the potential and actual practice of PBR. Cooperation with the institutions was predominantly experienced as respectful, but the right of PBR to participate in decision-making was considered limited. Involvement was mostly limited to information or consultation, with genuine co-decision-making being rare. Patient safety was a new topic for many, and more attention was desired. Key competence needs were basic knowledge of patient safety, knowledge of quality and risk management, and communication skills. Obstacles included unclear roles, limited resources and a lack of insight into safety-related processes (Brust et al., 2025).

The review (TS 2) identified international training programmes and materials such as guidelines, toolkits and e-learning courses. These mainly covered the basics of patient safety, communication and the role of patient representatives. Despite often low methodological quality and rare

evaluation, they provided valuable impetus for content and approaches (Rramani Dervishi et al., 2025).

The participatively developed 'Partners for Patient Safety' programme (P4PS; TS 3) combines an e-learning module with a practice-oriented workshop. The e-learning module prepares participants for the basics of patient safety, communication models and the role of PBR. In the workshop, what has been learned is applied in practice, barriers are analysed and goals for strengthening PBR involvement are defined (Blum et al., 2025). The P4PS programme is freely accessible at this link: https://t1p.de/f91ta

The implementation and evaluation (TS 4) showed high acceptance and good feasibility. The conditions for success were support from management, time resources and moderated workshops. Barriers included time constraints, limited digital skills and low employee participation. The preliminary effectiveness analysis showed a significant improvement in the participants' self-assessed skills in all relevant areas of patient safety and the integration of PBR (Brust et al., 2025).

Recommendations for practice regarding patient involvement in patient safety

Three primary target groups for the recommendations for action were identified: 1) managers in healthcare facilities, 2) members of the PBR, and 3) relevant stakeholders in the German healthcare system. For better understanding and accessibility, the recommendations were summarised in one-page flyers, which are briefly presented below.

Target audience 1: Healthcare facilities

The recommendations emphasise the need forstructural anchoring of the PBR. Its integration should not be additive, but rather integral to processes such as quality and risk management, complaint procedures or safety audits. The consistent integration of the PBR to promote the safety culture of institutions is highlighted, along with improved access and communication structures. This includes appointing designated contact persons, raising staff awareness of the recruitment of potential members, and providing internal information (e.g. from CIRS or complaint management). Proactive public relations work, for example through newsletters or information events, to promote the visibility and acceptance of PBR is emphasised.

The provision of resources is considered another critical success factor. This includes financial compensation, budgets for training, and a digital infrastructure. The definition of clear roles and participation agreements to promote binding cooperation is emphasised. In addition, joint training for PBR members and hospital staff is recommended in order to develop a common language and goals (Fig. 2).

Addressee 2: Patient advisory boards



Fig. 2: **Involvement of patient advisory boards – recommendations for hospital management. Own representation.**

The recommendations for PBR members focus on the development of skills, structures and practices thatenable effective participation. Clarity about roles and responsibilities is central. This includes dealing with internal hospital processes and patient rights, but also regularly reflecting on one's own function within the advisory board and in relation to the hospital. In addition, clear goal definition and transparent communication of expectations are identified as ways to strengthen participation.

Another focus is on the visibility and recruitment of the advisory board. In order to increase its representativeness and legitimacy, its membership should be deliberately diverse. This requires low-threshold access, a good external image and structured introductory materials for new members. Empowering members through training was identified as crucial for building skills in patient safety and quality management. In addition, active participation in internal hospital processes such as audits or safety rounds is recommended, combined with a culture of open and respectful communication. Finally, networking with other PBRs for the exchange of experiences and mutual support was emphasised (Fig. 3).

Target group 3: Other actors in the healthcare system



Fig. 3: **Structure and work of patient advisory boards – recommendations for members of patient advisory boards. Own representation.**

At the systemic level, the recommendations are aimed at actors such as politicians, quality assurance institutions,certification bodies and professional associations. The recommendations include the creation of binding framework conditions for the nationwide establishment of PBRs. These include the integration of participation criteria into funding guidelines, certification procedures and quality standards, as well as the development of legal foundations. To promote competence, emphasis was placed on supporting and recognising training programmes, providing target group-specific materials and taking into account people with low digital skills. The involvement of multipliers and the establishment of nationwide networks for dissemination, knowledge transfer and the exchange of best practices are also recommended (Fig. 4).

Discussion

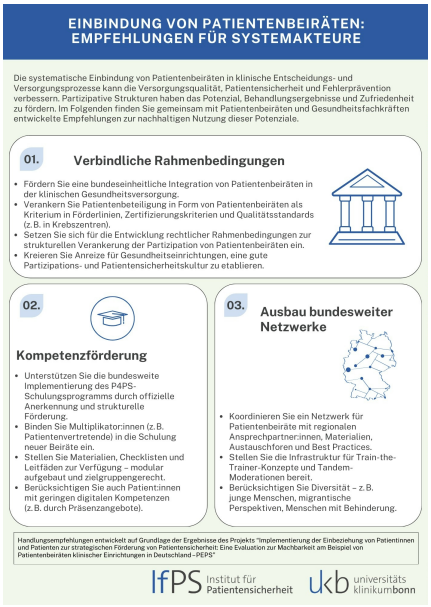


Fig. 4: **Involvement of patient advisory boards – recommendations for system actors. Own representation.**

Our goal was to strengthen the strategic involvement of PBR to promote patient safety in German healthcare facilities and, based on this, to develop practical recommendations for action. The key findings of the sub-studies show, firstly, a considerable discrepancy between the potential benefits and the actual practice of PBR involvement, which is often limited to information and consultation (Brust et al., 2025; Rramani Dervishi et al., 2025). Secondly, a previously unmet need for specific skills in the area of patient safety and communication among PBR members was identified, as well as a lack of knowledge about effective involvement on the part of the PBR and institutions (Brust et al., 2025). Thirdly, the development and evaluation of our P4PS programme demonstrates that such interventions are feasible, highly accepted and effective, and significantly improve the self-assessed skills of those involved (Blum et al., 2025; Brust et al., 2025). Fourthly, a participatory process has resulted in the derivation of agreed, target-specific recommendations for action for healthcare institutions, PBR and system actors, which form a holistic approach for a successful partnership between healthcare institutions and patient representatives in the field of patient safety.

The central recommendation is the structural and binding integration of PBRs into safety-related committees and processes in order to ensure sustainable participation that is independent of individual commitments. This is in line with international demands for the involvement of those affected in relevant decision-making processes that goes beyond mere consultation (Mertens et al., 2025; Narbutas et al., 2017). Informed access to safety-related information (e.g. anonymised CIRS reports) is essential to strengthen the role of PBRs and enable them to play an active role in quality promotion (Plamper & Meinhardt, 2008; Westerink et al., 2023). The provision of resources (time, money, infrastructure) addresses one of the most fundamental barriers and goes beyond the question of appropriate appreciation. It helps to ensure diversity of perspectives in the committees and reduces the appearance of purely symbolic involvement (Brust et al., 2025; Cepeda et al., 2025; Westerink et al., 2023). The recommendations for PBR members themselves, in particular the acquisition of patient safety-specific knowledge and communication skills, underline the need for mutual support. The skills gains achieved through the P4PS programme show that targeted training is effective and that the role of patient representatives can change – from relying solely on their own experience to providing multi-skilled advice that understands and communicates both the lives of patients and the systemic logic of healthcare institutions (Engler et al., 2024; Romme et al., 2024).

Our development of evidence-based recommendations for action and a proven training programme marks an important first step. The key challenge is the sustainable implementation of the recommendations. Permanent consolidation requires integration into existing structures and funding. One approach could be to establish "train-the-trainer" programmes in which committed members of PBR or qualified employees of the institutions are trained as moderators and multipliers (Jesus et al., 2025; Romme et al., 2024). At the same time, the content of training programmes such as the P4PS programme should be integrated into the curricula of existing patient academies and into the continuing education and training of PBR coordinators at healthcare facilities. Structural and financial anchoring can

ensure sustainable continuity and dissemination.

In order to be able to assess the effectiveness of the measures in a well-founded manner , further research is also needed, such as longer-term effectiveness studies that examine the effects of increased patient participation on patient safety indicators and metrics. Further methodological research is needed to develop and validate methods for measuring the specific influence of patients and PBR on patient safety in order to isolate their contribution from other quality initiatives and quantify their added value in an evidence-based manner (Oldfield et al., 2019; Sharma et al., 2017). In addition, it is important to assess the influence on soft but equally important factors such as safety culture, participation and patient trust in the institution. Finally, the transferability and adaptability of the concepts to other care sectors (outpatient care, rehabilitation, long-term care) and non-oncological departments must be critically examined.

The recommendations for action provide guidance and a concrete roadmap for healthcare practice. Healthcare facilities can view the recommendations as an opportunity to fundamentally strengthen their own safety culture by incorporating the valuable perspectives of their patients. PBRs should overcome ambiguities about their own roles and tasks and actively structure and communicate their own work. Finally, higher-level system actors are called upon to anchor the proposals in regulatory requirements in order to promote their broader and binding implementation.

Conclusion

The recommendations for action presented here show that the successful integration of PBRs into patient safety is not an altruistic concession, but a strategic investment in patient-oriented, more robust and learning-oriented healthcare. Their implementation requires a courageous step away from the symbolic involvement that is often still practised towards a genuine, resource-supported, constructive partnership.

Author declaration

The authors declare that there are no conflicts of interest.

Statement by the Ethics Committee

This project received a positive vote from the Ethics Committee of the Medical Faculty of the Rheinische Friedrich-Wilhelms-Universität Bonn (file number: 2024-236-BO; vote dated 30 July 2024).

Study registration

The project was pre-registered in the German Clinical Trials Register (DRKS; ID: DRKS00034733).

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Patient and family advisory councils as strategic partners for patient safety – Participatory development of practical recommendations for action from the PEPS project

Patient safety is a key objective of modern healthcare systems, yet many preventable incidents continue to occur. One approach that is rarely used is the engagement of patient and family advisory councils (PFACs) at the organisational level, which can provide important impetus for safety processes thanks to their experience and external perspective. In four consecutive studies of the PEPS project, needs were assessed, international approaches were reviewed, an educational programme ("Partners for Patient Safety," P4PS) was developed, and its acceptance and feasibility were evaluated. The results show that PFACs are usually engaged in an informative or consultative capacity, but need skills in patient safety, communication, and quality management. The P4PS programme demonstrates feasibility and preliminary effectiveness, showing that training can transform the role of patient representation – from experience-based input to structured, multi-competency consultation informed by both lived experience and system-level perspectives. Based on the results and a participatory strategy dialogue, practical recommendations for action were developed together with project participants for healthcare facilities, PFACs, and system actors. The central demand is the actual integration of PFACs into safety-relevant processes, supported by resources, clear roles, and joint training. In this way, patient engagement can be developed from a symbolic to a strategic partnership.

Keywords

Health education, Recommendations for action, Patient advisory councils, Patient engagement, Patient Safety

Citation

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