Schweizerische Eidgenossenschaft
Confédération suisse
Confederazione Svizzera
Confederaziun svizra

Federal Department of Home Affairs FDHA
Federal Quality Commission FQC

International experiences with patient and public involvement in the decision-making processes of healthcare institutions: an environmental scan

---

Report for the Federal Quality Commission

Authors (alphabetical order): Jean-Baptiste Babinet, Chantal Britt, Zora Föhn, Birgit Lauberau, Océane Pittet, Kevin Selby, Karin van Holten, Christian von Plessen

unisanté
Centre universitaire de médecine générale et santé publique • Lausanne

Berner Fachhochschule
Haute école spécialisée bernoise
Bern University of Applied Sciences

INTERFACE
Schafft Wissen | Entre science et pratique

The Federal Quality Commission (FQC) is an extra-parliamentary executive commission of the Federal Department of Home Affairs (FDHA). It supports the Federal Council with quality development in healthcare as part of the Federal Act on Health Insurance (HIA). For more information, see www.eqk.admin.ch.

The content of this report does not necessarily reflect the FQC's position.

Publication details

Published by

Federal Quality Commission (FQC)

Publication date

August, 2025

Citation

Babinet J-B., Britt C., Föhn Z., Lauberau B., Pittet O., Selby K., van Holten K., von Plessen Ch., [2025], [International experiences with patient and public involvement (PPI) in the decision-making processes of healthcare institutions], [en environmental scan], Bern: Federal Quality Commission (FQC)

Language of original report

English, German and French

Enquiries

Federal Quality Commission
Secretariat
c/o Federal Office of Public Health
Schwarzenburgstrasse 157, 3003 Bern
info@eqk.admin.ch
www.eqk.admin.ch

International experiences with patient and public involvement in the decision-making processes of healthcare institutions: an environmental scan

Report 1 for the Federal Quality Commission mandate “Empfehlungen für den systematischen Einbezug von Betroffenen, Angehörigen und der Bevölkerung in Entscheidungsprozesse von Behörden, Leistungserbringern und Versicherern im Gesundheitswesen”

Authors (alphabetical order): Jean-Baptiste Babinet, Chantal Britt, Zora Föhn, Birgit Lauberau, Océane Pittet, Kevin Selby, Karin van Holten, Christian von Plessen

Version 1.2, submitted 28.08.2025

1. Summary

Context: The Federal Quality Commission (FQC) promotes Patient and Public Involvement (PPI) in healthcare decision making to make Swiss healthcare more patient-centered. While shared decision-making is supported for involving individuals (micro-level), it is unclear which models are best for PPI in Swiss healthcare institutions. This report provides an overview of how patients and the public have been involved in decision-making processes on the meso (institutions providing care) and macro levels (authorities, payers) in other countries.

Methodology: We conducted an environmental scan with a literature review and interviews with key informants. We synthesized key themes in systematic reviews compiling experiences of PPI in decision-making processes at the meso and macro levels. In addition, we prepared country vignettes based on interviews with 9 healthcare experts from 5 countries (France, Canada, the Netherlands, Denmark and Germany) and grey literature from the United Kingdom and Austria.

Results: We included 44 reviews referencing approximately 2300 individual articles. PPI occurs in nearly all areas and domains of healthcare, contributing greatly to the relevance and quality of decisions and enhancing trust, with involvement mostly spanning from consultation to coproduction. Barriers include power imbalances, resource constraints, legal ambiguity, and a lack of systematic involvement. Enablers include engagement of patients early on and throughout projects, clear communication, adequate funding, and leadership support. Risks of PPI include tokenism, emotional and physical strain on patient partners, and an over-reliance on volunteer work. Overall, a lack of systematic evaluation makes assessing and comparing the quality and effectiveness of PPI difficult.

The country vignettes describe well-established PPI after decades of commitment. Legislation about the rights of patients and PPI emerged as a crucial enabler of sustainable and meaningful PPI (e.g., Germany and the Netherlands). National patient organizations unify and amplify patient voices in the political system (e.g., Denmark's national patient organization). The increasing demand for patient partners in all the countries is causing recruitment shortages and challenges to include patients from different socio-demographic groups. Finally, different profiles of patient partners are needed in different situations; training, experience and compensation are vital for roles that require professionalization, such as participation in political, governmental, regulatory or legislative committees.

Key questions for Work Package 2, "Context analysis":

1. To what extent does the culture in Swiss healthcare institutions today enable the involvement of patients and the public in decision-making processes? What resources are already available to support PPI in these decision-making processes?
2. Which national, cantonal or municipal laws and regulations are required to strengthen PPI in healthcare decision-making processes?
3. How do stakeholders view the creation of a national representative body for patients?
4. What do leaders of meso- and macro-level institutions need to implement PPI in their decision-making processes? What are possible mechanisms for sustainable funding?
5. How can leaders and institutions build PPI competencies and capacity among both healthcare professionals and patient partners?

1.2 Zusammenfassung

Kontext: Die Eidgenössische Qualitätskommission (EQK) fördert die Beteiligung von Patientinnen, Patienten und der Öffentlichkeit (Patient and Public Involvement, PPI) an Entscheidungsprozessen im Gesundheitswesen, um die Schweizer Gesundheitsversorgung patientenzentrierter zu gestalten. Während die partizipative Entscheidungsfindung auf individueller Ebene (Mikro-Ebene) unterstützt wird, ist unklar, welche Modelle sich für das PPI in Schweizer Gesundheitsinstitutionen am besten eignen. Dieser Bericht bietet einen Überblick darüber, wie Patientinnen, Patienten und die Öffentlichkeit in anderen Ländern an Entscheidungsprozessen auf der Meso- (Gesundheitsinstitutionen) und Makro-Ebene (Behörden, Kostenträger) beteiligt werden.

Methode: Wir führten eine Umweltanalyse durch, die eine Literaturübersicht und Interviews mit Schlüsselpersonen umfasst. Die zentralen Erkenntnisse wurden aus systematischen Übersichtsarbeiten gewonnen, die Erfahrungen mit PPI in Entscheidungsprozessen auf Meso- und Makro-Ebene zusammenfassen. Zusätzlich wurden Länder-Vignetten auf Basis von Interviews mit neun Gesundheitsexperten aus fünf Ländern (Frankreich, Kanada, Niederlande, Dänemark und Deutschland) sowie grauer Literatur aus dem Vereinigten Königreich und Österreich erstellt.

Ergebnisse: Wir berücksichtigten 44 systematische Übersichtsarbeiten mit insgesamt rund 2300 Einzelartikeln. PPI wird in nahezu allen Bereichen und Sektoren des Gesundheitswesens

umgesetzt. Es trägt wesentlich zur Relevanz und Qualität von Entscheidungen bei und stärkt das Vertrauen in die Entscheidungsprozesse. Die Beteiligung erstreckt sich von Konsultation bis hin zur Mitgestaltung (Co-Production).

Mehrere Herausforderungen erschweren die Umsetzung von PPI. Dazu gehören Machtungleichgewichte, begrenzte Ressourcen, rechtliche Unklarheiten sowie eine fehlende systematische Einbindung. Gleichzeitig ließen sich zentrale Erfolgsfaktoren identifizieren. Eine frühzeitige und kontinuierliche Einbindung von Patientinnen und Patienten, klare Kommunikation, angemessene Finanzierung sowie die Unterstützung durch Führungspersonen tragen wesentlich zur Wirksamkeit von PPI bei.

Trotz dieser positiven Faktoren sind mit PPI auch Risiken verbunden. In einigen Fällen bleibt die Beteiligung symbolisch, ohne tatsächlichen Einfluss auf Entscheidungen (Alibi Beteiligung). Zudem können emotionale und physische Belastungen für Patientenpartner entstehen. Eine übermäßige Abhängigkeit von unbezahlten Freiwilligen stellt ebenfalls eine Herausforderung dar. Ein weiteres übergeordnetes Problem ist das Fehlen systematischer Evaluation, was die Bewertung und den Vergleich der Qualität und Wirksamkeit von PPI erschwert.

Die Länder-Vignetten zeigen, dass PPI in einigen Ländern nach jahrzehntelangem Engagement gut etabliert ist. Gesetzliche Regelungen zu Patientenrechten und PPI erweisen sich als entscheidender Faktor für nachhaltige und wirkungsvolle Patientenbeteiligung, wie etwa in Deutschland und den Niederlanden. Nationale Patientenorganisationen spielen eine wichtige Rolle, indem sie die Stimmen der Patientinnen und Patienten im politischen System bündeln und verstärken, wie es beispielsweise die nationale Patientenorganisation in Dänemark tut.

Die steigende Nachfrage nach Patientenpartnern führt in allen untersuchten Ländern zu Rekrutierungsschwierigkeiten und Herausforderungen bei der Einbindung unterschiedlicher soziodemografischer Gruppen. Zudem werden je nach Kontext unterschiedliche Patienten- und Patientinnenprofile benötigt. Für Rollen, die eine Professionalisierung erfordern, wie die Mitwirkung in politischen, behördlichen oder regulatorischen Gremien, sind Schulung, Erfahrung und angemessene Vergütung essenziell.

Zentrale Fragen für Arbeitspaket 2 „Kontextanalyse“:

1. Inwieweit ermöglicht die heutige Kultur in Schweizer Gesundheitseinrichtungen die Beteiligung von Patientinnen, Patienten und der Öffentlichkeit an

Entscheidungsprozessen? Welche Ressourcen stehen bereits zur Verfügung, um die PPI in diesen Entscheidungsprozessen zu unterstützen?

2. Welche nationalen, kantonalen oder kommunalen Gesetze und Regulierungen sind erforderlich, um die PPI in Entscheidungsprozessen im Gesundheitswesen zu stärken?
3. Wie stehen die Akteure zur Schaffung einer nationalen Vertretung für Patientinnen und Patienten?
4. Was benötigen Führungspersonen von Institutionen auf Meso- und Makro-Ebene, um PPI in ihre Entscheidungsprozesse zu integrieren? Welche Mechanismen für eine nachhaltige Finanzierung sind denkbar?
5. Wie können Führungspersonen und Institutionen die Kompetenzen und Kapazitäten für PPI sowohl bei Gesundheitsfachpersonen als auch bei Patientenpartnern aufbauen?

1.3 Résumé

Contexte : La Commission fédérale de la qualité (CFQ) souhaite renforcer l'Implication des Patients et du Public (IPP) afin de rendre le système de santé suisse plus centré sur le patient. Si la décision partagée est déjà promue au niveau micro, les modèles adaptés à l'IPP aux niveaux méso (établissements) et macro (autorités, payeurs) restent à préciser. Ce rapport présente un aperçu des approches mises en œuvre dans d'autres pays à ces deux niveaux.

Méthodologie : Nous avons procédé à un état des lieux par une revue de littérature et la conduite d'entretiens auprès d'intervenants clés. Nous avons synthétisé les thèmes majeurs des revues systématiques compilant les expériences d'IPP dans les processus décisionnels à la fois aux niveaux méso et macro. En outre, nous avons préparé des vignettes nationales sur la base d'entretiens avec 9 experts en soins de santé venant de 5 pays (France, Canada, Pays-Bas, Danemark et Allemagne) et de la littérature grise du Royaume-Uni et de l'Autriche.

Résultats : Nous avons inclus 44 revues qui font référence à 2'300 articles. L'IPP a lieu dans presque tous les domaines des soins de santé, contribuant grandement à la pertinence et à la qualité des décisions et renforçant la confiance, par une implication allant principalement de la consultation à la coproduction. Pour les entraves, nous pouvons citer les déséquilibres de forces, les restrictions budgétaires, l'ambiguïté juridique et le manque d'implication systématique. Pour les éléments facilitateurs, nous pouvons relever l'engagement des patients dans l'entièreté des projets (de la conception, développement, à la dissémination), une communication claire, un financement adéquat et le soutien des dirigeants. Les risques liés à l'IPP comprenaient le

symbolisme (ou « tokenisme »), la pression à la fois émotionnelle et physique sur les patients partenaires et un usage excessif du bénévolat. Dans l'ensemble, l'absence d'évaluation systématique a rendu difficile l'évaluation et la comparaison de la qualité et de l'efficacité de l'IPP.

Les vignettes nationales décrivent une IPP bien ancrée après des décennies de partenariat et d'engagement. La législation relative aux droits des patients et à l'IPP s'est révélée être un facteur crucial pour la mise en place d'une IPP durable et significative (cf les exemples allemands et hollandais). Les organisations nationales de patients permettent d'unifier et renforcer la voix des patients dans le système politique (cf l'organisation nationale de patients danois). La demande croissante de patients partenaires entraine des pénuries de recrutement et des difficultés à inclure des patients issus de différents groupes sociodémographiques. Enfin, différents profils de patients partenaires étaient nécessaires dans différentes situations ; la formation, l'expérience et la rémunération sont essentielles pour les rôles qui nécessitent une professionnalisation, comme par exemple la participation à des comités politiques, gouvernementaux, réglementaires ou législatifs.

Questions clés pour le work package 2, "Analyse du contexte" :

1. Dans quelle mesure la culture des institutions de santé suisses permet-elle aujourd'hui l'implication des patients et du public dans les processus décisionnels ? Quelles ressources sont déjà disponibles pour favoriser l'IPP dans les processus décisionnels ?
2. Quelles sont les lois et réglementations nationales, cantonales ou municipales nécessaires pour renforcer l'IPP dans les processus décisionnels en matière de santé ?
3. Comment les parties prenantes voient-elles la création d'un organe national de représentants de patients ?
4. De quoi les dirigeants des institutions des niveaux méso et macro ont-ils besoin pour mettre en œuvre l'IPP dans leurs processus décisionnels ? Quels sont les mécanismes possibles pour un financement durable ?
5. Comment les dirigeants et les institutions peuvent-ils renforcer les compétences et les capacités nécessaires en matière d'IPP pour les professionnels de santé ainsi que pour les patients partenaires ?

1.4 Sintesi

Contesto: La Commissione federale per la qualità (CFQ) promuove il coinvolgimento dei pazienti e del pubblico (CPP) nel processo decisionale in ambito sanitario per rendere il sistema sanitario svizzero più incentrato sul paziente. Mentre i processi decisionali condivisi sono è supportati per coinvolgere gli individui (micro-livello), non è chiaro quali siano i modelli migliori per la CPP nelle istituzioni sanitarie svizzere. Questo rapporto fornisce una panoramica di come i pazienti e il pubblico sono stati coinvolti nei processi decisionali a livello meso (istituzioni che forniscono cure e assistenza) e macro (autorità, enti finanziatori) in altri Paesi.

Metodologia: Abbiamo condotto una scansione ambientale con una revisione della letteratura e interviste con key informants. Abbiamo sintetizzato i temi chiave delle revisioni sistematiche che raccolgono le esperienze di CPP nei processi decisionali a livello meso e macro. Inoltre, abbiamo preparato vignette nazionali basate su interviste a 9 esperti di sanità di 5 Paesi (Francia, Canada, Paesi Bassi, Danimarca e Germania) e sulla letteratura grigia del Regno Unito e dell'Austria.

Risultati: Abbiamo incluso 44 revisioni. La PPI si è verificata in quasi tutte le aree e i settori dell'assistenza sanitaria, contribuendo notevolmente alla rilevanza e alla qualità delle decisioni, con un coinvolgimento che va dalla consultazione alla coproduzione. Tra gli ostacoli vi sono gli squilibri di potere, la mancanza di risorse, l'ambiguità giuridica e l'assenza di un coinvolgimento sistematico. I fattori abilitanti sono stati il coinvolgimento dei pazienti fin dalle prime fasi e per tutta la durata dei progetti, una comunicazione chiara, finanziamenti adeguati e il sostegno della leadership. I rischi della CPP includono il tokenismo, la tensione emotiva e fisica dei partner dei pazienti e l'eccessiva dipendenza dal lavoro gratuito[NP1] dei volontari. Nel complesso, la mancanza di una valutazione sistematica ha reso difficile la valutazione e il confronto della qualità e dell'efficacia della CPP.

Le vignette dei Paesi hanno descritto una CPP consolidata dopo decenni di impegno. La legislazione sui diritti dei pazienti e sulla CPP è emersa come un fattore cruciale per una PPI sostenibile e significativa (ad esempio, Germania e Paesi Bassi). Le organizzazioni nazionali dei pazienti hanno unificato e amplificato le voci dei pazienti nel sistema politico (ad esempio, l'organizzazione nazionale dei pazienti della Danimarca). La crescente richiesta di pazienti partner in tutti i Paesi causa carenze di reclutamento e sfide per l'inclusione di pazienti appartenenti a diversi gruppi socio-demografici. Infine, sono necessari diversi profili di pazienti partner in situazioni diverse; formazione, esperienza e compenso sono fondamentali per i ruoli che richiedono professionalizzazione, come la partecipazione a comitati politici, governativi, normativi o legislativi.

Domande chiave per il Work Package 2, "Analisi del contesto":

1. In che misura la cultura delle istituzioni sanitarie svizzere consente oggi il coinvolgimento dei pazienti e del pubblico nei processi decisionali? Quali risorse sono già disponibili per sostenere il PPI in questi processi decisionali?
2. Quali leggi e regolamenti nazionali, cantonali o comunali sono necessari per rafforzare la CPP nei processi decisionali in ambito sanitario?
3. Come vedono le parti interessate la creazione di un organismo nazionale di rappresentanza dei pazienti?
4. Di cosa hanno bisogno i leader delle istituzioni sanitarie di livello meso e macro per implementare la CPP nei loro processi decisionali?
5. Come possono i leader e le istituzioni costruire competenze e capacità di PPI sia tra gli operatori sanitari che tra i pazienti?

2. Context

2.1 Why patient and public involvement in decision making?

Patient and public involvement (PPI) in decision-making processes is a means of improving healthcare at multiple levels. PPI can change the culture of healthcare, making it more democratic and humane. It gives a voice and influence to those who use healthcare services, i.e. patients, caregivers, citizens and can help develop mutual understanding and a shared language about priorities for healthcare. PPI can positively influence decision-making processes at all levels (macro-, meso-, and micro-level decisions). It can improve healthcare delivery by better aligning with patient needs, either from PPI in policy decisions like the prioritisation of resources (macro-level), or in the co-design of services (meso-level), or finally in shared decision-making for individual healthcare decisions (micro-level). PPI can strengthen public trust in and acceptance of health-policy decisions by increasing transparency and promoting accountability to those who are being served by the healthcare system. If deliberate steps are taken to engage with underrepresented populations, PPI can be a means of reducing disparities and challenging power imbalances. Internationally, the World Health Organization's Global Patient Safety Action Plan 2021–2030 emphasizes the role of patients and families as partners in safe care.

2.2 A recognized need for greater PPI in Swiss healthcare

The Swiss Federal Quality Commission (FQC) promotes PPI to foster a more patient-centered healthcare system. This initiative aligns with multiple national reports and initiatives. In their 2019 report *Enhancing the Quality and Safety of Swiss Healthcare*, Vincent and Staines propose to “strengthen the involvement of patients and caregivers as partners.” The 2022 update of *Quality development in health insurance*, which outlines the quality strategy in healthcare of the federal council, promotes patient-centricity as one of five areas for action. The Federal Council's strategies *Health2030* and *Strategy on the Control of Non-Communicable Diseases, 2017–2024* explicitly place patients and the public at the center of healthcare initiatives. The changes proposed (empowering patients, greater coordination between services, greater access to information) all underscore the importance of involving those affected in the development of strategies and action plans from the outset. Other national reports go in the same direction, including the publication *Involving patients and relatives* (SAMS 2016), the agenda for nursing research in Switzerland 2019-2029 (Swiss Association for Nursing Science VFP/APSI 2019 and 2023), and the work plan for involving consumer and patient organisations (Swissmedic 2021).

These concerted efforts reflect a national commitment to integrating patient and public perspectives into healthcare decision-making, thereby enhancing the quality and responsiveness of health systems.

2.3 Why this report?

The objectives of and what constitutes PPI vary widely. This heterogeneity makes it difficult for decision-makers in healthcare institutions to know where to start. Many more publications and guides describe PPI in research than in the governance of healthcare institutions and the institutions that oversee healthcare (i.e. authorities and payors). PPI is not as widespread in Switzerland as several other countries. Swiss decision makers could benefit from lessons learned in other health systems to implement PPI as efficiently and meaningfully as possible..

This report provides an overview of PPI in the decision-making processes of healthcare institutions using international examples, with an emphasis on practical examples in institutions that have made PPI systematic and sustainable. This was done from the perspective of an interdisciplinary team based in Switzerland.

The report is the first part of a 3-part mandate from the FQC of the Federal Department of Home Affairs (FDHA) to produce practical recommendations that encourage systematic PPI in decision-making processes of healthcare institutions. It is part of the larger vision of the FQC that PPI is an essential part of improving the quality of healthcare in Switzerland.

2.4 Key research questions

1. What practical examples exist of PPI in the decision-making processes of healthcare institutions? What types of decision-making processes? In what types of healthcare institutions?

2. What are the learnings from the experiences described with PPI in decision-making processes of healthcare institutions? What are the contextual factors that influence successful involvement?

3. Methodology

3.1 Study design, patient and public involvement and advisory board

We performed an environmental scan with a literature review and interviews with key stakeholders. We worked with two patient partners (JBB and CB). Both were involved in conceptualizing the study and preparing the report. JBB also contributed to the literature search (screening of abstracts and titles) and the interviews (drafting the interview guide, performing interviews), and data analysis. Further, our preliminary results and conclusions were discussed with an advisory board with 4 Swiss health professionals and 3 other patient partners.

3.2 Operational definitions

We defined healthcare institutions as groups of individuals who provide and organize care, create the legal framework, or reimburse healthcare. Based on the Montreal model (Pomey et al. 17-61) and similar frameworks (Carman et al.), we focus on two levels of PPI, meso and macro, and not the micro level. We use the following definitions:

- **Micro**: Involvement of patients and members of the public in decisions about their own healthcare (ex: shared decision-making).
- **Meso**: Providers of care, as defined by Article 34 of the LAMal (federal law on basic health insurance): hospitals, clinics, care homes, homecare, etc.
- **Macro**: Authorities or associations (office of public health, commissioners, insurance companies)
- **Macro**: Governments (i.e. elected officials and government commissions).

We did not address PPI activities from disease specific organizations (ex: cancer leagues) or professional organizations (ex: medical associations), unless these organizations provide or oversee routine healthcare.

PPI was defined based on the Montreal model to include the levels of consultation, involvement, and partnership/co-construction (Pomey et al.). We did not include studies where patients and the public were only provided with information. We did not include reviews containing only studies of individual-level decision-making (i.e. shared decision-making). We did not include examples of research projects or one-time quality improvement projects.

With regards to decisional processes in organizations, we recognize the following domains:

- Mission, vision, and strategy
- Budgeting
- Hiring / Choice of leadership
- Governance and structure

We considered the impact, costs, and implications of PPI at all of these levels.

3.3 Literature search

A research librarian helped design our search strategy. We searched in Medline, Embase, CINAHL EBSCO, Web of Science, Business Source Premier and Google Scholar from the year 2000 to December 6th, 2024. The core concepts were:

- Patient and public participation, including communities, caregivers and consumers, AND
- Decision making, including policy making and governance, AND
- Healthcare institutions, including organizations, insurers and facilities

After an initial search generated approximately 20,000 titles, we chose to add the following:

- AND Literature review, including systematic and scoping reviews and metaanalysis

The final search strategy is included in appendix 1. In addition, we manually screened references of included articles for reports and websites about PPI. We thus performed a review of reviews, acknowledging this limited our ability to capture more recent publications. We also included reviews that cited or were cited by these articles.

Titles and abstracts were uploaded to the software EPPI-Reviewer (EPPI Centre, London), which contains a machine-learning classifier that prioritizes certain titles and abstracts for review based on decisions made to date. One author reviewed each title and abstract until we were no longer finding relevant articles. Any uncertainties were resolved by discussion between 2 to 4 co-reviewers. Full texts were then reviewed by at least 2 reviewers. At this step, we included articles that were reviews or collections that compiled actual experiences and case studies of PPI in governance or decision-making processes

We excluded articles that were:

1. Conceptual frameworks or editorials
2. Focused on PPI for one-time projects, research, or teaching
3. Focused on institutions which lobby or inform healthcare institutions, such as cancer leagues or professional organizations.

We then extracted information from each review about the review methodology, type of healthcare institution. We did not formally evaluate the quality of the articles. Finally, we synthesized key conclusions across the included articles.

3.4 Interviews

We conducted 1.5-hour interviews with 9 healthcare experts from 5 countries. These experts were chosen because they are involved in the governance of healthcare institutions which represent positive examples of PPI in decision processes. We used convenience sampling targeting a variety of roles such as administrators, patient partners, researchers affiliated with hospitals, and leaders of patient organizations.

We prepared a semi-structured interview guide with sections for context and current practices, learnings and impact, and challenges and recommendations (the guide is included appendix 1). All interviews were conducted with the video-conferencing software Webex. We recorded interviews and took notes and based our synthesis on these sources (interviews were not transcribed). We then synthesized content by country, completing with relevant articles, institutional reports and websites that were mentioned by the informants.

4. Results

4.1 Review of reviews

We included a total of 44 reviews, which referenced approximately 2300 individual articles. A detailed table with all extracted information from the reviews is in the 2nd appendix. The reviews were published between 2002 and 2024, and the period covered by the included articles ranged from 1966 to 2023. Geographically, the studies were conducted in diverse settings, with a notable concentration in high-income countries such as the United Kingdom, Canada, the United States, Australia, and several European countries, while a smaller number of studies examined PPI in low- and middle-income countries. Moreover, 13 articles explicitly involved patients in the review process.

Some articles focused on decision-making at a single level of organizations, while others addressed multiple levels. Specifically, 18 articles discussed PPI within meso-level healthcare institutions, such as hospitals and organizations involved in the development and planning of healthcare services, while 27 articles examined PPI at the level of healthcare authorities, including health technology assessment (HTA) bodies and governance units. Notably, none of the reviewed articles addressed the role of insurers in PPI. Most studies referenced the general population, encompassing patients and consumers, while 12 articles specifically considered the involvement of populations with special needs, such as adolescents, older adults or vulnerable populations. Some articles also explored broader subjects related to PPI without focusing on specific institutional settings.

4.2 Content analysis of articles

The content analysis yielded the overarching themes of Implementing PPI, How to Do PPI, and the Effect of PPI.

4.2.1 Implementing PPI

Involvement at different organisational levels: We found examples of PPI at all levels—micro, meso, and macro—with varying degrees of involvement, from consultation to co-production. These levels correspond to individual patient care (micro), healthcare organization management and quality improvement (meso), and policy and governance (macro). Some included reviews included descriptions of individual patient care, though that was not a focus of our review. While involvement was found across all levels, many studies reported low or consultative involvement, which often lacked meaningful influence.

Barriers and enablers: Barriers to effective PPI were reported in eight articles and spanned multiple contexts, including organizational, political, community, ethical/legal, logistical, structural, and decision-making. Common barriers included power imbalances, limited resources, misaligned timelines, and late or hurried inclusion of patients in the decision-making processes. Additional challenges involved difficulties in recruiting and maintaining diverse participants, issues with data privacy, and inadequate resources for community engagement. In contrast, enablers of PPI included efforts to address these barriers. Successful strategies involved commitment to power-sharing, early involvement, fostering trust between patients and healthcare professionals and reflexive practices to improve group dynamics. Other enablers included clear communication, transparency regarding objectives, possible impact and roles, sufficient time for participation, and collaboration with local patient organizations to ensure inclusivity and accessibility. These factors were found to be essential for creating a supportive environment in which PPI can thrive.

4.2.2 Best practices of PPI

Recommendations and best practices: In terms of improving the effectiveness of PPI, a number of recommendations and best practices were highlighted. These included the development of a clear and well-defined institutional strategy for PPI, with preconditions such as adequate time, resources, and training. Continuous support and coaching for both patients and staff involved in processes with PPI was also emphasized, along with predefined evaluation and feedback mechanisms to assess PPI in practice. Ensuring sufficient resources and funding for PPI activities was critical for their sustainability, as was the integration of patient partners into implementation oversight. Respecting diverse contributions was also identified as important in fostering meaningful involvement.

Best practices for PPI focused on in-person and collective deliberation methods, which were found to be more effective than remote methods in encouraging authentic participation. Engaging credible community leaders, adopting standardized measurement tools for evaluation, and involving patients early in service planning were also identified as successful practices. In particular, integrating PPI from the outset of healthcare decision-making ensures that patient and public voices can shape healthcare processes meaningfully.

Special considerations for different groups: Special considerations for specific groups were emphasized in several articles, highlighting the need for culturally sensitive approaches and inclusive strategies to engage young people, older adults, minority and disability groups as well as individuals with specific diseases. These groups require tailored approaches to ensure their voices are heard and considered in healthcare decisions.

4.2.3 The Effect of PPI

Impact and evaluation: According to literature reviews, PPI enhances healthcare quality, reduces costs, and strengthens trust in healthcare institutions. Its impact spans the healthcare system, providers, patients, and society, making care more efficient, inclusive, and responsive. In various settings, PPI has improved patient-provider communication and service quality. It has increased patient trust. and contributed to shorter hospital stays, fewer adverse events, and reduced malpractice claims. Additionally, organizations adopting patient-centered approaches report better employee retention and lower operating costs.

Several literature reviews highlight the empowering effects of PPI on patients, emphasizing improvements in health literacy, confidence, and self-efficacy. Engaged patients better understand their conditions, treatment options, and self-care responsibilities, leading to improved adherence to medical recommendations. Research also suggests that PPI contributes to enhanced psychological well-being, as patients feel more in control of their healthcare decisions.

PPI may improve healthcare efficiency and cost-effectiveness. Studies show that engaged patients often choose more conservative treatments, reducing unnecessary interventions. As described in a case-study (van Leersum et al.), a patient-centered hospital reorganization achieved a 16% cost reduction within three years, alongside an increase in patient recommendation and a decrease in the hospital-specific mortality rate. This underscores how PPI can enhance both healthcare outcomes and financial sustainability.

The lack of standardized measures and methods to evaluate the effectiveness of PPI was a major gap in the literature. The absence of clear evaluation metrics has made it difficult to assess the impact of PPI on healthcare decision-making. Another key challenge was the inconsistent use of terminology, as studies used a wide range of terms for PPI and its mechanisms, leading to ambiguity in definitions and implementation.

Costs and risks: The costs of PPI were underreported, with only one article discussing direct monetary costs and non-monetary burdens such as time and effort. Similarly, few studies discussed the risks of PPI, but two articles highlighted concerns that PPI could sometimes replace rigorous evaluation, serve as a tool for legitimization rather than meaningful involvement, impose emotional burdens (particularly on parents), create fatigue, or reinforce power imbalances.

Patient experience: The psychological and emotional experiences of participants in PPI were largely unexamined. A few studies noted feelings of tokenism and frustration among participants, particularly when their involvement was not impactful or meaningful. Only, one article directly addressed the emotional experience of participants during meetings.

4.3 Interviews

Nine individuals were contacted for interviews, all of whom accepted. Five worked primarily with macro-level and three primarily with meso-level institutions, though almost all worked across different institutions. Two identified as patient partners, while a third had a significant lived experience of illness but was not hired as a patient partner. Full details of the country profiles are in appendix 3, with additional cases for Austria and the United Kingdom based on the study of websites and reports.

Table 1: Profile of people who completed interviews

Country	Institution / Organisation	Interviewee	Role
FRANCE	AP-HP (Public hospitals of Paris)	Marion LANLY	Service leader for quality, Patient Partnership & Experience
	French Prime Minister's services	Alexandre BERKESSE	Former Co-director at CEPPP and University Hospital of Montreal (CHUM) Program director - Citizen's training and mobilization
CANADA	French Prime Minister's services	Alexandre BERKESSE	Former Co-director at CEPPP and University Hospital of Montreal (CHUM) Program director - Citizen's training and mobilization
	Unité de Soutien SSA Québec & University Hospital of Sherbrooke	Catherine WILHELMY	Patient partner, co-Director Unit for learning health system of Québec
	University of Montreal	Marie Pascale POMEY	Researcher
	CEPPP / CHUV	Mathieu JACKSON	Patient partner, Doctoral fellow
DENMARK	Danish Patient Organization & ViBIS	Annette WANDEL	Vice Director
THE NETHERLANDS	Erasmus School of Health Policy & Management	Hester VAN DE BOVENKAMP	Professor of Patient Sciences
	St. Antonius Ziekenhuis	Jet WESTERINK	PhD candidate 'Patient participation in Value-Based Health Care'
GERMANY	Gemeinsamer Bundesausschuss, G-BA	Sabine HAFNER	co-lead Staff Unit for Patient Representation (Stabsstelle Patientenbeteiligung) of the Federal Joint Committee (Gemeinsamer Bundesausschuss, G-BA)

4.3.1 Overview of the country vignettes

Table 2: Synthesis of interview content by country, completed with relevant literature.

Country	System analysis	Learnings and challenges	Recommendations
FRANCE	Centralized legal framework helps create structures, but also bottlenecks. Local implementation varies.	- Patient partners do not have a legally recognized title and therefore need to prove their legitimacy. Almost all patient partners work on a voluntary basis unless they have another title - Lack of coordination between competency centres that can create heterogeneous implementation - Lack of diversity of patient partners to ensure proper representativeness nationally	- Take into consideration the legal context - Change and create a proper legal status for patient partners - Find inspirational leaders, (e.g a duo of a patient partner and a scientific representative)
CANADA	Organic, bottom-up development of PPI fueled by regional, project-based experiences.	- Gap between practices in research and in healthcare institutions: the status of patient partners in institutions is less clear and often on a voluntary basis - The implementation of PPI is variable - A variety of PPI profiles are needed - Lack of resources to implement PPI in primary and long-term care. And budgets are short-term and precarious - The success of PPI is still person-dependent	- Harmonize PPI processes across the country - Build a PPI community based on skills identified from clinicians and patients - Share a common political and ethical vision
DENMARK	A strong national voice for PPI: Long experience, with a renewed focus on the quality of PPI in daily practice	- Well established in Denmark and the Danish health law has been instrumental - Risk of tokenism or pseudo participation is omnipresent - the recruitment of patient partners with lived experiences is a challenge - A new digital platform to connect patient partners and facilitate learning is in the making - Evaluating the impact of PPI is difficult	- Legislation is key but not sufficient - Have PPI in the education curriculum - Create a national platform to get knowledge and support - Unify voices under one Patient Organisation
THE NETHER-LANDS	Mandatory client councils in all healthcare institutions and patient associations as the third voice in collective	- PPI is well established in the Netherlands - Widespread at both the meso and macro levels, through well-established associations - Ambiguous status of patient partners - The evaluation of PPI is quite weak - Challenges to ensure a diversity of voices (as of today, most involvement comes from	- Set robust processes for PPI to ensure sustainability and high quality - Train patient partners, especially in roles requiring more leadership and technical knowledge

	healthcare decision-making	people with higher socioeconomic status)	
GERMANY	Twenty years of impact on national reimbursement decisions through patient recommendations at the Federal Joint Committee (G-BA)	- Patient representatives need high-level professional competencies, which can distance them from the lived experience of patients - Patient representatives give their opinion, but do not vote. This creates ambiguity, but protects them from the political responsibility of decisions - Recruitment and lack of diversity of patient representatives are major challenges - Decision processes of the G-BA are long, complex, political and at times tough for patient representatives	- Promote collaboration and a more inclusive culture - Prepare and focus for collaboration - Aim to reach a consensus

4.3.2 Detailed presentation of PPI implementation by each country

A series of text boxes presents different approaches to PPI in decision making, each with their own peculiar settings with its advantages and disadvantages.

German legislation places PPI at the highest level of governance, the reimbursement negotiations are indeed between healthcare providers and insurers.

Box 1: German example of legislation for PPI in policymaking. The Gemeinsame Bundesausschuss (G-BA) is the primary decision-making body in Germany's healthcare system, managing service coverage under statutory health insurance for ~74 million citizens. Comprising 13 members, including impartial stakeholders, health insurers, and healthcare providers, the G-BA oversees which treatments and medications are reimbursed. **Patient representatives have been involved since its creation in 2004, with their role and financing (from health insurance companies) defined by federal law.** The ~300 patient representatives are supported by the Staff Unit for Patient Representation. Currently, four umbrella organizations, representing about 150 patient organizations, are recognized and able to contribute patient partners. Patient representatives can propose investigations but do not have voting rights in the G-BA's main negotiations.

In France, competency-and capacity building are part of the French centralised system, institutional and regional PPI training programs are universally available for both patient partners and healthcare professionals.

Box 2: French example of building capacity through national laws and widespread offering of training in PPIT France has a long history of patient partnership, with key milestones including the 2002 Kouchner law on health citizenship, the 2009 hospital reform law strengthening patient rights, and the 2016 healthcare reform promoting shared care pathways. A 2019 law recognized patients as contributors to medical education, while the Haute Autorité de Santé (HAS) issued recommendations in 2020 and 2023. Recent reports by the Académie Nationale de Médecine and the Conseil National de l'Ordre des Médecins highlight **patient partnership in research, education, clinical medicine, and governance.**

The lived experience provides legitimacy in the Canadian example, though the implementation can be heterogeneous and more dependent on first-class patient partners

Box 3: Canadian example of prioritizing patients' experiential knowledge. PPI in Québec has grown from the involvement of patient partners in specific initiatives, often funded as research projects or quality improvement initiatives. After 15 years, most provinces now engage in PPI in governance through consultations and advisory councils. Funding bodies for healthcare research and quality improvement require PPI in all projects. **The focus of PPI has been on mobilizing the lived experience, most often with survivors of severe illnesses (i.e. cancer) or people living with chronic diseases.** Patient partners have legitimacy more because of their lived experience than their training or ability to develop policy or maintain an association. A 2018 publication from the Québec government, *Reference Framework for Users' Committees and In-*

Unlike Canada, in Denmark, the patient voice is professionalized based on a variety of skills, and the lived experience is not necessarily needed. Representativeness and the bureaucratic burden may diminish the quality of the deliverables.

Box 4: Danish example of a professional patient voice. In Denmark, the umbrella organization Danish Patients (DP) plays a crucial role in representing the interests of patients and their relatives. It represents nearly 1 million members through 23 smaller patient associations, advocating for patient rights and interests at national and regional levels. DP focuses on a holistic view of patient care, engaging in lobbying, policy development, research, and evaluations. With an annual budget of approximately 2 million CHF sourced equally from the national budget, member contributions, and contract research, DP's governance includes an elected board and a dedicated secretariat. DP's activities include lobbying, policy formulation, knowledge generation and dissemination, contract research, and evaluations. The organization also provides coaching and support to other organizations and projects. **DP's expertise is rooted in its diverse team of employees, who bring backgrounds in administration, business, communication, lobbying, coaching, research, evaluation, and teaching. Notably, DP does not focus on employing patients with lived experience, unless that is needed in specific instances.** It recommends remunerating patient partners for their expenses and time, although this recommendation is not yet universally adopted by healthcare organizations. Key challenges of this approach include the ongoing recruitment of patients with a lived experience, and representativeness and avoiding too much emphasis on bureaucracy that can diminish the quality of the deliverables.

The Dutch example, or the neo-corporatist approach, emphasizes consensus and cooperation. Evaluating the impact of patient participation, however, remains weak.

Box 5: The Dutch healthcare system has a strong tradition of patient participation, initiated by the 1996 Participation of Clients in Healthcare Institutions Act (Wmcz), which established client councils in healthcare institutions. The 2018 revision enhanced users' rights, allowing them to meet management, request investigations, and provide consent. **Organized into regional and national umbrella organizations, hundreds of patient associations represent patients at various societal levels, engaging regularly in collective healthcare decision-making.**

Characterized by a neo-corporatist approach, the Dutch model emphasizes consensus and cooperation among stakeholders, often referred to as the "polder model." Funding for disease-specific associations comes from member contributions, government support, and, to a lesser extent, the pharmaceutical industry. While many national association representatives are paid, local and regional council members generally volunteer.

Challenges include recruiting diverse patient partners and clarifying their status, as most work without formal contracts. Evaluation of patient participation impact remains weak, making it difficult to assess effectiveness. Despite this, many examples demonstrate how patient input improves healthcare decisions.

To enhance PPI, it is essential to invite and listen to patients, publicly share successful applications, and foster a culture of respect and openness. Training patient partners, particularly in leadership roles, will help formalize their contributions and improve healthcare responsiveness.

Two further country vignettes were developed based on documentation alone, without interviews. A study of government reports and websites from Austria showed that they are at a similar stage as Switzerland.

Box 6: The Austrian government is interested in PPI, but practice and regulation remain limited. A 2023 feasibility study by Gesundheitsförderung Austria and Gesundheit Österreich, funded by the Federal Ministry of Social Affairs, Health, Care, and Consumer Protection identified 146 examples of citizen participation, with only 70 in healthcare, highlighting the need for a more structured approach. Participation in the examples involves engaging diverse groups in decision-making, ensuring social inclusion, and expanding perspectives. However, clear objectives, transparent decision-making processes, and adequate support (financial resources, networking, and training) are necessary. Participation promotes health equity, but reaching marginalized groups remains challenging. **To improve participation at scale, the authors recommend establishing three structures: a Competence and Coordination Office for Participation, a participation process portal, and a civil society forum.** To institutionalize participation, Austria should develop a structured framework within the 2024–2028 Preventive Measures Strategy. A comprehensive approach must clarify representation, decision-making topics, necessary processes, and effective support mechanisms to enhance patient-centered care and equity.

The United Kingdom’s National Health Services (NHS) have a strong tradition of PPI, which remains central despite repeated reforms and systemic problems.

Box 7: England has implemented a solid legal and practical anchoring of PPI at crucial decision points of the NHS during repeated re-organizations. The UK has been a leader in PPI research, contributing significantly to scientific literature in this area. This leadership is reflected in its National Health Services (NHS). A core component of NHS organization is service commissioning, managed by statutory entities responsible for planning, budgeting and delivering healthcare locally. Over time, different models have been used: Primary Care Trusts (pre-2013), Clinical Commissioning Groups (2013–2022), and currently, Integrated Care Systems (ICSs). The National Health Service Act 2006 (amended in 2022) legally mandates public involvement in commissioning. **Section 13Q requires that patients, carers, and representatives be engaged in service planning, decision-making, and major changes to care provision.** This ensures transparency and accountability in shaping NHS services.

Detailed guidance outlines how patient involvement should be implemented, and regular evaluations assess the effectiveness of these efforts. The impact of the upcoming 2025 NHS reforms on PPI remains uncertain, but public participation is expected to remain a key principle in UK healthcare governance.

5. Conclusions

We found evidence of widespread and longstanding PPI in countries with healthcare systems that share varying degrees of similarities with Switzerland. PPI can impact decision making in nearly all domains and all levels. Drivers for implementation, organizational needs, benefits and risks are well-established. PPI is generally considered beneficial, though few reports have attempted to quantify that benefit or its impact on costs.

Based on our environmental scan, we propose the following main conclusions about requirements for the implementation of PPI in the decision-making process of healthcare institutions:

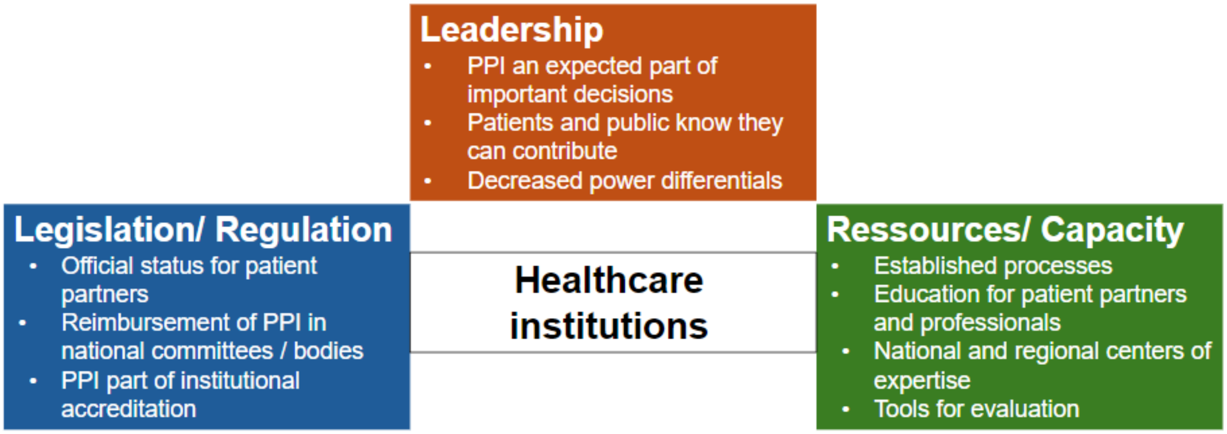
1. Long-term commitment to meaningful involvement by politicians, policymakers, professionals and civil society.
2. Each context requires its own implementation strategy (from meso to macro level), with flexibility according to objectives, context and process.
3. Fair and inclusive processes supported by resources and training opportunities.

5.1 Long-term commitment to implementation

PPI implementation, particularly at a national level, is a gradual process requiring long-term commitment, dedicated funding, and supportive legal frameworks to ensure sustainability. When PPI is too focused on individual projects, it suffers from a short-term vision and instability. If it depends too much on a limited number of individuals, the departure of those individuals can put years of implementation into peril. Interviewees from the province of Québec, Canada, underlined how their reliance on project funding and pioneers has contributed to chronic instability, heterogeneity in the implementation of PPI and frustration among patient partners.

Politicians and policymakers can use several mechanisms to facilitate the implementation of PPI in the decision-making processes (Figure 1). Legislation or regulations are a powerful means, but they take time. For instance, France, the Netherlands, Canada and the UK have laws that oblige healthcare institutions including hospitals and nursing homes to establish client / user councils. These councils are involved in governance processes spanning from managing user complaints to giving input on strategic priorities. The role of these councils is generally consultative according to the involvement degrees of the Montreal model. German legislation places PPI at the highest level of governance, the reimbursement negotiations between healthcare providers and insurers (Box 1). Another related normative approach is embedding PPI requirements into hospital accreditation, as done in Canada and the Netherlands. For instance, patient partners participate in the auditing of healthcare institutions by Accreditation Canada.

Figure 1: Mechanisms facilitating the implementation of PPI in healthcare institutions



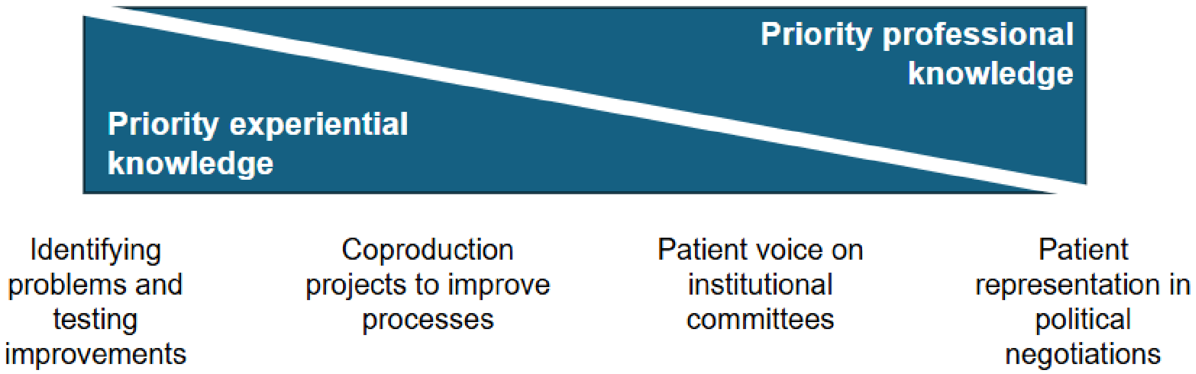
Strong leadership from both healthcare professionals and patient partners is key for integrating PPI in routine governance. The interviews show that widespread adoption of PPI requires a change of culture. Convincing opinion leaders of the added value of PPI can accelerate implementation. In Canada, healthcare leaders have formed personal relationships with leading patient partners, thus decreasing power differentials and modeling broader implementation. Leadership on the patient side has been instrumental in increasing visibility of PPI and of its potential impact. Many patient associations have been the result of these efforts. For example, experienced patient partners in Québec have created a patient-led association called *Experiences.* It functions as a community of practice that helps less experienced patient partners develop their posture and role.

Implementation of PPI requires resources and access to patient partners. Training opportunities for patient partners–and health professionals who work with them–as well as established standards (see also section 5.3), are another important driver of implementation. In several countries, the knowledge resources are developed and maintained by national competency centers, like Danish patients or INVOLV in the Netherlands. Larger institutions, such as hospitals or hospital groups, also invest in support units for PPI, some of them in cooperation with universities, like the Centre of Excellence on Partnership with Patients (CEPPP) in Montreal, Canada, and the Public or the Department for patient experience of the Public Hospitals of Paris (AP-HP). The CEPPP is attached to the University of Montreal and its hospital. It is co-lead by patient partners and researchers who are among academic world leaders in the field of PPI. In France, institutional and regional training programs are universally available for patient partners and healthcare professionals alike (Box 2).

5.2 Multi-level involvement with varied objectives

PPI occurs at different levels of healthcare decision-making, from local operational improvement projects to policy formulation. The tasks and contributions of patient partners across these levels of engagement are widely different. In a local quality improvement project in a hospital unit, for instance, the lived experience with this service is a crucial contribution. In national Health Technology Assessments (HTA), representativity of a broad range of interests and negotiation skills are priorities (Figure 2).

Figure 2: Different patient partner profiles needed based on level of PPI intervention



For example, initiatives to improve the patient experience in Dutch hospital departments always include patients who are cared for by that department, beginning with identifying problems (consultation), to eventually co-designing improvements. Local clinicians often initiate these processes by inviting patients of the service. Patients are generally not remunerated for this kind of work. Confusion about the roles of patient partners creates a lot of debate as mentioned in the country interviews. So, clarifying the differentiation of PPI across the spectrum of tasks is a crucial element of best practice standards (Boxes 3 and 4).

It must be noted that flexibility in defining roles and tasks is not contradictory to the respect and application of best practices (See 5.3). For example, a transparent engagement strategy should always be defined and communicated during the recruitment of patient partners. Further, healthcare professionals should acknowledge that patient partners often bring knowledge not just from a single disease or department, but from their community and their experience navigating complex healthcare systems (Dumez and L'Espérance). Finally, as patient partners gain professional knowledge, either through training programs or by repeated participation in initiatives, they gain specific professional knowledge. This professionalization should be recognized, both in status and remuneration (see Boxes 3-4).

Patient partners should be acknowledged for their growing expertise but also receive appropriate recognition in terms of status (being regarded as equal contributors in decision-making) and remuneration (e.g. fair compensation for their time and expertise). As patient partners reach a certain level of expertise they should be treated as skilled contributors deserving of professional respect and access to fair pay/compensation (see 6.1).

5.3 Fair and inclusive processes

A recurrent, clear message from the review articles is that successful PPI must be based on transparent, fair and inclusive processes. A clear and structured approach ensures that patient partners have a genuine role in decision making rather than being included symbolically. These learnings should inform the implementation of PPI in Switzerland. A few of the systematic reviews are particularly relevant and should be highlighted.

For instance, at the health system level, a systematic review of 23 studies identified key context factors associated with a higher likelihood of policy impact from a PPI intervention (Baumann and Reinhold). These include strong commitment from decision-makers, a partnership-based decision-making process, and early involvement of stakeholders in shaping the agenda. Transparency about how input will be used is essential, along with mechanisms to ensure that recommendations are translated into practice.

For quality improvement initiatives, it is particularly important to have *active* patient involvement (Carolina et al.) given the variable effectiveness of different engagement strategies. A systematic review of 48 studies identified key techniques to enhance patients’ input, such as allowing patients to influence the agenda, ensuring they participate at multiple stages with flexibility in the levels and approaches of involvement, and building in reward mechanisms such as feedback and evaluation (Bombard et al.). Creating a receptive context through democratic dialogue, external facilitation, and training is also critical. Leadership actions play a vital role, with actions such as involving decision-makers early, ensuring engagement occurs before decisions are finalized, and maintaining ongoing patient participation. However, the study also warns against tokenistic involvement, where patients feel their contributions are disregarded. These studies collectively highlight that successful PPI initiatives require careful planning, strong commitment from decision-makers, and a genuine willingness to integrate patient perspectives into decision-making.

How to promote this type of PPI? It is helpful to return to Figure 1 and the available means of providing resources and building capacity. The Danish Patients organization invests heavily in coaching its committee members. In France, training programs reinforce patient competencies and prepare professionals. In Canada, a university-based center of excellence has developed a series of online courses.

5.4 Strengths and limitations of this environmental scan

Strengths of this environmental scan include our broad search criteria, the inclusion of multiple source types (publications, grey literature, and interviews) and the narrative country profiles. Limitations include the fact that we did a review of reviews, rather than of individual PPI experiences. We likely lose some of the details important to individual successful initiatives. We are also limited by the content of the literature we identified and synthesized, making it difficult to quantify the precise impact of PPI. Indeed, formal evaluation is not yet the norm, especially not at a national level that would allow us to compare between countries.

6. Key questions for Work package 2

6.1 Current status in Switzerland

It is helpful to reflect on progress in Switzerland to date on these three axes, notably commitment to PPI implementation, multi-level involvement, and the dissemination of fair, transparent and inclusive processes.

PPI in Swiss healthcare institutions has mostly been carried out by ‘pioneer’ individuals and institutions, without legislation or regulations. The decentralized nature of the healthcare system makes culture change slow and limits the impact of individual leaders. Though PPI is not yet an expectation or the norm, many people recognize that a slow culture change is happening. The FQC is building capacity for PPI with their project aiming to create an online, national platform for

PPI matchmaking and information (Cahier des charges - Plateforme visant à favoriser l'implication des patients, des proches et du public dans le système de santé.pdf). This project, led by the Swiss Patient Organization, should be completed in 2028.

In terms of multi-level involvement, there is not yet a legitimate, dependable patient voice in federal and cantonal government decisions about healthcare. The Swiss patient organization (SPO) has historically primarily focused on helping patients voice complaints or know their rights. That is changing, however, with their new patient council and desire to be a voice in politics (Über uns :: SPO Patientenorganisation). A recent FQC mandate sought the perspective of 20 Swiss patient organisations on how to improve the quality of Swiss healthcare (Pflichtenheft Auswahlverfahren bei der Übertragung von Aufgaben mit Abgeltung nach Art. 77d der Verordnung über die Krankenver). The preliminary report underlines that patients and patient organisations are increasingly consulted for healthcare decision making, but rarely involved at the levels of collaboration or partnership. The patient organizations themselves propose the creation of a national umbrella organization for joint representation.

The best example of multi-level involvement in one healthcare organization is probably the 3P+P (patients, public, caregivers + providers) program of the Geneva university hospital (HUG). This program meets with recent patients potentially interested in PPI, defines their objectives, and links them with committees or institutional projects needing input (Plateforme du programme Patients partenaires + 3P - HUG).

For the fair and inclusive processes, the Swiss Clinical Trial Organization (SCTO) has taken a leading role in research, with the publication of guidance documents and a repertoire of relevant projects (Patient and Public Involvement (PPI) - scto). Further, the SCTO partnered with the University of Basel and EUPATI Switzerland to create an in-depth, multi-day training program in German for patient partners (Patient and Public Involvement (PPI) | Department of Clinical Research | University of Basel). A similar program at the HUG contributes to establishing best practices (Réseau partenariat en recherche clinique). An online platform from Unisanté gives similar information in a simplified format (www.forces-sante.ch). Furthermore, the first national PPI symposium took place in late 2024 and efforts are now underway to create a Swiss PPIE (Patient and public involvement and engagement) network to encourage the sharing of ideas and successes between institutions in Switzerland (19) Swiss PPIE network | Gruppen | LinkedIn).

6.2 Key questions for WP 2

While preparing our conclusions, key questions emerged that will need to be addressed during our second work package.

- *To what extent does the culture in Swiss healthcare institutions today enable the involvement of patients and the public in decision-making processes? What resources are already available to support PPI in these decision-making processes?*

Several international stakeholders underlined that PPI has become an expected part of decision-making in their institutions. They would feel uncomfortable if an important committee at a hospital did not include patient partners or if patient organizations were not represented in key negotiations. This culture change is important for making PPI a routine contribution to important decisions. Anecdotally, readiness and willingness to adopt PPI remain uneven across Swiss institutions. Key barriers include a lack of awareness about the value of PPI, uncertainty about how to implement it meaningfully, and limited funding. Some early adopters of PPI in decision-making processes have likely developed resources for implementation and standards for hiring and remuneration. If these resources can be shared or adapted, it may accelerate next steps.

- *Which national, cantonal or municipal laws and regulations are required to strengthen PPI in healthcare decision-making processes?*

A legal foundation for PPI is necessary to formalize the role of patient partners, ensure fair representation, and integrate PPI into healthcare governance and provide the necessary resources. Decision-makers like legislators, authorities and institutions have an important role to play in promoting culture change on patient engagement as an integral part of decision-making and providing the necessary resources.

- *How do stakeholders view the creation of a national representative body for patients?*

Inspired by the Danish and Dutch models, a national representative body could operate at multiple levels, ensuring legitimacy and stability. A national umbrella organization representing patients can coordinate efforts, advocate for patient involvement, and provide structured input into healthcare decision-making. As mentioned above, Swiss patient organizations expressed interest in such a structure during a recent FQC project. Public funding may be needed, at least in part, to ensure its independence. It is unclear whether existing organizations (Swiss patient organization and Pro Senectute) have the legitimacy to fulfil this mandate, or should contribute to a new organization.

- *What do leaders of meso- and macro-level institutions need to implement PPI in their decision-making processes? What are possible mechanisms for sustainable funding?*

In interviews, leaders of institutions that had successfully implemented PPI in their decision-making processes had dedicated staff, access to materials, and funding. Such resources are needed to coordinate, support, and remunerate patient partners, to support healthcare professionals and to promote fair and inclusive processes. In some countries, these costs have primarily been covered by external or internal funding linked to projects and initiatives, as is the norm in research. Some resources are provided by patient organizations, who then receive government subsidies to assure stability and independence from industry or single institutions. Combined funding models of membership contributions, consulting and public funding are available. German legislation mandates that the cost of the G-BA including PPI is covered via the contributions of the insured and employers.

- *How can leaders and institutions build PPI competencies and capacity among healthcare professionals and patient partners?*

A national digital platform is being developed by the Swiss patient organization to facilitate the recruitment of patient partners and diffuse best practices. A national association may soon be formed to support patient partners and share best practices. Local initiatives, usually linked to universities, have developed training modules and consulting services. What other resources healthcare institutions need to support their PPI initiatives? Also important, how can we ensure fair compensation and long-term engagement of patient partners?

A key component of sustainable PPI is a common understanding and recognition of the patient partner role or job title. Despite decades of PPI experience, patient partners abroad often use other job titles such as consultant, research fellows etc. A clear title is important for recognition, training, professional development and remuneration. Given that some patient partners choose not to be paid or cannot be paid, this title should not just be for paying salaries. Instead, it should facilitate team composition and the creation of leadership opportunities.

References

Baumann, Lisa Ann, and Anna Katharina Reinhold. "Public and patient involvement in health policy decision-making on the health system level – A scoping review." *Health Policy*, October 2022, pp. 1023-1038, https://www.sciencedirect.com/science/article/pii/S0168851022001919.

Bombard, Yvonne, et al. "Engaging patients to improve quality of care: a systematic review." *Implementation Science*, July 2018, p. 98, https://implementationscience.biomedcentral.com/articles/10.1186/s13012-018-0784-z.

Carman, Kristin, et al. "Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies." *Health Affairs*, 1 Feb 2013, https://www.healthaffairs.org/doi/10.1377/hlthaff.2012.1133.

Carolina, Bergerum, et al. "How might patient involvement in healthcare quality improvement efforts work-A realist literature review." *Health Expectations*, October 2019, pp. 952-964.

Dumez, Vincent, and Audrey L'Espérance. "Beyond experiential knowledge: a classification of patient knowledge." *Social Theory & Health*, April 2024, https://doi.org/10.1057/s41285-024-00208-3.

Pomey, Marie-Pascale, et al. "Le « montreal Model » : Enjeux du Partenariat Relationnel Entre Patients et Professionnels de la Santé." *Santé Publique*, 2015, https://doi.org/10.3917/spub.150.0041.

Pomey, Marie-Pascale, et al., editors. *Patient Engagement: How Patient-provider Partnerships Transform Healthcare Organizations*. Springer International Publishing, 2019. Accessed 27 March 2025.

van Leersum, Nicoline, et al. "Cure for increasing health care costs: The Bernhoven case as driver of new standards of appropriate care." *Health Policy*, March 2019, pp. 306-311, https://www.sciencedirect.com/science/article/pii/S0168851019300028.

Appendices:

1. Literature search strategy and semi-structured interview guide
2. Literature review extraction table
3. Detailed country vignettes based on interviews and documentation