Research Involvement and Engagement

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The pedagogical liminality of patient and public involvement in initial healthcare professional education: an umbrella review

Olivia Gross[1*] and Yannick Ruelle[1,2]

Abstract

Objectives Patient and public involvement in undergraduate healthcare professional education (PPI-PE) raises questions about its value and the ways it can be implemented, which has been explored by several literature reviews from various angles. This study aimed to take stock of our current knowledge of the foundations and effects of PPI-PE, the structure of programs of this type, their implementation conditions and identify any gaps in the studies conducted so far. The aim was also to identify the questions that run through the studies, pinpoint their foundations and implicit assumptions, and make sense of any discordant elements.

Design Three databases were searched to conduct an umbrella review based on the recommended quality criteria.

Results The 27 reviews included were based on 529 independent articles. The analysis carried out has enabled us to consolidate existing knowledge of stakeholders' motivations, patient recruitment process, the implemented educational initiatives and their impact. Numerous studies agree on the benefits of PPI-PE. In contrast, there are few studies on patient profiles, and the lack of grounding in intervention theories does not help to structure curricula.

Conclusion The results explain the lack of chrono-pedagogical reflection. At this stage, it would be useful to develop realistic evaluations of whose aim is to link effects to contextual elements and the mechanisms that produce them, to optimize actions. Despite the well-documented benefits of PPI-PE, its limited integration suggests a form of pedagogical liminality. This may stem from institutional inertia in medical and nursing education, where entrenched traditions, power dynamics, and the dominance of qualitative research create barriers to change.

Plain English summary

Objectives Many scientific articles are devoted to the implementation of patient and public involvement in the initial training of healthcare professionals (PPI-PE). The aim of this study was to gather the current state of knowledge on the subject. The aim was also to identify the questions that run through the studies, pinpoint their foundations and implicit assumptions, and make sense of any discordant elements.

Design The synthesis was based on existing structured literature reviews.

Results 27 literature reviews covering 529 separate articles were analyzed. The analysis carried out has enabled us to consolidate existing knowledge of stakeholders' motivations, patient recruitment process, the implemented

*Correspondence:
Olivia Gross
olivia.gross@univ-paris13.fr

Full list of author information is available at the end of the article

educational initiatives and their impact. Numerous studies agree on the benefits of PPI-PE to understand patients' perspectives, develop students' empathy and help them to be more respectful of patients' priorities. In contrast, there are few studies on patients' profiles or on the methods needed to obtain the best outcomes.

Conclusion PPI-PE remains under-funded and under-implemented, which cannot be rationally explained, given the well-documented benefits of this approach. Clear political incentives promoting a systematic PPI approach in professional training are needed to overcome the resistances that this matter of fact seem to reveal.

Introduction

Historically, alongside with bed learning in clinical settings, medical education have been book-based to accumulate knowledge. However, this type of learning has proven insufficient to cope with the complexity of situations. It has also been complemented by other pedagogies, such as skills-based approaches and problem-based learning. Regardless of their merits, these pedagogies have not fully transformed students' interpersonal skills, which remain inadequate [1]. It is well-documented that students' empathy declines over the course of their studies and that most pedagogical approaches aimed at addressing this issue – such as exposure to complexity-inadvertently exacerbate it, not to mention the terrible impact of the hidden curriculum on students empathy [2]. Additionally, teaching often fails to address all of the issues that matter to patients, a problem compounded by the perpetuation of certain practices and ideas through generations of caregivers, despite evolving societal contexts and patients' expectations [3]. Consequently, patients' expectations are frequently unmet, leading to dissatisfaction and a reluctance to seek care [4].

To address these limitations, patient and public involvement in undergraduate health professional education (PPI-PE) has been proposed [5]. À la différence des apprentissages au lit des malades, au cours desquels ces derniers n'ont qu'un role passif, PPI-PE takes place in universities et les patients are then involved in teaching as active teachers. Il s'agit de donner à entendre aux étudiants leur voix authentique, plutôt que de se limiter à les représenter via des analyses de cas cliniques, des jeux de rôle ou des simulations.

There is growing interest in this type of teaching, as evidenced by the increasing number of studies conducted over the years. Systematic reviews are prominent in this stream of literature. These literature reviews examine, from various angles, the knowledge acquired about PPI-PE. This study aimed to synthesize these reviews, that is, identify what is known about the foundations and effects of PPI-PE, the structure of such programs, and their implementation conditions, as well as pinpoint any gaps in the existing studies. This study also aimed to identify the issues running through them, reveal their foundations and implicit assumptions, and make sense of discordant elements.

Method

Type of study

An umbrella review was carried out to synthesize a large corpus of data [6]. This review adhered to the quality criteria set out by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [7]. The review protocol was registered on the PROSPERO register of systematic reviews on May 5, 2023 (registration number CRD42023427682).

Terminology

The use of the term "patient" has long been controversial because "the idea of active participation sits poorly with it." [8] However, the results of a recent scoping review showed that the people involved prefer this term over alternatives, such as "consumers of care" or "persons with lived experience." [9] The keywords used to identify reviews were adapted for each database, but this paper uses the term "patient" throughout.

Data extraction

PubMed®, Embase®, and Cinahl® databases were searched until August 27, 2023, and a literature review was conducted until this the time of the writing of this article

Table 1 Search equations for identification in databases

Databases	Equations with keywords	Equations with titles
Medline®	(((patient participation[MeSH Terms]) OR (community participation[MeSH Terms])) AND ((professional education[MeSH Terms]) OR (students[MeSH Terms])))	(((patient*[Title]) OR (consumer*[Title])) AND ((medic*[Title]) OR (health*[Title])) AND ((educ*[Title]) OR (teach*[Title])))
Embase®	('patient participation'/exp OR 'patient participation') AND ('medical education'/exp OR 'medical education' OR 'paramedical education'/exp OR 'paramedical education' OR 'health student'/exp OR 'health student') AND ([english]/lim OR [french]/lim) AND [review]/lim	('patient*':ti OR 'consumer*':ti) AND ('medic*':ti OR 'health*':ti) AND ('educ*':ti OR 'teach*':ti) AND ([english]/lim OR [french]/lim) AND [review]/lim
Cinahl®	MW consumer participation AND (MW students OR MW medical education OR MW health personnel education)	(TI patient* OR TI consumer*) AND (TI medic* OR TI health*) AND (TI educ* OR teach*)

(June 2024). For each of these databases, the search queries were developed by combining criteria related to patient participation and education. Initial queries were developed from the thesauri of each database. As there are no keywords for PPI-PE in these thesauri, a search by title was also conducted. Searches were limited to literature reviews and articles published in French and English. Table 1 presents the full set of search strings used.

Data selection

For an article to be included, it had to have reviewed patient involvement as teachers or members of a teaching team in initial training programs for healthcare professionals, en anglais ou en français, sans limite géographique. Excluded reviews focused exclusively on (1) simulations or standardized patients (because of the difficulty in identifying whether they are real patients or actors playing a role); (2) continuing education; (3) interactions taking place in care settings; and (4) social work. Unstructured reviews, that is, those that do not report the article selection process or list the articles) were also excluded. Article selection was conducted by the authors of this paper. Only articles that met al.l of the criteria were included. In line with PRISMA recommendations, reviews not identified through this selection process but by researchers, were added before the analysis. Lastly, following the methodology suggested for umbrella reviews [6], the authors occasionally revisited the original articles to gather additional information.

Data analysis

To address the questions raised (Table 2), a descriptive analysis was conducted by the authors of this paper to outline the relevant disciplinary field. The themes were organized using the 5W1H framework as follows: why (Q1), who (Q2), where (Q3), when (Q4), what for (Q5), and how (Q6). The content was analyzed inductively. Towle and Goldophin's continuum [10] was used to organize users' actions to assess the depth of their integration (Q4). Program effects (Q5) were categorized using Kirkpatrick's [11] four-level scale (level 1: students' reactions; level 2: students' learning; level 3: resulting behaviors; and level 4: impact on practices and organizations). When specified, the quality of the underlying studies was noted car même si cette mesure ne capture pas nécessairement la qualité globale d'une revue au sens strict [12], elle constitue un moyen de garantir une certaine transparence et de guider l'interprétation des résultats dans un contexte d'hétérogénéité des études. If several reviews mentioned the same result, the authors ensured that this was not based on the same underlying article.

Table 2 Summary of the review questions

Material	Systematic literature reviews
Concept	Patients as colleagues of teachers in the initial training of future healthcare professionals
Research questions	Q1. Why: why is it being implemented? Q2. Who: who are the patients involved (what is their profile) ? Q3. Where: what are they involved in and what do they do? Q4. When: at what stage of the curriculum are they involved? Q5. What for: for what effect? Q6. How: how is their integration promoted?

Results

Description of reviews included

The extraction and selection procedures yielded 25 literature reviews, and 2 additional reviews were identified using other methods. The analysis covered 27 reviews (Fig. 1). These were based on 773 articles, but because of frequent duplication, ultimately, 529 distinct articles were covered (1 article mentioned in 7 reviews, 8 articles in 5 reviews, 4 articles in 13 reviews, 34 articles in 3 reviews, and 93 articles in 2 reviews).

Table 3 presents the selected articles, the type of review carried out, the quality criteria of the review, the disciplinary field covered by the study, the language of the listed articles, the number of articles included, and the range of the years of publication of the articles. Table 4 shows the objectives and focus areas of each review categorized into three rating levels (absent theme, addressed theme, and main theme).

The most frequently covered health issue was mental health (7 out of 27), particularly in nursing programs (4 out of 7). Except HIV ($n=1$), the other reviews do not focus on or mention any specific health issue.

Stakeholders' motivation (the "why")

Motivation of institutions

Institutions conduct programs to engage their local communities, to demonstrate that they are socially responsible and not disconnected from the populations they serve and that they are attentive to communities' needs and expectations [13, 14].

Motivation of teachers

Most teachers report being highly motivated by these teachings, even if some are apprehensive that patients may use these opportunities to settle personal scores [15]. In general, they believe in the value of PPI-PE and expect it to compensate for the lack of meaningful interactions in a clinical setting [16]. The evolution of best practices is seen as the main motivation—opening students' minds [17], aligning patient expectations with professional practices [18], making the discipline [19] or education more attractive, powerful, and transformative [13], being more

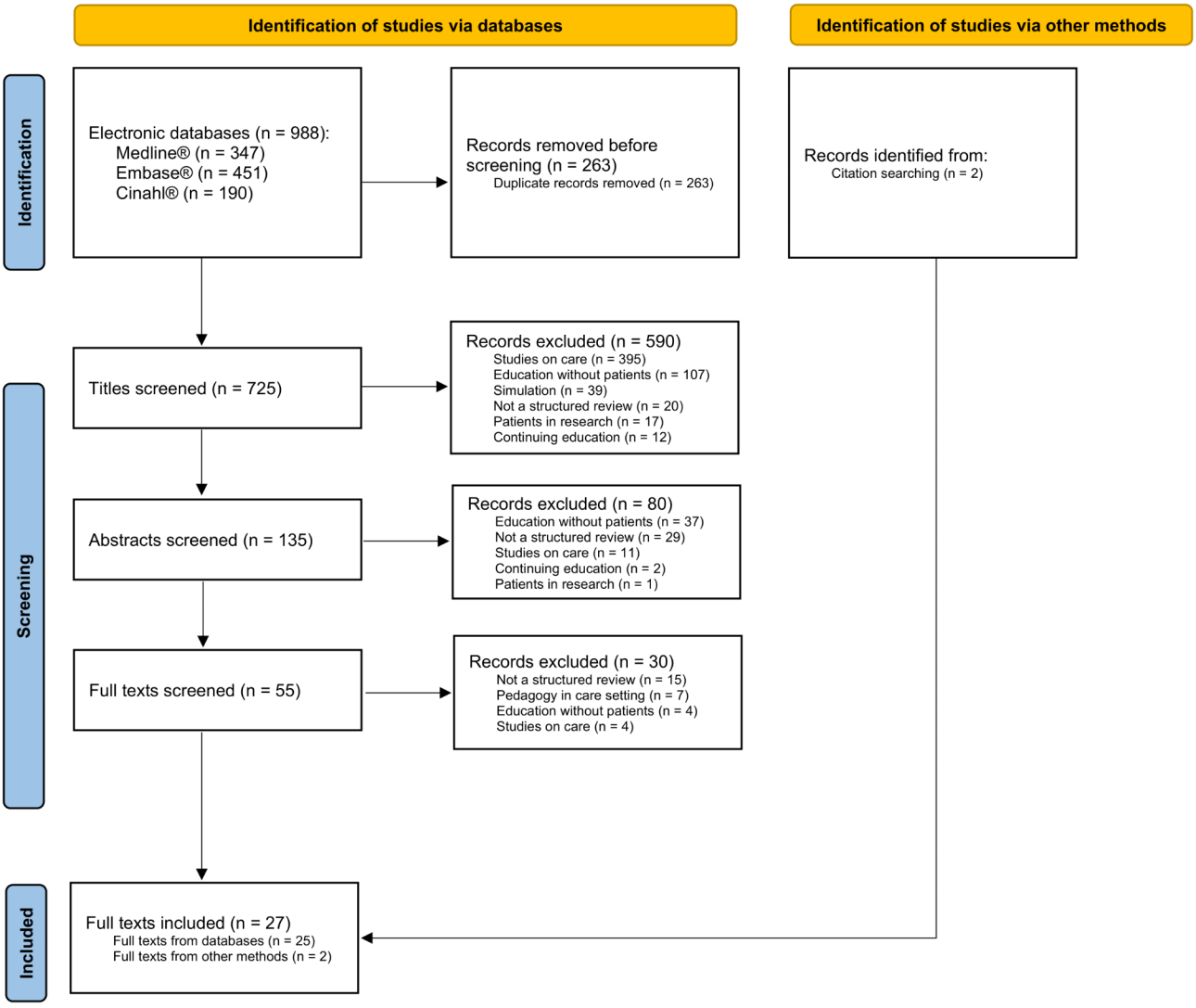

Fig. 1 Flow chart of the umbrella review

inclusive of diverse perspectives [14, 20], and rebalancing power dynamics (especially in mental health) [19].

Motivation of patients

Patients view their contribution as a way to turn their negative experiences into something positive [21]. Depending on the discipline, their objectives differ. In nursing, their main objective is to promote patient-centered care [16], while in mental health, they primarily aim to reduce stigmatization in care [22]. Generally, they participate in these programs out of an altruistic motivation—to improve the patient–caregiver relationship [18, 20, 23]. To achieve this, they advocate against students' preconceived notions and the use of medical jargon and stereotyped responses, strive to provide knowledge about local health resources, acquire information about the effects of hospitalization, and encourage students to build partnership-based relationships with their patients [22]. Furthermore, they ensure that all information is communicated clearly and honestly [15]. They are also motivated by interprofessional collaboration through sharing real-life situations [23] and their personal experiences [24]. Lastly, they seek to influence teaching priorities [24]. However, to maintain their motivation, it is essential that they are well integrated into the teaching team [17].

Patients' profile (the "who")

The process of selecting patients for a teaching role is not always explained clearly in the articles [24]; however, one aspect remains central to this discussion—the authenticity of the patients to be recruited. In other words, the authors wonder who is a real patient [25]. They seem to be individuals with a lived experience of illness, excluding sick healthcare professionals; "real" patients are those who are not influenced by other value systems [23] because their role is to communicate their own

Table 3 Characteristics of included literature reviews

First author/Year[α]	Review design	Included articles number[β]	Included articles period	Included articles languages	Discipline/Main theme[γ]	Quality criteria
Alberti 2023 [17]	Mixed method systematic review	33[β]	2012–2022	English Italian	Nursing education	Extraction and quality assessment by two independent reviewers. A third team member discussed discrepancies. Use of a tool for quality appraisal. Participative research (patients included).
Arblaster 2015 [22]	Structured review	36	1996–2013	English	Mental health education	Quality assessment by the first author. Use of a tool for quality appraisal.
Bennett-Weston 2023 [31]	Systematic review	7	2006–2020	English	Healthcare professional education	Complete agreement between three authors. Use of a tool for quality appraisal.
Boshra 2022 [29]	Systematic review	14	2006–2019	English	Healthcare professional education	Study selection by five authors. Dat extraction by two authors. No tool for quality appraisal.
Burnier 2022 [26]	Structured narrative review	41	2004–2019	English French	Healthcare professional education	Not available
Dijk 2020 [14]	Systematic review	49	2003–2018	English	Medical education	Quality assessment by two authors. Use of a tool for quality appraisal.
Gordon 2020 [13]	Systematic review	39	1978–2016	English	Medical education	Full screening by three authors. Inclusion by two authors. Data extraction by three authors. Use of a tool for quality appraisal. Participative research (patients included).
Goulet 2015 [38]	Systematic review (only on Cinahl®)	26[β]	1999–2014	English French	Nursing education[γ]	Not available
Happell 2014 [15]	Systematic review	30	1999–2012	No limits	Mental health education	Eligibility assessment by one author. No tool for quality appraisal.
Jha 2009 [16]	Systematic review	47	1981–2006	English	Medical education	Inclusion by two authors. Use of a tool for quality appraisal.
Kang 2020 [19]	Systematic review	14	2011–2020	English Korean	Mental health nursing education	Study selection by two independent researchers. No tool for quality appraisal.
Lawes-Wickwar 2023 [30]	Systematic review	20	2004–2020	English	Digital Technology	Screening of titles and abstracts by seven authors. Independent screening of 10% of articles by two authors, disagreements discussed with a third author. Use of a tool for quality appraisal. Participative research (patients included).
Miller 2020 [37]	Systematic review (only on Medline®)	31[β]	1995–2014	Not available	Psychiatric education	Not available
Morgan 2009 [23]	Structured literature review	44[β]	1999–2006	English	Healthcare professional education	Participative research (patients included).
Namer 2022 [34]	Structured narrative review	15	1990–2020	English	HIV/AIDS in healthcare education	Screening by two authors. No tool for quality appraisal.
Nguyen 2021 [28]	Systematic review	12	1999–2019	English	Pharmacy education	Screening and data extraction by one of authors, reviewed by three other authors. Use of a tool for quality appraisal.

Table 3 (continued)

First author/Year[α]	Review design	Included articles number[β]	Included articles period	Included articles languages	Discipline/Main theme[γ]	Quality criteria
Ní Chianáin 2021 [36][α]	Scoping review	37	2008–2020	English	Healthcare professional education	Independent screening by two authors. Data extraction by two authors, discrepancies resolved through discussion with a third member. No tool for quality appraisal. Participative research (patients included).
Perry 2013 [27]	Systematic review	10	1988–2010	English	Mental Health education	Independent screening by two reviewers. Use of a tool for quality appraisal.
Porter 2019 [39]	Systematic review	13[β]	1976–2018	No limits	Nutrition education	Each stage conducted by two authors working independently and in duplicate, discrepancies resolved by a third team member. Use of a tool for quality appraisal.
Repper 2007 [18]	Structured narrative review	38	1982–2004	English	Healthcare professional education	Data extraction by two authors. No tool for quality appraisal.
Rowland 2019 [24]	Structured meta-narrative review	295[β]	1969–2018	Not available	Healthcare professional education	Data extraction by six authors. No tool for quality appraisal. Participative research (patients included).
Scammell 2016 [20]	Systematic review	11	1997–2014	English	Pre-registration nurse education	Independent screening and data extraction by two authors, discrepancies resolved through discussion with a third member. No tool for quality appraisal.
Soon 2020 [35]	Scoping review	58	1995–2018	English	Healthcare professional education	Independent screening and data extraction by two authors, discrepancies resolved through discussion with a third member. No tool for quality appraisal.
Stanyon 2024 [21][α]	Systematic review	20	2012–2023	English	Mental health in health education	Screening of titles and abstracts by six authors. Independent screening of articles by two authors. Data extraction by eight authors. Use of a tool for quality appraisal. Participative research (patients included).
Stretton 2023 [32]	Scoping review	28	1998–2021	English	Healthcare professional education	Full screening by three authors. Data extraction by two authors. No tool for quality appraisal.
Terry 2012 [33]	Structured review	8	1999–2009	English	Mental health nursing education	Review by a single author. Use of a tool for quality appraisal.
Wykurz 2002 [25]	Systematic review	23[β]	1978–2001	English	Medical education	Full screening and data extraction by two authors. No tool for quality appraisal.

[α] *Two literature reviews were added by other methods than identification via databases. Ní Chianáin 2021 by citation searching, and Stanyon 2024 by literature monitoring.*

[β] *In Alberti 2023, 33 articles were included, but they corresponded to 27 studies. In Goulet 2015, 26 articles were described, but only 20 are listed in the references. In Miller 2020, 31 articles were described, but only 25 are listed in the references. In Morgan 2009, 44 articles were included, but they corresponded to 41 studies. In Rowland 2019, 295 articles were described, but only 81 are listed in the references. In Porter 2019 et Wykurz 2022, some articles focused on continuing education or training in care settings, whose results were not included in our synthesis.*

[γ] *Goulet 2015 announces articles on nursing education, but also includes articles from other disciplines.*

Table 4 Synthesis of contents of the included literature reviews

First author/Year	Main objectives/questions, according to the authors	Contents to answer umbrella review questions					
		Q1 (Why)	Q2 (Who)	Q3 (Where)	Q4 (When)	Q5 (What for)	Q6 (How)
Alberti 2023 [17]	To evaluate the effects of patient involvement on students, patients and academic staff.					Main objective	Addressed
Arblaster 2015 [22]	To evaluate evidence existing to guide mental health consumer participation at each stage of the education process. To evaluate evidence existing to support the effectiveness of consumer participation in mental health education in producing graduates with recovery-oriented practice capabilities.	Main objective		Main objective		Main objective	
Bennett-Weston 2023 [31]	To synthesize how theory shapes the understanding of patient involvement in health and social care education.					Main objective	Main objective
Boshra 2022 [29]	To evaluate patient-involved interventions that promote empathy among medical students.			Main objective	Addressed	Main objective	
Burnier 2022 [26]	To extract from the literature the definitions given for the following terms: patient educator, patient instructor, patient mentor, partner patient, patient teacher, volunteer patient, in order to clearly identify their roles and level of engagement.		Main objective	Main objective			
Dijk 2020 [14]	To identify the scope of active patient involvement in medical education, addressing the current knowledge gaps relating to rationale and motivation for involvement, recruitment and preparation, roles, learning outcomes and key procedural contributors.	Addressed	Addressed	Main objective		Main objective	Main objective
Gordon 2020 [13]	To describe what service user involvement is taking place in medical education. To evaluate what extent this involvement impacts the student's education. To clarify how and why such learning may be impacted by service user involvement.		Main objective	Main objective		Main objective	Main objective
Goulet 2015 [38]	To identify the main scientific literature on patient involvement in the education of health professionals.					Main objective	
Happell 2014 [15]	To establish the extent to which consumers participate in the education of mental health professionals and the outcomes of this involvement.			Main objective		Main objective	Main objective
Jha 2009 [16]	To provide updated integrated evidence on the role of the involvement of patients in medical education.	Addressed	Main objective	Main objective		Main objective	Main objective
Kang 2020 [19]	To identify the latest trends in mental health nursing education using consumer involvement and provide evidence to develop educational programs that can be utilized in the future.			Addressed		Main objective	
Lawes-Wickwar 2023 [30]	To present the variety of digital technologies that have been used in medical teaching when patients and/or carers are also involved, and what has been the experience of patients, students and educators alike.		Addressed	Main objective		Main objective	
Miller 2020 [37]	To inform a critical discussion evaluating the role of patients and carers in psychiatric education.		Addressed	Main objective		Main objective	
Morgan 2009 [23]	To identify models, approaches and strategies used to involve service users in the design, delivery, assessment and evaluation of healthcare education curricula; the perceptions of key stakeholders about user and carer involvement in healthcare education; the impact of involvement in education on students' knowledge and skills; the impact of involvement in education on the quality of care received by the service user.			Main objective		Main objective	Addressed
Namer 2022 [34]	To collate the experiences of involvement of people living with HIV/AIDS in teaching.			Main objective		Main objective	

Table 4 (continued)

First author/Year	Main objectives/questions, according to the authors	Contents to answer umbrella review questions					
		Q1 (Why)	Q2 (Who)	Q3 (Where)	Q4 (When)	Q5 (What for)	Q6 (How)
Nguyen 2021 [28]	To explore how patients are actively involved in pharmacy education within educational settings, the roles that patients play and the content that they deliver, as well as the impact of their involvement, in terms of students' learning outcomes and patient outcomes.			Main objective		Main objective	Addressed
Ní Chianáin 2021 [36]	To caracterize how are the patient's illness experiences gathered to inform simulated participants (SP) roles; how SPs represent these illness experiences in simulation; what impact, if any, real experiences of illness have on learners.			Main objective		Main objective	
Perry 2013 [27]	To answer the following questions: 1. What can the current evidence base reveal about the effects of mental health service user involvement in the teaching of interpersonal skills to mental health students? 2. What are the effects of this type of involvement in comparison with more traditional methods of teaching? 3. What were participants' experiences of this type of involvement? 4. Does mental health service user involvement in the teaching of interpersonal skills to mental health students have any negative effects?		Addressed			Main objective	
Porter 2019 [39]	To synthesize learning outcomes that result from involvement of patients in nutrition and dietetic student education, and to consider whether these interactions promote patient-centered care.					Main objective	
Repper 2007 [18]	To describe approaches taken to involve consumers in the education of health professionals and the advantages, disadvantages, impact and ethical implications of different approaches.	Addressed		Main objective		Addressed	Main objective
Rowland 2019 [24]	To make sense of a conflicting literature that spanned many fields, and also look at how these fields have influenced one another.						
Scammell 2016 [20]	To determine to what extent service users are involved in pre-registration general nurse education.			Main objective		Main objective	
Soon 2020 [35]	To identify how consumers are involved, recruited and retained in nursing, midwifery and allied health curricula			Main objective			Main objective
Stanyon 2024 [21]	To identify the impact of involvement in mental health professional education on the patients with mental health conditions involved	Main objective		Main objective		Main objective	
Stretton 2023 [32]	To identify and map the available evidence regarding patient-led teaching in medical and allied health education	Main objective		Main objective		Main objective	

Table 4 (continued)

First author/Year	Main objectives/questions, according to the authors	Contents to answer umbrella review questions					
		Q1 (Why)	Q2 (Who)	Q3 (Where)	Q4 (When)	Q5 (What for)	Q6 (How)
Terry 2012 [33]	To explore the nature of service user involvement in the classroom in pre-registration mental health nurse education. To gain insight into the prerequisites and processes needed to prepare for service user involvement in the classroom. To consider the reported outcomes of service user involvement for student learning. To examine the evidence of student engagement with this type of teaching and learning style. To better understand the ethical challenges presented by involving service users in the classroom.				Main objective	Main objective	Main objective
Wykurz 2002 [25]	To identify the roles and settings in which patients participate as teachers and to discover the benefits for learners, the patients who par- ticipate, and the educational institutions involved.			Main objective		Main objective	Main objective

experiences or messages. It is also ruled out that they act as standardized patients, who follow a pre-defined scenario [24, 26]. Moreover, both students and teachers repeatedly question the representativeness of the patients included in these programs [15, 18, 23, 27]. Regarding patient recruitment, some argue that only their motivation matters [18]. Others provide a list of desired qualities (without any studies to support them) as follows: good teachers [25], effective communicators, non-anxious individuals, individuals capable of handling uncomfortable questions, and individuals without a personal agenda against the medical profession [16]. Finally, regarding university pedagogical committees, some believe that the participation of association representatives should be prioritized, while others fear collaborating with these groups, whom they consider too politicized [14].

Disciplines and levels of integration (the "where")

Integration of patients was uneven across training programs [15]. Nevertheless, it is considered very common in psychiatry; in 2006, 50% of articles referred to integration of patients [18], and, in 2013, 74% of psychiatry courses reported that they integrated patients [15]. Since 2011, it is said to be common in nursing education in the UK, where patient participation is a regulatory requirement, particularly in mental health courses [20]. Between 1999 and 2009, 12 articles reported on courses in pharmacy education [28]. However, these data do not reflect the frequency of such courses or the number of patients and students involved.

Because of concerns about "token" participation, the main question is: how can we ensure that patient participation is not merely symbolic? To synthesize knowledge, a significant proportion of reviews reference Towle and Goldophin's [10] grid, which has the following six levels: level 1: scenarios, simulated cases; level 2: volunteers in clinical settings; level 3: testimonials; level 4: teaching and assessment; level 5: involvement in curriculum development; and level 6: academic stakeholder.

Patient participation is highly varied, ranging from minimal involvement in the form of providing feedback to students to the status of academic actors [15]. The reviews do not agree on the dominant level of patient participation, with some suggesting level 3 [29] and others suggesting levels 4 [13] or 5 [21]. Most importantly, this scale fails to reflect reality, as patients may be involved in curriculum development without being involved in teaching [21].

In the early 2000s, most interventions focused on musculoskeletal disorders; students interacted with patients who gave them feedback on the quality of their gestures, while others were carried out by parents who made students aware of their children's issues [25]. Since then, these teachings have accounted for only a small

proportion of interventions. Most of the reviews mention videos of vignettes depicting the experience of illness and care relationships [30], as well as live testimonials on care relationships and the challenges encountered by patients. These testimonials also provide an opportunity for patients to promote interprofessional approaches [31, 32]. Some testimonials are followed by group reflection sessions [29].

Contributions to problem-based learning (level 4 of patient participation) are also reported [33, 34] as well as the organization of face-to-face meetings with small groups of students [29, 32, 35], who are sometimes hosted by patients in their homes [16, 29, 32]. Students have also been able to shadow patients in hospitals and in their everyday lives [29]. In the context of HIV, immersion in community spaces are organized [34]. Plays written by patients have been performed in front of students, which are then followed by a debate [34]. Patients also participated in evaluating students' essays, primarily in non-cognitive domains [14]; this type of contribution is mentioned in 7 of the 58 articles included in a 2020 review [35] (mainly in mental health).

The results for level 5 of patient participation varied across different reviews—2 out of 39 studies [13], 12 out of 58 studies [35], 4 out of 9 studies [21]; the more recent the programs, the more frequently this was observed [14]. When this level is reached, patients identify skills to be developed in future caregivers [15, 34, 35], prioritize lessons (via focus groups or the Delphi method), define the objectives of a program [15, 16, 18, 21, 34], produce educational resources (videos, simulation scenarios, and teaching design) [16, 35, 36], and design evaluations [35].

Moreover, they are sometimes involved in the recruitment process for other patients [22, 35] and students [20, 35]. The latter type of contribution was found mainly in Australia [14, 35] and less so in the UK, particularly within selection panels for student nurses [20].

Integration remains complicated at levels 5 and 6 of Towle's scale [10] because of lack of resources, excessive bureaucracy, and academic resistance [17]. Level 6 of patient participation was found mainly in Australia and less so in the UK. For example, at the University of Southampton (UK), following the Australian model, a patient was appointed as lecturer to embody the university's commitment to inclusion and guide the implemented programs [15]. At the University of Leeds (UK), both a patient and a patient engagement specialist were recruited to provide ongoing support to a group of patients and various programs [14].

When to intervene (the "when")

This dimension remains underexplored outside of programs aimed at developing students' empathy, where studies *most commonly involve third-year students* [29]. One comparative study showed that the group of students who had access to PPI-PE at the start of their studies benefited more than the group who only had access to it later [33]. Nevertheless, this topic remains a matter of contention. Most authors believe that this should be implemented as early as possible, while others argue that it should wait until students encounter challenges in the field [33]. One article argued that all modules should include at least one session delivered by service users to reinforce the idea that all aspects of mental health can benefit from patients' perspective [33].

Program effects (the "what for")

Regarding the feelings of students, patients, and teachers

Most studies have concluded that students are satisfied [17–19, 23, 27, 30], except in the case of simulations [23]. Students appreciate the opportunity to ask patients questions that they would not typically ask in a clinical setting [27]. They report feeling reassured when they are taught relational skills and a patient-centered approach by real patients [17]. However, they may feel anxious before the start of the course [15]. This anxiety reduces after the course ends [33], and although they may feel uncomfortable intervening in front of patients [19, 27], this discomfort diminishes when interactions occur in the absence of their usual teacher [32].

The emotional effect felt by students is mostly positive [17, 18]; they appreciate the opportunity to listen to patients' stories and believe that this helps develop their *self-awareness for critical reflexive practice* [18]. Nevertheless, one article—considered to be of moderate quality by the authors who analyzed it—mentions that this depends on the pedagogical skills of the patients, and that at times, the testimonials can be perceived to be too subjective, particularly in the context of mental health [19].

Indeed, in the field of mental health, the results are slightly contrasting; while it was reported that most studies found students to be satisfied, three older studies presented more negative results. A 2003 study revealed that some students perceived patients to pursue goals different from their own [15]. A 2006 study found that some students question the educational value of patients, considering them unqualified in this regard [27]. A 2009 study showed that students find it difficult to handle criticism of care services [15].

Finally, regarding the participation of patients in student selection panels, the students involved expressed their support for the proposal, citing the experience of patients as care recipients [20].

Patient satisfaction was also explored. They may have had some initial fears, such as not being up to the task or worry that students would look down upon them and see them through the lens of a diagnosis [33]. These fears may have been reactivated by some of the students'

questions or behaviors [37]. Most of the time, patients come to realize that they have useful and unique knowledge [21, 29], that students are caring and enthusiastic, and that students value their contributions [23]. Their self-esteem increases [20, 21, 23, 25, 28], and they are happy to develop new skills [17, 18, 21, 28].

Patients derive the maximum satisfaction when they fully engage in the training, through testimonials, teaching, and student evaluations. When teachers provide them support before the intervention [33] and a debriefing afterwards [21, 33], patients' satisfaction increases. Conversely, it is less important when this does not happen; when the teaching team does not explain to patients what is expected of them [15] and ignores their suggestions [20, 21]. However, generally, patients are not sufficiently debriefed after their lessons, and many of them feel that their role continues to be less recognized in universities [15, 17]. Teachers declare themselves to be satisfied; they feel that students benefit from unique perspectives and that students improve their interpersonal skills [38]. The teachers' enthusiasm is genuine, even if they find it difficult to manage the anxiety of students who want to ensure that the curriculum is fully covered [15]. Additionally, teachers may regret having underestimated the time required for preparation and follow-up of these interventions and fear that patients may feel used when the university does not truly recognize them [20].

Regarding student learning

Almost all the review authors agreed on the usefulness of PPI-PE, described by both researchers and students as transformative [17, 20, 32–34]. The exception is digital formats, which the authors of the review dedicated to this largely attribute to the prevalence of simulation in this setting [30].

The key contributions are patient-centricity [17] and linking theory with practice. Students say their perceptions of patients [19, 33, 38] and views about certain situations has changed [19, 22, 27, 34]; they find patients to be stronger and more resilient than they thought [27]. They better understand the frustrations experienced by patients during care [27, 33] and identify areas for improvement in the healthcare system [15, 31]. Finally, in mental health, their perspectives on patients' recovery became more optimistic [19].

The results of pre-post studies have shown that students become more sensitive to the needs and expectations of vulnerable populations and socio-cultural specificities [31]. The results of high-quality comparative studies have shown that students understand a disease better via the patient's narrative [30], which is reflected in their clinical management, as they gain more confidence in their clinical skills [15, 39]. Two randomized studies showed progress in terms of medical knowledge and knowledge retention [29], which was confirmed in 5 out of 6 studies using a digital format of teaching [30].

Regarding student behavior

Students reported that their attitudes and behaviors have changed about chronic illnesses, children's disabilities, family involvement, psychiatric disorders, and the care of the elderly [19, 22, 27]. They feel better prepared to handle relational aspects [18, 28]. In particular, they have embraced the value of shared decision-making [27]. They are more self-reflective [18, 19, 33, 39] and see a person where they previously saw only a patient, which counterbalances the "them and us culture" they witness in the field [33]. In their view, these lessons will positively influence their future practice [22, 28, 33].

Several studies that used pre-post questionnaires have also shown a similar trend [28, 29, 32], which signifies that students' interprofessional skills have improved [28].

Several randomized studies [14, 18, 27], notably based on simulated consultations [28], have confirmed these results (the only exception showed no inter-group differences [27]), provided the interventions take place in person rather than via pre-recorded video [22]. They demonstrated improvement in individualization of care [18, 27], better management of complex cases [37], reduced use of medical jargon [18], and a decrease in stigmatizing attitudes towards people with physical or mental disabilities [22, 27, 28, 32]. The review study on student empathy found that "all studies demonstrated improved empathy post-intervention." [29].

Changes in long-term care population

No study has assessed the direct benefit of intervention on patients in care [13]. Studies showed that students conveyed more hope to their patients [33] when they were still in training. A situational observational study showed greater awareness among students—now doctors—of the impact of cancer on their patients' lives [18, 23]. Another mental health study showed that compared with the control group, the intervention group was more likely to suggest that patients involve their loved ones in their care [23].

Regarding the durability of changes, the authors deduced from the strong interpersonal experiences undergone by students that their learnings will be profound and lasting [17, 20]. However, few studies have confirmed this [32]. Those that do have shown that the effects last [22, 31] long afterwards [22] (except one study [28]).

Patient integration (the "how")

Patients were recruited mainly through community organizations [16, 28, 35], patient associations [14, 16, 28], newsletters, and social networks [16, 35]. Two mental

health studies reported that recruitment was carried out among student patients, which placed the students concerned in emotional distress [15, 37]. Different practices were followed to prepare patients for their intervention. In the case of musculoskeletal diseases, only patient–instructors received intensive training [16, 18, 25]. In other programs, only information on training objectives was usually provided [14, 15, 18]. Several studies have pointed out that overly-extensive training risks undermining the expected authenticity of the program [14, 18] and that the program may not sufficiently focus on users' priorities [18]. In contrast, other studies have suggested holding meetings to discuss difficulties encountered and peer mentoring [16, 31, 35]. In mental health, the importance of co-constructing the project by agreeing on its framework and principles is emphasized; patients are given the right to not answer all of the students' questions [33], and recruitment and preparation are sometimes carried out by social enterprises [19]. Some necessary conditions are also mentioned, such as concomitant preparation of students [31, 38], debriefing after class [33], and remuneration [38]. At present, the principle of remuneration has been accepted [35, 37], but the amount involved varies (from €8/hour to £350/day) [14]. Various measures have been planned to facilitate the integration of patients (provision of equipment, access to parking, icebreaking activities, etc.) [35]. Lastly, the workload involved in managing these programs should not be overlooked [14, 31]; some studies have argued for a stronger commitment on the part of universities and the creation of dedicated structures benefiting from human resources [14].

Research limitations and limitations of this study

In 2009, only 1 out of 8 programs was based on intervention theories [16]. By 2023, this figure had not risen, prompting the study authors to say that "the field is largely a theoretical one." [31] The size of programs is modest, although some have the potential to be scaled up for a larger number of participants [20, 22, 33]. Studies are mainly qualitative, except in pharmacy curricula, in which quantitative aspects predominate [28]. Furthermore, the studies are of average quality, whether qualitative [33] or quantitative [22, 27]. In particular, they mainly report self-reported changes [13, 14, 19, 20, 22] and are carried out by teams that developed the programs [33], with some authors supporting the idea of multicenter studies [14, 20].

Note that studies have focused mostly on in situ experiences (of learners, patients taking part in teaching, and teachers) and rarely on the impact on patients in care or on what remains of them in the long term [17]. Moreover, no financial cost-benefit analysis has been carried out [14]. As for the studies that were carried out, only ¼th of it has been subject to ethical approval [33]. Furthermore, in the absence of a Medical Subject Heading (MeSH) term for users, it is difficult to locate relevant articles [17, 35], and the reviews have relied almost exclusively on articles written in English, which does not guarantee exhaustiveness. The authors also pointed out that in the articles they reviewed, it was difficult to identify whether the patients were "genuine" or simulated [30].

One review addressed both genuine and simulated patients' profiles [39] but the results regarding simulated patients were excluded from this umbrella review to focus on patients who did not assume a role other than their own. Some reviews also included programs conducted in clinical settings or involving students who had already graduated [25, 39]; such studies were excluded from this analysis. It was difficult to distinguish results according to the quality criteria of the study that produced them because of lack of clear indications from the authors of the primary articles [17, 33] and not all review authors carried out this analysis. Finally, despite our vigilance, given the number of duplicates found, it is likely that the same study has been cited in different reviews, which may give the false impression of a multitude of consistent data.

Discussion: pedagogical, theoretical, and research perspectives

Implementation methods and effects

Several PPI-PE studies have been conducted in the last 30 years (especially in mental health). In most cases, they were carried out by the practitioners involved. Numerous systematic reviews of the literature have also been conducted. Most of them have focused on the implementation ($n = 16$ out of 27) and effects of PPI-PE ($n = 20$ out of 27). It seems pointless to re-measure student satisfaction and gains in empathy or level of patient-centeredness and understanding of a holistic patient experience. It is also well established that PPI-PE enhances students' sensitivity and their desire to meet the needs of the people they care for. Tous ces résultats vont dans le sens de ce qui était attendu du PPI-PE, à savoir l'amélioration de l'expérience patient, en termes de relation de soins. On peut néanmoins regretter qu'aucune recherche chrono-pédagogique n'ait été menée. Ainsi, aucune recherche n'a comparé l'impact d'une PPI-PE intervention en croisant ses objectifs et le niveau d'étude des étudiants. At this stage, it would be beneficial to develop some theory-driven evaluations (realist evaluations) [40] aimed at linking effects with contextual elements and the mechanisms that produce them, to better understand how interventions work thus to optimize actions. Indeed, the analytical methods used by the study authors and the leading studies do not allow for the association of an effect with a specific intervention modality or any other contextual

element (e.g., patient profile, quality of university support, year of training, and the number of students per course) (except a few [34]). This would compensate for the lack of intervention theory noted by the study authors.

Towards an intervention theory for a PPI-PE program in late undergraduate health professional education

Many reviews have mentioned, in one way or another, that students undergo a transformative experience. According to the theory of transformational learning, transformation is possible when old frames of reference are abandoned after recognizing their limitations [41]. Although this issue is not addressed in the articles we examined, in the studies which have been included, we assume that PPI-PE have not been conducted at the very beginning of their training. Indeed, for students to recognize their limitations, they had to deal with real situations, which only happens late in the curriculum. A PPI-PE theoretical foundation emerges from this. When used late in the university curriculum, a theory intervention of a PPI-PE's program articulates transformational learning [41] and pragmatism, in which everything starts from experience [42]. This raises a few issues. It is important to consider the emotions experienced by students when listening to patients' stories given that their role in transformational learning is well established. Moreover, "emotions determine what students do NOT want to forget." [43] That said, from a pragmatist's perspective, "familiarity breeds indifference," [44] so it is likely that these testimonials should not be excessively repeated but carefully distilled over the course of their training.

Challenges

The following limitations were identified. First, there are difficulties inherent to this type of research. As a result, Towle and Goldophin's scale, which is widely used, does not allow for certain pedagogical actions to be carried out by patients, such as providing feedback in the form of testimonials to enrich the simulation scenarios. In fact, this type of contribution does not fall into level 3 or 5 of this scale. Refining this scale would allow for better differentiation between programs (based on the number of patients involved at a university, their status, the actions taken, etc.).

Second, the results showed that some students find it difficult to take into account certain patient stories, which they feel are too subjective. Therefore, the teaching team should better prepare these presentations and support students in recognizing both the limitations and richness of these accounts, thereby generating a broader reflection on the scope of qualitative interviews. They could also remind students that learning is often associated with friction and being pushed out of one's comfort zone [43]. Additionally, it would be beneficial to counterbalance individual feedback with collective feedback by involving user associations.

The points illustrated in the previous paragraph are linked to the issue of patient representativeness, which concerns both students and teachers. "Representativeness" implies that a patient who resembles all of the patients seen in consultation can be considered representative of all patients. This allows the exclusion of patients who are too knowledgeable or have expertise in their subjects. Indeed, patients are often seen as being too naïve or knowledgeable, which ultimately results in their exclusion [45]. It would be valuable to explore how patients see themselves in this context. No study has addressed whether the most vulnerable feel that they are being adequately represented by those who teach on their behalf. Regarding the search for a patient who is representative of others, or the so-called "authentic" patient, the endeavor is futile; there is no universal patient voice that can be embodied in a single individual. Thinking otherwise leads to essentialism. But above all, all patient profiles have their place in teaching, provided they are engaged within a framework that aligns with their skills, keeping in mind that like any teaching, theirs can only aim for a limited number of objectives at a time.

Designing a structured curriculum

While many training courses report that they include patients, it is difficult to obtain a comprehensive view of their participation. These may remain isolated initiatives, led by a few individuals with varying levels of support from their institutions. None of the articles in any of the journals reviewed in this study deals with a reasoned and structured faculty program. Indeed, the absence of a dedicated structure within faculty does not help, even though such a structure could facilitate patient recruitment, recognition of their role, and the organization and structuring of a program throughout all of the years of study.

The absence of a reasoned structure reflects the lack of genuine institutionalization of PPI-PE, despite its implementation and the impressive volume of research dedicated to it. While it is true that the assessments corresponding to level 4 of the Kirkpatrick scale are brief, this is generally beyond the scope of PPI-PE, largely because of the difficulties involved in setting up the necessary studies [46]. Additionally, a recent study showed that good results at level 3 directly predict results at level 4 [47]. Therefore, there is no clear explanation for the reported lack of institutional support and insufficient embedding of PPI-PE [48].

Given the achievements and the range of health disciplines covered, PPI-PE can no longer be considered a pedagogical innovation. Indeed, this type of innovation is

defined primarily by novelty, referring to "a new mode of teaching that differs from the usual courses with the aim of improving learning." [49] However, simply considering the dates and quantity of the articles cited in the analyzed journals leads to the conclusion that it lacks novelty.

This leads us to believe that the lack of recognition reported by the patients mentioned in the surveyed articles extends beyond their individual experiences. De plus, les résultats montrent que l'absence de recognition concerne aussi les enseignants qui portent les PPI programs qui regrettent le manque de soutien de leur institution. Indeed, with a few exceptions, we are witnessing an established phenomenon that we define as pedagogical liminality, meaning pedagogical action is assigned a permanent in-between position—neither completely rejected nor fully included. Presumably, this is because of excessive caution and resistance, regardless of the rational reasons given by the results of the studies carried out. Et c'est ainsi que « despite the potential in establishing partnership between patients and healthcare providers, resistance to patients engagement and collaboration from family members and clinicians persist » [50]. Le peu d'appétence au changement de manière générale de la Medical education [51] n'aide en rien. De même, la prévalence des études qualitatives dans le champ du PPI-PE comme dans celles sur le développement des compétences interpersonnelles freine probablement leur implémentation. En effet, les recherches qualitatives are often perceived as less rigorous in academic settings where evidence-based medicine (EBM) standards favor quantitative methodologies. This misalignment between research traditions and institutional expectations probably creates an additional barrier to embedding PPI-PE into structured curricula.

If rational reasons play no part in the resistance encountered, then evidence only fails to address pedagogical liminalities. This encourages to invoke other value systems. Specifically, prioritizing actions over evidence by supporting the development of interventions, even if it means reconvening in a few years to learn from the pedagogical experiments conducted and comparing them with one another. However, to advance in this direction, institutional players need to be confident in their roles and feel that what is being implemented is based on sound principles, free from epistemic and ideological corruption. That's why there is a need for institutional policies who acknowledge the legitimacy of patient involvement in teaching, not merely as an experimental approach but as an essential pedagogical component. More specifically, we plead for recommendations that encourage systematic implementation throughout the curriculum by incorporating a mix of intervention formats. Furthermore, this would have the advantage of taking PPI-PE out of the context of localized, haphazard initiatives that are too reliant on specific individuals.

Conclusion

This umbrella review described the current state of knowledge regarding patient participation in the education of future healthcare professionals (PPI-PE). A considerably amount of knowledge has been acquired, but studies continue to repeat themselves. It is well established that PPI-PE helps students understand patients' perspectives, develop empathy, and be more respectful of their priorities. However, universities have not yet fully embraced the idea of integrating patients into professionals training programs. The results of this study indicate that PPI-PE faces a pedagogical liminality, i.e., pedagogical action is assigned a permanent in-between position because of excessive cautiousness and resistance independent of rational reasons. To get out of this rut, clear political incentives promoting a systematic PPI approach in professional training are needed.

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OG and YR designed the study and carried out documentary research and data analysis. YR prepared the tables. OG wrote the main manuscript texte. Both of them reviewed the manuscript.

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Author details
[1]Laboratory Education and Promotion of Health (UR3412), University Sorbonne Paris North, Bobigny, France
[2]Department for Family Medicine (DUMG), University Sorbonne Paris North, Bobigny, France

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