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Patient experience journey mapping: established public health methodology or strategic decision-making element in a patient-driven healthcare?

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Мапа досвіду пацієнтів: загальноприйнята методологія громадського здоров'я або стратегічний елемент прийняття рішень у пацієнт-орієнтованій системі охорони здоров'я?

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Introduction

Patients and patient communities are being considered as crucial stakeholders of modern healthcare systems with deeper involvement in health technologies' development/assessment (HTA), regulatory processes, delivery of patient support services, shared decision-making, policy and advocacy programs, defining an incremental and expected value of innovations, health literacy and peer support initiatives. Value-based healthcare is impossible without holistic understanding of patient experience data (PED) mapped throughout the generic patient journey or pathways, analyzed on regular basis, then transferred to the actionable insights and recommendations.

There are many definitions and connotations of patient experience and therefore PED. The simplest definition of patient experience is what a patient "thinks, feels and says about the experience of a service, process or product he/she/they has/have encountered" [1]. Patient experience is increasingly recognized as one of the three pillars of quality in healthcare alongside clinical effectiveness and patient safety, but there is not healthcare connotation only, as it covers much broader life ecosystem [2]. European Medicines Agency (EMA) defines PED as data collected via variety of patient engagement activities and methodologies to collect patient experience on their health status, symptoms, disease course, treatment preferences, quality of life and impact of healthcare [3]. US Food and Drug Administration (FDA) also provides detailed PED definition: information that captures patients' experiences, needs and priorities related, but not limited to: (1) the symptoms of their condition and its natural history; (2) the impact of the conditions on their functioning and quality of life; (3) their experience with treatments; (4) input on which outcomes are important to them; (5) patient preferences for outcomes and treatments; and (6) the relative importance of any issue as defined by patients" [4; 5].

In recent years there has been a shift towards patient engagement – essential driver for PED collection and generation [6; 7]. World Health Organization (WHO) defines patient engagement as "the process of building the capacity of patients, families, carers, as well as health care providers, to facilitate and support the active involvement of patients in their own care, in order to enhance safety, quality and people-centeredness of health care service delivery" [8].

Although interrelation and interdependence of patient engagement and PED generation have broadly been acknowledged, there is still methodological inconsistency and unclarity on how PED should be categorized, formatted and mapped as per the existing good practices and common experience. PED may be available in different formats – from strictly formalized and validated patient reported outcomes' measurements (PROM) to real-world PED (RWD) and patient insights – non-formalized, exploratory format [9]. This challenge introduces PED scoping and inclusion bias when the opportunity to reflect value/meaningfulness for patients is limited and significant part of PED is unpublished or remains under "grey literature" category. Therefore, Patient Experience Journey Mapping (PEJM) is considered as optimal solution and format for the holistic PED systematization and presentation; the recently developed tools such as PFMD PE&PED Navigator and US NHC Patient Experience Mapping Toolbox established the foundation for PEJM concept implementation [10; 11; 12].

Patient experience journey map/mapping is the holistic consolidation of several types of aggregated

PED (collected from several sources) with actionable insights and possible implementation steps (patient impact, business processes, regulatory decisions and HTA). Initially established as public health tool to navigate patient experience across the healthcare systems and throughout the care pathways, then identify unmet needs and service gaps, PEJM is becoming an essential part of evidence generation strategy, clinical development programs, target value profile substantiation, clinical outcomes assessment strategy, business planning and decision making within the biopharmaceutical/medical device industry, academic institutions, patient communities and overall healthcare [13; 14; 15; 16]. The series of FDA Patient Focused Drug Development (PFDD) guidelines (2020–2023) and recent public consultations around the EMA Reflection paper (2025) welcome early discussions with regulators about ways to generate robust PED, format for its consolidation and presentation, approaches to analysis, and further submissions as a critically important part of New Drug Applications (NDAs), Biologics License Applications (BLAs), and supplemental applications [3; 4; 5; 17; 18; 19; 20; 21].

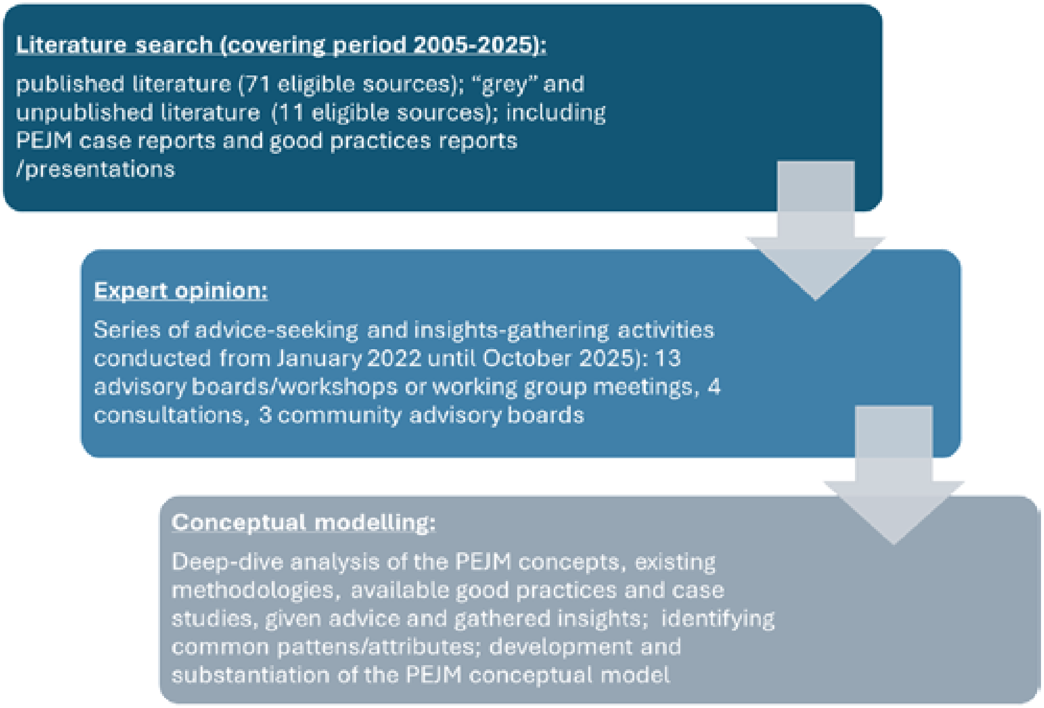
This study **aims** to outline the evolution of patient experience research and PED generation, to analyze the existing methodological approaches and best practices to map patient experience journey and to substantiate the PEJM conceptual model.

Object, materials and research methods

This research has explored the combined methodology including bibliosemantic method (literature search), experts’ opinion and conceptual modeling method. It summarizes the work done by authors over the period from January 2022 to October 2025 also contributing to the global Patient Focused Medicines Development (PFMD) Working Group on Patient Engagement and Patient Experience Data (PE&PED project) [22].

The key research milestones are presented at Fig.1.

Literature search covers the period of 2025–2025 (20 years) with the objective to understand the evolution of patient experience studies and to address research questions on how mapping methodologies and approaches have been changing over time. Published, “grey” and unpublished literature and resources were taken into consideration with the assumption that not all case studies and good practices were appropriately reported and published in peer-reviewed literature. The search engines/databases (PubMed and Embase) were used to identify the published sources by the following key words: *patient experience map, patient experience journey maps, patient journey, journey map, patient journey map, patient journey mapping, patient experience mapping, patient pathway, experience mapping, experience map*. The Google search and available online resources, such as PFMD Synapse Patient Engagement Network and regulators/HTA agencies websites were explored to identify “grey” literature and unpublished sources, such as project reports, presentations, case studies, narratives, good practice examples, materials developed by third parties and shared data of file (without any individual, proprietary, confidential or private information). PRISMA Flow Diagram Template for Literature Reviews was used to summarize search results through sources’ identification, screening, then final inclusion of totally 82 eligible sources (of 149 identified in total): 71 eligible



Literature search (covering period 2005-2025):
published literature (71 eligible sources); “grey” and unpublished literature (11 eligible sources); including PEJM case reports and good practices reports /presentations

Expert opinion:
Series of advice-seeking and insights-gathering activities conducted from January 2022 until October 2025): 13 advisory boards/workshops or working group meetings, 4 consultations, 3 community advisory boards

Conceptual modelling:
Deep-dive analysis of the PEJM concepts, existing methodologies, available good practices and case studies, given advice and gathered insights; identifying common pattens/attributes; development and substantiation of the PEJM conceptual model

Fig. 1. The key research milestones

sources (of 134 identified sources of published literature) and 11 eligible sources (of 15 identified sources of "grey" and unpublished literature.

Alongside literature search, the expert opinion supported the development of the PEJM conceptual model. The series of advice seeking and insights gathering activities were conducted as a part of the focused patient experience sessions within the dedicated medical conditions/disease areas, advisory workshops/advisory boards, working group meetings and consultations to inform development of the correspondent PEJM on living with those conditions. 58 subject matter experts took part in the advice-seeking and insights-gathering activities from January 2022 to October 2025 representing patient communities (39 patient experts/caregiver experts/patient advocates and/or members of patient organizations, 17 healthcare professionals, 2 other experts). Activities had both digital/online (46) and face-to-face/hybrid (12) format and discussion outputs were recorded, some of meetings explored AI-driven tools (Copilot). Experts' feedback was analyzed and considered from the methodological perspective with particular focus on the following aspects of patient experience research: existing pathways of generic patient journeys, available PED, sources of PED, methods of PED generation, categorization of patient experience, power of evidence and potential for publication (publicability) in peer-reviewed journals, risks evaluation and mitigation, ways of PED and PEJM validation, PEJM communication and publication, graphic design of PEJM and their visual presentation, the roles of virtual patient profile and patient persona, value of PEJM for individual patients and their families. As the members of PFMD WG, authors also considered feedback from public consultations around PE&PED project and lessons learnt from the practical implementation of PFMD PED Navigator.

Based on the literature findings and experts' opinion, deep dive analysis of the existing mapping methodologies, available good practices and case studies, authors developed and substantiated the PEJM conceptual model. This has been done by synthesizing and comparing information from various sources and understanding evolution of patient experience studies over the last 20 years with the aim to gain a holistic understanding of the PEJM, its key attributes and elements.

Research results

The research findings are structured by key thematic areas, patterns and attributes of PEJM and PED studies: 1) terminology challenge and definitions; 2) evolution of patient experience research; 3) PED generation and PEJM development purposes; 4) PEJM conceptual model.

1. Terminology challenge and definitions

Bibliosemantic search yielded different connotations and stakeholders' understanding of the following terms and definitions: pathway, care continuum, patient journey and patient experience map; this has been confirmed by experts who demonstrated inconsistent understanding of those terms and different their interpretation in terms of reflection of patient experience living with a medical condition and/or co-morbidities. Pathway, or patient pathway is the most commonly used term over the last two decades and had a strong connotation with patients'/caregivers' navigation within the certain healthcare systems or hospitals [23–27]. Healthcare systems may use standard pathways for their work and management of patients, for example, the "NHS England Pathways" is a clinical tool used for assessing, triaging and directing the public to urgent and emergency care services [28; 29; 30]. There are not only healthcare system-level standard pathways, but district- and hospital-level pathways developed for several medical conditions as standards of care [31; 32; 33]. Generally speaking, a pathway may be either an ideal/standard or real algorhythm and individualized milestones a patient passes living with a certain medical condition(s) throughout its/their natural history, and/or within a healthcare system, infrastructure and services provided [34; 35; 36]. It's important to note that any pathway doesn't reflect patient experience at all; however, it may be used as a skeleton/basic structured model for developing PEJMs.

The care continuum is a widely used term defining the model that represents the full range of health and care services a patient may use over time, from preventative care to chronic illness management, and end-of-life care [37]. It emphasizes a coordinated, person-centered approach that ensures seamless transitions between different levels of care, such as moving from hospital to home-based care. The care continuum concept has globally been proposed for HIV care by WHO/UNAIDS in 2015, then practically implemented in big cities, countries and regions ("The HIV care continuum is a public health model that outlines the steps or stages that people with HIV go through from diagnosis to achieving and maintaining viral suppression (a very low or undetectable amount of HIV in the blood") [38]. There has been experts' agreement that care continuums reflect rather process of care and desirable outcomes than patient experience (or just narrower aspects of experience related to pathway milestones within healthcare).

The significant diversity of opinions or even contradictory points of view and definitions were found around the term of patient journey. Positions and attitude of patient communities to the term "patient journey" are vary: some communities accept such term, support and use it widely; some disapprove and criticize it, suggesting alternatives. Within scientific and professional communities this term has been in broad use both formally and informally with many connotations: patient pathway, step-by-step algorithm, individualized patient experience, common pattern or generic patient experience, customer journey, patient experience journey, and others [39–49]. More recent publications always connotate patient journeys with patient experiences living with certain medical conditions [34; 39; 50–57]. Generic patient journeys are also being presented distinctly from standard pathways, highlighting presence of PED associated with specific milestones, or stages. European Reference Network for rare Neurological Diseases (ERN-RND) and EURORDIS, having extensive experience within PEJM development for several rare conditions indicate two essential elements for patient journey development: they are being developed driven by patients' or caregivers' expertise, and they should be focused on unmet patient needs and service gaps ("..Patient Journey offers a straightforward approach to improve the quality of healthcare services by making visible the needs and experiences of patients and/or caregivers who have become experts through their lived experience. Patient Journeys can serve to identify and fill the gaps in care pathways for rare conditions, as well as they can also be used for other purposes, for example, to ensure that clinical guidelines are developed to meet patients' specific and diverse needs and experiences, from symptom onset to follow-up") [58; 59].

Patient journeys are also considered at both individual and community levels reflecting individual patient/caregiver and aggregated/common experiences respectively, which creates additional terminology challenge. Patient experts stressed that metaphorically speaking, two people travelling from point A to point B cannot have the same experience, even though they use the same transportation and accommodation, which with medical means even more complexity for patients living conditions or having comorbidities and taking care. Experts agreed that these terms should reflect individual experience rather than common ones. Many publications still describe aggregated patient experience and title it as "patient journey", however in fact they present PEJM. At the same time, several individual cases are also presented as patient journeys [13; 31; 36].

The first prototypes and attempts to map patient journeys and define the terms "patient experience mapping" (PEM) and "patient experience journey mapping" (PEJM) took place in 2006–2015 from the simple concepts based on disease stages or natural history/epidemiological profiles, sequence/timeline of events, or locations where a treatment/care have been provided [39; 41; 42; 48; 51; 60; 61]. More generally, terminology refers to the consecutive series of 'touch points' between the patient and the service where patient experience is actively shaped [1; 26; 37; 81] as well as process mapping [33; 34; 48], patient journey modelling [41], journey mapping [64], and client journey mapping [28; 56]. Correspondingly, the PEJM or PEM definitions were based on the approaches used: mapping by the key experiences and recommendations over the duration of illness [23; 26; 36; 54; 65]; mapping by location [25; 52; 66]; mapping by event [63; 67; 68]; by roles and input by involved stakeholders [69]; by time of consecutive events [43; 45] and other approaches. In the big scoping review (2022) E. Dawies et al. defines "...patient journey mapping as a patient-oriented project that has been undertaken to better understand barriers, facilitators, experiences, interactions with services and/or outcomes for individuals and/or their carers and family members as they enter, navigate, experience and exit one or more services in a health system by documenting elements of the journey to produce a visual or descriptive map" [70].

S. Mccarthy et al. (2016) proposed patient journey map ontology exploring the 3 dimensions: patient persona, medical timeline and medical pathway and this approach enable the 3- or possibly multi-dimensional/multi-factorial consideration of patient experience within a healthcare system [15]. Notably, the medical pathway has a mixed format and includes the 8 compounds and some of them reflect patient experience, not just pathway, such as emotional journey, physical journey and goals (alongside encounters, tasks, constraints, actors, and device touch points). The proposed patient journey map template is individualized but not aggregated data tool. Finally, authors admit that the developed ontology was intended for modelling healthcare service reform rather than holistic consolidation of PED.

Later research (2022–2025) has been focusing on more holistic consolidation of PED within a pathway of similar frameworks [10; 12; 71–76]. For example, the PEM toolbox (PEMT) was developed as a part of patient focused drug development (PFDD) initiative by US National Health Council (NHC) and partners – to leverage PED generation as critical element of real-world data (RWD) generation and research. PEMT is a resource for understanding symptomology, sequence of events surrounding disease onset and experiences within the health system, and, finally, experiences living with and treating chronic disease [10]. Driven by PEMT and the fact that generation and collection of data from patients' experiences across all aspects of their lives is emerging as a critical aspect in research and healthcare to deliver evidence-based patient unmet needs, health outcomes and impact, PFMD working group developed the PED Navigator – the disease-agnostic tool aimed at meeting the needs of multiple stakeholders and illustrates the potential use of PED in diverse contexts [22]. PED Navigator allows to navigate areas of impact as defined by patients and methods to capture PED as well as to understand the various usage possibilities of PED for various health stakeholders and settings (medicines development continuum, healthcare processes). Public consultations and multi-stakeholder feedback on the piloting and practical implementation of the PFMD PED Navigator highlighted its importance for PEJM development projects and mapping/consolidating several categories of patient experiences and heterogenous sources of aggregated PED [12].

Although there are still terminology challenges and misconceptions, the recent PED and PEJM research has added clarity and better defined the key terms of pathway, patient journey and PEJM (Fig. 2).

2. Evolution of patient experience research

The research conducted has allowed us to identify key historical milestones of patient experience research and understand the evolution of PEM and PEJM initiatives. These findings are summarized at Fig. 3.

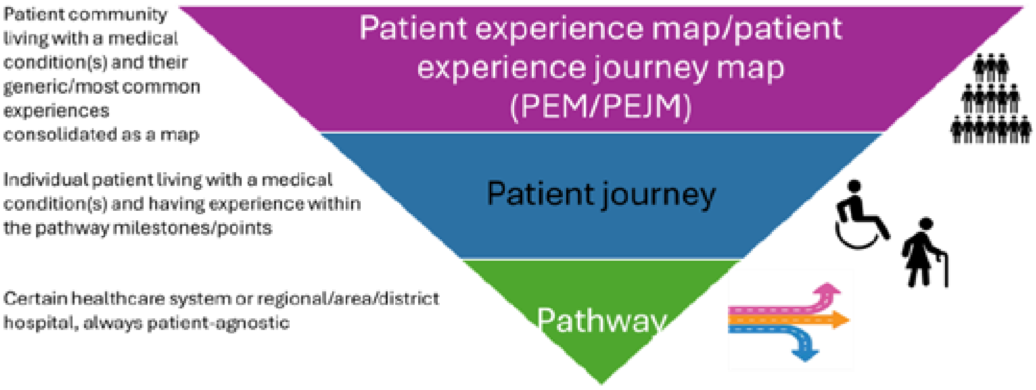


Fig. 2. Summarized terminology and connotation levels for pathway, patient journey and PEJM

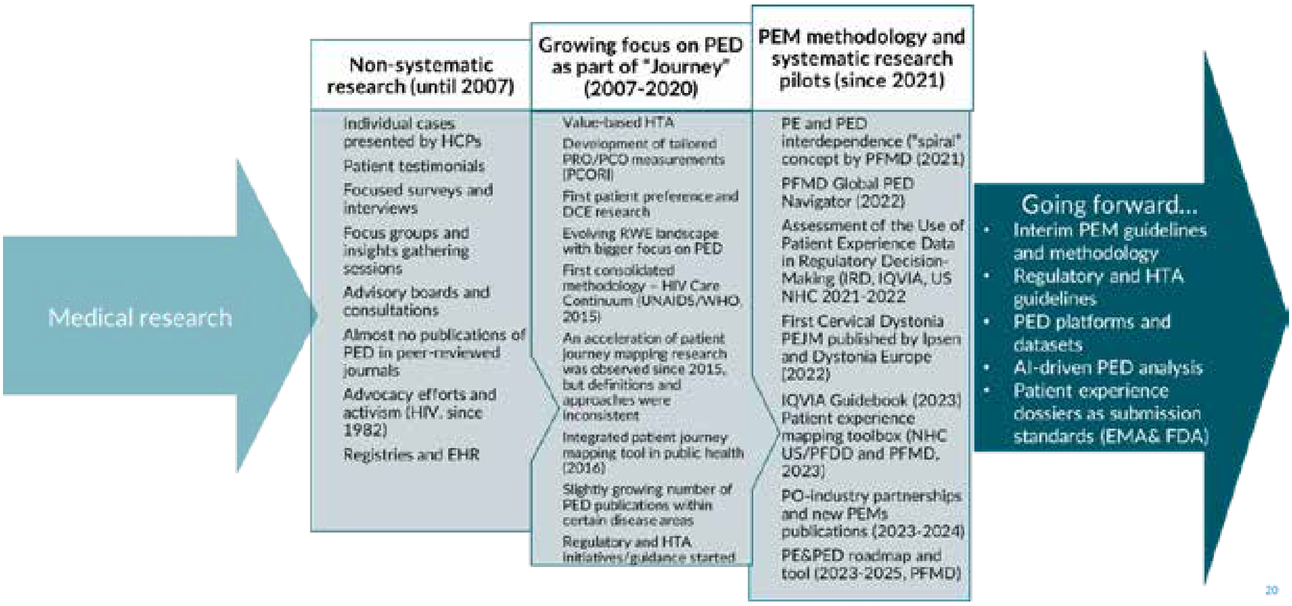


Fig. 3. History and evolution of patient experience research
Abbreviations: HCP – healthcare professional; EHR – electronic health records; HIV – human immunodeficiency virus (HIV infection); HTA – health technology assessment; PRO/PCO – patient reported/ centered outcome; PCORI – patient centered outcomes research institute (US); RWE – real world evidence; WHO – World Health Organization; UNAIDS – Joint United Nations Programme on HIV/AIDS; PE – patient engagement; PFMD – patient focused medicines development; PFDD – Patient focused drug development; US NHC – National Health Council (US); PO-patient organization; AI – artificial intelligence; ENA – European Medicines Agency; FDA – Food and Drug Administration (US)

Over the long period of time, patient experience had not been in focus of medical research. If generated within the clinical trial settings (for example, through patient surveys or interviews as a part of a study design), PED was not separated and therefore not appropriately reported or reported with interpretation by healthcare professionals (HCPs). There had been limited number of PED publications in peer-reviewed medical journals and overall low visibility of PED. Grey literature and unpublished data represented mostly cases or good practices of patient engagement, patient-driven or joint initiatives, policy and advocacy efforts, reports by patient organizations (POs) or HCPs. The earliest example of evidence-driven advocacy and activism is HIV/AIDS campaigns organized on regular basis by patient communities worldwide throughout 80-90 years of XX century, also supported by several healthcare organizations and HCPs [77; 78]. Later, many other disease-focused patient communities prioritized PED-driven advocacy to actualize and substantiate the medicines research agenda [7; 40; 79; 80]. Methodologically, the relatively simple PED generation technics were common and explored broadly by healthcare stakeholders: advisory boards, consultations, focus groups and insights sessions, ethnography, interviews/questionnaires, surveys and more technically advanced, such as registries and electronic health records (EHR) developing the foundation for real world data generation. To summarize this stage, the PED research has not been systematic until late 2000-s.

As mentioned in the above section, since 2006 there has been a growing focus on mapping the patient journey exploring the simple models and embedding PED into the pathways or key journey milestones [13; 39; 41; 51; 60]. Value-based healthcare and outcomes assessment prompted the development and validation of general and condition-specific patient reported outcomes measurements (PROMs), then their inclusion to the studies design as endpoints. Patient-centered outcomes research has been the key scientific focus of the established institution in the US (Patient Centered Outcomes Research Institute – PCORI). Alongside PROs as quantitative type of PED within clinical trial settings, first patient preference studies in the format of discrete choice experiment (DCE) were designed and conducted. Quantitative PED across the real-world settings had better representation over time, however their format and reporting remained inconsistent [16; 21; 79; 82; 83].

First publications on conceptual modelling of patient journey mapping took place in 2015–2016 and they addressed the challenges of public health reforms and care optimization rather than aimed to generate PED throughout the patient pathways [15; 66; 81]. Then, over the period of 2015–2022 the acceleration of patient journey mapping research was observed, with 76.5% increase of articles published (n = 62). However, definitions and methodologies were indefinite and highly heterogenous [70]. Later deep dive analysis on PED publications among several disease and therapeutic areas yielded imbalanced presentation of quantitative vs qualitative PED as well as well-presented vs underrepresented PED by disease and therapeutic areas [84–86]. Finally at this stage, regulators had initiated discussions around patient-focused drug development (PFDD) and importance to consider PED as a part of regulatory and HTA submissions [19].

The last stage of PED research evolution is still ongoing with the new anticipated milestones to be driven by regulators and HTA agencies. It has been started from fundamental research initiatives by US NHC and PFMD based on the paramount "spiral" concept of interdependence and interrelation between patient engagement and PED generation; two important tools have been developed and presented: PEM toolbox and PED Navigator [10; 12; 22; 80]. Some independent assessments took place in 2020–2023 on using PED for regulatory and HTA decision-making and preferred formats of PED presentation [18; 19; 20; 21]. The PEJM emerging methodologies have been supported and piloted by several stakeholders, including patient communities, academic institutions and biopharmaceutical& medical device industry. There were first publications of condition-specific PEJMs developed in close partnership with patient organizations and patient experts but not all PEJMs are being published [71; 72; 73; 87].

Going forward, there is the switch towards qualitative PED and ways to evaluate it with potential value of AI-driven technologies [21; 62; 88]. The multi-sectorial dialog has been initiated, and it's anticipated that next milestones of PED research and PEJM sophistication will be tailoring regulatory and HTA expectations, then requirements in robust patient data.

3. PED generation and PEJM development purposes

PEJM may address different stakeholders' needs. First and foremost, PEJM is being considered as disease awareness and educational tool for people living with medical conditions and their families – to navigate their journeys through the healthcare systems. Patient organizations as PEJM co-developers and partners or owners believe that PEJM (presented or shared in different formats) may be an important resource for planning their patient support services as well as valued source of evidence for advocacy activities [76; 89]. Although there is growing expectation that PED and PEJM should be well communicated and finally published in a peer-reviewed medical journal with plain language summary (PLS), not all developed PEJMs are published due to several reasons. It refers to the purposes of PEJM development, power and robustness of PED used for PEJM, design and format of PEJM, and other factors. Our literature search and experts' opinion identified the following PED generation and PEJM development purposes (Tabl. 1).

4. PEJM conceptual model

E. Cherif et al. (2020) highlighted: "Bringing together findings of patient experience, pathway, and profiles would help all the stakeholders involved to develop better practices for the healthcare process" [23]. The latest patient journey mapping initiatives demonstrated some complexity with key elements and attributes. For example, PED Navigator by PFMD has 4 separately developed tools and each one reflects no more than 2 interdependent areas: areas of impact/specific impact and prioritization approaches/methodologies (tool 2); areas of impact/specific impact and selected and prioritized patient-centered outcomes (tool 3); stakeholders and PED to be used throughout the medicines development continuum/life cycle (tool 4); stakeholders and key milestones of the healthcare process (tool 5) [22]. At the same time, there is no ontology or taxonomy of PEJM multi-attributes with understanding of their interdependence and interrelation. It becomes apparent that like the patient journey map ontology proposed by S. Mccarthy et al. (2016), a similar, but more advanced conceptual model shall be considered for PEJM ontology with holistic inclusion of highly heterogenous PED.

There are the following 8 PEJM attributes in the newly proposed PEJM conceptual model:

1. Stage of a journey/pathway or disease-specific care continuum, or any other relevant milestone.
2. Types of experience.
3. PED publication status.
4. PED source.
5. Types of PED and outcomes measurement.
6. PEJM geographic scope.
7. Disease or therapeutic area.
8. PED presentation type.

Table 1

Identified PED generation and PEJM development purposes

Purpose	Good practice examples and case studies
Disease awareness and education tool	PEM has been published online on the PO web-resource [89]. Upon joint PEJM communication campaign, the disease-related conversations in social media became more intensive and some HCPs acknowledged more newly diagnosed patients in their clinics.
Data exchange with patient communities and national adaptations	Upon peer-reviewed publication of the Global PEJM, the published patient experience was discussed by the members of patient community at the national level. The Nationally adapted PEJM has been agreed. PEJM has been translated into several European languages and available online [59].
Regulatory submissions and decision-making	84% of submissions approved by FDA CDER or CBER by February 5, 2021, contain PRO as PED, 3% – NHS and 3% patient preference study. Proportion of approved NME NDAs and BLAs with patient experience data submitted is higher for many therapeutic areas [18].
HTA Submissions and decision-making	In 2019 NICE and Myeloma UK published an analysis of the patient preference data use for decision making [83]. Acceptance of submissions containing RWE with the focus on HRQoL, burden of illness (BOI), natural history of disease, dis-utilities and treatment patterns were higher in 2022–2021 (n=1508 submissions) [20].
Improve patient experiences and services delivery within a healthcare system	Justifications provided in the published literature for undertaking a patient journey mapping research project (2012–2020) [70]: – Inform health service redesign/improvement (33%); – Develop a deeper understanding of a person's entire journey through a health system(s) (17%); – Identify delays in diagnosis/treatment (12%); – Identify gaps in care/unmet needs (10%); – Evaluate continuity of care across health services and regions (9%); – Understand/evaluate the comprehensiveness of care (8%); – Understand how people are navigating health systems (7%); – Compare patient experiences with practice guidelines/standards of care (3%); – Not specified (1%).
Medicines development strategy	Company initially considered the intravenous administration of the new treatment for HIV, however, upon patient advisory board and several focus groups the decision was made to develop intramuscular injection formulation. Patient experts were concerned that intravenous medicine's delivery may trigger relapses of injectable drug use among certain categories of people living with HIV. Company developed the second candidate/molecule and decided to hold on its further development by having first candidate with better potential. Upon collecting PED where patients highlighted the importance of managing the specific symptoms, the decision was made to continue with the second candidate.
Planning tool	Companies use the patient PEJM to incorporate global business planning or integrated asset development planning templates.
Budgeting, investments, and cost allocations	Study budget has been reviewed as a result of study design/protocol change driver by PED and patient experts' advice (new, active arm, instead of placebo arm).

Abbreviations: NICE – National Institute for Health and Care Excellence (UK); NHS – Natural History Study (also National Healthcare System, UK); FDA CDER – Food and Drug Administration Center for Drug evaluation and research (US); FDA CBER – Food and Drug Administration Center for Biologics evaluation and research (US); NME – new molecular entity; NDA – new drug approval; BLA – Biologics License Application; HRQoL – health related quality of life; HIV – human immunodeficiency virus; PRO – patient reported outcome.

The first and second attributes create the traditional 2-dimentional architecture of PEJM, when several types of patient experiences are relevant to the specific pathway/journey stage or milestone; most of early prototypes and published PEJMs have this architecture as basics. Other attributes characterize the PED aggregated within the 2 dimensions and sorted data out by different categories: publication status, source, format, scope, relevance and presentation type. On exceptional basis (if PEJM is being developed for ultra-rare conditions and no aggregated PED is available), the individual data and insights could be captured, subject of country privacy regulations and agreements with patients and their families.

The proposed PEJM conceptual model is summarized at Figure 4 and more details for attributes are provided in Table 2.

The proposed PEJM conceptual model could be implemented either through manual PEJM development or interactive digital solutions, which is preferable option taking the modern requirements. Those steps are beyond our current research scope and in radar of several stakeholders and initiatives now.

Discussion of research results

Over the relatively short period of time, patient journey mapping concepts have been transforming from public health/healthcare systems' tools driven by the intention to improve pathway – to the holistic consolidation of the aggregated and highly heterogenous PED with addressing not only public health challenges, but also the HTA and regulatory requirements as well

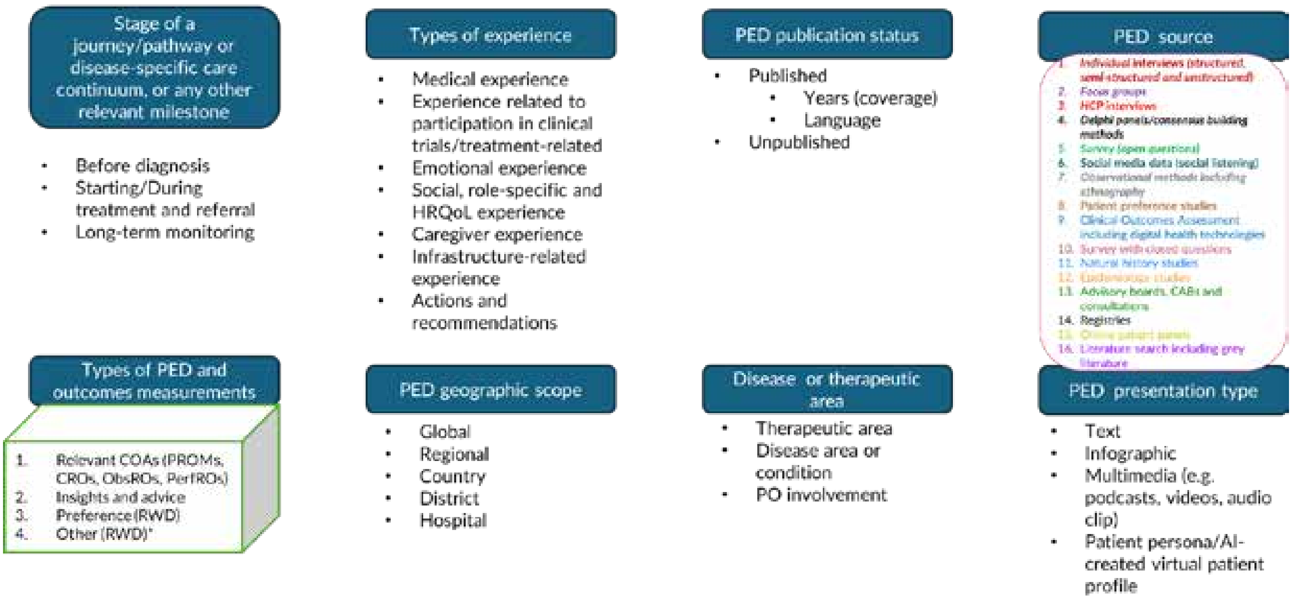


Fig. 4. Proposed PEJM Conceptual Model (Ontology)
Abbreviations: HRQoL – Health related quality of life; CAB – community advisory boards; HCP – healthcare professional; COA – clinical outcomes assessment; PROM – patient reported outcome measurement; ObsRO – observer reported outcome; PerfRO – performance reported outcome; RWD – real-world data; PO – patient organization

Table 2

Proposed PEJM attributes and their characteristics

	Attribute	Characteristics and sub-categorization, if relevant
1	**2**	**3**
1	Stage of a journey/pathway or disease-specific care continuum, or any other relevant milestone	Most medical conditions (including rare conditions) have standard stages, such as pre-diagnosis/diagnosis, starting treatment and events/milestones during the treatment course(s), stable on treatment or surveillance/long-term monitoring. However, this attribute is always condition-specific and may have significant variations. Other pathway/journey mapping principles and milestones categorization apply, as mentioned above: by location (for example, outpatient department-hospital-rehabilitation center etc.); by event (for example, before jaundice manifestation/after); by roles and input by involved stakeholders (for example, patient had been managed by GP, then referred to neurologist, then referred to rehab specialist etc.); by time, natural disease history/progression or consecutive events (for example acute/sub-acute/chronic phase, exacerbations, complications development or long-lasting sequela). Pathway is the subject of significant heterogeneity across healthcare systems/countries, districts and even separate hospitals.
2	Types of experience	– Medical experience: consecutive series of 'touch points' between the patient and the healthcare service where diagnosis-, treatment/health-technology-, prevention-, rehabilitation and medical care directly related experience could be collected. Examples: symptoms and physical manifestations, taking medication and experiencing adverse events, complications and disease exacerbations, co-morbidities' manifestations, peri-operative or peri-natal experience. – Experience related to participation in clinical trials – special type of medical experience, as the treatment/device may not be registered (including first in human studies, device formative studies, and early phases of clinical development). – Emotional experience – patient experience related to psychological status/wellbeing, including but not limited to cognitive function, feelings and emotions. – Social experience, role-specific experience and daily functioning – the separate category of patient experience directly reflecting the disease/condition impact on social life, role, and relationships (employee, friend, partner, parent, family member, financial stability and economic implications). – Health related quality of life (HRQoL) may be considered as the separate integrated PED reflecting impact of the disease/condition on daily life, or as a part of social experience (depending on condition in focus). – Caregiver or care partner's experience: any data shared by people close to a patient or supporting them (parent, partner, child, relative/family member, friend, social worker). In many cases (young children, mental health issues or severe cognitive disorder) caregivers speak on behalf of patients reporting their experience. It is also important to consider impact of a disease/condition on caregivers' lives. – Infrastructure-related experience – special type of patient experience related to certain medical/healthcare setting, resources and services provided: hospital, HCPs/personnel, systems and satisfaction with them. – Actions and recommendations – prospective and incremental type of experience focused on what should be done to change/improve patient outcomes/experience. May include guiding principles, tasks, shared

Continuation of Table 2

1	2	3
		decisions, goals and targeted to several stakeholders: patients themselves, caregivers, POs and patient advocates, HCPs, academic institutions, biopharmaceutical and device industry, governments and health authorities. – Unmet needs, service gaps and patient expectations are traditionally incorporated within the specific type of experience (for example, chronic pain and medicine-induced rash is under medical experience, anxiety or "brain fog" is under emotional/cognitive, long waiting list is under infrastructure-related). However, for some conditions the best practice is to summarize unmet needs (for example, rare diseases), therefore the format may vary.
3	PED publication status	– Published (in peer-reviewed literature) – "Grey literature" might have a consolidated and physically available PED (data on file, web-resource, printed report, slide set), but has never been published – Unpublished The date of publication and original publication language should be indicated.
4	PED source	Any source of PED generated through qualitative, quantitative or mixed methodology should be taken into consideration for PEJM, including but not limited to: – Individual interviews (structured, semi-structured and unstructured) – Focus groups – HCP interviews – Delphi panels/consensus building methods – Survey (open questions) – Social media data (social listening) – Observational methods including ethnography – Patient preference studies – Clinical Outcomes Assessment including digital health technologies (e-diaries, wearables etc.) – Survey with closed questions – Natural history studies – Epidemiology studies – Advisory boards, CABs and consultations – Registries – Secondary use of data – Online patient panels – Literature search including grey literature
5	Types of PED and outcomes measurement	This attribute addresses the question on how PED is being measured (considering the methodological opportunities and limitations, for example, to what extent Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS) specific to reflect patient experience living with cervical dystonia?). PED might be reported through the following measures: – COAs (Quantitative reporting by patients: PROMs; by observers, for example caregivers or independent observers – ObsROs; by clinicians – CROs etc.) – Patient preference (Quantitative or Mixed methods) – Advice, insights, narratives and testimonials (Qualitative methods) – Health records (Mixed) and other RWD.
6	PEJM geographic scope	– Global – Regional – Country/National – District – Hospital level Global PEJM can only reflect generic aggregated PED.
7	Disease or therapeutic area	– Disease or condition area (for example, post-stroke spasticity, pregnancy) – Therapeutic area – Involvement of any PO (disease/condition-focused or umbrella-type patient organization or any other organization or community, if involved in PEJM development)
8	PED presentation type	PED may be presented in different formats, and they define PEJM design and architecture. It is important to differentiate the PED reporting (as described under attribute 6) and PED presentation, as follows: – Text – Infographic – Multimedia (video, podcast/audio) – Patient persona (including AI-created virtual patient profiles, animation etc.) – Other creative design solutions.

as medicines/devices development strategy, target value profiles (TVPs), planning and decision making. Having minimum and unstructured, frequently individualized PED, the early patient journey mapping models were focused on the pathway. In addition, the direct input from patient communities was limited, if not present; those models were driven by public health specialists or HCPs who did seek pathway modification and care optimization. Our research didn't find any fundamental work in relation to PED management and categorization to be done before the first publication of PED Navigator and PEM toolbox, albeit many authors acknowledged importance of patient engagement to get insights or generate any PED.

Dynamic changes within regulatory and HTA environment worldwide, deployment of value-driven healthcare strategies and value-based assessment principles by payors, moving from the concept of target product profile (TPP) to target value profile (TVP) with value attributes and meaningfulness defined by patients, personalization of health technologies, patient advocacy efforts, activism and empowerment of many patient communities as well as broad implementation of the principle "Nothing about us without us!" – prompted deeper academic interest and more planned and systematic PED generation activities by several stakeholders, in close partnership with patient communities. Some PED pool has been generated by patient organizations, but has not been published yet in the peer-reviewed literature. Whilst PED is now considered as vital element of PEJM, and PED generation is the expected milestone of PEJM development, the methodological framework remains inconsistent: what data generation technics should be prioritized, how to generate PED with enough scientific power, how to generate publishable PED and therefore PEJM, how to made PED more available for all stakeholders, how to mitigate possible risks and address data privacy requirements, and other questions. It becomes apparent that regulators and HTA authorities will shape the methodology and address those questions in the overseen future informing the requirements for PED in submissions and throughout the appraisal procedure.

The series of FDA guidelines on PFDD as well as EMA reflection paper on PED have set some basic recommendations and expectations from PED as part of NDA submissions, albeit more detailed technical documents are yet to be developed and endorsed. Regulators encourage early discussions with stakeholders and developers to agree what type(s) of PED to be generated and to be used to measure the value of a technology under development. Regulators welcome the PED diversity and acknowledge that while some types of PED (such as patient-reported outcomes, PROs) have already been accepted as efficacy endpoints for clinical trials, there is less experience with other PED types such as patient preferences or with qualitative data from patient engagement activities. Special focus is supposed to be made on qualitative PED research throughout the medicines/technology's development continuum alongside healthcare process and real-world settings. The EMA Reflection paper provides specific examples where PED could and should be considered: non-clinical research, clinical trial design, clinical trial conduct, regulatory benefit-risk assessment and decision making, assessment of major contribution to patient care, reimbursement decisions and post-marketing safety monitoring. We assume that such expectations will require the dedicated format of PED reporting, presentation and submission, where the proposed PEJM conceptual model may demonstrate methodological value and applicability.

According to the opinion of experts/partners involved in their development, both published and unpublished PEJMs should be used by patient organizations as disease awareness and educational tools. Alongside driving public health and care pathway modification, health technologies and medicines development, regulatory and HTA procedures, such aspects of PEJM may have the direct impact on patient outcomes and ease patient navigation across the national healthcare systems. However, such assumptions on PEJM impact require further analysis and evidence. PEJM should be assessable to public and national patient communities, which can be addressed through open access publication and parallel provision of a plain language summary (PLS). Generic global PEJM may or may not be nationally adapted, subject of a pathway specifics in a country, stakeholders' judgement and regulatory/HTA requirements in terms of PED. If adaptation and PEJM content changes aren't required, a PEJM can be translated into a local language – to ensure clarity and understandability of PEJM content.

Authors must admit the following limitations of this research: the only sources in English were taken into consideration, online search, existence of unpublished resources and cases of good practices authors were not aware of, selection bias of PEJM development initiatives, methodological limitations of expert opinion. The proposed PEJM conceptual model will need further methodological piloting and practical implementation, in particular, through the interactive digital solutions and platforms, taking multi-dimensional nature of PEJM attributes and high heterogeneity of PED. Authors cannot predict to what extent the anticipated PED assessment methodology may explore the existing PEJM models and approaches by regulators and HTA authorities, however, ready to multi-sectorial collaboration in this area expecting more research in the coming years.

Prospects for further research

Prospects for further research are also related to the study of PED use and implementation of the PEJM methodology in Ukraine.

Conclusions

By exploring the combined methodology, this study provides a detailed landscape of patient experience research evolution, clarifies terminology, defines categories of PED, highlights the purposes for PED generation and PEJM development, and substantiates the PEJM conceptual model based on the proposed multidimensional ontology.

PED is critical driver for value-based healthcare and involves diverse data types capturing people lived experiences. Patient engagement is essential for generating robust PED. Over the long period of time, PED was reported and published inconsistently across several disease and therapeutic areas also being disconnected from pathway research and analyses. Methodological unclarity and terminology challenges exist around pathways, care continuums, patient journeys, and PEJM.

PEJM is evolving as a strategic approach across healthcare sectors, supported by recent initiatives such as PFMD PED Navigator and US NHC PEM Toolbox. Patient Experience Journey Mapping (PEJM) consolidates heterogeneous PED sources into actionable insights and recommendations to provide disease awareness and education for patient communities, inform healthcare decision-making, strategies, planning, HTA and regulatory submissions.

Expert input and bibliosemantic research over the period of 20 years informed the development of the PEJM conceptual model driven by the 8 PED attributes. Although this model summarizes existing approaches and good practices, it could be implemented further through interactive digital solutions. Additional PEJM research and more detailed guidance is anticipated to address regulatory and HTA requirements in terms of PED submissions and appraisal procedures.

References

1. Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Qual Saf Health Care. 2006;15:307–10.

2. Defining Patient and Human Experience; Available from: https://theberylinstitute.org/defining-patient-experience/ (Accessed 3 November 2025).

3. EMA Reflection paper on patient experience data (29 Sept 2025); Available from: https://www.ema.europa.eu/en/patient-experience-data-ped-reflection-paper (Accessed 3 November 2025).

4. U.S. Food and Drug Administration (FDA). Patient-Focused Drug Development: Collecting Comprehensive and Representative Input (PFDD Guidance 1 [final]); 2020. Available from: https://www.fda.gov/media/139088/download (Accessed 3 November 2025).

5. U.S. Food and Drug Administration (FDA). Patient-Focused Drug Development: Methods to Identify What Is Important to Patients (PFDD Guidance 2 [final]); 2022.

6. Deane K, Delbecque L, Gorbenko O, et al. Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative; BMJ Innovations. 2019;5:43–5.

7. The global Patient Engagement map and network; Available from: https://patientengagement.synapseconnect.org/ (Accessed 3 November 2025).

8. World Health Organization (WHO): Patient Engagement/ Technical Series on Safer Primary Care. Available from: https://iris.who.int/server/api/core/bitstreams/02ba76d1-b1a8-4bf4-94b5-92fce3ff4c92/content (Accessed 3 November 2025).

9. Gorbenko O. Elevate your patient engagement strategy through data and insights. Presentation at the Reuters Events Pharma 2023 (April 18–20, 2023, Barcelona, Spain).

10. Oehrlein EM, Burcu M, Schoch S, Gressler LE. Enhancing Patient Centricity of Real-World Data Research: An Exploratory Analysis Using the Patient Experience Mapping Toolbox. VALUE HEALTH. 2023;26(1):10–7. DOI: 10.1016/j.jval.2022.10.002.

11.Patient Focused Medicines Development (PFMD). Highlighting recent trends in the fast-evolving patient engagement & patient experience data landscape. Available from: https://patientengagement.synapseconnect.org/resources/highlighting-recent-trends-in-the-fast-evolving-patient-engagement-patient-experience-data-landscape (Accessed 3 November 2025).

12. Willgoss et al. Co-creation of the Global Patient Experience Data Navigator: a multi-stakeholder initiative to ensure the patient voice is represented in health decision-making Research Involvement and Engagement. 2023;9:92. DOI: 10.1186/s40900-023-00503-9.

13. Davies EL, et al. Reporting and conducting patient journey mapping research in healthcare: a scoping review. Journal of Advanced Nursing 2023;79(1):83–100. DOI: 10.1111/jan.15479.

14. Joseph AL, Kushniruk AW, Borycki EM. Patient journey mapping: current practices, challenges and future opportunities in healthcare. Knowledge Management e-Learnimg: Int J. 2020;12(4):386–404. DOI: 10.34105/j.kmel.2020.12.021.

15. McCarthy S, et al. An integrated patient journey mapping tool for embedding quality in healthcare service reform. Journal of Decision Systems. 2016;25;1:354–368. DOI: 10.1080/12460125.2016.1187394.

16. Williams B, Gorbenko O, Gjurovic Culibrk AM. Patient centricity in evidence generation: clinical outcome assessments and gathering patient experience data. Presented at the Medical Affairs Professional Society Annual Meeting, 23–26 March 2025, New Orleans, USA.

17. Almeida D, et al. Leveraging patient experience data to guide medicines development, regulation, access decisions and clinical care in the EU. Front. Med. 2024;11:1408636. DOI: 10.3389/fmed.2024.1408636.

18. Assessment of the Use of Patient Experience Data in Regulatory Decision-Making / Report prepared by Eastern Research Group, Inc. June 2021.

19. Bertelsen N, Dewulf L, Ferrè S, Vermeulen R, Schroeder K, Gatellier L, Sargeant I, Luzuriaga D, Chapman H, Brooke N. Patient Engagement and Patient Experience Data in Regulatory Review and Health Technology Assessment: A Global Landscape Review. Therapeutic Innovation and Regulatory Science. 2024;58(1):63–78. DOI: 10.1007/s43441-023-00573-7. Epub 2023 Sep 24. PMID: 37743397; PMCID: PMC10764510.

20. Samaha D, Engen A, Tavares E, Szawara P. IQVIA Workshop materials on RWE and patient data/ISMPP Europe, London 24–25 Jan 2023.

21. Using Patient Experience Data to Evaluate Medical Interventions. Generating, understanding and using patient experience data within and alongside clinical trials. Editor: Dr Matthew Reaney/IQVIA 2023.

22. Together for improved evidence generation and healthcare decision-making for, and with patients. Discover the first co-created Global Patient Experience Data Navigator now. Available from: https://pemsuite.org/ped-navigator/ (Accessed 3 November 2025).

23. Cherif E, Martin-Verdier E, & Rochette C. Investigating the healthcare pathway through patients' experience and profiles: Implications for breast cancer healthcare providers. BMC Health Services Research. 2020;20(1):735.

24. Gartner J, Abasse KS, Bergeron F, Landa P, Lemaire C, Côté A. Definition and conceptualization of the patient-centered care pathway, a proposed integrative framework for consensus: a concept analysis and systematic review. BMC Health Service Resources. 2022;26;22(1):558. DOI: 10.1186/s12913-022-07960-0.

25. Geerse C, van Slobbe C, van Triet E, & Simonse L. Design of a care pathway for preventive blood pressure monitoring: Qualitative study. JMIR Cardio. 2019;3(1):e13048. DOI: 10.2196/13048.

26. Mulkins AL, McKenzie E, Balneaves LG, Salamonsen A, & Verhoef MJ. From the conventional to the alternative: Exploring patients' pathways of cancer treatment and care. Journal of Complementary & Integrative Medicine. 2016;13(1):51–64. DOI: 10.1515/jcim-2014-0070.

27. Sudbury-Riley L, Hunter-Jones P, & Al-Abdin A. Introducing the trajectory touchpoint technique: A systematic methodology for capturing the service experiences of palliative care patients and their families. BMC Palliative Care. 2020;19(1):104.

28. Dawson S, Gerace A, Muir-Cochrane E, O'Kane D, Henderson J, Lawn S, & Fuller J. Carers' experiences of accessing and navigating mental health care for older people in a rural area in Australia. Aging & Mental Health. 2017;21(2):216–223.

29. NHS Pathways. Available from: https://digital.nhs.uk/services/nhs-pathways (Accessed 3 November 2025).

30. National service model for an integrated community stroke service / NHS England February 2022. Available from: https://www.england.nhs.uk/wp-content/uploads/2022/02/strokeintegrated-community-service-february-2022.pdf (Accessed 3 November 2025).

31. Berrueco R, Caballero N, López-Tierling M, Benedicto C, González-Anleo C, Rodríguez-Nieva N, Nadal D, Vinyets J, Jabalera M. Mapping the Patient Experience in a Pediatric Hemophilia Unit: Our Patient Journey. J Clin Med. 2024;13(20):6235. DOI: 10.3390/jcm13206235. PMID: 39458185; PMCID: PMC11508278.

32. Journey Mapping to Improve Patient-Family Experience and Teamwork: Applying a Systems Thinking Tool to a Pediatric Ambulatory Clinic. Qual Manag Health Care. 2023 Jan-Mar 01;32(1):61–64. DOI: 10.1097/QMH.0000000000000409. PMID: 36579687.

33. Murry LT, Al-Khatib A, Witry MJ. Using journey mapping to understand the patient experience with selecting a Medicare part D plan using a pharmacy consultation service. Explor Res Clin Soc Pharm. 2021 Mar 31; 1:100006. DOI: 10.1016/j.rcsop.2021.100006. PMID: 35479501; PMCID: PMC9030676.

34. Frew GH, Abraham I, Lancaster D, Drake PJH, & Cassell JA. Evaluating the patient experience of an emergency burns assessment service in a UK burn unit using a service user evaluation questionnaire and process mapping. Burns. 2020;46(5):1066–1072. DOI: 10.1016/j.burns.2019.11.004.

35. Gualandi R, Masella C, Viglione D & Tartaglini D. Exploring the hospital patient journey: What does the patient experience? PLOS One. 2019;14(12):e0224899. DOI: 10.1371/journal.pone.0224899.

36. Zoylner IA, Lomborg K, Christiansen PM, & Kirkegaard P. Surgical breast cancer patient pathway: Experiences of patients and relatives and their unmet needs. Health Expectations. 2019;22(2):262–272. DOI: 10.1111/hex.12869.

37. Meyer MA. Mapping the Patient Journey Across the Continuum: Lessons Learned From One Patient's Experience. J Patient Exp. 2019 Jun;6(2):103–107. DOI: 10.1177/2374373518783763. Epub 2018 Jun 25. PMID: 31218254; PMCID: PMC6558942.

38. HIV Care Continuum; Available from: https://www.hiv.gov/federal-response/other-topics/hiv-aids-care-continuum (Accessed 3 November 2025).

39. Ben-Tovim DI, Dougherty ML, O'Connell TJ, & McGrath KM. Patient journeys: The process of clinical redesign. Medical Journal of Australia. 2008;188(6):S14–S17.

40. Crosier A, & Handford A. Customer journey mapping as an advocacy tool for disabled people. Social Marketing Quarterly. 2012;18(1):67–76.

41. Curry JM, McGregor C, Tracy S. A systems development life cycle approach to patient journey modeling projects. Stud Health Technol Inform. 2007;129(Pt 2):905–9. PMID: 17911847.

42. Epstein M, Barmania N, Robin J, & Harbo M. Reforming the acute phase of the inpatient journey. Clinical Medicine. 2007;7(4):343–347. DOI: 10.7861/clinmedicine.7-4-343.

43. Jackson K, Oelke N.D, Besner J, & Harrison A. Patient journey: Implications for improving and integrating care for older adults with chronic obstructive pulmonary disease. Canadian Journal on Aging-Revue Canadienne Du Vieillissement. 2012;31(2):223–233.

44. Martin CM, Grady D, Deaconking S, McMahon C, Zarabzadeh A, & O'Shea B. Complex adaptive chronic care-typologies of patient journey: A case study. Journal of Evaluation in Clinical Practice. 2011;17(3):520–524. DOI: 10.1111/j.1365-2753.2011.01670.x.

45. Momen N, Kendall M, Barclay S, & Murray S. Using timelines to depict patient journeys: A development for research methods and clinical care review. Primary Health Care Research & Development. 2013;14(4):403–408. DOI: 10.1017/s1463423612000618.

46. Percival J, & McGregor C. An evaluation of understandability of patient journey models in mental health. JMIR Human Factors. 2016;3(2):e20. DOI: 10.2196/humanfactors.5640.

47. Sayvong R & Curry J. Using patient journey modelling to visualize the impact of policy change on patient flow in community care. Medinfo 2015: Ehealth-Enabled Health, 216:429–433.

48. Trebble TM, Hansi N, Hydes T, Smith MA, & Baker M. Process mapping the patient journey: An introduction. BMJ. 2010;341:c4078. DOI: 10.1136/bmj.c4078.

49. Yu P. Documenting the cancer journey. Arch Pathol Lab Med. 2015 Mar;139(2):160. DOI: 10.5858/arpa.2013-0562-ED.

50. Bowers D, Fheodoroff K, Khan P, Harriss JP, Dashtipour K, Bahroo L, Dashtipour K, Harriss JP, Khan. The patient journey. European Neurological Review. 2016;11(2):87–95.

51. Doherty D, Benbow SM, Craig J, & Smith C. Patients' and carers' journeys through older people's mental health services: Powerful tools for learning. Dementia: The International Journal of Social Research and Practice. 2009;8(4):501–513.

52. Fennelly O, Blake C, FitzGerald O, Caffrey A, Fletcher L, Smart K, Corcoran S, Shé ÉN, Casserley-Feeney S, Desmeules F, & Cunningham C. Advanced musculoskeletal physiotherapy practice: The patient journey and experience. Musculoskeletal Science & Practice. 2020;45:102077. DOI: 10.1016/j.msksp.2019.102077.

53. Gualandi R, Masella C, Piredda M, Ercoli M, & Tartaglini D. What does the patient have to say? Valuing the patient experience to improve the patient journey. BMC Health Services Research. 2021;21(1):347.

54. Lamprell K, & Braithwaite J. Patients as storytellers of healthcare journeys. Medical Humanities. 2016;42(3):207–209.

55. Outlaw P, Tripathi S, & Baldwin J. Using patient experiences to develop services for chronic pain. British Journal of Pain. 2018;12(2):122–131. DOI: 10.1177/2049463718759782.

56. Schildmeijer K, Frykholm O, Kneck A, & Ekstedt M. Not a straight line-patients' experiences of prostate cancer and their journey through the healthcare system. Cancer Nursing. 2019;42(1):E36–E43.

57. Zomerdijk LG, & Voss CA. Service design for experience-centric services. Journal of Service Research. 2009;13:67–82.

58. EURORDIS Guide to developing a patient journey (2024). Available from: https://download2.eurordis.org/publications/GuideDevelopmentPatientJourney-2024.pdf (Accessed 3 November 2025).

59. Patient Journey. Rare Neurological Diseases different needs at different times. Available from: https://www.ern-rnd.eu/wp-content/uploads/2025/10/ERN-RND_Flyer_PJ_RND_en.pdf (Accessed 3 November 2025).

60. Bessant J, & Maher L. Developing radical service innovations in healthcare – The role of design methods. International Journal of Innovation Management. 2009;13:555–568.

61. Doyle C, Lennox L, & Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open. 2013;3(1):1–18.

62. He Q, Du F, & Simonse LWL. A patient journey map to improve the home isolation experience of persons with mild COVID-19: Design research for service touchpoints of artificial intelligence in eHealth. JMIR Medical Informatics. 2021;9(4):e23238. DOI: 10.2196/23238.

63. Barton E, Freeman T, Baum F, Javanparast S, & Lawless A. The feasibility and potential use of case-tracked client journeys in primary healthcare: A pilot study. BMJ Open. 2019;9(5):e024419.

64. Bearnot B, & Mitton JA. "You're always jumping through hoops": Journey mapping the care experiences of individuals with opioid use disorder-associated endocarditis. Journal of Addiction Medicine. 2020;14(6):494–501.

65. Hoffmann-Vold AM, Bendstrup E, Dimitroulas T, Hesselstrand R, Morais A, Peltomaa R, Smith V, Welling J, Vonk MC, & Wuyts WA. Identifying unmet needs in SSc-ILD by semi-qualitative in-depth interviews. Rheumatology. 2021;15(12):5601–5609.

66. Kelly J, Dwyer J, Mackean T, O Donnell K, & Willis E. Coproducing aboriginal patient journey mapping tools for improved quality and coordination of care. Australian Journal of Primary Health. 2017;23(6):536–542. DOI: 10.1071/PY16069.

67. Kalantari M, Hollywood A, Lim R, & Hashemi M. Mapping the experiences of people with achalasia from initial symptoms to long term management. International Journal of Pharmacy Practice. 2020;28(1):64.

68. Simonse L, Albayrak A, & Starre S. Patient journey method for integrated service design. Design for Health. 2019;3(1):82–97. DOI: 10.1080/24735132.2019.1582741.

69. Sijm-Eeken M, Zheng J, & Peute L. Towards a lean process for patient journey mapping – a case study in a large academic setting. Digital Personalized Health and Medicine. 2020;270:1071–1075. DOI: 10.3233/shti200326.

70. Davies EL, Pollock D, Graham A, Laing RE, Langton V, Bulto L, & Kelly J. Reporting of patient journey mapping in current literature: A scoping review protocol. JBI Evidence Synthesis. 2022;20(5):1361–1368.

71. Artyomenko, et al. Understanding the experience of people living with primary biliary cholangitis (PBC): Further development of an experience map/Presented at EASL 2024. Milan, Italy. 5–8 June 2024. Available from: https://www.postersessiononline.eu/173580348_eu/congresos/EASL2024/aula/-THU_178_EASL2024.pdf (Accessed 3 November 2025).

72. Benson M, et al. Development of a patient journey map for people living with cervical dystonia. Orphanet J Rare Dis. 2022;17:130. DOI: 10.1186/s13023-022-02270-4.

73. Charalambous M, Wilkie A, Ramos DW, Lunde G, et al. Methodology of the experience-based co-design of a post-stroke spasticity journey map by patients, caregivers and healthcare professionals in Europe. Presented at the World Stroke Congress (WSC), Barcelona, Spain 22–25 October 2025.

74. Joseph AL, Monkman H, Kushniruk A, Quintana Y. Exploring Patient Journey Mapping and the Learning Health System: Scoping Review. JMIR Hum Factors. 2023 Feb 27;10:e43966. DOI: 10.2196/43966. PMID: 36848189; PMCID: PMC10012009.

75. Oehrlein EM, Schoch S, Majercak K, Gressler LE, Costantino RC, Love TR, Perfetto EM; National Health Council's Patient Experience Mapping Workgroup. Development and Testing of a Chronic-Disease Patient Experience Mapping Toolbox. Patient. 2024 May;17(3):263–274. DOI: 10.1007/s40271-023-00658-3. Epub 2024 Jan 3. PMID: 38172406; PMCID: PMC11039502.

76. Ramos DW Lunde G, Smiceska MB, Charalambous M, et al. Mapping the journey and experience of people living with post-stroke spasticity / Presented at the European Life After Stroke Forum (ELASF) Prague, Czechia. 10–11 March 2025.

77. Colvin CJ. Evidence and AIDS activism: HIV scale-up and the contemporary politics of knowledge in global public health. Glob Public Health. 2014;9(1–2):57–72. DOI: 10.1080/17441692.2014.881519. Epub 2014 Feb 5. PMID: 24498918; PMCID: PMC3964196.

78. Elford J, Bor R, Summers P. Research into HIV and AIDS between 1981 and 1990: the epidemic curve. AIDS. 1991 Dec;5(12):1515–9. DOI: 10.1097/00002030-199112000-00015. PMID: 1814334.

79. Gorbenko O. The role of patients and community representatives in value-based assessment of health technologies and respective decision-making processes within healthcare. Economic and law of health protection. 2016;2(4):10–22.

80. Schroeder K, Bertelsen N, Scott J, et al. Building from patient experiences to deliver patient-focused healthcare systems in collaboration with patients: a call to action. Ther Innov Regul Sci. 2022;56:848–858.

81. McCarthy S, O'Raghallaigh P, Woodworth S, Lim YY, Kenny LC, & Adam F. Embedding the pillars of quality in health information technology solutions using "integrated patient journey mapping" (IPJM): Case study. JMIR Human Factors. 2020;7(3):e17416. DOI: 10.2196/17416.

82. Hiligsmann M, Liden B, Beaudart C, et al. HTA community perspectives on the use of patient preference information: lessons learned from a survey with members of HTA bodies. International Journal of Technology Assessment in Health Care. 2024;40(1):e17. DOI: 10.1017/S0266462324000138.

83. Measuring Patient Preferences An exploratory study to determine how patient preferences data could be used in health technology assessment (HTA). Project report. Myeloma UK; June 2019. Available from: https://www.myeloma.org.uk/wp-content/uploads/2024/09/NICE-Patient-Preferences-Report.pdf (Accessed 3 November 2025).

84. Ale S, Rosenberg A, Gorbenko O. Mapping the patient experience data across 6 disease areas. Medical Affairs/7BBP0015 Design and Evaluation of Medicines for Human Use; MSc dissertation poster presented at the Symposium of Centre for Pharmaceutical Medicine Research, King's College London, 28 August 2025.

85. Stones SR, Oliver J, Gorbenko O, et al. Characterizing patient experience publications in rare diseases, neuroscience, and oncology. 20th Annual Meeting of ISMPP – Storytelling: Its Art and Power/April 29–May 1, 2024; Washington, DC, USA.

86. Thomas S, Gorbenko O, Oliver J, Elliott K, Stones S, Politt C. Characteristics of Qualitative-Based Patient Experience Data Publications in Rare Diseases, Neuroscience and Oncology/ Presented at the 2025 European Meeting of the International Society for Medical Publication Professionals, 27–29 January 2025, London, United Kingdom.

87. Kushniruk AW, Borycki EM, & Parush A. A case study of patient journey mapping to identify gaps in healthcare: Learning from experience with cancer diagnosis and treatment. Knowledge Management & E-Learning. An International Journal. 2020;12(4):405–418. DOI: 10.34105/j.kmel.2020.12.022.

88. Medical Affairs: Textbook. Chapter 13 "Patient Centricity". Medical Affairs Professional Society. 2024:161–175.

89. 5 key stages in the cervical dystonia patient journey. Available from: https://dystonia-europe.org/about-dystonia/patient-journey/ (Accessed 3 November 2025).

Purpose. This study aims to outline the evolution of patient experience research and PED generation, to analyze the existing methodological approaches and best practices to map patient experience journey and to substantiate the PEJM conceptual model.

Materials and methods. The research combined literature review, expert opinions, and conceptual modeling done from January 2022 to October 2025. A bibliosemantic search covering 20 years (2005–2025) identified 82 eligible sources, including published and grey literature. Expert consultations involved 58 subject matter experts from patient communities, healthcare professionals, and others, conducted in digital and face-to-face formats. Feedback focused on generic patient journeys or pathways, PED sources and generation methods, evidence quality, validation, communication, design and visual presentation of PEJMs. The Patient Focused Medicines Development (PFMD) Working Group's PED Navigator tool also informed the PEJM conceptual model development.

Results. The research highlighted significant variability and inconsistent stakeholders' understanding terms such as pathway, care continuum, patient journey, and patient experience map. Modern usage increasingly associates patient journey mapping with patient experience, identifying unmet needs and service gaps. Many published "patient journeys" are in fact aggregated PEJMs. Early patient journey mapping efforts (2006–2015) focused on disease stages, timelines, or locations of care. Various mapping approaches include key experiences, event sequences, stakeholder roles, and time-based events. Later, the ontology was proposed with dimensions of patient persona, medical timeline, and medical pathway, including emotional and physical journeys. This approach prototyped multidimensional consideration of patient experience but was intended for healthcare service reform rather than holistic PED consolidation. Recent tools like the Patient Experience Mapping Toolbox (PEMT) by the US National Health Council and the PFMD PED Navigator have advanced holistic PED consolidation, enabling navigation of impact areas defined by patients and various methods to capture PED. Based on existing good practices, pilots and prototypes, experts' advice and literature search results, the PEJM conceptual model was developed and substantiated driven by multidimensional ontology with 8 PED attributes.

Conclusions. Although this model summarizes existing approaches and good practices, it could be developed and implemented further through interactive digital solutions and wider piloting by several stakeholders across disease or therapeutic areas. Additional PEJM research and more detailed guidance is anticipated to address regulatory and HTA requirements in terms of PED submissions and appraisal procedures.

Key words: patient experience map, patient journey, patient journey map, patient pathway, experience map.

Мета. Дослідження ставить за мету окреслити основні етапи вивчення досвіду пацієнтів і генерації даних досвіду, проаналізувати наявні методологічні підходи та найкращі практики з розробки мап досвіду пацієнтів, на основі чого обґрунтувати концептуальну модель розробки мапи досвіду пацієнтів.

Матеріали та методи. Дослідження поєднувало кілька методів: бібліосемантичний метод, методи експертних оцінок та концептуального моделювання, що проведені у період із січня 2022 по жовтень 2025 року. Бібліосемантичний пошук, що охопив період 20 років (2005–2025), виявив 82 відповідні джерела, включно з опублікованою літературою та іншими джерелами. У консультаціях взяли участь 58 експертів з пацієнтських спільнот, медичних працівників та інших як у онлайн, так і в очному форматах. Зворотний зв'язок був сфокусований на загальних або індивідуальних маршрутах пацієнтів, джерелах і методах генерації даних досвіду, якості даних та їх підтвердження, комунікації, дизайні та візуальному представленні мап. Інструмент PED Navigator та участь авторів у робочій групі міжнародної програми PFMD також сприяли розробці концептуальної моделі мапи досвіду пацієнтів.

Результати. Дослідження виявило значну варіативність і непослідовність зацікавлених сторін у розумінні і тлумаченні термінів і визначень, таких як маршрут, континуум, шлях досвіду пацієнта та мапа досвіду пацієнта. Сучасне використання дедалі більше асоціює маршрут або шлях пацієнтів із їхнім досвідом, виявленням незадоволених потреб і прогалин у наданні послуг. Багато опублікованих «шляхів пацієнтів» насправді є консолідованими мапами досвіду. Ранні зусилля з розробки мап досвіду пацієнтів (2006–2015) були зосередженні передусім на стадіях захворювання, термінах або місцях надання допомоги. Різні підходи до побудови мап досвіду пацієнтів включають ключові досвіди, послідовності подій, ролі зацікавлених сторін та події, що базуються на часі. Пізніше була запропонована онтологія з вимірами особистості пацієнта, медичної хронології та клінічного маршруту, включаючи емоційний та фізичний досвід життя з медичним станом. Цей підхід виступив прототипом багатовимірного врахування досвіду пацієнтів, але більшою мірою був спрямований на реформу медичних послуг, а не на цілісну консолідацію даних досвіду пацієнтів. Останні інструменти, такі як Patient Experience Mapping Toolbox (PEMT) від Національної Ради охорони здоров'я США та PFMD PED Navigator, інтенсифікували всебічну консолідацію досвіду пацієнтів, що дозволяє орієнтуватися серед сфер впливу, визначених пацієнтами, та різні методи фіксації досвіду. На основі наявних найкращих практик, пілотних проєктів і прототипів, порад експертів і результатів пошуку літератури була розроблена концептуальна модель мапи досвіду пацієнтів та підтверджена багатовимірна її онтологія з 8 атрибутами даних досвіду пацієнтів.

Висновки. Хоча ця модель узагальнює наявні підходи та найкращі практики, її можна розвивати та впроваджувати надалі через інтерактивні цифрові рішення та ширше практичне впровадження зацікавленими сторонами в різних сферах охорони здоров'я. Очікується, що додаткові дослідження мапи досвіду пацієнтів та детальніші рекомендації відповідатимуть вимогам регуляторних органів і експертних агенцій з оцінки медичних технологій у частині подання даних досвіду пацієнтів та процедур їх оцінки.

Ключові слова: мапа досвіду пацієнтів, шлях пацієнтів, мапа шляху пацієнта, процес побудови мапи шляху пацієнтів, процес побудови мапи досвіду пацієнтів, маршрут пацієнтів.

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