

Review Article

How can we describe impact of adult patient participation in health-service development? A scoping review



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ABSTRACT

Objective: Patient participation represents a worldwide policy, but its impact lacks research. This study investigates impact of patient participation in health-service development by providing a comprehensive overview of how the literature describes it.

Method: A scoping review with a broad search strategy was conducted. The literature was examined for study characteristics, purpose for, approaches to and impact of patient participation. The data were analyzed using a thematic analysis.

Results: The 34 included primary studies reported impacts of patient participation that were interpreted to constitute two categories: 1. The participatory process' impact on involved patient representatives and health professionals, and the organization's patient participation practice itself. 2. The participatory service developments impact on the design and delivery of services regarding patients and health professionals, and the organization.

Conclusion: The literature describes a broad variation of impacts from health-service development, relevant for health professionals and patient representatives when initiating or participating in such processes. Our review provides an overview and discussion of these types of impact.

Practice implications: The findings can be of practical relevance to those aiming to develop services, quality indicators regarding effects of patient participation, or to further investigate aspects of participatory service development.

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1. Introduction

Patient participation in health-service development, represents a longstanding policy worldwide [1–3]. Motivated by democratic, consumerist or efficiency promoting intentions [4–6], governments encourage patient participation when health services are to be developed or enhanced [6–9]. The aim is to offer services that suit patients' needs [6,10–12].

Patient participation can be understood as depicting “the common goal to include the patient in the healthcare system” [12, p. 5] across relations between health professionals and patients in their treatment (micro-level), health services organization (meso-level), and society and its governing authorities (macro-level) [12]. In this scoping review we investigate patient participation in the context of health-service development. The term *patient participation* as used in this review refers to the meso-level and “... the active participation in planning, monitoring, and development of health-services of patients, patient representatives, and wider public as potential patients” [13, p. 1]. We apply the term *patient representatives* (PRs) when referring to persons with experiential knowledge involved in health-service development who may or may not be affiliated with a patient organization. The term *patients* as used here addresses persons receiving health services, including their **informal carers**. Furthermore, *health professionals* (HPs) as used here refers to professionals of different occupations in health-services and social-services, including managers and administrators.

Research supports that incorporating user perspectives can enhance care delivery and governance and inform organizational health care policy and planning [14]. Patient participation is also associated with improved quality, responsiveness, access to and use of services, and better health outcomes [15]. However, despite the governmental encouragement and potential benefits, engaging persons with experiential knowledge in service development is not a common practice within healthcare [7,16–21]. HPs also express uncertainty about “(. . .) why and how to do involvement well and how to involve and support a diversity of patients and the public, rather than a few selected individuals” [8, p. 627].

This review is part of a larger participatory research project aiming to contribute to enhance involvement practices in health service development. The project is instigated due to a need for research concerning approaches to patient participation in health-service development [15,21–23], and what impact combining patient and professional knowledge in health service development may have [11,14,17,18,21,22,24]. Despite being part of a participatory research project, this review investigates patient participation in health-service development, not patient participation in research. The investigation is also limited to the development of services for adults with chronic mental or physical illness or conditions, or disabilities (Appendix A).

This review intends to provide an overview of existing research concerning impact of adult patient participation in health-service development. We will use the findings to make further inquiries about the characteristics, context and impact of participatory health-service development, in separate sub-studies. This means that even though approaches to and impact of patient participation

in health-service development depend on the context in which they take place [15,18], in this review we choose to identify impacts in a broad sense and outside of contextual aspects.

The objective of the current scoping review is therefore to investigate how impact of adult patient participation in health-service development is described in the literature. We focus the following questions:

- What characteristics of the studies, the study participants and the service development with patient participation are described?
- What purposes for and approaches to patient participation are reported?
- What impacts associated with patient participation in health-service development are described?

2. Methods

Patient participation in health-service development is an emerging field of research, and the literature is based on a wide range of study methodologies [11,18,25]. The scoping review process described by Arksey and O'Malley [26] is considered relevant in new fields of research characterized by a variety of study methodologies and where “(. . .) the trajectory of published articles of some content areas makes it difficult to ascertain the extent of the landscape” [27, p. 1]. We thus have chosen to conduct a scoping review according to Arksey and O'Malley's [26] five-stage framework, as enhanced by Levac [28] and Daudt [29]. This involves synthesizing results from research of different designs, making it important to show how the analysis are conducted and ensure that the included studies are of good quality [28].

2.1. Overarching participatory approach

The study-group involved in this scoping review included one co-researcher with experiential knowledge trained in research methods, one experienced healthcare professional trained in research methods, one researcher experienced in patient participation theory and research, one researcher experienced in the scoping review methodology and next of kin research, and one healthcare professional and PhD-student who also initiated the project. The members have been involved in all stages of the review process.

2.2. Broad search strategy and database search

The study-group was heavily involved in defining the search strategy, a highly iterative process. We ended up with applying a broad variety of synonyms, conducting many and extensive pilot searches and reviewing abstracts while simultaneously enhancing the search strategy and clarifying the inclusion and exclusion criteria. A senior academic librarian, in close collaboration with the first author, developed a systematic literature search using MeSH-terms and free text search terms combining a comprehensive set of synonyms and terms for patient participation in health-service

Table 1
MeSH-terms and free text search terms applied in the search*.

MeSH-terms	Free text search terms and synonyms
Patient participation	patient, user, representative, carer, caregiver, lay, stakeholder, public, client, in combination with participation, involvement, collaboration, engagement, evaluation, consultation, view, express, perspective
Service development	health-services, delivery of healthcare, quality of healthcare, quality improvement, healthcare reform, health-service planning, hospital, rehabilitation, mental health-services, primary care services, community services

* The list is not exhaustive.

development. The searches complied with the PICO principles, and applied a combination of “OR” within groups and “AND” between groups. The terms applied in the search included terms from the databases’ thesauruses and free text term (Table 1).

Searches were conducted in Medline (Ovid), Embase (Ovid), PsycInfo (Ovid), Cochrane Library (all) and SweMed + during March 2019. The search strategies were peer-reviewed by another librarian. To avoid bias, no restrictions concerning date, language, publication type or study design were applied. The complete search strategy is displayed in Appendix B.

The search of the online databases resulted in 12 235 articles when duplicates were removed. Our broad search strategy led to a high number of studies, including many irrelevant ones. The first author initially sorted through the studies, leaving 167 titles and abstracts for further evaluation. Of these, 97 titles were retrieved to be read in full text and to have their reference lists manually checked for additional titles. This process rendered 110 full text articles to be read by the first author and a member of the study-group. Of these, 76 were excluded, leaving 34 primary studies to undergo analysis in this review (Fig. 1).

2.3. Inclusion and exclusion of studies

In order to be included, studies were required to describe service development initiatives in health services for adults with

mental or physical chronic illnesses or conditions or disabilities, report an approach to participation and describe some form of impact of the involvement. Although the study-group mainly agreed about the inclusion of studies, agreeing on how to understand impact of patient participation required discussion, echoing previous research stating that identifying impact is a complex task [8,11,13,14,18,21,30–33]. The complete inclusion and exclusion criteria are displayed in Appendix A.

To be included in this review, the studies also had to pass an MMAT assessment [34], ensuring that they held a good methodological quality (Appendix C).

2.4. Analysis of impact of patient participation

After having included the 34 primary studies constituting this review, we charted each study’s objective, design, type of service development initiative, purpose for and approach to patient participation in service development, results and conclusion.

We conducted a thematic analysis in order to identify, analyze and synthesize the extracted data [35]. We identified studies that stated or implied the purposes for involving PRs in service development. Discussing the purposes and grouping by similarities, we interpreted the purposes to belong to four categories (Table 2). Relying on a broad understanding of impact, we identified impacts of patient participation, discussing them and

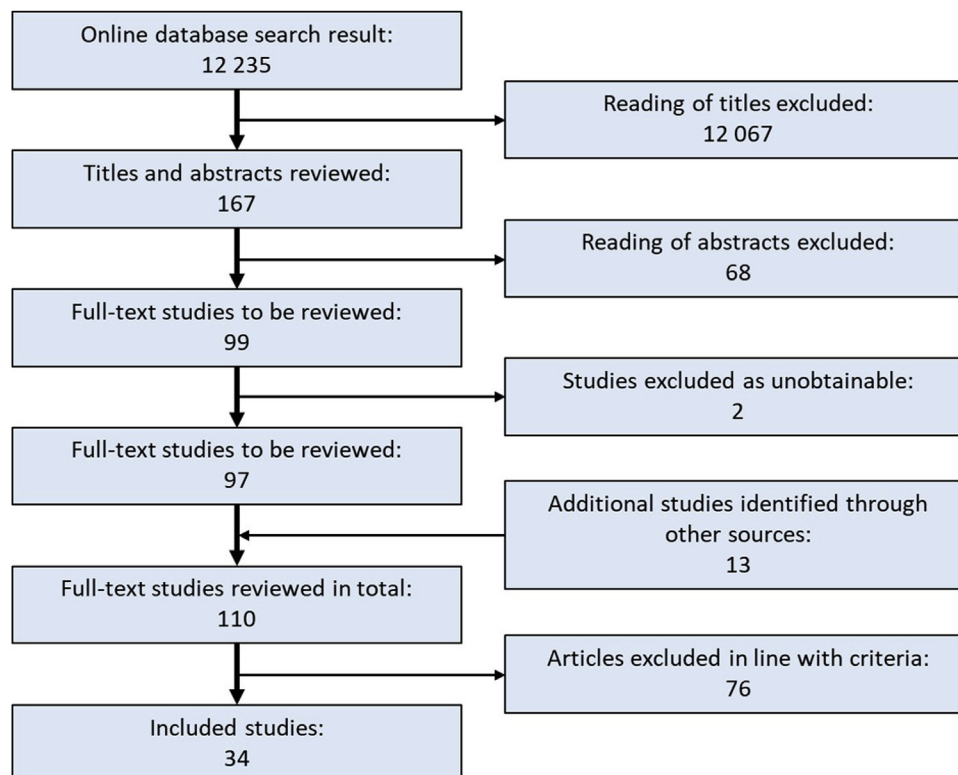


Fig. 1. Included and excluded studies .

Table 2
Summary of reported purposes for patient participation in health-service development.

Type of purpose	Primary studies* [ref.]
To develop or enhance services of an organization	[49], [61] [63],
To develop patient participation strategies or routines in an organization	[36], [42], [54], [60] [64],
To evaluate a service development intervention	[38], [46] [59],
To evaluate patient participation as part of a service development intervention	[52]

* A total of 12 studies had reported or implied the purpose for patient participation.

grouping by similarities. 66 different impact groups emerged, which we named according to type. Then we examined the various types of impact, searching for overall categories. We identified two main categories based on whether the specific impact could be attributed to the process of collaborating to develop the health-service, or to the outcome of that process – to the design and delivery of services. We subsequently found that the two main categories could be understood to represent three impact areas each – connected to what their impact was seen to affect. Each identified type of impact was placed in one of six impact areas (Tables 3 and 4).

The study-group validated the results of the thematic analysis by examining their relevance and applicability. Then they carefully scrutinized the analysis as a whole, and the results from our scoping review were finalized.

3. Results

The findings of the 34 primary studies included in the current review are presented in accordance with the three research questions.

3.1. Characteristics of primary studies

The studies' characteristics are displayed in Table 5. All of the included studies were conducted in one of eight Western countries. Near half were from the United Kingdom (Table 6).

They were carried out between 1998 and 2017, with the majority (23/34) after 2010.

The studies' objectives represented a wide range (Table 5). Only three studies aimed to assess impact of involvement in service development [36–38]. A third of the studies (12/34) reported involving patients or PRs as partners in research groups or research processes [36,39–49]. Based on their own findings, half of the studies (18/34) provided advice on how to conduct successful collaborative health-service development (Table 7) [39,40,42,45,46,48,50–61]. The four most frequently listed success criteria were to ensure leader support (3/18), clarify roles and expectations (6/18), embed PRs as part of the team (4/18), and establish mutual respect among the participants (5/18).

Most studies had a qualitative research design (29/34), whereas one [38] relied on a mixed-method design, two [36,62] on a quantitative non-randomized design, and another two [63,64] on a quantitative descriptive design (Appendix C). Two thirds (23/34) employed two or more research methods to generate data. The most frequently used methods were in-depth interviews (24/34), observation (11/34) and focus group interviews (10/34). Seven studies applied questionnaires or surveys to produce data.

3.1.1. Study setting, diagnosis and participant characteristics

The settings of the 34 studies are displayed in Table 5. Two thirds (22/34) of the studies researched aspects of specialized care. Those performed in primary care settings (11/34) included studies of homebased services and health promoting activities. An

Table 3
Summary of reported impact of patient participation on involved patient representatives (PRs) and health professionals (HPs), and on the organization's involvement practice.

PRs*	IMPACT OF THE COLLABORATION PROCESS ON: HPs**	The organization's patient participation practice
Aided in dissemination and implementation	Changed attitudes toward UI positively	Decreased power imbalances between staff and patients
Balanced out power differences among patient participants	Enhanced understanding of patients' situation	Expanded UI practices outside organization
Conformed to managerial control	Increased insight into patients' needs	Expanded UI practices within organization
Empowered	Increased collaboration competency	Fostered mutual understanding and accountability
Enhanced collaboration skills	Increased empathy for patients	Hired PRs to motivate organizational change
Enhanced understanding for professionals' work	Increased motivation for organizational change	Increased community participation
Enhanced UI experience through normative managerial control	Increased opportunities to listen and reflect on practice	Increased informal communication between the involved outside project
Expanded social network	Raised concerns about representativeness	Integrated patient perspective
Experienced fear of repercussions	Realized the need to know how to involve patients in service development	Involved patient representatives in professionals' education
Experienced lack of confidence owing to not knowing what was being discussed	Realized that resources are needed for service development with UI	
Experienced reluctance to be involved	Realized the need for a skilled facilitator for service improvement with UI	
Experienced wariness about being the only PR	Resolved anxiety over issues of tokenism and representativeness	
Fostered self-development	Saw UI as time- and resource consuming	
Increased need for education and support		
Increased well-being and/or belonging		
Marginal impact possibilities due to professionals' conduct		
Took on a professionalized PR role		

* The patient representatives (PRs) speak on behalf of patients (including carers) in the service development.

** The health professionals (HPs) are professionals of different health related occupations, including managers/administrators, involved in the service development.

Table 4

Summary of reported impact of patient participation on design and delivery of services related to patients, health professionals (HPs) and the organization.

Patients*	IMPACT ON DESIGN AND DELIVERY OF SERVICES RELATED TO:	
	HPs**	The organization
Decreased wait times and accelerated admission process	Changed clinical practice	Decreased costs
Enhanced access to services	Enhanced patient centered orientation in care	Decreased hospital admissions
Enhanced patient satisfaction/experience	Increased carer involvement in clinical work	Employed lay workers to enhance services
Enhanced relevance of services	Increased UI in clinical work	Enhanced accreditation measures and transparency
Improved health outcomes	Increased time spent in direct contact with patients	Enhanced patient information/communication
		Enhanced patient safety
		Established new arenas for collaboration
		Established new position for professional or advocate
		Established new service/project
		Increased referrals to the organization
		Increased service coverage/number of services
		Increased service efficiency
		Made changes to enhance services and service delivery
		Prioritized service provision and improvements
		Reached more of the hard to reach patients
		Realized the need for financial support for UI practices
		Shifted organizational culture toward more involvement

* The patients (including carers) of the services that have been developed with patient participation.

** The health professionals (HPs) working in the organization which have undergone service development with patient participation.

essentially equal number of studies focused on services related chronic illness (13/34) and mental illness (12/34). However, some studies addressed service development covering several diagnoses, while others described service development concerning the organization as a whole and did not address any specific diagnosis or condition.

The characteristics of the study participants were generally not reported. This may have been to protect anonymity, or because such information was not considered relevant to the research questions. The eight studies [36,37,41,45,47,52,60,65] that did convey this information revealed a total of 2591 participants between the ages of 18 and 67 years, of whom 1525 (59 %) were women.

3.2. Purpose for and approach to patient participation

Looking for possible trends, we identified the included studies' that reported purposes for and approaches to patient participation. A third (12/34) of the studies [36,38,42,46,52,54,56,60,61,63,66,67] reported or implied why PRs were invited to engage in the health-service development, and each purpose belonged to one of four categories (Table 2). As white-papers encourage patient participation, the researchers in the remaining studies may not have thought it necessary to express the involvement purpose, or they may not have had a clear purpose, other than ensuring participation.

Patient participation was carried out in many ways in the studies (Table 8), and several studies reported engaging PRs in different ways in different phases. In some studies, patient participation approaches in the service development project were the same as in the research, for example where the study applied a participatory action research design. The most frequent approach was PRs being members of working groups aimed at developing services (18/34), second to acting as members of patient councils (10/34).

Cross referencing the purposes with the reported involvement approaches, we found no indication that any of the purposes and involvement approaches appeared more often together than others.

3.3. Impact of patient participation

The studies included in this scoping review report an array of impacts of patient participation (Appendix D) which we subdivided into two categories: 1) *impact of the participatory service*

development process (Table 3) *impact of patient participation on the design and delivery of services* (Table 4).

3.3.1. Impact of the participatory service development process

We here present the impact of collaboration between PRs and HPs. The impact areas are differentiated according to what this process is interpreted as affecting, namely: 1) the involved PRs 2) the involved HPs, or 3) the patient participation practice itself.

3.3.1.1. Impact of the collaboration process on the PRs. In 10/34 studies [46,49,52,54,60,65–69], the authors reported that PRs enhanced their collaboration skills as a result of being involved in the service development. Participating in service development was also reported to have fostered PRs' personal growth in seven studies [38,42,66–70]. This impact may reflect on another impact noted in 8/34 studies, namely that the PRs felt empowered by their participation [49,55,65,67–70].

In 5/34 studies [36,47,63,65,66], PRs reported feeling a sense of well-being or belonging due to participating in service development. This may be associated with an expansion of the PRs' social network, an outcome reported in three studies [45,66,69]. For example, Roberts and co-workers [66] reported that involved PRs perceived the collaboration group as "a home base" and a place to meet others.

Another reported impact was that PRs aided in dissemination and implementation of the service development projects in which they were involved (7/34) [36,40–42,49,54,67]. This may be related to PRs' capacity-building and enhanced understanding of professionals' work [65,66,68]. This may also be related to findings revealing that the PRs took on a professionalized role in the service development, extinguishing the boundaries between being a professional and a person with experience [54]. This entailed the PRs being employed and paid for their services.

Not all collaborative service development led to positive experiences for the PRs involved. Speaking one's mind in the group also led to fear of repercussions [48,68], lack of confidence [48], wariness of being the only representative present [48], and reluctance to be involved in similar processes in the future [48,57]. This may be associated with PRs feeling a need for education and support in order to contribute meaningfully (4/34) [43,48,51,57], or that they have limited possibilities to influence the process due to professionals' attitudes or conduct (4/34) [51,53,54,69]. Such challenges may have caused PRs to allow managers to control the process and its outcomes, as reported in four studies [47,51,65,69].

Table 5
Characteristics of primary studies and nature of involvement in the primary studies.

AUTHOR, YEAR [ref].	COUNTRY	CHARACTERISTICS OF PRIMARY STUDIES			NATURE OF PATIENT PARTICIPATION	
		Study setting	Diagnosis	Study objective	Purpose of patient participation	Approaches to patient participation
Armstrong et al., 2013 [39]	UK	Specialized care - outpatient services	Lung cancer, Abdominal Aortic Aneurysm, Chronic Kidney Disease	To characterize and identify the strengths and weaknesses of contrasting approaches to patient involvement in quality improvement.	Not reported	Members of program projects' core teams.
Baker et al., 2016 [40]	Canada	Specialized care - outpatient services	Not reported	To describe three initiatives to engage patients in quality improvement and health system redesign efforts in three Canadian healthcare contexts and identify key success factors in these efforts.	Not reported	Members of projects core team. Members of steering committee, evaluation committee and research team preparing grant applications. Recruiters of other patient advisors.
Berg et al., 2015 [41]	Norway	Specialized care - outpatient services	HIV/AIDS	To present a unique example of how service users' involvement led to a complete organizational redesign of an outpatient HIV clinic in Southern Norway.	Not reported	Leader and members of patient board. Engaged in research process.
Boaz et al., 2016 [42]	UK	Specialized care - inpatient services	Lung cancer and acute illness	To explore the different roles adopted by 63 patients that emerged during and after four participatory quality improvement interventions, and the nature of their impact upon implementation processes and outcomes.	To enhance understanding about how to facilitate local quality improvement implemented by patients and staff working together.	Engaged (patients and carers) in patient events for sharing of experiences, co-design group work, implementation and evaluation work.
Brooks, 2008 [50]	UK	Specialized care - inpatient services	Not reported	To explore the relationship of the nPRsing profession to public participation as enacted through a UK-based patient and public council, located in an acute hospital.	Not reported	Members of Patient and Public Council.
Cook et al., 2010 [43]	USA	Specialized care - outpatient services	Mental illness (mainly bipolar disorder), substance addiction, diabetes, heart disease	To describe a public-academic collaboration between a university research center and the Texas state mental health authority to design and evaluate a unique "money follows the person" model called self-directed care.	Not reported	Members of the Community Advisory Board. Recruited and hired the program's director and Self-Determination-Care advisors. Involved in all stages in the projects Participatory Action Research.
Croft et al., 2016 [51]	UK	Specialized care - inpatient services	COPD and other diagnosis	To explore public involvement in different health settings, particularly in relation to how managers influence public involvement.	Not reported	Members of Patient Refence Groups, commissioning organizations and governing bodies. Part of consultation events with the general public in local geographical areas. Member of project group.
Curry, 2006 [44]	UK	Primary care - outpatient services	COPD	To evaluate the impact of the urgent care team, to find out whether it represented an improvement in service provision for patients and so guide improvement and development of the service.	Not reported	
de Souza et al., 2016 [45]	UK	Specialized care - outpatient services	Rheumatic disease	To improve the patient experience of rheumatology outpatient services with three distinctive strands: (i) formation of an independent patient group, (ii) initiation of patient educational evenings, and (iii) development of a mobile application.	Not reported	Members of project group and of independent patient group. Participants in focus groups. Involved as patient experts in patient education activities.
Forbat et al., 2008 [46]	UK	Specialized care - inpatient services	Lung cancer	To identify the role of engaging people affected by cancer in service development in influencing healthcare professionals and service users' attitudes toward, and enactment of, engagement.	To investigate how engaging service users in service development may influence healthcare professionals and service users' attitudes toward, and enactment of, engagement.	Members of collaborative working groups and health boards. Patients with experience from the service and family members participated in focus group discussions prior to and following the intervention to evaluate the service development.
Grogan et al., 2012 [67]	Ireland	Specialized care - inpatient and outpatient and weekend services	Haemophilia	To describe the development of a patient partnership program and its impact on quality improvements in a comprehensive haemophilia care service.	Not reported	Involved in focus groups to explore patient experiences with services. Members of new Patient Partnership Panel.
Kennedy, 2010 [66]	UK	Primary care - outpatient services	Not reported	To explore the experiences of lay food and health workers and professionals involved in delivering local food and health initiatives, to improve understanding of the perceived benefits associated with their involvement and wider opportunities for promoting health.	Not reported	Engaged as lay-workers in community-based public health initiatives. Involved in focus groups to explore experiences with lay engagement.

Table 5 (Continued)

AUTHOR, YEAR [ref.]	COUNTRY	CHARACTERISTICS OF PRIMARY STUDIES			NATURE OF PATIENT PARTICIPATION	
		Study setting	Diagnosis	Study objective	Purpose of patient participation	Approaches to patient participation
Lavoie-Tremblay et al., 2014 [52]	Canada	Specialized care - inpatient services	Chronic illness	To explore the perceptions of healthcare workers about engaging patients as partners in care redesign teams under a program called Transforming Care at the Bedside (TCAB), and to examine the facilitating factors, barriers, and effects of such engagement.	To investigate health-care workers' opinions about partnering up with patients.	Partners in redesign teams engaged to communicate with patients and their families about tested changes, in implementing service development and increasing engagement from patients and their families in the redesign process. Patient representatives were involved with hospitalized patients and joined in all the discussions, planning, and actions of the redesign teams.
Malfait et al., 2017 [53]	Belgium	Specialized care - inpatient services	Not reported	To determine the impact of a stakeholder involvement committee on hospital policy and to map the decision processes by which this impact was achieved.	Not reported	Members of Stakeholder Involvement Committees involved in hospital policy decision-making.
Martin & Finn, 2011 [54]	UK	Primary care - outpatient services, homebased care, health promotion activities	Cancer	To utilize literature to offer new insights into the practice of service-user involvement.	To provide new insights about involving service users.	Partners with professionals in management teams responsible for managing and developing new services. Members of service user forums and steering groups. Members in regular multi-disciplinary teams and in project-management teams.
Nathan et al., 2014 [68]	Australia	Primary care - outpatient services	Not reported	To provide a view from Community Representatives' perspectives, which challenges many assumptions about how they choose to act and how they may impact health-service policy and practice.	Not reported	Members of a range of hospital (clinical, quality improvement) and community led committees. Part of Community Representative Networks. Engaged in Community Participation conferences.
Newton et al., 2013 [61]	Australia	Primary care - outpatient services, homebased care, health promotion activities	Anorexia nervosa	To report on the development of the Body Image, Eating Disorder Treatment and Recovery Service and its initial 18-month evaluation.	To develop and implement a model for a community eating disorder service bridging the primary and specialist continuum of care.	Local stakeholders, consumers, carers and non-government organizations were consulted about service improvement. Patients entering the service were interviewed and completed a battery of self-reported measures at intake and at a 12-month follow-up.
Peikes et al., 2016 [69]	USA	Primary care - outpatient services	Not reported	To identify important considerations for primary care practices and other providers considering establishing Patient and Family Advisory Councils, as well as ways to improve established Patient and Family Advisory Councils and areas for future research.	Not reported	Members of Patient and Family Advisory Councils.
Perreault et al., 2010 [55]	Canada	Specialized care - inpatient services	Mental illness	To describe the experience of a standing panel of psychiatric outpatients over a period of five years.	Not reported	Members of the Panel of Mental Health service users. Ten patient representatives participated in a Panel evaluation meeting together with staff representatives and organizers.
Pilgrim & Waldron, 1998 [65]	UK	Primary care - outpatient services	Mental illness	To report on a piece of action research about user involvement in one locality, which attempted to take users beyond the role of passive suppliers of opinion and encouraged their role as active negotiators of change.	Not reported	Attendees of action research group to change mental health-services.
Renedo & Marston, 2015 [47]	UK	Specialized and primary care - in- and outpatient services	Not reported	To examine how patients construct ideas of 'quality improvement' when collaborating with healthcare professionals in improvement work, and how they use these understandings when attempting to improve the quality of their local services.	Not reported	Members of quality improvement working groups. Members of steering groups. Engaged in training for patient representatives to become "effective" user representatives. Engaged in conferences to support healthcare teams about improvement methods and patient involvement, and in

Table 5 (Continued)

AUTHOR, YEAR [ref].	COUNTRY	CHARACTERISTICS OF PRIMARY STUDIES			NATURE OF PATIENT PARTICIPATION	
		Study setting	Diagnosis	Study objective	Purpose of patient participation	Approaches to patient participation
Rise & Steinsbekk, 2015 [36]	Norway	Specialized care - inpatient services	Mental illness	To investigate whether implementing a development plan intending to enhance user participation in a large health-service organization had any effect on the patients' experiences of user participation.	To enhance user participation in the organization.	meetings to discuss issues regarding the service development program. Members of project group for establishing the development plan for user participation. Members of development plans implementation group.
Robert et al., 2003 [48]	UK	Specialized care - inpatient services	Mental illness	To explore the involvement of mental health-service users in the redesign of inpatient mental health-services in six Trusts participating in a multi-regional National Health-service modernization program.	Not reported	Members of six participating sites' local project groups. Part of the research process by interviewing service users about their experiences of inpatient care.
Roberts et al., 2013 [63]	UK	Specialized care - inpatient services	Intellectual disability	To illustrate how a human rights approach to healthcare can apply across a range of services to bring about meaningful and positive change within the lives of service users, using both 'top-down' and 'bottom-up' models of change.	To improve services for people with intellectual disabilities within a mental health trust by means of national policy and legislation.	People with intellectual disabilities were members of service user groups led by multidisciplinary professionals, and members of project group.
Schwartz et al., 2013 [49]	Canada	Specialized care - outpatient services	Mental illness	To identify consumer and provider values of recovery and to see if and how consumer-provider dialogue might function in an institutional setting.	To develop a process for knowledge exchange that supports recovery-oriented care.	Part of Participatory Action Research group, involved in all stages.
Serapioni & Duxbury, 2014 [56]	Italy	Health district level and specialized care - inpatient services	Not reported	To contribute to knowledge on the effectiveness and failings of contemporary public participation approaches within the health system.	Not reported	Leader of and members of Mixed Advisory Committees.
Sharma et al., 2016 [57]	USA	Primary care - outpatient services	Not reported	To understand how Patient Advisory Councils (PACs) are organized and identify common challenges and perceived benefits of high-functioning PACs.	Not reported	Members of Patient Advisory Councils.
Sitzia et al., 2006 [58]	UK	Specialized care - inpatient services	Cancer	To present findings from an independent, qualitative evaluation of the nature and outcomes of a "partnership" model.	Not reported	Members of Cancer Partnership Groups. Members in the reference group of the evaluation study.
Storm et al., 2011 [37]	Norway	Specialized care - inpatient services	Mental illness	To study the possible effect of an intervention program designed to (1) increase attention to user involvement and (2) increase user involvement at the inpatient departmental level.	Not reported	Participated in a dialogue seminar consisting of providers, service user representatives, family members, and patients. Part of educational program. Member of monthly staff meetings.
Tataw & Ekundayo, 2012 [64]	USA	Primary care - outpatient services, homebased care, health promotion activities	Prostate cancer	To assess participatory planning in the Mississippi Prostrate Cancer Project.	To assess participation in a prostate cancer project and assessing the implications of the findings for community health program planning, intervention research, and community development practice.	Member of Community Advisory Board, after having received training on roles and advocacy.
Thomson et al., 2015 [59]	UK	Specialized care - outpatient services	Multiple sclerosis	To report on the Multiple Sclerosis Outpatient Future Group study which demonstrates how, through working with a Design Researcher, speculation through analogies can be used as a design tool by non-designers in a service improvement project.	To improve participation within service improvement activities for persons with multiple sclerosis.	Part of collaborative future groups` to explore service improvement possibilities through use of analogies and physical props, as facilitated by a Design Researcher.
van Draanen et al., 2013 [60]	Canada	Primary care - outpatient services, homebased care, health promotion activities	Mental illness and homelessness	To examine lessons learned from the People with Lived Experience advisory body (Caucus) in the Toronto Site of the At Home/ Chez Soi Research Demonstration Project on Homelessness and Mental Health.	To describe implementation of an advisory body of people with lived experience (caucus) and what contributed to meaningful inclusion.	Members of the People with Lived Experience advisory body (Caucus). Part of study team.
Weeks et al., 2009 [38]	USA	Primary care - outpatient services, homebased care, health promotion activities	Risk for HIV	To report on the outcomes of a training and intervention program, both for those trained to deliver the intervention to their peers, and for their drug-network contacts who were recruited into the study.	To report on outcomes from a program involving peers that deliver an intervention.	Engaged and trained as Peer Health Advocates to conduct HIV prevention. Recruited peers in the drug-using network - extending the network of persons disposing risk prevention information.

Table 5 (Continued)

AUTHOR, YEAR [ref.]	COUNTRY	CHARACTERISTICS OF PRIMARY STUDIES			NATURE OF PATIENT PARTICIPATION	
		Study setting	Diagnosis	Study objective	Purpose of patient participation	Approaches to patient participation
Wood et al., 2009 [62]	Australia	Specialized care - inpatient services	Mental illness	To develop and test a standardized clinical handover discharge strategy for improving information transfer between private mental health hospitals and community practitioners.	Not reported	Member of project steering committee.

Table 6

Geographic distribution of studies.

Country	Number of studies
United Kingdom	15
Canada	5
USA	5
Australia	3
Norway	3
Belgium	1
Ireland	1
Italy	1

3.3.1.2. Impact of the collaboration process on the HPs. The most frequently reported impacts on HPs were that collaborating with PRs in health-service development positively changed the HPs' views and attitudes toward involvement (12/34) [42,46,48–52,55,57,58,65,69], and gave insight into patients' needs (9/34) [45,48,52,55,57,60,66,67,71]. That HPs developed empathy [69] and a better understanding of patients' situations [40] were also reported.

Boaz and colleagues [42] found that HPs appreciated the opportunities to listen and reflect on practice, and that collaboration with PRs to enhance care increased the HPs' motivation for organizational change. After having collaborated with PRs, HPs saw it as important to engage PRs from the start, including planning the project's purpose [52].

Participatory service development also increased the HPs' collaboration competency (5/34) [46,49,52,66,67], an impact also reported on patients. To illustrate, one study found that the professionals realized "(. . .) that previous engagement had tended to be a paternalistic or superficial, paying 'lip service to patient and public involvement'" [46, p. 88].

This experience may be closely linked to HPs' reduced fear of involvement [49] and lessened concerns about tokenism and PRs' representativeness [46,57] after participatory service development. However, two studies reported that the service development with patient participation heightened professionals' concerns about representativity. The RPs involved in the projects were not considered adequately representative of marginalized groups in their target population [65,69].

Being part of service development with patient participation led several HPs to realize the need to allocate resources (9/34) [39,45,50,51,54,57,58,68,69], and to see participatory service development as a time- and resource-consuming activity [39]. These impacts may explain some HPs' calls for a skilled facilitator to lead the process (3/34) [60,65,69].

3.3.1.3. Impact of the collaborative process on the organization's patient participation practice. Among the 34 studies included in this review, 29 reported that involving PRs had some type of impact on organizational patient participation practice.

In 11/34 studies [40,42,45,48,51,52,54,60,66,67,69] the collaboration between PRs and HPs led to an integrated patient perspective in the service development. Having different perspectives available in the process also fostered mutual understanding among the participants (9/34) [42,46,49,50,52,57,58,67,71].

The most frequently reported impact of participatory service development was that it expanded patient participation within the organization (16/34) [36,37,40,41,46,47,49,52,55,58,60,65,66,71–73]. Being part of a participatory project also increased informal communication between HPs and PRs about other matters [45,49]. This may be manifested in two other reported impacts, namely an expansion of patient participation activities outside the organization (7/34) [40,42,47,49,55,65,71], and increased community participation [38,70].

Where PRs and HPs engaged in improving services, this seemed to balance out power differences among the participants (7/34) [42,46,48,49,54,66,68]. One study suggested that the co-production redistributed power by allowing the participants with intellectual disabilities to gain more control and a better understanding of how to become active agents of change [66]. This impact may also reflect PRs being hired to motivate healthcare workers to make changes that will enhance the quality of services in an organization [39,47].

3.3.2. Impact of patient participation on the design and delivery of services

Here we present reported impacts of service development with patient participation on 1) patients, 2) the HPs, and 3) on the organization.

3.3.2.1. Impact of patient participation in service development on patients. Of the impacts with direct relevance for patients, the one most frequently described (9/34) was enhanced access to services [38,44,45,55,58,63,68,71,73]. Other impacts were decreased wait times and a simplified admission process (5/34) [40,44,45,57,73]. Participatory service development was reported to have increased the relevance of the services offered (5/34) [45,54,69,73,74], improved health outcomes for the patients (4/34) [38,44,51,63], and enhanced patient satisfaction and experience (5/34) [40,44,45,52,74]. However, two studies investigating the implementation of a plan to enhance patient participation in the organization found no associated effect on patient satisfaction with the service [36,37].

3.3.2.2. Impact of patient participation in service development on HPs. The impact on the HPs within an organization is closely linked with the impact on the organization itself. Still, various types of reported impact can be traced to the way HPs carry out their clinical practice.

Five studies reported that the HPs changed the way they worked after a service development project with patient participation [43,55,58,65,70]. For example, HPs changed how

Table 7

Summary of reported success criteria for health-service development with a team of patient representatives (PRs) and health professionals (HPs)*.

Project timeline	Success criteria for participatory health-service development
Before	<ul style="list-style-type: none"> • Identify rationale and purpose for patient participation • Ensure senior leader support • Identify resources for reimbursement and implementation • Conduct a purposive recruitment process • Engage more than one PR to provide mutual support and enhance confidence • Ensure participation of PRs in ways that suit their preferences and health status • Ensure time and commitment from all participants • Ensure that PRs are in place from the start • Ensure a team orientation, opportunity and space to work together • Ensure that the facilitator of the service development has the necessary skills to handle the participatory process
During	<ul style="list-style-type: none"> • Conduct frequent meetings, and other opportunities for bonding among team members • Create a supportive context with the use of common language, good listening, trust, openness, and mutual respect among the participants • Empower team members to express their views, discuss and share perceptions • Provide joint education and coach on strategies and best practices for patient participation • Explore divergence in values • Address openly concerns, risks, and potential tensions • Identify priorities, set tangible goals, and outcomes • Clarify expectations, roles, and responsibilities • Come to an agreement about the purpose for establishing a team consisting of PRs and HPs • Discuss how to achieve the desired outcomes • Track progress and ensure that the team members see the changes happening
After	<ul style="list-style-type: none"> • Make changes visible to patients and HPs of the organization • Implement and evaluate the service development as a team • Disseminate results as a team

* The summary is based on the included studies' reported findings, without considering the type of involvement, the type of health-service improvement, and its context, or the characteristics of the service user groups that the involved PRs represent. The reader may also look to suggestions made in the following studies: Armstrong et al., 2013 (Box 1, p. e44), Baker et al., 2016 (Table 1, p. 180–81), Malfait et al., 2017 (success factors 1–3, p. 70), Schwartz et al., 2013 (facilitating factors a–d, p. 115) Sharma et al., 2016 (Table 2, p. 778), van Draanen et al., 2013 (lessons learned 1–5, p. 185).

Table 8

Summary of reported approaches to patient participation in health-service development.

Patient participation approach	Number of studies*
Members of collaborative working groups	18
Members of patient councils	10
Members of steering boards or committees	8
Involved in workshops or consultation events	6
Involved in a focus group interview	5
Acting as peers or lay workers	2

* The total exceeds 34 because studies reported more than one patient participation approach.

they “broke bad news” to cancer patients due to PRs' input [65]. They also increased their time spent in direct contact with patients [40] and enhanced their patient centered orientation in care [44,58].

After the implementation of “an intervention program designed to increase attention to user involvement and increase user involvement at the inpatient departmental level” [37, p. 29], HPs

increased patient participation in general in their daily work, engaging patients and their carers to a greater extent than before. In contrast, in several of the five pilot projects that Martin and Finn [54] investigated, professionals did not know how to involve patients in service development, indicating a need to educate professionals about this.

3.3.2.3. Impact of patient participation in service development on the organization. The most frequently reported service improvement impacts were tangible and “easy to fix”. For instance, half of the studies (16/34), all with a qualitative design, reported that the organization's communication with and information to patients had improved [39–42,45,48,53,55,57,58,60,65,66,68,71,73]. Also, half of the studies (18/34) reported a number of smaller service-enhancing changes having been made in response to patient input in the service development process [41,42,44,45,47,48,52,53,55,57,58,63,68,70–74]. Enhanced patient safety was a reported impact in four studies [38,40,45,53].

Participatory service improvement was reported to be a creative process that facilitated generating new ideas for

improvements (4/34) [36,40,41,68]. One reported impact was that lay workers were employed to enhance services for patients and carers (5/34) [38,41,42,70,73]. Two studies described how the engagement of peers and lay workers enabled access to persons who HPs struggled to reach [38,70]. Another two studies reported that the service development resulted in establishing a new position [60,68]. It was noted, however, that this impact was contingent on available funding.

On the administrative or managerial level of organizations, the participatory service development was also associated with decreased hospital admissions [44,51] and reduced costs [40,51]. Reported impacts from patient participation also entailed different service provision priorities [42,48], increased referrals to the organization [45,63], and increased service provision [38,41,70]. Having patient representatives “on board” also enhanced accreditation measures and transparency [40]. However, four studies reported that patient participation in service development demanded steady financial support from the organization in order to be sustainable [53,57,68,69].

Seven of the 34 studies reported that the participatory service development shifted the organizational culture toward more involvement [40–42,45,46,51,58]. Two studies reported that the organizations established new collaborative arenas to enhance design and delivery of services [46,71]. For instance, a patient panel was established to work together with the organization’s haemophilia team [71]. Finally, five studies reported that the participatory project increased service efficiency [38,44,57,63,73].

4. Discussion and conclusion

4.1. Discussion

This scoping review comprises 34 primary studies published between 1998 and 2018. It addresses the studies’ purposes for, chosen approaches to, and reported impacts of patient participation in health-service development. Half of the studies were conducted in the United Kingdom, the rest in elsewhere in Europe, North America and Australia, and the majority (29/34) had qualitative research design. In general, the reporting of participant number and characteristics was poor. Half of the studies offered advice on how to conduct successful health-service development with patient participation. Two thirds of the studies were set in specialized care; half investigated development of service for somatic illnesses, and the other half concerned mental health. The terms describing, and the approaches applied to involving PRs in the improvement initiatives were many and varied, echoing the findings of recent reviews [14,17,21,75]. Most often, PRs were part of working or project groups (18/34), perhaps indicating efforts to comply with white papers encouraging patient participation when developing or improving services [1–3].

Our analysis identified many types of impact from patient participation in service development. For instance, the PRs reported capacity building and self-development, but also tokenistic involvement and little impact, confirming evidence from previous reviews [7,14]. Professionals saw benefits in involving PRs in new projects, but also experienced participatory service development as resource-demanding [7]. In their review, Bath and Wakerman [15] found that service enhancements prompted by input from PRs led to improved health outcomes for the patients. The results of the current review support this finding and confirms earlier findings that further research on effects of patient participation is needed [8,11,13,14,18,21,30,33].

Patient participation in health-service development represents healthcare policy all over the world [2,3]. In this review, 15 studies are from the UK, five each from the United States and Canada, and three each from Australia, Norway, and the rest of Europe. Though a

publishing bias may partly explain this focus on Western cultures, the countries from which the studies originate can be understood to share a political climate that favors patient participation in care and treatment and service development.

However, the broad variety of both the terminology and the approaches applied for patient participation in health-service development, may pose challenges for those embarking on participatory service development, as pointed out in previous reviews [7,11,18,20,76]. Similar to Ocloo and Matthews’ [8] results, one of the primary studies included in this review [54] found that professionals did not know how to involve PRs in service development. It is likely that not knowing “how to” also affects the reporting of various aspects and impacts regarding patient participation in service development [21]. However, a third of the primary studies included in our review reported that professionals’ attitudes toward involvement changed to the better after they had participated in service development alongside PRs. Near half of the studies also reported that conducting participatory service development expanded patient participation within the organization (16/34), and increased PRs’ participatory activities outside the organization (7/34). These findings may also be seen in relation to reviews investigating benefits from participatory research, where conclusions support that involving stakeholders in research leads to more participatory research in the organizations [77,78].

Awareness about various approaches to patient participation can affect health professionals’ attitudes and experiences, normalizing the practice of involving PRs in service development [21]. Furthermore, patient participation is founded on both democratic and consumer-oriented reasoning, operating side by side [4–6]. From the democratic perspective, patients have a right to take part when issues concerning their health or services are at stake, and to be involved in this way a goal in itself. Involvement also signals recognition of a person’s status as a citizen [5,6,10,79]. From a consumer-oriented perspective, patients are seen as customers who know best what is right for them and are free to choose the services they need [5]. Perhaps, then, it is less important what this participatory practice is called, and more important simply “to do it”, if the goal is to increase patient participation and enhance the quality of healthcare services globally. Moreover, “doing it” may strengthen participatory practices in general in an organization and its partners, perhaps helping open up new possibilities for different groups in the population to voice their needs and be heard.

Context is a conditioning factor when interpreting types of impact from patient participation [15,18], and separating impact from its context makes it difficult to establish whether a type of impact stems from patient participation or other factors [13,18,31]. Still, in this review we have identified impacts in a broad sense and outside of contextual aspects. To our knowledge, this is the first published review to supply an overview of the broader impacts of patient participation in health-service development.

In order to provide this comprehensive overview, we have had to identify impact from primary studies with diverse research designs. We have thus tried to be explicit about how the analysis was conducted and to ensure a good methodological quality of the included studies [28]. Based on an MMAT assessment [34], we commented on quality aspects of five studies [36,39,62,66,68], but excluded none (Appendix C).

Conducting this review, we have also had to narrow the reviews scope and to apply exclusion criteria that may have led us to miss important studies, and to synthesize and compress the depth of analysis. Including only literature in English and Scandinavian languages published in peer reviewed journals, we may have faced a publishing bias and have risked missing studies of relevance written in other languages. Though a scoping review is considered a robust approach [27], there is still a need for greater consistency

in labelling, definition, methodology, and reporting in scoping reviews, and the variability that characterizes scoping reviews can also be seen as limiting their potential [27,80].

When developing the search strategy for our review, all members of the research team were involved. The members' different perspectives proved especially useful in this phase of the review process, when inconsistent terminology called for discussions about which terms to rely on. Though resource limitations necessitated that the initial sorting was done by the first author alone, this procedure might not have identified all relevant studies. We also did a manual check of the reference lists of the full text studies we included. Searching additional online literature databases might also have led to identification of more studies, though we believe we searched the most relevant databases.

4.2. Conclusion

The literature describes a broad variation of impacts from health-service development, relevant for health professionals and patient representatives when initiating or participating in such processes. Our review provides an overview and discussion of these types of impact (Tables 3 and 4).

The results imply that conducting participatory service development can expand patient participation practices within the organization, and to the organization's partners. The results also indicate a need to describe and understand impact of patient participation in health-service development in a broad sense. Based on our findings, we propose that when looking for impact from patient participation, one should consider possible impact arising merely from being involved in a participatory service development initiative, as well as impact arising from changes that the process leads to for the patients, the HPs, and the organization. This means that the context in which patient representatives are involved in service development must also be understood and researched in a broad sense.

We support conducting research by applying Halabi and colleagues' [12] generic term patient participation and their framework of dimensions of patient participation, constituting a micro-, meso-, and macro-level. Based on the findings from our review, however, there is a need for research concerning the meso-level. We suggest incorporating patient participation in health-service development on the meso-level to a stronger degree in the proposed framework [12]. We believe this can further enhance the quality of this useful framework and help in further advancing knowledge production about participatory service development.

To enhance the knowledge base for participatory service development, outcomes from the collaboration between PRs and HPs must be further investigated, including potential long term consequences. Furthermore, a closer investigation of the impact of participatory service development on patients and HPs, viewed from their own perspectives, is needed. There is also a need to identify what context constitutes with regard to participatory service development, and what role context plays for chosen approaches to and impact of patient participation in health-service development. As Andersen [81] stated, knowledge about the context can enable development of systems for patient participation where different means can complement one another, perhaps also strengthening the practice of involvement.

4.3. Practice implications

This review's findings can be relevant for health professionals and patient representatives when initiating or participating in health-service development on the meso-level or macro-level [12]. The summary of reported success criteria (Table 7) may be of support when conducting participatory health-service

development. Also, the mapping of types of impact (Tables 3 and 4) may be of help in the planning phase of service development, if needing to discuss wanted outcomes, and how to reach them. Furthermore, we propose looking to the mapping of types of impact if the aim is to develop quality indicators on effects of patient participation, or conduct research concerning aspects of participatory health-service development.

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Declaration of Competing Interest

There are no financial or other ties involved in the current work that may cause a conflict of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2020.02.028>.

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