



## The impact of patient and public involvement in healthcare services: A conceptual review spanning social sciences and health sciences

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### ABSTRACT

To understand patient and public involvement (PPI) and its potential impact in the healthcare services more comprehensively, the social science literature on public participation in governing public services must be integrated with the health science literature. To facilitate planning and evaluation of PPI-activities, the aim of this article is to review conceptual discussions of involvement/participation and impact, and summarize and integrate these in a way that advances the conceptual understanding of impact of PPI in healthcare services. Based on the review, we present a conceptual integration chart of impact areas, categories and types. There are three overarching areas: (i) impact on individuals; (ii) impact on the health system; and (iii) impact on decision-making processes and society. The overarching areas contain the categories: (i) citizens, patients, and decision-makers; (ii) service provision, and public health; and (iii) decision-making, policy and state, and public and society. Under these categories, the most commonly encountered impact types are presented.

### 1. Introduction

Patient and public involvement (PPI) can be defined as the “active participation of citizens, users and carers and their representatives in the development of healthcare services and as partners in their own healthcare” (British Medical Association, 2015). The rationales for PPI can be grouped into two broad arguments. Firstly, the moral argument suggests that those affected by, or paying for, the healthcare services should have a say in what is done and how. Secondly, the consequentialist argument suggests that involvement will lead to improvements in, for example, the care quality, efficiency and health outcomes. An extensive body of literature reports how PPI activities are carried out in different parts of healthcare systems, but knowledge regarding its results or outcomes is still limited (Modigh, Sampaio, Moberg, & Fredriksson, 2021). We thus do not know whether PPI-activities, as suggested, lead to proposed benefits, including improved health, increased user satisfaction, improved service delivery and better democratic processes (Coulter, 2005, 2011; Palmer et al., 2019). This has led to an increasing focus among researchers on how to evaluate or assess the impact of PPI in the healthcare services.

Measuring and summarizing evidence of the impact of PPI in healthcare services and governance is complicated, not least because PPI

is multifaceted with a myriad of different approaches, involved stakeholders, goals etcetera. Importantly, in the one end of PPI is individual patient involvement, which most often occurs in direct care and in treatment decisions, and is often framed as patient engagement and realized through, for example, shared decision-making, digital e-health solutions, patient surveys and Patient Advice and Liaison Services. It often involves efforts to improve the quality of care, health outcomes and patients’ experience, and ensure appropriate and effective treatment and care (Coulter, 2007, 2011). More collective forms of patient involvement may be co-design processes or patient organizations. In the other end of PPI, there is collective public involvement (participation of a group or community or similar) taking place at the levels of service organization and system/policy, and which encompasses the broader perspective of the public (or citizens). It is at these levels in the healthcare system that strategic decisions on healthcare supply and priorities are made (Carman et al., 2013; Tritter, 2009). It often involves organizational or general policy changes (Coulter, 2007, 2011) and can take the form of, for example, citizen councils, citizen dialogues/meetings or citizen juries. Involvement at this level is often referred to as *public participation* by political scientists investigating participatory and deliberative democracy in various fields, such as environmental policy and urban planning. This type of participation is rooted in the movement

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towards participatory and deliberative democracy, while the patient engagement movement is rather a striving to counteract medical paternalism (Hogg, 1999; Warsh, 2014). We argue that to understand PPI and its potential impact more comprehensively, the literature on public participation must be integrated with the literature on PPI. It should be added that between individual patient involvement and collective public involvement, a mix of different types of involvement is observed, where some types of individual involvement may influence collective matters as well. A wide range of PPI activities exist, which also vary between healthcare systems. For example, PPI activities can be divided into who is involved (patients/the public), whether involvement is individual or collective, whether involvement is direct or indirect (the extent to which participant take part in actual decision making), and whether involvement is proactive or reactive (the extent to which PPI activities are prompted) (Tritter, 2009).

Today there is no agreed definition of impact of PPI in healthcare, and no preferred evaluation model or evaluation tool, although a number of measurement instruments/tools have been put forward (Acuña Mora, Sparud-Lundin, Moons, & Bratt, 2022; Clavel et al., 2021; Dukhanin et al., 2018; Phillips et al., 2016; Ree et al., 2019). Most of these tools are developed to assess the impact of PPI within some particular setting, or are project-specific, and few tools are developed on the basis of theory (Abelson et al., 2018; Boivin et al., 2018; Tritter, 2009). Since PPI activities can be very different from each other, we can expect these activities to have different potential outcomes or impact, although such expectations are often not made explicit beforehand. This risk leading to differing or unrealistic expectations of what the PPI activity will include and result in, which may cause dissatisfaction, distrust and undermine legitimacy (Charles & DeMaio, 1993; Flood, 2015; Madden & Speed, 2017). For instance, is the purpose to change the individual's health behaviour, to improve access to healthcare or facilities, to understand public priorities or to increase the system's legitimacy? To facilitate planning and evaluation of PPI-activities, the aim of this article is to review conceptual discussions of involvement/participation and impact, and summarize and integrate these in a way that advances the conceptual understanding of impact of PPI in healthcare services. It is important to remember, however, that PPI is not just a means to an end but holds intrinsic value that can be realized through its processes rather than solely through its outcomes.

## 2. Methods

This article constitutes a conceptual review, following the approach described by Hulland (2020), and employing an interpretive qualitative synthesis approach (Mbau & Gilson, 2018). According to Hulland, a conceptual review primarily aims to synthesize existing knowledge, focusing on establishing common ground to build a new and enhanced conceptualization rather than generating new ideas. It resembles a theory synthesis seeking to "achieve conceptual integration across multiple theories or literature streams" (Jaakkola, 2020, p. 21). A conceptual review includes five key elements, which we adhered to: (i) establishing the scope and domain under review, (ii) integrating and synthesizing extant knowledge within the domain, (iii) resolving inconsistencies, (iv) highlighting gaps in the existing literature, and (v) setting an agenda for future research. We also tried to follow the best practices related to process, value, and communication as suggested by Hulland (2020).

### 2.1. Element (i): establishing the domain and scope

The domain investigated is the impact of patient and public involvement in healthcare services and governance, and not in health research. In this domain, there are numerous empirical studies and a limited number of conceptual ones, and there is thus a need for a synthesis of previous work. To advance the understanding of impact of PPI, it is crucial for the synthesis to encompass not only individual patient

involvement but also extend to the literature on public participation. The scope of this conceptual review includes: (i) conceptual articles about public participation and its potential effects in the broader literature on social and political science, and (ii) conceptual articles about patient and public involvement and its potential impact in the health science literature. The latter includes research focusing on collective involvement of patients and members of the public as well as patient engagement/participation/involvement at the individual level. The review covers various topics, including the emergence of public and patient involvement (clarifying goals and expected outcomes), the diverse range of involvement approaches and their typologies (influencing the type of impact an activity is expected to produce), the current state of evaluation (identifying challenges and existing efforts to address them), and impact categorizations.

A literature search was carried out to find articles containing conceptual discussions with bearing on patient and public involvement in healthcare and its impact. Since there is no definition of what impact is, we also searched for effects or outcomes of PPI. A database-search between 1980 and 2021 resulted in 4279 articles after removing duplicates (see search results in [Supplementary file 1](#)). The purpose was to sift out the most relevant articles from the perspective of conceptual knowledge of interest for advancing the understanding of impact of PPI in healthcare services. We also conducted a snowball search for relevant studies in the articles' reference lists. We considered it conceptual knowledge if the article contained theoretically or empirically derived categorizations/classifications of impact (thus excluding studies reporting on discrete outcomes) or discussions on contexts, strategies and approaches of importance for understanding what impact is and how it can be measured. In the final version, 60 articles are included.

### 2.2. Elements (ii-iv)

Elements ii-iv are partly overlapping and presented in an integrated way in the results section. Integrating and synthesizing extant knowledge (ii) centres on summarizing and grouping existing knowledge in an effective way despite disparities in individual study focus. Identifying and resolving inconsistencies (iii) is an important step and inconsistencies can be found in relation to theory, methods or in the definitions of constructs. Highlighting gaps implies looking across existing knowledge to identify important gaps or unconsidered connections that hinder the development of the field. Elements ii-iv result in a chart of potential categories of impacts of PPI and element (v): an agenda for future research, is commented in the final section of the article.

## 3. Results

This conceptual review includes (i) conceptual articles about public participation and its potential effects within the broader literature on social and political science, and (ii) conceptual articles on patient and public involvement and its potential impact within the health science literature. We begin by presenting our integration and synthesis of public participation in the governance of public services more broadly, followed by a focus on patient and public involvement in healthcare services. The third results section presents a synthesis of these two bodies of literature and a chart outlining potential impacts.

### 3.1. Public participation in governing public services

#### 3.1.1. Motivation for public participation

The literature on public participation, which refers to "the practice of consulting and involving members of the public in the agenda-setting, decision-making, and policy-forming activities" (Rowe & Frewer, 2004, p. 512), describes an increase in public participation in a range of sectors such as environment, transport and healthcare since the social movements during the 1960s (Abelson & Gauvin, 2006; Burton, 2009;

Marent et al., 2015; Rowe & Frewer, 2004). The drive toward participation emerged from a declining trust in the process of representative democracy (Michels, 2019; Michels & Binnema, 2019) and in those traditionally involved based on being elected or appointed as experts (Rowe & Frewer, 2004). Calls were made for greater legitimacy, accountability, and responsiveness (Rowe & Frewer, 2000).

The argument behind public participation is that relying solely on voting in elections is insufficient as citizens may become alienated from politics when decision-making power is delegated to representatives (Michels, 2011). Citizens must therefore also have the opportunity to participate more directly in decisions that affect them (Burton, 2009; Michels, 2019). According to theories on participatory and deliberative democracy, more direct participation is beneficial for democracy; it enhances issue knowledge and civic skills, fosters a sense of community, and promotes willingness to be active in public life (Michels, 2011, 2019). It gives citizens a say in decision-making and opportunity to influence the policy process (Michels, 2011), which ideally serves the democratic values of legitimacy, justice and effectiveness of public action (Fung, 2006). However, some argue that direct participation is idealistic rather than realistic because people are either too self-interested or passive and lack the time, knowledge or motivation to participate (Callahan, 2007).

### 3.1.2. Many different types of public participation with unclear effects

The number of participation methods has multiplied over the years (Rowe & Frewer, 2004, 2005), with Rowe and Frewer identifying more than 100 different approaches, including citizen review boards, consensus conferences, game simulations, interactive websites, planning cells, study circles and surveys (Rowe & Frewer, 2005). However, considerable uncertainty persists regarding the quality and effectiveness of public participation (Burton, 2009; Michels & Binnema, 2019; Rowe & Frewer, 2004).

A key distinction can be made between individual and collective participation, based on whether citizens participate as individuals, offering individual opinions, or collectively as a group (Abelson & Gauvin, 2006; Michels, 2011). Examples of the former include surveys, while focus groups exemplify the latter (Rowe & Frewer, 2004). Participation also ranges from passive receipt of information to active engagement in decision-making processes, as seen in focus groups and advisory committees (Burton, 2009; Rowe & Frewer, 2000, 2004). Additionally, Michels (2011) differentiates between participation methods focused on decision-making and those aimed at opinion formation. Another distinction lies between conventional (invited) or unconventional/contestatory (uninvited) participation, examples of the latter including demonstrations, political strikes, street protests, and boycotts (Weale et al., 2016).

To differentiate engagement methods, Rowe and Frewer (2005) have developed a typology focusing on key aspects that may also affect the methods' effectiveness, i.e. what types of impact are possible: (i) participant selection; (ii) facilitation of information elicitation; (iii) response mode; (iv) information input; (v) medium of information transfer; and (vi) facilitation of aggregation. Different combinations of these mechanisms lead to different potential outcomes, but currently there is no evidence to support that one method is superior; it rather depends on the specifics of a particular situation (Burton, 2009; Rowe & Frewer, 2000). Participant selection is also one of the dimensions in Fung's Democracy Cube (Fung, 2006), while the other key aspects correspond to communication and decisions in the Democracy Cube.

### 3.1.3. Challenges in evaluating public participation

It is important to evaluate public participation for a number of reasons: financial, practical, ethical/moral and research/theoretical reasons (Rowe & Frewer, 2004). The sustained use of some public participation activities may hinge on inertia or a lack of protest rather than the activities' actual effectiveness. Burton (2009) highlights two reasons contributing to the dearth of evaluations. Firstly, there is an

emphasis on the rights-based conception of participation (a moral argument) making empirical scrutiny less pressing. Secondly, there are practical difficulties associated with evaluation, as well as difficulties in establishing causality. It is, for example, difficult to find ways to measure institutional and societal impacts from, for example, deliberative forums or advisory committees, while isolating them from other influences. Furthermore, contextual and environmental factors will affect the particular participation activity, and the implementation may be poor in one place, leading to ineffective participation, but successful in another (Rowe & Frewer, 2000). Some aspects of a public participation activity may also work well while others may not (Abelson & Gauvin, 2006), and sometimes it can also be difficult separating between how a participatory activity is designed and how it is applied (Rowe & Frewer, 2005).

Moreover, differentiating between proximal and distal outcomes, immediate versus longer-term results that may manifest years later and may be confused with outcomes of other efforts, adds complexity to evaluation. There is also a distinction between perceived and actual impacts, making participant experiences difficult to interpret (Abelson & Gauvin, 2006). Choosing appropriate effectiveness measures and collecting the necessary information further contribute to the difficulties in evaluating public participation (Aubin & Bornstein, 2012). This is a field where controlled experimental studies are challenging, as such studies require certain aspects to be manipulated and held constant—something that is not feasible with politics and other societal processes (Rowe & Frewer, 2000).

### 3.1.4. Evaluating the effectiveness of public participation

Evaluations are often framed as assessing the effectiveness of participatory activities. A broad distinction can be drawn between evaluating the process (how participation activities unfold) and the outcomes (the results) (Chess, 2000; Rowe & Frewer, 2004). Rowe and Frewer (2004) argue that outcome evaluation is often considered most desirable since it addresses more directly whether the public participation activity has achieved its intended effects (however not capturing the moral aspect). Yet, due to challenges in accurately measuring outcomes, process evaluations often become surrogates (Rowe & Frewer, 2004). Consequently, the majority of criteria for assessing effective public participation concentrate on evaluating an efficient process rather than measuring effective outcomes (Rowe & Frewer, 2000). Among outcome-oriented evaluations, most have focused on the impact of public participation on the participants, such as the participants' level of knowledge and skills, identification with the community, or capacity for future participation (Michels, 2019). Significantly less research has focused on the impact on the policy process or decision-making (Abelson & Gauvin, 2006).

Consistent with the broad distinction outlined above, Abelson and Gauvin (2006) present a conceptual map of public participation evaluation, distinguishing between i) process and ii) outcomes, and suggesting several factors to evaluate (see also Aubin & Bornstein, (2012)). Processes can be evaluated concerning representativeness, quality of deliberation, procedural rules, and implementation. One of the most common evaluation criteria is representativeness, which is extensively discussed in the literature (Martin, 2008). Outcomes can be evaluated with regard to (i) decisions or policies (e.g., policy responsiveness, effectiveness and efficiency); (ii) decision-makers (trust in institutions and decision-makers); and (iii) participants and general public (e.g. knowledge, issue salience, capacity for future civic and political engagement). Abelson and Gauvin emphasise that decision-makers are a crucial but an often-overlooked intermediate outcome, given their significant influence over policy. Studies may involve examining increased knowledge or changed attitudes among decision-makers. Among their evaluation criteria, Rowe and Frewer (2000) (see also Rowe et al., 2008) point to *influence*, emphasizing that the activity's outcome should genuinely impact policy and be perceived as such, rather than merely legitimizing pre-determined decisions. Establishing prior acceptance about how the output will be used and its potential impact on policy

(related to task definition) can be useful.

Focusing primarily on decisions or policies (but also decision-makers and participants), [Beierle and Cayford \(2002\)](#) point to five goals that should be assessed: (i) the incorporation of public values into decisions; (ii) improvement of the substantive quality of decisions; (iii) resolution of conflict among competing interests; (iv) building trust in institutions; and (v) educating and informing the public. These goals highlight the challenge of clearly distinguishing between processes and outcomes, which may render this distinction less useful. Additionally, [Abelson and Gauvin](#) argue that an evaluation of public participation should cover the context of the policy process since the context shapes the outcomes of the process and effects its participants ([Abelson & Gauvin, 2006](#)). Contextual attributes (not included in their 2003 model ([Abelson et al., 2003](#))) include factors like the issue, attributes of the sponsoring organization, type of decision being made, decision timeline, socio-political characteristics, political will, and community factors ([Aubin & Bornstein, 2012](#); [Rowe & Frewer, 2004](#)). An analytical framework of conditions for successful public participation by [Gelders et al. \(2010\)](#) proposes largely the same types of factors, dividing them into seven categories with 37 questions, such as whether the right participants are involved and if the objectives clear and consistent.

### 3.1.5. Outcomes of public participation

Moving from models that assess the effectiveness of participatory activities, some scholars have placed a more explicit focus on effects or benefits. [Burton \(2009\)](#), for example, distinguishes between effects of participation on (i) participating individual citizens encompassing educational and integrative functions (i.e., developmental benefits), and (ii) politics and decision-making (i.e., instrumental benefits) ([Michels, 2019](#)). The developmental benefits include enhanced self-esteem, greater control over life, understanding of one's own interest, identity expression and a greater sense of social integration. Instrumental benefits are linked to improved quality of decisions, both in terms of managerial efficiency and political legitimacy. Managerial efficiency is enhanced by bringing in a wider range of relevant views, while political legitimacy increases when more people accept the operating rules or principles of the decision-making system (for a discussion on how legitimacy is conceptualized and engendered in relation to deliberative and participatory democracy, respectively, see [Zakhour \(2020\)](#)). Focusing solely on the individuals, [Michels \(2019\)](#) draws a similar distinction between an (i) educational function of public participation (where the participants increase their knowledge and civic skills, become more competent and confident of their ability to influence policy) and an (ii) integrative function (where participants increasingly feel they are part of the community, also assuming more responsibility for decisions). These two overarching functions align with [Gaventa and Barrett's \(2012\)](#) typology of four democratic and developmental outcomes: (i) the construction of citizenship, including e.g. increased civic and political knowledge; (ii) the strengthening of practices of participation, involving e.g. increased capacities for collective action; (iii) the strengthening of responsive and accountable states, incorporating e.g. greater realization of rights; and (iv) the development of inclusive and cohesive societies, including e.g. the inclusion of new actors and issues in public spaces.

Focusing on the macro-effects of public participation, [Michels and Binnema \(2019\)](#) introduce a threefold categorization of impact: (i) instrumental; (ii) conceptual; and (iii) strategic—each with both political and social dimensions. Instrumental impact occurs when policy input influences decision-making, implementation, or concrete actions by policy-makers, as well as the actions of individuals or organizations in the community. In terms of policy effects and citizen input, [Schwanholz et al. \(2021\)](#) discuss various types of policy effects that can arise from participation. Except from no effect, i.e. when citizen input has no impact on substantive policy decisions, they describe it as a diffuse policy effect if decision-makers consider citizen input in a non-binding way, a significant policy effect if implementation of citizen

input is linked to framework conditions, and a binding policy effect if citizen input or suggestions are implemented. [Thurston et al. \(2005\)](#) categorize such outcomes into governance or operational policy decisions and governance or operational policy statements — the latter being less formalized and therefore more challenging to evaluate. Returning to [Michels and Binnema \(2019\)](#) categorization, conceptual impact pertains to more indirect effects of participation. It implies a gradual change in orientation or insight due to participation, such as policymakers becoming more responsive to participation and citizen proposals, and the emergence of new forms of participation. Lastly, strategic impact refers to how participation output strengthens one's own position or weakens the position of another actor (in politics or in society) in a permanent conflict on goals and interests. With some overlaps and differences, [Bing \(2012\)](#) suggests that the benefits of public participation in policymaking can be classified as (i) substantive; (ii) normative; and (iii) instrumental. He defines substantive benefits to include the encouragement of multiple perspectives, an improved understanding of issues, and better solutions. Normative benefits encompass individual and social learning through participation that enriches both the individual and the society. Instrumental benefits include diffused conflict, increased transparency, and increased buy-in and social trust.

In summary, based on the conceptual discussions on public participation and its potential impact we can conclude that there are numerous process dimensions that can be evaluated, as well as a variety of outcomes. This includes impacts related to the individual participants (with a developmental vs integrative function), the public, decision-makers and impacts on policy and decision-making (political legitimacy vs managerial efficiency), as well as impacts on society. We can also conclude that use of concepts in the literature is not uniform, which poses a challenge when trying to create an evidence base. In [Table 1](#), we summarize and attempt to integrate and separate the different types of impact found in the social science literature.

## 3.2. Patient and public involvement in the health services

### 3.2.1. Involvement in healthcare: a shift in perspectives on decision-making

The growing emphasis on patient involvement in clinical settings is in part a response to medical paternalism ([Hogg, 1999](#); [Warsh, 2014](#)), where patients are expected to trust professionals to act in their best interest and comply with their advice as passive recipients of care rather than active partners ([Fredriksson & Tritter, 2017](#)). This type of disempowerment can be detrimental to health, and patients should instead be regarded as partners and experts. By engaging patients in shaping their care and treatment to align with their needs and preferences, both health outcomes and patient satisfaction with the care experience can be improved ([Carman et al., 2013](#); [Clavel et al., 2021](#)).

According to [Charles and DeMaio \(1993\)](#), the increased focus on involvement reflects a shift where the authority of expert and professional knowledge has gradually been challenged. This shift implies a change in thinking about “who has the right to make what health care decisions in whose interests” ([Charles & DeMaio, 1993](#), p. 883). At the treatment level, it reflects an increased recognition of experiential knowledge and the importance of incorporating patients' experiences, values and preferences. At the policy level, it reflects that technical expertise does not give providers the sole right to make value considerations and resource allocation decisions. Nonetheless, a number of researchers have observed concerns among professionals and organizations about the legitimacy of experiential knowledge, and a hierarchy of power still exists ([O'Shea et al., 2019](#)). In this regard, there may be differences between, for example, physicians and nurses. Acknowledging that patients' engagement is influenced by both the opportunities provided to patients to engage by organizations and their employees (depending, for example, on how they value patient and public knowledge), and by personal characteristics and circumstances, [McDermott and Pedersen \(2016\)](#) identify five ‘ideal types’ of patient roles: invited

**Table 1**  
Summary of different types of impact or benefits of public participation.

Developmental	Instrumental	Conceptual	Strategic	Substantive
<i>Educational</i> (individual-level): e.g. increased knowledge and civic skills, confidence <sup>a b</sup>	Politics and decision-making: e.g. improved quality of decisions (managerial efficiency and political legitimacy) <sup>a</sup>	Indirect effects such as policymakers becoming more responsive to participation and citizen proposals <sup>c</sup>	Strengthens one's own position or weakens the position of another actor in politics or society <sup>c</sup>	Encouragement of multiple perspectives, improved understanding of issues and better solutions <sup>d</sup>
<i>Integrative</i> (individual-level): e.g. feelings of being part of a community and sense of social integration <sup>a b</sup>	Influence on decision-making or implementation of concrete actions by policy-makers or the actions of individuals or organizations <sup>c</sup>			
<i>Normative</i> : Individual and social learning from participation enriches both the individual and society <sup>d</sup>	Diffused conflict, increased transparency and social trust <sup>d</sup>			

<sup>a</sup> Burton (2009).

<sup>b</sup> Michels (2019).

<sup>c</sup> Michels and Binnema (2019).

<sup>d</sup> Bing (2012).

patients, involved patients, invisible patients, inarticulate patients and patients needing inducements.

### 3.2.2. Conceptual vagueness relating to patient involvement and public involvement

As highlighted in the article introduction, the spectrum of PPI extends from patients participating in decisions about their individual care to the collective engagement of patients and the public in planning, developing services, and policy-making (the latter overlapping with public participation). To exemplify this, Coulter (2011) identifies distinct high-level policy goals for individual engagement (with a focus on patients: such as ensuring appropriate and effective treatment and care) and collective engagement (with an emphasis on citizens: such as increasing public understanding of health issues), Supplementary file 2. The same type of ideas are presented by Kreindler (2009), who describes involvement as a continuum ranging from consumerism (viewing patients as customers who deserve to be satisfied) to participatory democracy (viewing patients as citizens who have a right to participating in shaping services). Consumerism concentrates on individual perspectives, while participatory democracy emphasizes the collective process of discussion and interaction. Recently, de Leeuw (2021) progressed and nuanced consumer representation in health decision-making by introducing "the Consucrat" (not unchallenged, however) which is a type of consumer representative within the healthcare system who has become a semi-professional or career advocate. They often navigate complex roles at the intersection of patient advocacy and healthcare bureaucracy.

Taking an ideal-type approach, Fredriksson and Tritter (2017) argue that patients have sectional interests, as health service users, contrasting with citizens who engage as 'public policy agents' reflecting societal interests. Patients draw on experiential knowledge, while the public contributes collective perspectives generated from diversity. However, there is not a singular public, but different public interests. Yet, the composition of the public is rarely discussed in the PPI literature, and Conklin et al.'s (2015) review study on the impact of public involvement in healthcare policy revealed that the term 'public' was not defined or operationalized. Examples included representatives of patient organizations, ordinary citizens, disinterested individuals, members of a community and local residents.

Referring specifically to patient involvement, there is a conceptual vagueness and a multitude of partly overlapping concepts used in both practice and research. This contributes to uncertainties about what can be expected from different types of involvement. For instance, Entwistle and Watt (2006) developed a framework encompassing the full range of activities associated with patient involvement in treatment decision-making. These activities cover both micro-social and psychological (information processing) issues and pay attention to patients' subjective experiences of involvement, considering not only what

patients and clinicians do and say but also how they think and feel. Furthermore, to enhance conceptual clarity, Castro and colleagues (2016) discuss the concepts of patient participation, patient-centeredness and patient empowerment, concluding that significant differences exist in terms of antecedents, attributes, empirical referents and consequences; the latter indicating potential impact. Similarly, Higgins et al. (2017) unravel the meaning of patient engagement at the clinical level, while Rooke and Oudshoorn (2020) analyse patient engagement within nonclinical settings. These are synthesized in Table 2 and potential impacts compared to the classifications by Coulter and Ellins (2006), see Supplementary file 2, and Dukhanin et al. (2018), see Table 3.

### 3.2.3. Difficulties measuring the impact of PPI: no universally preferred evaluation model or tool

In their exploration of key concepts and approaches related to the evaluation of involvement in health services improvement and redesign, Abelson et al. (2018) identify four overarching goals for evaluation of PPI. The first two goals aim to generate evidence on effective practices and improve engagement quality (what works and under what conditions), while the third emphasizes accountability and value for money, i. e. demonstrating that organizational requirements for engagements have been met. The fourth goal: linking the level and quality of involvement to outcomes, focuses on understanding changes resulting from PPI. Although arguing for the importance of measuring progress, Coulter acknowledges the formidable challenge of monitoring progress toward established goals (Coulter, 2011, p. 5). In part this is because policy documents often lack specification regarding the expected impact of the PPI activity and how to measure it (Matthews et al., 2019). Establishing causal associations between PPI and improvements in health outcomes, quality of care at a system level, or service changes is very difficult (Bombard et al., 2018). In fact, PPI activities can be described as complex interventions with several interacting components, with sometimes demanding tasks, many involved groups or organizational levels, a far-reaching tailoring of the activity, and variability in outcomes. This complexity has implications for the development and evaluation of such activities, such as the recognition that a lack of impact may reflect implementation failures or poor processes rather than being an effect of the PPI activity itself. The complexity means that a range of impact measures will be needed (Killoran & Kelly, 2010) and there is today no universally preferred evaluation model or tool, although various measurement instruments have been proposed (Acuña Mora, Sparud-Lundin, Moons, & Bratt, 2022; Clavel et al., 2021; Dukhanin et al., 2018; Phillips et al., 2016; Ree et al., 2019). These tools, including questionnaires, scales, interview guides, or observation grids, are commonly self-administered (Boivin et al., 2018). While many tools are designed for specific settings, they often lack an explicit conceptual

**Table 2**  
Definitions of related concepts of patient involvement.

	Attributes	Consequences (impact)	Classified according to <a href="#">Dukhanin et al., 2018</a> ; <a href="#">Coulter &amp; Ellins, 2006</a>
Patient participation <a href="#">Castro et al. (2016)</a>	<ul style="list-style-type: none"> <li>• Participation in decision-making</li> <li>• Active engagement in a mix of activities</li> <li>• Partnership</li> </ul>	<ul style="list-style-type: none"> <li>• Improved quality of care</li> <li>• Higher accessibility</li> <li>• Increased patient safety</li> <li>• Increased patient satisfaction</li> <li>• Better informed patients</li> </ul>	<ul style="list-style-type: none"> <li>• Impact on services provided</li> <li>• Impact on services provided</li> <li>• Impact on services provided</li> <li>• Impact on engagement participant/experience</li> <li>• Impact on engagement participant/knowledge</li> </ul>
Patient-centredness <a href="#">Castro et al. (2016)</a>	<ul style="list-style-type: none"> <li>• Biopsychosocial perspective</li> <li>• Patient as unique person</li> <li>• Sustainable and genuine relationship between patient and caregiver</li> </ul>	<ul style="list-style-type: none"> <li>• Improved health outcomes</li> <li>• Improved quality of care</li> <li>• Enhanced adherence</li> <li>• Improved illness-related knowledge</li> <li>• Improved health behaviour</li> <li>• Decreased healthcare utilization</li> </ul>	<ul style="list-style-type: none"> <li>• Impact on engagement participant/health status</li> <li>• Impact on services provided</li> <li>• Impact on engagement participant/behaviour</li> <li>• Impact on engagement participant/knowledge</li> <li>• Impact on engagement participant/behaviour</li> <li>• Impact on services provided</li> <li>• Impact on engagement participant/health status</li> <li>• Impact on engagement participant/behaviour</li> <li>• Impact on engagement participant/knowledge, experience, behaviour</li> <li>• Impact on engagement participant/experience</li> <li>• Impact on engagement participant/health status</li> </ul>
Patient empowerment <a href="#">Castro et al. (2016)</a>	<ul style="list-style-type: none"> <li>• Enabling process</li> <li>• Personal change</li> <li>• Self-determination</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated self</li> <li>• Sense of mastery and control</li> <li>• Self-management</li> <li>• Improved quality of life</li> </ul>	<ul style="list-style-type: none"> <li>• Impact on engagement participant/health status</li> <li>• Impact on engagement participant/knowledge, experience, behaviour</li> <li>• Impact on engagement participant/experience</li> <li>• Impact on engagement participant/health status</li> </ul>
Patient engagement (clinical level) <a href="#">Higgins et al. (2017)</a>	<ul style="list-style-type: none"> <li>• Personalization of the approach to care</li> <li>• Access to necessary resources</li> <li>• Commitment to pursuing quality care</li> <li>• Nurturing the relationships between actors in the encounter</li> </ul>	<ul style="list-style-type: none"> <li>• Increased patient safety</li> <li>• Reduced costs</li> <li>• Care coordination</li> <li>• Identification of best practices</li> </ul>	<ul style="list-style-type: none"> <li>• Impact on services provided</li> <li>• Impact on organization or system</li> <li>• Impact on services provided/organization</li> <li>• Impact on organization or system</li> </ul>
Patient engagement (non-clinical level) <a href="#">Rooke and Oudshoorn (2020)</a>	<ul style="list-style-type: none"> <li>• Power</li> <li>• Communication</li> <li>• Collaboration</li> <li>• Information sharing</li> </ul>	<ul style="list-style-type: none"> <li>• The goals and objectives of the organization reflect the interests of patients</li> <li>• Partnerships with equal power</li> <li>• Patient engagement is improved through positive experiences of participation</li> <li>• Improved organizational outcomes</li> <li>• Health care becomes more effective and care coordination more organized leading to better experiences for patients</li> <li>• Continuous improvement to the patient engagement experience</li> <li>• Greater understanding and awareness of healthcare design challenges and opportunities for patients, leading to enhanced self-efficacy and self-determination</li> </ul>	<ul style="list-style-type: none"> <li>• Impact on organization or system</li> <li>• Impact on services provided</li> <li>• Impact on engagement participant/experience</li> <li>• Impact on organization or system</li> <li>• Impact on services provided; Impact on engagement participant/experience</li> <li>• Impact on engagement participant/experience</li> <li>• Impact on engagement participant/knowledge</li> </ul>

Sources: [Castro et al. \(2016\)](#); [Higgins et al. \(2017\)](#); [Rooke and Oudshoorn \(2020\)](#); [Dukhanin et al., 2018](#) and [Coulter and Ellins \(2006\)](#).

framework, limiting comparability. Existing tools for evaluating PPI-activities also more often include context and process indicators compared to outcome indicators ([Boivin et al., 2018](#)). The Public and Patient Engagement Evaluation Tool (PPEET) developed by [Abelson et al. \(2019\)](#), for instance, is aimed at different target groups, and assesses: (i) the processes, outputs and perceived impacts of engagement activities from the perspectives of citizens, patients and family members; (ii) the planning and execution of the engagement activity from the perspective of engagement implementers; and (iii) the culture and practices supporting public and patient engagement from the perspective of senior management and leadership in organizations.

In addition, PPI activities are also embedded in a context of health governance, and [Thurston et al. \(2005\)](#) argue that it is often impossible to link a specific policy decision to a PPI activity because it is pulled out from its social context and policy community. The authors argue that outcome evaluations should consider the complexity of the policy and decision-making process, the many opportunities to influence actions, and the iterative nature of the process, and short- and long-term outcomes. Measuring changes in service design, policy, and practice is particularly complex, with few tools addressing organizational impact ([Kreindler & Struthers, 2016](#)). For example, in a review of public

involvement in health-care policy, [Conklin et al. \(2015\)](#) found studies covering different public involvement types (consultation, participation, engagement, partnership, community development, representation), methods (e.g. round tables, surveys, citizens' jury and partnership-based collaboration) and goals (e.g. to understand better the needs of all sections of the community to provide appropriate primary care, to engage the public in priority-setting for health technology assessment, and to reduce health inequalities through co-ordinated activity of different agencies). The authors concluded that the indicators used to examine and determine outcomes remained poorly specified and inconsistent.

### 3.2.4. Classification of PPI activities and frameworks to evaluate PPI impact

Classifying activities can serve as an initial step in evaluating impact, since the design of involvement (i.e., the PPI activity) significantly shapes the possible impact and its beneficiaries. [Charles and DeMaio \(1993\)](#) present an analytical framework with three key dimensions—(i) domains; (ii) role perspective; and (iii) level of participation—whose combinations offer a spectrum of involvement activities, methods, and potential impacts, see [Supplementary file 2](#) for details and a comparison. [Carman et al. \(2013\)](#) make a similar division to Charles and DeMaio in a

widely cited article about patient and family engagement. They argue that participation can occur at multiple levels of engagement, affecting the types of potential impact: (i) direct care; (ii) organizational design and governance; and (iii) policy making. At these levels, patients commonly engage with clinicians, organizational leaders and frontline managers, and community leaders and politicians, respectively. This correspond to Halabi et al.'s (2020) three levels of participation: (i) micro; (ii) meso; and (iii) macro.

Moreover, Carman et al. (2013) introduce a continuum of engagement that considers how information flows between the patient and provider and the level of patient activity in decisions: consultation, involvement, and partnership and shared leadership. This aligns with Grande et al.'s classification model of patient engagement methods (Grande et al., 2014), which identifies three main components: (i) passive information provision; (ii) information provision and activation; and (iii) information provision, activation and collaboration. In Wait and Noltes' (2006) evaluative framework, this is termed the spectrum of involvement (from high to low degree of control), and complements the distinctions between who the public is (the citizen-taxpayer; the citizen-collective decision-maker; the citizen-patient), why involvement takes place (a democratic vs consumerist perspective), and the area for public involvement (priority setting, the planning of services, including resource allocation, and the delivery of services, including treatment decisions and patient choice).

When it comes to outcome categorizations, much of the conceptual work is based on empirical investigations rather than theory derived (see e.g., Bombard et al., 2018; Mockford et al., 2012; Sandvin Olsson et al., 2020). Restall's (2015) conceptual framework, based on interviews, illustrates outcomes of citizen-user involvement in mental health service policymaking, dividing it into (i) personal; (ii) substantive; (iii) instrumental; and (iv) normative dimensions. Personal outcomes (micro-level) are impacts on the people who participate. Substantive outcomes (meso-level) relate to the quality of decisions and services, while instrumental outcomes (meso-level) increase the legitimacy of policy decisions. Normative outcomes promote democratic values (macro-level). Most of the empirical impact categories found in the literature can be sorted under these dimensions. For example, in Farmer et al.'s (2017) practical tool for planning and evaluating involvement (helping managers to identify the target group, involvement activity, potential outcomes and outcome indicators, as well as contextual factors that could affect participation), the authors outline five types of outcomes: service improvement (service quality and safety, costs), responsabilisation (appropriate service use), health improvement, citizen influence and community capacity, and democratic participation. Here we find substantive, personal and normative impacts. One of the most commonly mentioned substantive outcomes are impact on service planning and development such as re-design of buildings, the location of services, provision of transport and changes to appointment systems (Bombard et al., 2018; Mockford et al., 2012; Sandvin Olsson et al., 2020). Some studies, however, focus more on aggregate and embedded outcomes. Approaching involvement from a holistic perspective, Thurston et al. (Thurston et al., 2005) highlight the health of the population as the ultimate outcome, but stress the importance of understanding public participation initiatives as a process. Thurston et al. categorize policy outcomes into governance and operational policy decisions, which are formally recorded, and governance and operational policy statements, which are less formalized and thereby more difficult to evaluate.

Personal outcomes are the primary impacts presented by Tambuyzer et al. (2014), Halabi et al. (2020) and Coulter and Ellins (2006). Tambuyzer et al. (2014) developed a comprehensive model for evaluating patient involvement, identifying its (i) determinants; (ii) essential elements; and (iii) outcomes. Determinants include facilitators and barriers, such as communication with patients and the attitudes of healthcare professionals towards patient involvement. Essential elements encompass factors such as the reasons for involvement, on what

organizational level involvement takes place, participatory method, and power dimension. They specify two types of outcomes: i) short term-outcomes such as empowerment, recovery, satisfaction, accessibility of care, quality of care, and better health, and ii) long-term outcomes, such as improved quality of life. Three out of four of Halabi et al.'s (2020) groups of expected outcomes can be classified as personal: (i) better health outcomes, such as better control of chronic condition, decreased hospitalisation and readmission, improved emotional and physical health status, and the ability to carry out activities of daily life; (ii) greater patient satisfaction including overall quality of care, healthcare professionals and the healthcare relationship; and (iii) increased patient participation (enhanced care experience that will ensure empowerment, activated personal responsibility to act on one's behalf, increased shared decision making, and greater use of chronic disease services). The last group: (iv) improved healthcare system (an environment where decision-making is shared, staff relationships are collaborative, leadership is transformational and innovative practices are supported) is rather substantive. In many ways, Halabi et al.'s grouping resembles Coulter and Ellins's (2006) categorization of outcomes of patient-focused interventions: (i) impact on knowledge; (ii) impact on experience; (iii) impact on service utilization and costs; and (iv) impact on health behaviour and health status, as shown in Supplementary file 2. Most of these are personal outcomes.

Lastly, conducting a systematic review of metrics for evaluating patient, public, consumer and community engagement in organization-, community-, and system level healthcare decision-making, Dukhanin et al. (2018) developed an empirically derived taxonomy of potential metrics. They organized the metrics found in 199 studies into the two main categories: process metrics and outcome metrics. Process metrics were clustered in four domains: (i) direct process metrics; (ii) surrogate process metrics; (iii) preconditions for engagement metrics; and (iv) aggregate process metrics, see Table 3 for details. As for outcome metrics, they identified the three domains: (i) internal outcomes; (ii) external outcomes; and (iii) aggregate outcomes. Internal outcomes include impact on: (a) engagement participants, such as improved knowledge (i.e., personal outcomes). It also includes impact on (b) services provided by the organization or system, such as improved quality or decreased utilization of services, and impact on (c) organization or system (on its policies, procedures or resources, e.g., redesign of staff roles, or staff training policies, or expanding its patient engagement program). External outcomes were split into two sub-domains, including impact on: (a) the broader public, such as strengthened public support for the organization, and on (b) population health generally, such as decreased health inequalities. Aggregate outcomes were reserved for the cost effectiveness of engagement. Sofaer (2019) has however suggested a recasting of the metrics in the form of a logic model, providing evaluators with a timeline to suggest when to focus on certain metrics. The logical model is divided into: Inputs; Initial Processes; Eventual Processes; Initial Outcomes; Intermediate Outcomes; and Long-term Outcomes.

In summary, in the same way as for public participation, we can conclude, based on the conceptual discussions on PPI and its potential impact, that there are many process dimensions that can be evaluated, as well as a great number of potential outcome dimensions. The outcomes can be grouped into impacts related to *individuals, service provision, decision-making and policy and the society*.

### 3.3. Chart of potential impacts: a synthesis

Based on the conceptual review of the literature on impact of patient and public involvement in both social sciences and health sciences, we present a conceptual integration of impact areas, categories and types spanning these both literatures. In this version, not all potential impacts are included, but the most commonly encountered in the literature. For user clarity, we opted for self-explanatory names for overall categories and subcategories, avoiding terms like substantive, instrumental, and

**Table 3**  
Process metrics and outcome metrics as summarized by [Dukhanin et al., 2018](#)

Process metrics	Outcome metrics
<b>Direct process metrics</b>	<b>Internal outcomes</b>
a .Participants' real control over decision process	a .Engagement participants—knowledge, skills, views, confidence or self-esteem, empowerment, satisfaction, sense of ownership, trust
<b>Surrogate process metrics</b>	b. Services provided by the healthcare organization or system—efficiency and cost-effectiveness of services, number of complaints on services, Service availability, services quality and safety, services responsiveness to needs (including needs of subpopulations), sustainability of the services, user experiences with services, utilization of services
a .Formal power	c. Organization or system—Additional potential connections or partnerships with other groups or organizations, diversity of funding sources, funding and resources availability, visibility of organization, accountability of organization to the participants served, staff views on engagement, staff satisfaction, informal (unwritten) organization or system procedures, formal (written) organization or system policies, redesign of staff roles, staff recruitment, staff training, explicit change to organization or system process of decision-making, presence of racism in system, level of public reporting (e.g., making annual report available to the public)
b. Organizational commitment to engagement	<b>External outcomes</b>
c. Participation	a .Broader public (outside the organization or system) —capacity for future involvement in the organization by the community, level of control over decisions made by the organization or system, awareness or knowledge of health issues, support of the organization or system, involvement as part of social change outside the organization, stigmatization of others
d. Tailoring the engagement to participants' needs	b. Population health—population health status, level of health inequalities
<b>Preconditions for engagement metrics</b>	<b>Aggregate outcome</b>
a .Participant-initiated engagement	a .Overall cost-effectiveness of engagement
b. Recruitment and membership	
c. Representativeness and accountability	
d. Resources provided to participants	
e. Training for participants	
f. Training for staff	
<b>Aggregate process metrics</b>	
a .Respect	
b. Transparency of decision-making	
c. Trust	
d. Legitimacy of decision-making	
e. Level of participation	

Source: [Dukhanin et al. \(2018\)](#). Adapted version focussing on outcome metrics. More metrics are included in the original article.

normative impact, which may vary in usage among different authors and pose challenges in comprehension. It is important to note that the impact types specified in this chart can be measured in a number of ways, using a range of different sources of data.

In [Table 4](#), our chart comprises three overarching areas that are synthesized from the impact areas found in the review of the public participation and PPI literatures, respectively: (i) impact on individuals, (ii) impact on the health system, and (iii) impact on decision-making processes and society. Concerning *individuals*—the first category—we distinguish between citizens (members of the public), patients, and decision-makers. The majority of impact types are identified in relation to the patients: further divided into knowledge, experience, health behaviour, health status, and utilization (with additional examples of sub-types presented in the table). These impacts typically result from involvement in direct care and treatment decisions. A notable addition from the public participation literature involve impacts related to individuals as citizens. These can broadly be divided into educational outcomes, such as civic and political knowledge and skills, and integrative outcomes, such as identification with the community. These impacts often stem from collective activities. Additionally, a general citizen impact is a sense of empowerment. Decision-makers form another sub-category, being for example politicians, civil servants and managers at different levels within the health system, who may also be healthcare professionals. Types of impact on decision-makers encompass knowledge, attitudes, and responsiveness to participation and citizen proposals.

The second area pertains to *the health system* and impacts on service provision, and public health. Similar to the third area, *Decision-making processes and society*, these impacts result from involvement at the levels of service organization and system/policy. Impacts on service provision constitute a comprehensive category of impacts that could potentially encompass all types of services improvements. Sub-types include quality of care, access, patient safety, responsiveness to needs, cost effectiveness, system efficiency, innovation, planning and development, and sustainability. These sub-types can be further specified into various aspects. For example, quality of care may refer to a number of disease- and treatment specific outcomes, while improved access could refer to, for

example, opening hours, service relocation or new booking systems. Ultimately, PPI may also impact population health status and the level of health inequalities in the population. However, in practice, it is exceptionally challenging to find evidence supporting this causal relationship.

The third area involves *decision-making processes and society*. Concerning decision-making, PPI may yield various impacts, focusing on both improving the quality of decisions and the decision-making process. Similar to the second category, these impacts result from involvement at the levels of service organization and system/policy. An example of the latter is increased transparency. Relevant impacts include the incorporation of public values, inclusion of multiple perspectives, and resolution of conflict among competing interests. Consequently, this sub-category encompasses both aspects of managerial efficiency (wider range of relevant views) and political legitimacy (acceptance of operating rules or principles). Concerning policy and state, a crucial impact is that PPI, or input from PPI activities, affect policy decisions and improve policy responsiveness. Other potential impacts include PPI contributing to the accountability and legitimacy of the state or local governments. It could also lead to a greater realization of rights. Lastly, various impacts can be attributed to the public and society. This includes educating and informing the public, creating issue salience. In addition to building trust in institutions, PPI enhances democratic participation, creates capacity for future civic and political engagement, and may contribute to the inclusion of new actors and issues in public spaces. It has the potential to enhance community capacity, leading to a more inclusive and cohesive society.

#### 4. Discussion

In the results section, we integrated and synthesized extant knowledge about impact from public participation and patient and public involvement found in social sciences and health sciences respectively, with an emphasis on summarizing and grouping relevant conceptual reasoning dispersed across various studies. After integrating and synthesizing the two literatures, we present a chart of potential impacts resulting from patient and public involvement in healthcare services, with three overarching areas: (i) impact on individuals; (ii) impact on



**Table 4**  
Chart of potential impacts resulting from patient and public involvement in healthcare services.

Individuals		Health system		Decision-making processes and society			
Citizens	Patients	Decision-makers	Service provision	Public health	Decision-making	Policy and state	Public and society
<ul style="list-style-type: none"> <li>Educational benefits:</li> <li>• Knowledge and skills (civic and political)</li> <li>• Confidence and self-esteem</li> <li>• Understanding of own self-interests</li> <li>Integrative benefits:</li> <li>• Identification with community</li> <li>• Social integration</li> <li>• Identity expression</li> <li>• Sense of empowerment</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge - conditions and complications</li> <li>- selfcare</li> <li>- treatment options and outcomes</li> <li>- comprehension and recall of information</li> <li>• Experience</li> <li>- patient satisfaction</li> <li>- patient-doctor communication</li> <li>- confidence to manage health</li> <li>- self-care</li> <li>- social support</li> <li>- involvement</li> <li>• Health behaviour</li> <li>- treatment adherence</li> <li>- symptom control</li> <li>- lifestyle and health-related behaviour</li> <li>• Health status</li> <li>- quality of life</li> <li>- psychological well-being</li> <li>- functional ability</li> <li>- disease severity</li> <li>• Utilization</li> <li>- hospital and emergency admissions (length of stay)</li> <li>- Outpatient visits</li> <li>- Cost to patients</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge</li> <li>• Attitudes</li> <li>• Implementation of actions, concrete actions</li> <li>• Responsiveness to participation and citizen proposals</li> <li>• Insight due to participation</li> </ul>	<ul style="list-style-type: none"> <li>• Service improvement</li> <li>- quality of care</li> <li>- access</li> <li>- patient safety</li> <li>- responsiveness to needs</li> <li>- cost effectiveness</li> <li>- system efficiency</li> <li>- innovation</li> <li>- planning and development</li> <li>- sustainability</li> <li>• Staff knowledge and attitudes</li> <li>• Staff satisfaction</li> <li>• Efficient use of resources</li> <li>• Legitimate system</li> <li>• Reduced complaints</li> </ul>	<ul style="list-style-type: none"> <li>• Population health status</li> <li>• Level of health inequalities</li> </ul>	<ul style="list-style-type: none"> <li>• Substantive quality of decisions</li> <li>• Incorporation of public values</li> <li>• Inclusion of multiple perspectives, wider range of relevant views (managerial efficiency)</li> <li>• Improved understanding and better solutions</li> <li>• Resolution of conflict among competing interests</li> <li>• Acceptance of operating rules or principles (political legitimacy)</li> <li>• Transparency</li> </ul>	<ul style="list-style-type: none"> <li>• Policy decisions</li> <li>• Policy responsiveness</li> <li>• State accountability</li> <li>• State legitimacy</li> <li>• Greater realization of rights</li> </ul>	<ul style="list-style-type: none"> <li>• Educating and informing the public</li> <li>• Capacity for future civic and political engagement</li> <li>• Issue salience</li> <li>• Building trust in institutions</li> <li>• Inclusive and cohesive society, social capital</li> <li>• Democratic participation</li> <li>• Community capacity</li> <li>• Inclusion of new actors and issues in public spaces</li> </ul>

the health system; and (iii) impact on decision-making processes and society. The chart can serve as a resource for those deciding to carry out or evaluate PPI activities, in particular in trying to establish what outcomes they are aiming for and how these will be measured. The chart should be viewed as a complement to measuring process dimensions, which can be equally important for enhancing involvement. We perceive the chart as an initial effort to amalgamate the conceptualization of impacts in the social science-literature and the health science-literature and we encourage fellow researchers to revise and further improve this chart. To enhance the chart further, there is room for incorporating additional impacts and organizing them into meaningful groups. Other aspects could also be included by incorporating literature that uses the term ‘benefits’ to describe desired outcomes from PPI.

Among other things, we identified in our conceptual review that there are great differences in the use of theory in relation to the conceptual work, with less theoretical approaches in the health sciences literature, in which conceptualizations are often based on empirical investigations or reviews. We can also conclude that frameworks for evaluation of involvement or participation include more process measures than outcome measures. The relative lack of theoretical exploration concerning the outcomes or impacts of PPI is a gap that should be highlighted and be part of the agenda for future research in this area. Depending on the nature of the PPI activity, theories from psychology, sociology, communication or political science could be a great starting point, as well as theories used within the field of community interventions. We also highlight a gap concerning conceptual thinking

relating to macro-level involvement, that is involvement aiming to influence policy-making or decision-making in healthcare in matters that are strategic and of a collective nature. It is in this area that the PPI-literature can probably benefit the most from the social science literature, in particular from theory on participatory and deliberative democracy, and potentially from organizational studies. This is particularly relevant in healthcare systems governed democratically at national and/or local levels. Furthermore, our integration and synthesis of existing conceptual work involved resolving inconsistencies in construct definitions across studies, seen for example in Table 1, where different types of impact are laid out. We can note, however, that it is difficult to draw clear distinctions between certain concepts, for example instrumental and substantive impacts, given their overlapping usage by different authors. Therefore, we recommend that researchers carefully explain the meanings they attribute to the concepts they use when evaluating and theorizing involvement, to enhance transparency and contribute to the evidence base on the impact of PPI.

### 5. Conclusion

To advance the conceptual understanding of the impact of PPI in healthcare, the social science literature serves as a necessary complement to the predominantly empirical health science literature. Social science perspectives are helpful for understanding impact, particularly in the context of public (or citizen) involvement, which often occurs collectively at the meso or macro level and focuses on strategic and

policy-related matters. This type of involvement is tightly intertwined with democratic functions in society rather than being carried out in the clinical environment. Based on our conceptual review, we present a chart of potential impacts arising from PPI in healthcare services. We encourage others to further develop this framework, which can be used as a support for identifying and evaluating desired impacts alongside key PPI process indicators.

### CRedit authorship contribution statement

**Mio Fredriksson:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Filipa Sampaio:** Writing – review & editing, Validation, Methodology. **Linda Moberg:** Writing – review & editing, Validation, Methodology, Conceptualization.

### Ethics committee approval

Not necessary because the study did not involve the use of human subjects.

### Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the author(s) used ChatGPT in order to improve the language of the manuscript. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the published article.

### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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### Appendix A. Supplementary data

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