



# **Targeted literature review – Understanding the description and application of patient agency in the healthcare context**

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## Executive summary

Patient agency is a term often used interchangeably in relation to the patient healthcare journey. In order to develop a universally recognised meaning of the term there is a need to understand how it is being defined and discussed in literature. This literature review focuses on reviewing research which has incorporated the term 'patient agency' and attempted to explain what it means but has often fallen short on reaching a consensus of its meaning, or recommending the correct and practical use of the term.

What is patient agency when considering passive vs active patients going through their healthcare journey? How do you support patients to be empowered and engaged in their healthcare and establish control without compromising their journey? This literature review will discuss the importance of viewing patient agency as a framework, focusing on the patients' decisions to engage in their healthcare, and in turn how they then interact with the environment; (1) taking/deciding on the level of ownership of one's health, (2) individual attributes (capabilities, motivation) and (3) environmental interactions (opportunities).

## Introduction

Involving patients in their care has been prevalent in the healthcare sector over the past several years (Coulter et al, 2017). The healthcare sector is paying more attention to addressing issues such as low levels of health literacy and disempowering approaches, which are associated with patients not actively participating in their own care (Joseph-Williams et al, 2021, Coulter et al, 2017). This has given rise to initiatives where the focus has been to improve patient empowerment, increase patient engagement and improve shared decision making (Elins & Coulter, 2005) and engage the wider communities (Boivin et al, 2022). The underpinning principle of these initiatives has been to give patients more control and opportunity based on their individual strengths, needs and preferences (Elins & Coulter, 2005). These needs and strengths can differ depending on the changes that will occur over time in any given system. The importance of having resilience through these approaches refers to the ability of individuals and systems to adapt, evolve and survive as a result of change and crisis (Boivin et al, 2022).

With patients taking an increasingly active role in their own healthcare and when interacting with healthcare providers, terminology such as 'expert patient', 'patient empowerment' and 'action competence' has been applied more widely and other terms such as 'the impatient patient' have also been coined to describe an active and interactive patient role (Bereczky, 2013). Yet, clear

definitions of these concepts are lacking, meaning they are often used interchangeably making it difficult to distinguish between them. The value of patients' experiential knowledge gained from living with a chronic condition should not be underestimated, and can provide doctors with valuable insight on the experience of living with a certain disease. The Montreal Model recommends that the patient is an essential partner in the decisions that affect them, and suggests that patients should be partnered as experts in their care (Pomey et al, 2015).

It is unclear how the concept of 'patient agency' is represented in the literature, what descriptions of the concept entail, how it differentiates from other terminology and the factors that underpin it. Furthermore, there is a need to understand how agency is exercised when people become patients who encounter the healthcare system.

The aim of this targeted literature review is to establish a clear consensus and a common definition of the term 'patient agency' across all stakeholders; the focus is to understand how patient agency has been described across disease areas, irrespective of a specific disease.

One definition of 'patient agency' described it as "the abilities and capabilities of patients to act, contribute, influence and make decisions about their healthcare". It depends on both the willingness of patients to participate, and the constraints imposed by healthcare providers, services and systems (Bok et al, 2022).

The themes that European Haemophilia Consortium Think Tank (EHC TT) underpin in their 'patient agency' description are the concepts of shared decision-making, patient empowerment, the spectrum of engagement, cultural change and health literacy.

## Research aims and objectives

The aim of the targeted literature review is to identify and analyse the existing body of published literature that has focused on patient agency.

The specific objectives are to:

- Build on the existing knowledge on what factors/challenges impact patient agency
- Critically review existing knowledge on the concept of patient agency
- Understand the use of the concept patient agency across similar therapy areas
- Understand best practice methodologies which have defined the term patient agency.

The findings will generate the basis for the development of an overarching definition of patient agency that works across all stakeholders, including patients.

## Research questions

1. How is the term ‘patient agency’ used across therapy areas?
2. What are the reported factors/themes in the literature (e.g. barriers) that impact patient agency and why? How can these challenges be overcome?

## Methodology

### Search strategy

A systematic search technique was applied based on the pre-defined word structure [“PATIENT\* AGEN\*”] to identify all available published literature (peer reviewed and grey) around the concept of patient agency.

The search was carried out on two databases (EMBASE and PsycINFO) where a search strategy was applied (Table 1). Both databases cover a wide set of journals from disciplines such as sociology, anthropology, psychology, disease education etc.

Table 1 Search strategy

Item	Outline
Database(s)	EMBASE, PsycINFO
Time range	No restriction on date range
Location	EU
Search restrictions	Language restrictions: English
Publication types	No restrictions
Population/Therapy	Any
Search strings	“PATIENT* AGEN*”
Hand searches	We will search the references lists of included papers to identify any additional relevant studies

All papers were screened for titles, abstracts and, where appropriate, full texts based on a set of pre-defined inclusion/exclusion criteria.

## Screening and Results

Due to the nature of this targeted review, we did not limit papers by adding restrictions on participants' characteristics such as disease. In order to identify any relevant literature, including unpublished and non-peer reviewed literature, we did not limit the search criteria to peer-reviewed articles. Articles from outside of the location criteria were reviewed and included if found to be relevant to the research questions. Conference papers and proceedings, dissertations and theses, reports and any government and official publication were included if identified and relevant.

Only literature published in the English language was included in analysis.

A total of 79 hits resulted from the search strategy and a further 5 papers were identified through hand searching of reference lists of included papers.

After removing duplicates, each reference was assessed for title and abstracts to make an assessment for inclusion or exclusion. A total of 16 papers met the inclusion criteria and were analysed in this targeted literature review.

## Data extraction & analysis

Data was extracted from articles which included at least one of the following:

- Reported definitions/descriptions of the term 'patient agency'
- Reported factors that impact patient agency
- Concepts e.g., shared decision-making/empowerment, partnerships, co-creation in healthcare, user/acceptance of lived experience, health literacy underpinning patient agency

Please see appendix 1 for the full data extraction table.

## Key Findings & Discussion

None of the studies focused on rare disease and patient agency. The studies reviewed either discussed the concept of patient agency, the underpinning concepts, or both, whilst referring to a range of different therapy areas. The description of the concept did not differ across these disease areas. There was a significant overlap between the concepts described as underpinning patient agency, such as shared decision making, empowerment through such processes, partnerships, co-creation, and health literacy, across the literature.

Some articles did not provide a definition of patient agency, but data was extracted to understand how the patient agency concept was being discussed or how it was being referred to in the article.

### Definitions/descriptions of the term patient agency - 'the ability to do X'

Patient agency descriptions/definitions were predominantly found to exist in articles when discussing decision making, choice(s), patient autonomy and capabilities to make decisions. Graham (2009) discusses patient agency as the capacity for autonomous action, stating that different scholars have addressed different moments: the preconditions for agentive action, the initiation of agentive action, the mechanisms of agentive action, and the resolution of agentive action—i.e. the final instantiation of change. An integrated understanding of agency suggests that

1. Agency is the process of instantiating change in the status quo.
2. Change will arise from series of rhetorical events over time.
3. Resisting authoritative forces (paternalistic approach) yet having to rely on them
4. A change becomes the status quo when new structures operate to maintain the change.

Other definitions/descriptions focused on the ability to take an action without need for much direction:

*'Decision making ability" or agency is the capacity of one individual to act autonomously and to make one's own free choices' (Hodgson, 2019)*

*"If I don't know I can find out": patient agency as the capacity to know' (Defossez, 2016)*

*"Restoring a sense of confidence and control through choice": patient agency as the capacity to decide' (Defossez, 2016)*

*'Patients' active participation' (Hunter et al, 2015)*

*'Patient agency is defined as practices to lead a meaningful life in the world as a person who has health problems' (Shim 2022)*

Patient's active participation not only refers to the ability to manage one/several conditions or take an active role in treatment decisions, but taking a more engaged approach in the wider aspects of the treatment landscape e.g. activism to reform clinical trials etc. (Epstein, 1995). Furthermore, patient agency was often discussed within a wider social context in which patients had to make their decisions, including how the environment/clinical encounter was a factor in determining the ability to make a decision. Koenig, (2011) discussed agency as something that

emerges in and through interaction with the healthcare provider, such as the process through which a patient initially vetoes but subsequently accepts a treatment recommendation. Patients demonstrate active participation in their own care according to the contingencies and constraints of the way the structures of the healthcare system allow.

Hunter et al's (2015) description further reflects this:

*'The healthcare system constructs identity, and thus agency for patients in the way it positions patients and the way it enables or constrains how patients position themselves.'*

Similarly in a more specific environmental setting e.g., a clinical setting, the agency to accept/refuse treatment was discussed. Here, agency was again referring to one's ability to accept/refuse treatment within a specific interaction and structure through their responses.

*'Patient non-acceptance was analyzed as an important interactional and structural resource that enhances patient agency in making treatment decisions. Specifically, when patients resist a physician's treatment recommendation, they create an opportunity to actively participate in how a treatment recommendation ultimately emerges as acceptable. This implies that through their responses, patients demonstrate a limited form of agency to actively participate in treatment decisions.'* (Koenig, 2011)

In other sources of the literature there has been a wider, somewhat abstract description of the term 'patient agency' where the agency is perceived as people having an active nature who can act according to their purpose and desire, depending on their experience of the social circumstances they find themselves in.

*'Realist social theory conceives of agency as people having an active and reflective nature, who can both habitually and purposefully act, depending on how they internally reflect on their social circumstances. Our unique identities enable us to be active agents that reflexively evaluate how we can act on our 'personal concerns' within particular social contexts.'* (Archer, 2000).

Koenig (2011) suggests agency is the 'ability to influence events in people's world according to preferences, needs and desires', whereas O'Hair et al (2003) define it as 'having choices and the competencies to act on them'.

Due to the nature of the concept, agency was discussed as a fluid concept, which could change depending on both internal (capability, motivation) and external or environmental factors.

However, no paper explicitly highlighted the conditions which need to be present for patients to

have agency. There were concepts mentioned that underpin patient agency, but there was no clear consensus on these, or in what order they should come, to allow agency to develop.

### Concepts underpinning patient agency - Fostering patient agency

A wide set of concepts were reported in the literature as underpinning patient agency (see Figure 1). These included health literacy, shared decision-making/self-management, empowering approaches, and doctor-patient communication enhancing the expert patient role and autonomy.

Figure 1. Concepts underpinning patient agency



Health literacy was a fundamental underpinning. Health literacy is having the skills such as language, literacy, numeracy, knowledge and understanding alongside the confidence to access, understand and evaluate and navigate health information services. The World Health Organisation (WHO) describes health literacy as ‘an act of agency in the choice of active verb phrases: access, understand, appraise, apply, make judgements, and take decisions’.

Health literacy in the WHO European Health Literacy Consortium is defined as:

*Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every-day life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (Kickbusch et al., 2013).*

The language used above highlights the need for active participation in healthcare encounters and interactions (Brach, 2013). It also implicitly highlights agency as something that exists within

a patient and/or their level of capability. Mediation of agency is therefore something one does within a given situation/context.

Health literacy is also perceived as an asset where the focus is on factors which give people more control over their own health (Nutbeam, 2008). Ahearn (2001) defines health literacy as 'the ability to understand, access, and use health-related tools and services in a given location'. Furthermore, health literacy has to do with the social and cultural practices that individuals and groups may engage in during the process of understanding, accessing and using health-related tools and services (Papen and Walters, 2008).

Shared decision-making is another concept that is underpinned in patient agency, where the focus is to ensure the patient is empowered to lead and have more informed discussions with their doctor. The goal of shared decision-making is that, in everyday clinical practice, HCPs invite patients to tell their stories; encourage them to talk about what is important to them; listen to and respect their views and values; give them the information they need in a personalised way; involve them in discussions and decisions about their care; give authority to their knowledge and share responsibility with them. HCPs need to be aware of potential for shared decision-making at all stages of the doctor-patient consultation, and consider each patient individually, neither underestimating nor overestimating their willingness to engage (Gulbrandsen, 2016).

Within this context, patient agency is influenced by how the cultural context of biomedical practice influences HCPs interaction with patients and the acknowledgement that both parties act under constraints from their positions. Structural forces shape the rules of conduct for both doctors and patients in clinical encounters. Understanding how agency operates within this setting would help us to better understand these interactions. This knowledge is needed to assess how to balance doctors' knowledge against patients' experiential, existential perspectives, and agency (Olaug et al, 2021). This can then cultivate a concise and tailored communication to support a collaborative decision-making process. Reciprocal communication can support a patient's autonomy whereas poor communication may lead to patients feeling disempowered, reducing their likelihood of being agents of change (Francis et al, 2019).

Expert patients, empowerment and patient centeredness were also discussed in the literature to underpin patient agency. However, similar to the above, the relationship between patient agency and these concepts was unclear. Each concept is well described in the literature and was expressed in detail in isolation, but the relationship or how it underpins patient agency specifically was not discussed. For example, patient-centred care is described as:

*'1: Exploring the illness experience, 2. understanding the whole experience 3. Finding common ground regarding management 4. Incorporating prevention and health promotion 5. Enhancing the doctor-patient relationship 6. being realistic about personal limitations.'* (Stewart 1995)

Similar to the above, the term expert patient was described as:

*'Expert patient, increase in patients knowledge (often enacted through a process of goal setting which is a shared endeavour).'* (Francis et al, 2019)

*'An expert patient need to be a person whose personal circumstances and associated knowledge are accommodated and respected.'* (Lassen et al, 2018)

The characteristics of an expert patient were described as someone who has:

*"patient autonomy"*

as well as

*"increased patient involvement in decision making and patient agency".* (Tate, 2019)

Within this context, the concept of agency appears to overlap with the ability to self-manage. Francis et al (2019) described self-management as:

*'The core components of the self-management approach - the informed, activated, empowered, expert patient whose motivated self, arises from their personal agency - and the prepared, proactive practice team working together in a collaborative partnership.'*

Those patients who were more assertive also achieve decision-making influence when they oppose actions directly, and were able to explain the rationale behind their decision-making (Ocloo et al, 2020). Patients can display ambiguous role-expectations in the sense that they swap in and out of different roles throughout the decision-making process: subordinating themselves as the traditional patient would, inviting collaboration where they can act as a partner in the process and asserting power to make the decisions (typically seen in empowered patients). In the most decisive moments, irrespective of how empowered patients were, they tended to hand the power of decision-making to healthcare professionals. Due to the nature of the roles, positions, and responsibilities this does not leverage the opportunity to enhance agency (Olaug et al, 2022).

## Factors impacting patient agency

One of the factors impacting patient agency was described in an EHC publication using the notion of 'control'

*The rhetoric of patient agency identified here are all, at root, concerned with the promotion of control: control through knowledge, control through prevention, and control through choice. One antonym of "control" is "chance," and it is undeniably the case that much of what happens to our bodies results by chance, through contingencies over which we are not always able to exercise control (Bok et al, 2022)*

Koenig (2011) also referred to the role of being in control:

*Being in control of one's medical care is something that mostly happens outside of the medical visit, what happens inside the visit can be crucial to whether patients follow or "veto" a physician's recommendations*

Other factors that were reported to impact patient agency were preferences, concerns and choices regarding how and when treatment was endorsed.

*The bodily aspect of life is an essential element that constitutes agency....the bodily dimension of life is taken as an immediate source for people to reveal their agency by redefining, rescaling and refocusing on the meaning of the dimension in their life....people reveal their agency by confirming and yet redefining the significance and meaning of the bodily aspect of life that is affected by illness (i.e., agency in a qualified and yet rediscovered control)...people with bodily constraints reveal agency all the more in efforts to overcome these very restraints head on and heed to nothing else in their life (i.e., agency in a funneled control in fights, prevention, self-healing, professional healing and dying) (Shim, 2022)*

Other factors reported in the literature that may impact patient agency were lack of/minimal involvement in decision-making, patient choice, patient acceptance, patient agreement, patient initiative/capacity, and sense of failure. Although implicitly, motivation/desire to *have* agency impacted *achieving* agency.

Concepts outside the individual, e.g., environment/context, that impacted patient agency were power relations, sharing of power in decision-making, and moving from a more hierarchical dynamic to a more collaborative approach. A collective approach is when the context and system supports the capability and motivation of patients allowing the patients to foster the ability to

take more ownership of their own health. Addressing the role of the environment/context would be useful in a description of 'patient agency' as they are agents within a system.

## Conclusion & Recommendations

In the healthcare context, patient agency is represented in various ways, including the language used in healthcare communication materials, the discourses of healthcare professionals and the communication directed towards empowering patients and their identity. Patients construct their identity in different ways that affect how they interact with the healthcare system and simultaneously manage their conditions.

Patient agency is also discussed in communications with healthcare professionals, showing that patients contest, accept, reject, and negotiate the type of roles (obedient/submissive/assertive/engaged etc) they assume in that setting (Nunes et al, 2017).

Patient agency is also discussed as a process wherein individuals acquire skills necessary to take control of their own health in each setting (Stevenson & Burke, 1992). The structures within a setting appear to impact the opportunity to exercise agency. For example, Kielman & Cataldo (2010) discuss how the context/structure that a patient is in can impact the opportunity for agency. They highlight that structural interventions shift the focus from individual or community capacity to change risk behaviours towards changing "risk environments". The basic premise here is that individuals have limited agency to control or respond to situations that place them at risk of disease.

The use of the term 'patient agency' in this space has therefore not been linear nor a well-defined, well understood definition.

There is a significant overlap between 'patient agency' and other concepts that are underpinned in the literature, and there is little to substantively differentiate these concepts from each other. However, the terminology used overlaps across literature.



- The capability of the specific patient population (includes both psychological and physical capability)
- The motivation to drive/be the driver for change i.e. the agent of change
- Providing the opportunity for change i.e. allow the opportunity for agency to occur and foster

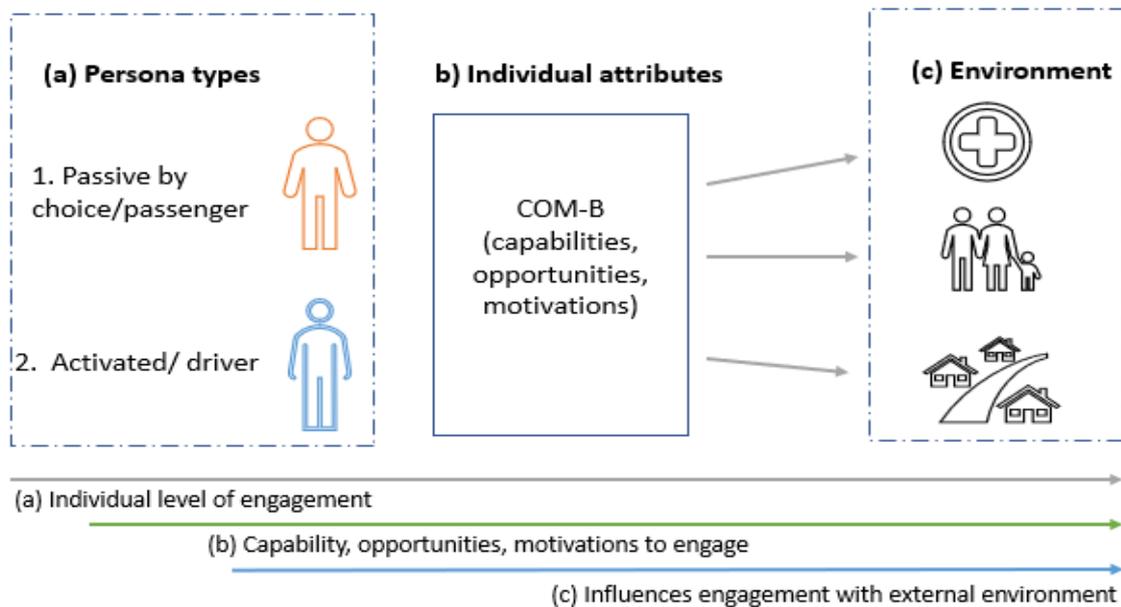
In light of the above, it is recommended that inspiration is drawn from the Behaviour Change Wheel (COM-B) (Michie et al, 2011).

The COM-B model is a widely used framework that can support in identifying what needs to change before a change can take place. The COM-B model represents the observation that change will occur when the person has the capability and opportunity to engage in the behaviour and is motivated to enact that behaviour. The COM-B model proposes that there are three components to any behaviour (B): Capability (C), Opportunity (O) and Motivation (M). In order to perform a behaviour, one must feel they are both psychologically and physically able to do so, have the social and physical opportunity and want or need to carry out the behaviour.

### **Proposed working definition of patient agency**

Patient agency revolves around change and the ability that is needed however, to conceptualise the term 'agency' there is an agreement that this is a fluid approach and dependent on the individual choice in engagement (Figure 2);

- a. Taking/deciding on the level of ownership of one's health
- b. Individual attributes (capabilities, motivation)
- c. Environmental interactions (opportunities)



**Figure 2:** Illustrates the dynamics relating to patients' choice and engagement in their care, also referring to the framework of patient agency

COM-B focuses on psychological capabilities, physical capabilities, physical opportunities, social opportunities, reflective motivation, and automatic motivation

The COM-B framework is a new layer of understanding individual decisional process when deciding on the rationale for why people may be a (1) passive vs (2) activated 'agent' in their disease journey. It may be worth assessing to understand individual attributes which can be mapped on to the COM-B framework to understand levels of engagement/agency.

This targeted literature review focused on understanding how the term 'patient agency' has been used across different therapy areas and what the reported factors/themes in the literature (e.g. barriers) that impact patient agency are. It is likely that this review did not capture articles that talk about the nature of agency using other terminology, however the focus was to understand how the term itself has been described and talked about.

Having reviewed the terms in the description of patient agency, there is evidence with reference to 'having the ability to do

X' as well as being an agent in a wider context (environment). Furthermore, the importance of agency as the 'movement' from a 'patient' to a 'person living with a certain disease' is not only

democratic in nature but also an empowering approach which appeals to the nature of what 'agency' stands for and why it matters. In order to further develop a coherent and consensus definition which is evidence based and is aligned with the existing descriptions, it is recommended that the COM-B model is applied to take it to the next logical step.

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