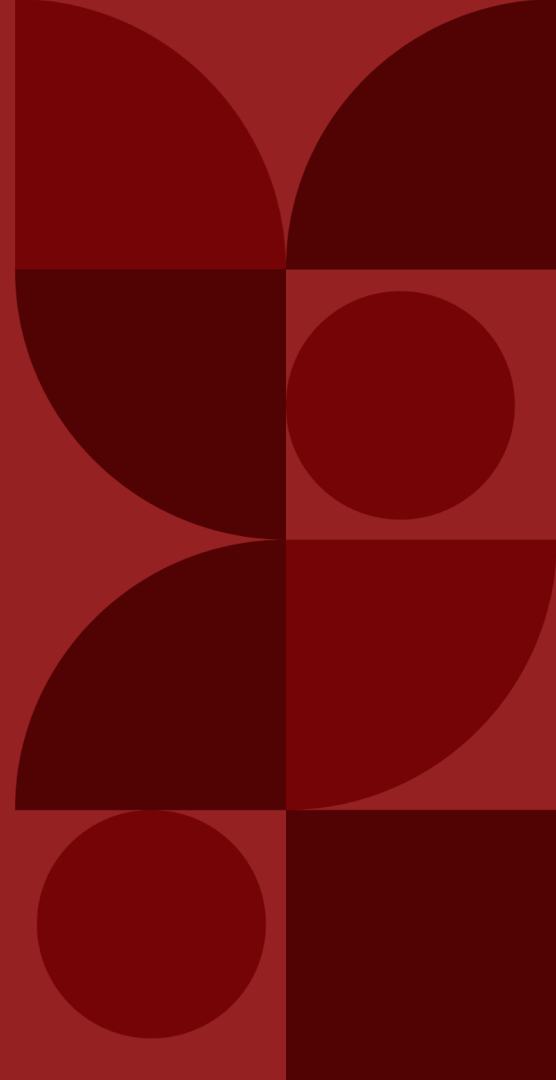# THINK TANK

# Guidebook:
# Patient agency
# challenges & interventions

# Prologue

In 2021, the patient organisation, the European Haemophilia Consortium (EHC) established its Think Tank as a platform to drive 'systems change' to work in parallel with the EHC's long-standing traditional advocacy efforts.

The Think Tank hosts several multi-stakeholder working groups called workstreams, which are open-ended and each addresses a specific topic. The EHC selected different topics based on key interest areas for our community and collaborators and trends in the healthcare sector at large. One of the first topics the Think Tank selected and worked on was patient agency.

The Patient Agency workstream's task was to unravel the challenges with patient agency and uncover different enablers that will lead to a change in the perception and the role of patients in the healthcare system.

This Guidebook is a starting point to address some of the challenges and leverage points the workstream identified through a series of online workshops hosted in 2021-2023. It is neither a step-by-step guide nor exhaustive on how to work with patient agency. We do, however, hope it can serve as a source of information to all who are interested in topics such as patient engagement, patient empowerment, and the role of the patient, all encompassed in the term patient agency.

We invite you to share your work with us for it to be included in the guidebook, for the guidebook to expand and remain relevant as concepts, ideas, and projects evolve.  You can reach out to us at thinktank@ehc.eu.

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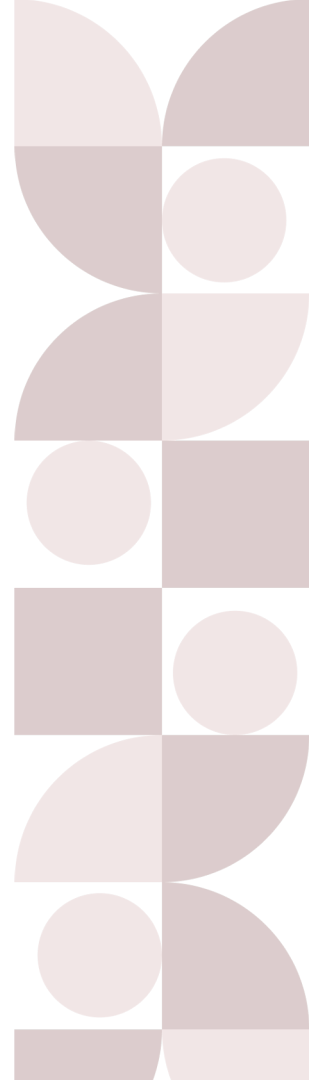TANK

# Systems change together with people

We live and operate in social systems with complex dynamics where change is more likely to endure and be sustained, where it was built from the roots up, interconnectedly.

The EHC Think Tank has as such focused on engaging with many stakeholders, harnessing their motivations to make an impact, grow, develop, evolve, and change, both themselves and the parts of the system that they operate in.

This Guidebook has only been possible through the valuable contributions of the EHC Think Tank Patient Agency workstream members.

Their extensive experience from various parts of the healthcare system and parts of the world, which they benevolently created the foundation for many interventions and future collaborations.

THANK YOU!

**THINK TANK**

# Table of contents

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# 00 Introduction

# Introduction to patient agency

Patient agency refers to the abilities and capabilities of patients to act, contribute, influence, and make decisions within the healthcare system in which they find themselves. Such agency is dependent not only on patients' willingness to participate but on the constraints they encounter in their own competence, interest, as well as their surrounding environment.

Patient agency as a framework, focuses on the patients' decisions to engage in their own health, and, in turn, how they then interact with the environment/context:

1. taking/deciding on the level of ownership of one's health,
2. individual attributes (capabilities, motivation), and
3. environmental/contextual interactions.



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# The importance of patient agency

Focusing on patient agency can help us to achieve a new cultural norm embedded at all systemic levels that healthcare is collaborative and emerges from patients' ownership/agency - of their own journey, path, decision-making, and quality of life.

However, transforming any system is challenging, and requires both individuals and institutions to adopt new and different behaviours.

The process of transitioning is often slow and may not even be immediately noticeable. At times it may even appear impossible for change to happen. It requires champions and a long-term commitment for a continuous pull.

As actors in the healthcare system, we possess the power to drive change. We might not have the power to reform the entire system, but we can as a minimum initiate change in our control sphere. Systems change involves shifting underlying conditions that perpetuate existing problems.

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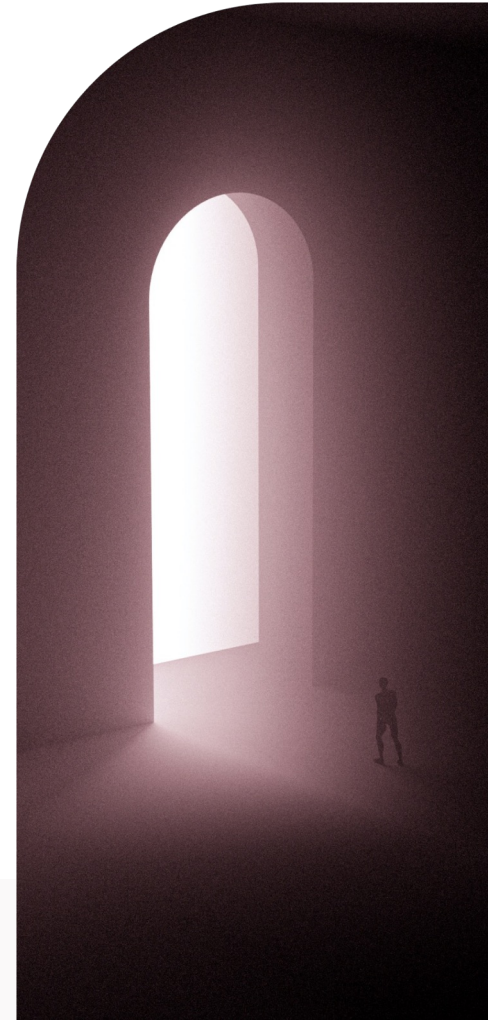# Leverage points as a framework for initiating change

We have drawn upon Donella Meadows' influential article, "Leverage Points: Places to Intervene in a System", as a theoretical foundation to understand change.

Meadows is one of the most influential system change theorist, and leading author to The Limits to Growth, explaining and developing change of systems, in particular ecosystems and sustainability. In 1999, Meadow introduces a list of places to intervene in a complex system in increasing order of effectiveness.

Identifying leverage points in a system does not inevitably lead to the desired change in the system. If anything, profound change often requires a test-and-error perceptive and persistence.

Nevertheless, the leverage points analysis offers a framework for change agents to consider if their idea or project creates the impact they hope to see, which is why we believe it is useful to introduce.

Read more: https://donellameadows.org/

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# Leverage points

Places to intervene in a system

**System**

**12** Constants, parameters & numbers

**11** Buffering capacity

**10** Physical & digital structures

**09** Delays

**08** Balancing feedback loops

**07** Reinforcing feedback loops

**06** Information flows

**05** Rules & regulations

**04** Self-organisation

**03** Goals

**02** Paradigms

**01** Transcending Paradigms
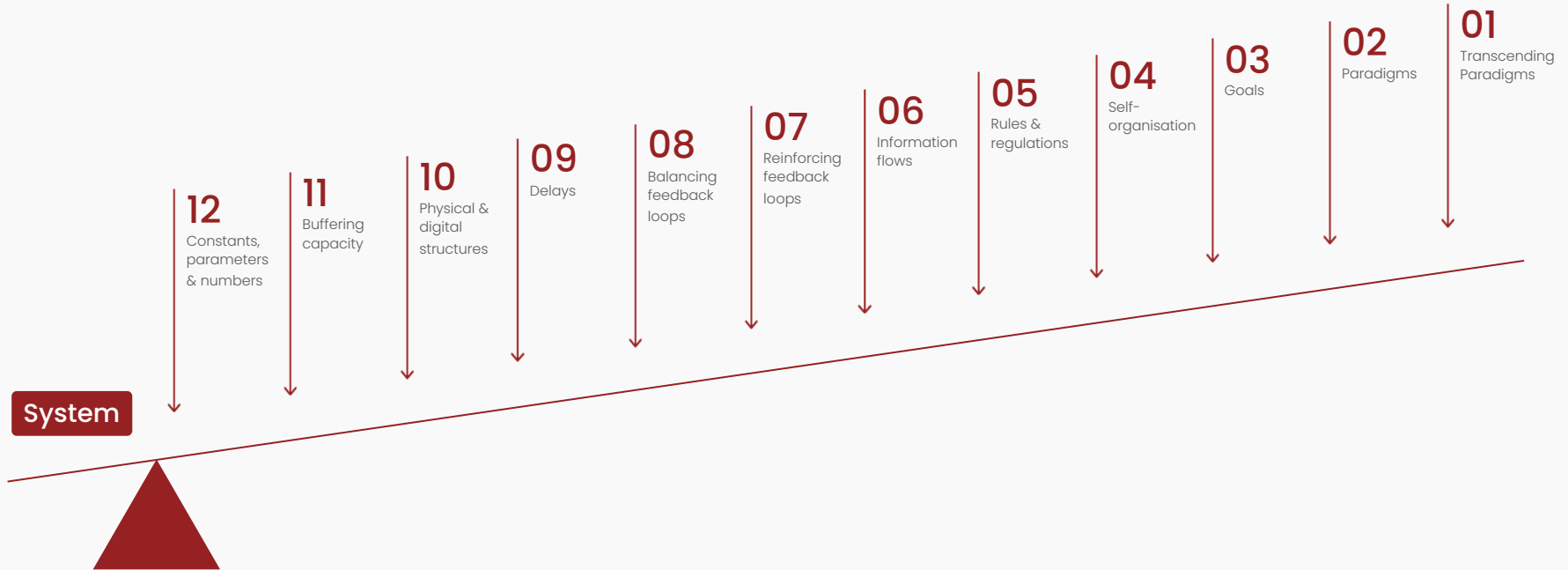
Credit: Donella Meadows

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# Places to intervene in a complex system in increasing order of effectiveness

**12**   Constants, parameters, numbers (such as subsidies, taxes, standards)

**9**   The lengths of delays, relative to the rate of system change

**11**   The sizes of buffers and other stabilising stocks, relative to their flows

**8**   The strength of negative feedback loops, relative to the impacts they are trying to correct against

**10**   The structure of material stocks and flows (such as transport networks, population age structures)

**7**   The gain around driving positive feedback loops

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# Places to intervene in a complex system in increasing order of effectiveness

**6** The structure of information flows (who does and does not have access to what kinds of information)

**3** The goals of the system

**5** The rules of the system (such as incentives, punishments, constraints)

**2** The mindset or paradigm out of which the system - its goals, structures, rules, delays, parameters - arises

**4** The power to add, change, evolve, or self-organise system structures

**1** The power to transcend paradigms

# How to read the leverage points scale

The list is not conclusive for all systems, and the order may shift. There is a common tendency to concentrate on the initial items on the list (12-6) as they seem more tangible and easier to tackle.

Nevertheless, if attention is solely directed towards items 12-6, substantial change is unlikely to happen unless behaviours, mindsets, norms, and paradigms are addressed.

The challenge lies in the fact that attempting to address those items ranked 5-1 will probably encounter considerable resistance to change from the system.

To grasp the details of the framework, we strongly encourage you to read the original paper: *Leverage Points, Places to Intervene in the System, by Donella Meadows.*

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# Structure of this guidebook

Each chapter presents a theme which is also a leverage point identified by Patient Agency workstream members.

The leverage points were identified from a system map containing challenges with related enablers and constraints. Based on an analysis and discussion of the map, four leverage points were considered significant to address first. These are:

- Narrative about patients
- Lived experience data
- Hierarchy of stakeholders
- Health literacy

In the first two chapters, one concrete idea is fleshed out in terms of considerations and impact.

The last two chapters contain a list of ideas to advance on the leverage point.

At the end of each chapter, there are examples of what others are doing in the field, and are great sources of inspiration when deciding on where to put your focus and efforts.

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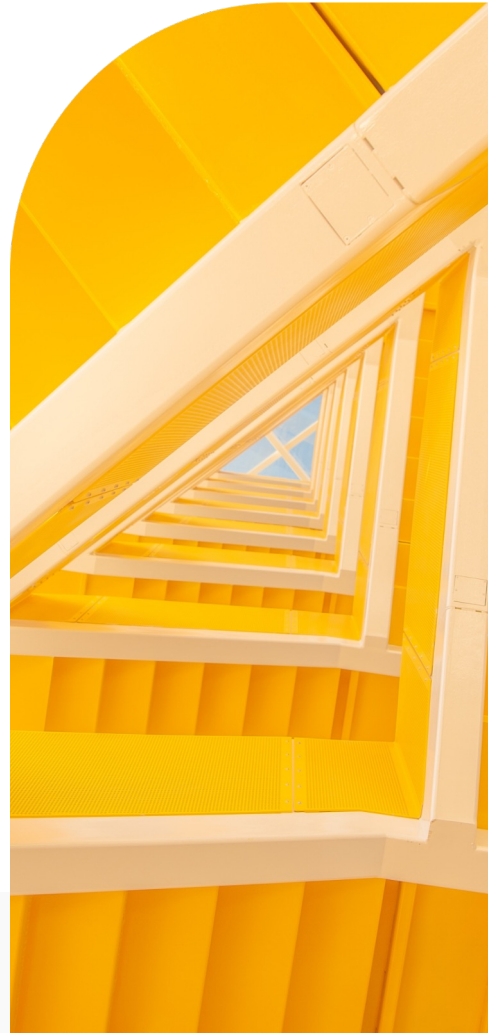
# 01

Narrative about patients

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# Narrative about patients

Underlying assumptions about 'the patient' create a narrative about the patient as a less capable and (passive) recipient of care. In particular, for people with chronic diseases, the role of the patient should be regarded broadly.

They are partners in their own treatment and care plans, and they are partners in the development of care pathways, treatment products, and support schemes.

'The patient' is a lot of different human beings, with different capabilities, values, and skills. At the same time, patients' level of engagement will vary due to elements such as interest, life situation, and graveness of the disease.

If we want to improve the healthcare system to a system with the ability to regard patients as people, and flexibility to tailor communication, treatment, and care accordingly, we need to change the narrative amongst stakeholders.

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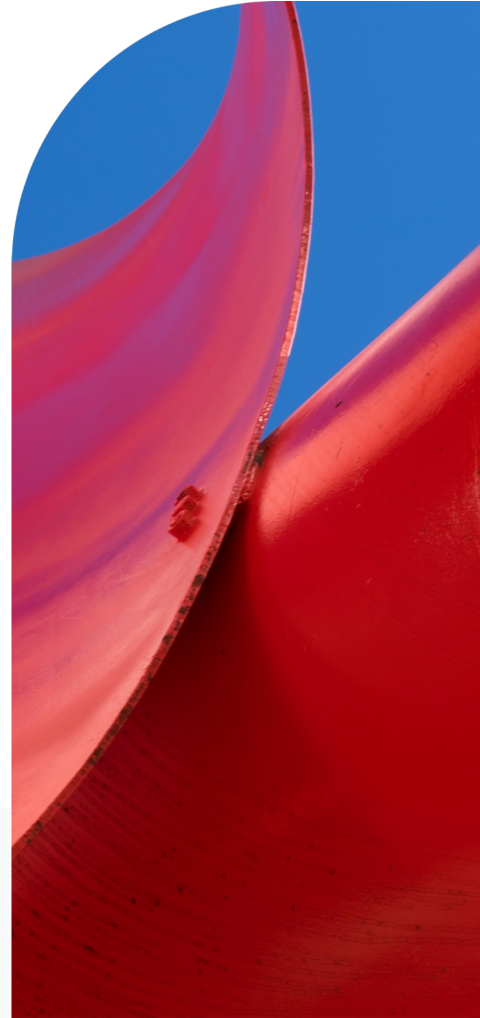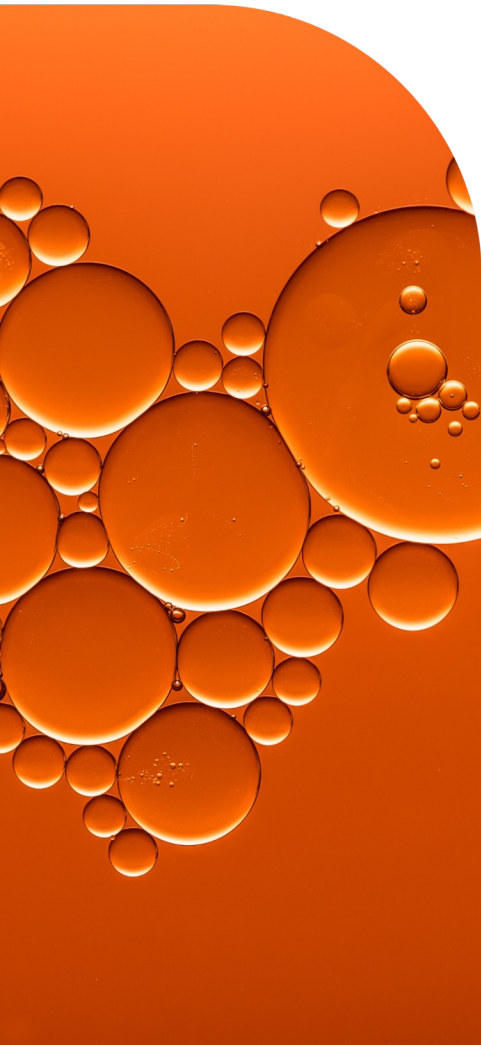
Patients are experts in their own chronic diseases as they are responsible for managing their condition 24/7, not just during medical appointments. They experience the symptoms, the impact on their quality of life, and the emotional toll it takes.

Factors such as lifestyle, relationships, work, and personal habits all play a role in managing a chronic condition. They make decisions about medication adherence, lifestyle modifications, and coping strategies in real time.

This subjective experience is a critical component of understanding the overall impact of the disease on the individual's life and may not be evident during a medical appointment.

While clinicians possess medical knowledge and expertise, they often interact with patients during brief appointments, which only provide a snapshot of the patient's life.

Recognising the patient as an expert in their own condition is a fundamental principle of patient-centred care. This approach involves collaboration between patients and healthcare professionals, acknowledging the patient's expertise, preferences, and goals in the decision-making process.

Recognising and actively involving patients in the management of their health can lead to more accurate diagnoses, improved treatment plans, and a better overall quality of life for individuals living with chronic diseases.

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# Raise awareness among medical students

The project's objective is to create training materials focusing on patient agency and partnerships by fostering collaboration between patient organisations and educational institutions. This collaborative effort seeks to reshape the interaction between patients and future clinicians.

The ultimate goal is to ensure that future patients receive personalised treatment tailored to their individual needs, experiences, and contexts. Anticipated outcomes include improved health results and enhanced mental wellbeing for patients, surpassing the current standards.

This approach is envisioned to instil greater trust in the healthcare system, motivating patients to take on a more proactive role in managing their health. Importantly, this proactive role is not only assumed by patients but is also recognised and encouraged by clinicians, emphasising a shared effort in achieving optimal healthcare outcomes.

THINK TANK

# Who will be impacted by the idea?

Patients and caregivers

Medical students

Healthcare professionals

Educational boards

Teachers

Administration of institutions

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# Who do we need to implement the idea?

→

## Patients and caregivers

Patients and caregivers should be part of designing the training materials, and, when relevant, be the trainers, for authentic input.

→

## Medical students

Medical students are the target group for the training, and their input on learning techniques, interests, and perceptions will help to design the trainings.

→

## Healthcare/educational institutions

It will be more impactful if the training is a part of established educational institutions or offered at healthcare institutions instead of by external independent organisations.

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# What else do we need to implement this idea?

Evidence and data to measure impact

Change in training setup or curriculum

Pilots & case examples before scaling

Champions at educational institutions to bring in patient agency and patients

Training experts

**THINK TANK**

# What are the different subtasks that will lead to a successful implementation of this idea?

Focus groups with patients

Focus groups with students & junior doctors

Focus with senior doctors to close gaps

Pilots in some universities or healthcare institutions

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# What will be the impact of this idea?

"

Educating medical students as early as possible is the key to people receiving high-quality, patient-centred care which will lead to better outcomes. This way, healthcare professionals will learn to focus on the whole person and not just on the condition.

Starting this initiative aimed at medical students is based on the assumption that it is easier to educate rather than reeducate with the hope that we can change cultures and behaviours across the health system.

"

**THINK TANK**

# What others are doing...

## Patient-Centered Outcomes Research Institute (PCORI)

PCORI is an independent organisation in the United States that funds research focused on patient-centred outcomes. They aim to provide evidence-based information to help patients and their healthcare providers make more informed decisions.

→ PCORI.ORG

## European Health Management Association (EHMA)

EHMA is an organisation that focuses on health management and policy, provides a platform for discussing patient-centred approaches in healthcare, and coordinates project such as the BeWell project which aims to develop a strategy for upskilling and reskilling the European healthcare workforce to address future challenges and changing societal expectations, incl. patient involvement and health literacy.

→ EHMA.ORG

## The Picker Institute

The Picker Institute is dedicated to advancing the principles of patient-centred care. They offer educational programmes and resources for healthcare professionals to enhance their understanding of patient perspectives and preferences.

→ PICKER.ORG

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# 02

From exclusively clinical data to collecting lived experience

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# Collecting lived experience

Collecting lived experience in healthcare refers to the systematic process of gathering first-hand accounts and narratives from individuals who directly encounter specific healthcare conditions, treatments, or healthcare systems. Its primary objective is to capture the subjective perspectives, emotions, and insights of patients, caregivers, and healthcare providers, thereby complementing quantitative data and clinical observations with valuable qualitative information.

Various methodologies are employed to collect lived experience data in healthcare. These include interviews, surveys, questionnaires, patient diaries/journals, online platforms, and social media. Furthermore, there is a growing trend of developing applications that enable patients to routinely report on specific measures, often combined with passive data collection from wearable devices.

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To ensure the systematic collection of data in predefined formats, a significant emphasis is placed on patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs).

These measures serve as widely adopted tools to assess the quality of healthcare experiences from the patient's perspective.

By utilizing PROMs and PREMs, healthcare providers, commissioners, and other stakeholders can make informed decisions regarding necessary improvements to their services.

Throughout the process of collecting lived experience data, it is essential to uphold ethical considerations. This involves obtaining informed consent from members, maintaining strict confidentiality, and safeguarding the anonymity of individuals involved.

Once collected, the data can be subjected to qualitative analysis, enabling the identification of prominent themes, patterns, and areas for enhancement in healthcare delivery, policy-making, and the promotion of patient-centred care initiatives.

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# From exclusively clinical patient data...

Patient-reported outcome measures (PROMs) serve as a link between the role of the patient and digital health/tools. On the positive side, healthcare providers are increasingly receptive to using PROMs, and there is growing recognition of the importance of real-world evidence (RWE), with patient experience data being used by institutions such as the European Medicines Agency (EMA). In addition, PROMs are also being developed for mental health.

Currently, too many different types of PROMs with varying definitions exist (e.g., PROMs, PREMs, Real life), making it difficult to establish the appropriate quality of life criteria.

Aligned, it can take a long time to validate PROMs in clinical trials, and they are used to measure real-life experiences, so they may require their own standards and validation tools.

Furthermore, gathering PROMs from individuals with low health literacy is challenging due to difficulties in understanding medical terminology, formulating accurate responses, and potential misinterpretation of survey questions. The reliance on proxy responders, social desirability bias, and cultural and linguistic barriers further complicate the process.

**THINK TANK**

# ...To collecting lived experience

These positive developments can be reinforced by highlighting the benefits of PROMs and RWE, encouraging patient participation, employing user-friendly technologies, providing training for healthcare professionals in using PROMs data, and ensuring that patient organisations are involved in the decision-making process to balance the decisions regarding treatment and care, and quality of life for patients.

Furthermore, it is essential to develop clear and culturally sensitive PROM instruments, improve health literacy, and ensure inclusive data collection methods.

In order to collect PROMs and RWE, network collaboration with tech companies and healthcare systems is fundamental with clear policies on data collection, ownership, maintenance, and usage.

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# Ideation ideas

## Narrative of collaboration

Collecting evidence of the input of patient agency and involvement

## Support dialogue between stakeholders

EMA survey of impact of patient involvement on scientific advice procedures

## Support dialogue between stakeholders

Clear direction from patient organisations on PROMs/PREMs in terms of policies on data collection, ownership, maintenance, and usage

**THINK TANK**

# From exclusively clinical data to collecting lived experience

The lived experiences of patients should be systematically documented and measured to enhance their role in decision-making and development processes in terms of medicine, care pathways, and social care.

One promising solution, gaining traction in different disease areas and with regulators, involves creating disease-specific *Patient Experience Data (PED)* dossiers that encompass and link to comprehensive, disease-specific records, white papers, guidelines, and other sources that give the full picture of living with the disease.

The idea

**THINK TANK**

# Who will be impacted by this idea?

→

## Patient and healthcare providers

The PED dossier will provide a one-stop place for anyone who needs to learn more about the disease, patient experiences, and treatment, and access updated relevant data sources.

→

## Regulators

Regulators can use the dossier to get a broader perspective of the disease and patient experiences, which is a type of data not necessarily collected in registries or clinical trials.

→

## Pharma and researchers

Researchers can use it to identify knowledge gaps and investigate alternative data sources, other than papers from peer-reviewed journals.

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# Who do we need to implement the idea?

→

## Patients and healthcare providers

It is crucial that patient communities and healthcare providers design, decide and add content to the dossier per GDRP regulations and EHDS principles.

→

## Regulators

To make it fit for purpose for regulators to use in due time before an intervention would come to market, advice for regulators is essential.

→

## Technical expertise

For the dossier to work in practice, it is central to get technical expertise to ensure that the dossier is automatically updated when shared in the relevant places.

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# What else do we need to implement this idea?

Patient experience data

_____

Governance structure

_____

Specific disease as a test

_____

Committed experts

_____

Long-term sustainability plan

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# What are the different subtasks that will lead to a successful implementation of this idea?

Set up a consortium of experts to design, decide and add content

Identify the technical solution

Agree on long-term sustainability plan

Vet with external experts

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# What will be the impact of this idea?

Implementing this idea will allow for a more appropriate and efficient use of the healthcare system. We will be able to have a 360-degree overview of the real burden of the disease and inspire other people suffering from the same disease to speak up and testify.
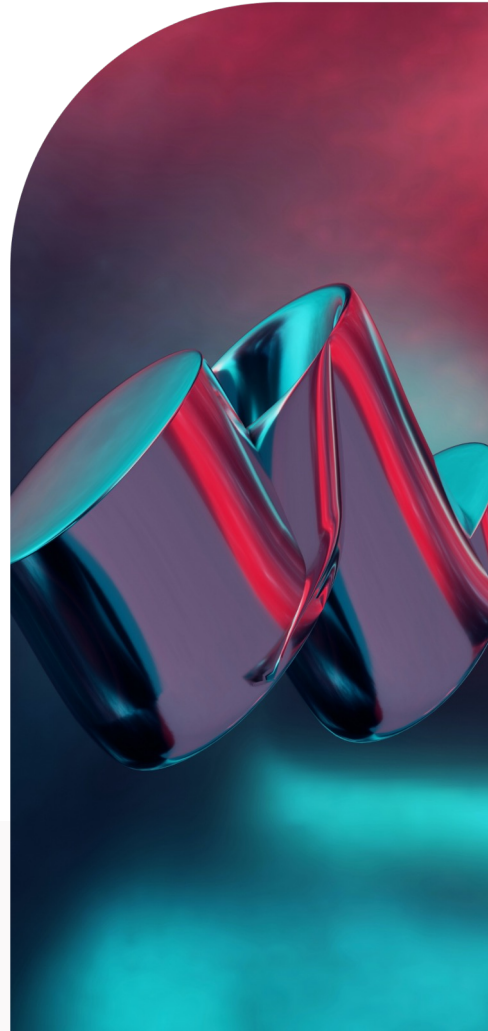
# What others are doing...

## Project Patient Voice

"Project Patient Voice" was a U.S. Food and Drug Administration (FDA) initiative designed to enhance the understanding of patient-reported outcomes from cancer clinical trials. The goal was to provide a platform for patients, caregivers, healthcare professionals, researchers, and the public to access information about the patient's experience during cancer clinical trials and display patient-reported outcome data in a way that is accessible and understandable to the general public.

→ [PROJECT PATIENT VOICE](#)

## Agency for Healthcare Research and Quality (AHRQ)

AHRQ is a federal agency in the United States that conducts research to make healthcare more accessible, equitable, and affordable. They collect and analyse patient experience data to improve the quality of healthcare.

→ [AHRQ.GOV](#)

## National Health Service (NHS)

The National Health Service (NHS) in England actively collects patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) to assess the effectiveness of healthcare services and improve patient care.

→ [NHS.UK](#)

**THINK TANK**

# 03

From hierarchy of stakeholders
to equal partners

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# From hierarchy of stakeholders…

The hierarchy of stakeholders relates strongly to the narrative about patients and the issues raised in the earlier chapter.

In the current hierarchy of stakeholders, there is a perception that patients need formal education to engage, as well as a persistent inability by other parties to regard patients as equal partners.

At the micro and meso levels, patient-centric care emerges. However, it is far from widespread or fully implemented.

On the meso and macro levels, patient communities have little influence and are not recognised as important stakeholders despite playing a key role in representing the full spectra of patients and being organised as a civil society organisation.

The hierarchy of stakeholders links to the concept of patients as 'end users'.

Patients should be truly listened to and involved from the very beginning to develop the best possible treatment, care, and the possibility to live a good life with a disease.

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# ...To equal partners

With growing awareness among various stakeholders in the healthcare system about the importance of involving patients in decision-making processes, this approach challenges the traditional top-down hierarchy of healthcare. Patient-centric healthcare requires promoting nurse-led care and shifting the focus at the system level from administration to actual care provision.

To initiate long-term change, there is a need to address the macro-level system shapers, i.e., policymakers, healthcare leaders, and governmental institutions, as they play a key role in establishing an enabling environment.

Patient organisations are crucial but also need to be given space to engage and a formalised role in decision-making, which macro-level actors are pivotal to. It will require dedicated resources to patient organisations for them to operate and represent their patients in an evidence-based way.

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# Ideation ideas

### Narrative of patients in collaboration

Evolving the title/definition of being a patient

---

### Support dialogue between stakeholders

Learn to deep listen to different stakeholders, understand their context and their remit

---

### Identify champions of collaboration and showcase successes of implementing patient agency

---

### Provide space to experiment with the adoption of patient agency & make the benefits and results visible

---

### Consensus conferences

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# What others are doing...

## Patient Focused Medicine Development (PFMD)

PFMD's goal is to improve global health by co-designing the future of healthcare for patients *with* patients.

Its mission is to bring together initiatives and best practices that integrate the voice of the patient thereby speeding up the creation and implementation of an effective, globally standardised framework.

→ PFMD.ORG

## Patients Included

The Patients Included movement promotes the involvement of patients in healthcare conferences and events, ensuring that these gatherings are accessible, informative, and inclusive of patient perspectives.

→ PATIENTSINCLUDED.ORG

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# 04

From variable health literacy to sustained health literacy

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# Health literacy

There has been a growing acknowledgment of the significance of health literacy both at policy and global levels, as evidenced by initiatives undertaken by organizations such as the World Health Organization (WHO) and the European Union (EU). However, despite this recognition, many clinicians maintain a belief that their current patient-centred approach is sufficient and that no further action is required.

Moreover, there exists an attitude among some healthcare providers that low health literacy is solely the responsibility of the patient, rather than a systemic issue. This perspective places the burden on patients to improve their own literacy levels, rather than necessitating healthcare providers to adapt their practices to accommodate patients with diverse levels of health literacy.

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Reframing limited health literacy as a challenge for healthcare providers rather than a problem solely attributed to patients is of paramount importance. Clinicians must actively acknowledge and address health literacy issues, recognising their crucial role in helping patients overcome these challenges. Consequently, health literacy initiatives must extend beyond the individual level and encompass systemic changes within healthcare organizations. One such example of a systemic approach is the implementation of pre-consultation procedures that involve sending patients relevant test results and supporting information ahead of their appointment.

This preparatory step ensures that patients are adequately informed and equipped to engage in meaningful discussions with their healthcare providers during the consultation. Additionally, it is imperative to allocate sufficient consultation time to optimise patients' understanding and address any questions or concerns they may have.

# From variable health literacy...

To effectively address health literacy disparities, healthcare systems must establish supportive structures that cater to patients and caregivers with varying levels of health literacy.

By doing so, the system itself becomes health literate, accommodating and empowering individuals to navigate the complexities of healthcare with greater understanding and confidence.

Dealing with health literacy can roughly be divided into three tiers:

1. Healthcare professional teams,
2. Prepared patients, and
3. Setup of the system, such as administration and communication flow.

From this perspective, it is important to call for quality and accredited training of healthcare professionals and ensure the patient's/caregiver's capabilities and confidence. With the use of complex medical terminology, the patient's ability to navigate the healthcare system and make informed decisions about their healthcare is affected.

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# ...To sustained health literacy

Changing the perception of healthcare providers and the system is critical to addressing existing gaps. The actors on the ground are the most relevant to involve: patients, caregivers, patient groups, and healthcare providers. Furthermore, policymakers and the general media landscape (all the various sources people get information from today) play a role in bridging the health literacy gaps.

Achieving effective change would require readiness both from the systems and the patients, which should be pursued through a coordinated push-and-pull strategy. This would involve effective communication leadership, strengthening linkages between stakeholders, and identifying beacons of best practices.

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# Ideation ideas

## Overcome barriers to health literacy

- Understand why some people are not health literate. Target those reasons first, that can be overcome.
- Shared decision-making toolkit, cohesive for both stakeholders, bespoke to each (healthcare professionals and patients)

## Educate patients

- Industry can play a role in healthcare literacy, for example, by creating lay language articles, abstracts, posters, etc., along with the scientific counterparts, published in journals and at congresses

## Educate healthcare professionals

- Peer-to-peer educational program, mentorship, hands-on experience on patient agency
- Brochure/booklet with points of attention in the journey from the perspective of a patient
- Engage with medical societies, through a shared platform for education and tools, to provide training or material at their scientific conferences/congresses

## Easily accessible 'helpdesk' for patients

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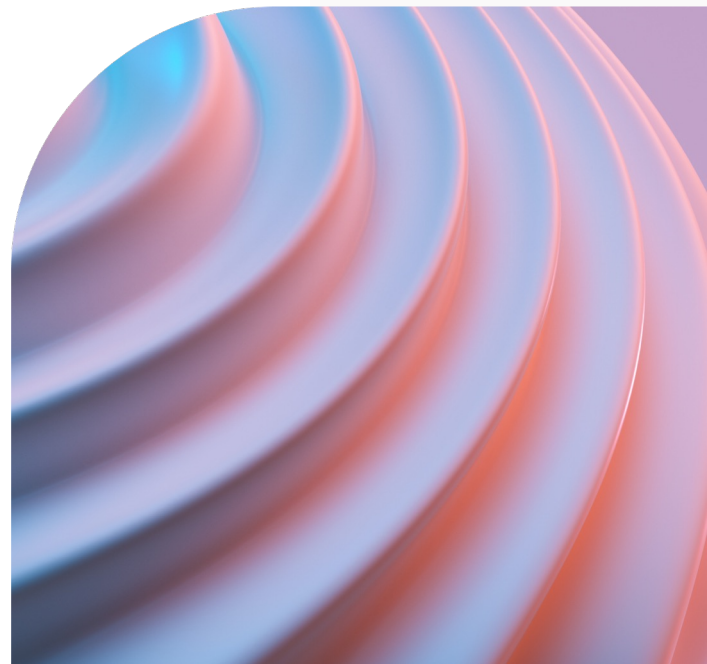
# What others are doing…

## Personalised Care Institute (PCI)

The PCI is accountable for setting the standards for evidence-based training in personalised care in England by educating and inspiring health and care professionals to deliver universal personalised care that takes into account an individual's strengths, needs, and expectations, in order to deliver the right care for them, and equipping health and care professionals with the knowledge, skills, and confidence to help patients get more involved in decisions about their care.

→ PERSONALISED CARE INSTITUTE

## Institute for Healthcare Improvement (IHI)

The IMI aims to improve health and healthcare worldwide by focusing on quality improvement initiatives, education, and training for healthcare professionals.

→ IHI.ORG

## Danish Institute for Patient Safety (DIPS)

DIPS works to improve patient safety, healthcare quality, and patient involvement in Denmark. They emphasise patient education, shared decision-making, and safety in healthcare.
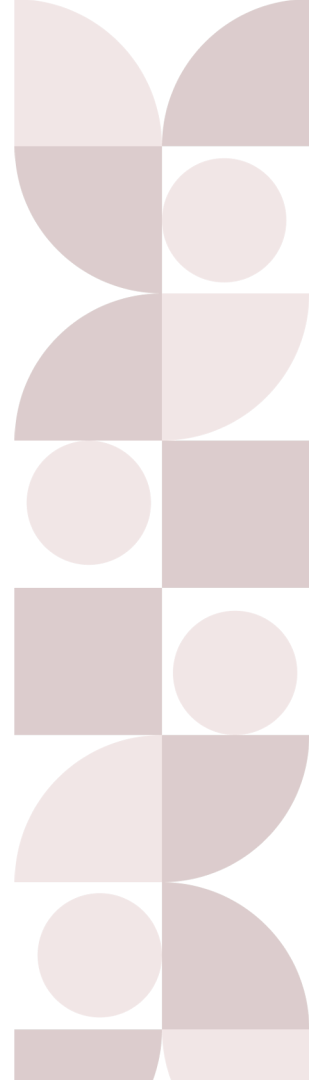
→ STPS.DK

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# 05

## Epilogue

We hope that the small paragraphs about each leverage point, the leverage points framework, the catalogue of ideas, and the examples from others have energised and inspired you.

Maybe it even encouraged you to explore more on systems change or to reach out to all the people who are making an effort to create positive change in our healthcare system.

This guidebook is meant to be a dynamic script that should be updated as readers and contributors learn and evolve their thinking.

Thank you for getting to the end.

Stay persistent!

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