



## Review Article

# CEmPaC ‘Reflections on Patient Empowerment’

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## Introduction

CEmPaC CiC, the European Centre for empowering patients and communities (<http://www.cempac.org/>) had its development hosted by EHFF, the European Health Futures Forum (<http://www.ehff.eu>) between 2017 and 2022, with financial support throughout this period from the Robert Bosch Stiftung. It established itself as an independent NGO in 2022, in the form of a UK based community Interest Company, led by Jim Phillips. One of its earliest projects in 2022 was to hold a round table on the future of the patient empowerment concept, with more than 20 invited expert participants from various disciplines and from a number of different European countries. The invitees were partly derived from the International expert group on patient empowerment, which meets on a quarterly basis.

The impetus for the roundtable was a short survey carried out a few months previously at the behest of the CEmPaC expert group, to interrogate how different European countries employed the concept of patient empowerment in practice, which revealed a very wide range of approaches, with only a limited degree of consensus across Europe.

## Background to the Submissions Collected

In preparation for the roundtable each of the invited participants was asked to make a statement about their personal view of the concept. The responses came from a wide range of professional viewpoints, and we felt that it was worthwhile publishing them as a collection of multistakeholder reflections on a complex subject. As a footnote, a notable omission was input from our colleagues at FAD Barcelona, leading experts on self-management in chronic diseases, who couldn't attend for timetabling reasons.

**Cecilia Vera-Munoz** (Assistant Professor of Biomedical

Engineering, PhD in Biomedical Engineering, M.Sc. Electrical Engineering and Computer Science, Universidad Politécnica de Madrid (Spain). She is an expert in the management and technical development of scientific and technical projects dealing with telematics applied to the social and healthcare sector).

The concept of citizen's empowerment has been among us for years now. There have been extensive debates about its definition and many attempts at establishing and adopting this concept in a universal manner. Nevertheless, even today, there is not an exact nor commonly accepted definition for empowerment, and it is highly probable that there will never be a consensus about this.

The concept itself is complex and it involves several variables, which are very different in each country or region. Instead of trying to agree on a universal model, the experts' efforts could focus on identifying a set of factors or aspects that are essential for empowerment to happen, together with a set of objectives that the model intends to achieve. In this sense, we could consider as a goal for health empowerment an increase of knowledge about health among the population, together with the acquisition of some skills for self-management and decision making.

The provision of tools, in many cases involving technology, can help towards achieving these goals. This has been done for years in several initiatives, and it has proven to be effective in empowering people. However, most of these tools are not widely used in real practice, and in the majority of countries around Europe people are not really involved in the decision-making processes regarding their health.

Despite its potential benefits, there seems to be a lack of adoption of the empowerment concept within the health domain. Ultimately, the proposal of citizens empowerment entails, not only the provision of tools, but a new way of doing things, new process-

es and new organization models, and the involvement of a series of stakeholders that goes way beyond the citizen themselves. Health empowerment implies a change of paradigm, a transformation of the health care organizations and the care provision, and this requires the development of new strategies and policies, and the commitment of the policy and decision makers within the health-care systems. Can we make this change? Are we prepared to do it? The key for finally achieving empowerment might be to focus on this transformation, and to develop a roadmap towards accomplishing this objective.

**Barbara (Basia) Kutryba** (Chief Specialist at the National Centre for Quality Assessment in Healthcare (NCQA) <https://www.cmj.org.pl/>; Vice-President of the Polish Society for Quality Promotion in Healthcare (TPJ) [tpj@tpj.pl](mailto:tpj@tpj.pl). President of the European Society for Quality in Healthcare (ESQH); Chair of the EU working/expert group on Patient safety and quality of care (2006-2017); WHO expert in the field of patient safety and patient involvement).

My reflection on citizens’ empowerment in health decision making does not bring any revelation, despite witnessing different models of healthcare provision and healthcare prevention across many countries for many years.

The issue of patient empowerment and involvement in self-care its presence or absence is a faithful companion to healthcare provision and the philosophy presented by different health systems. Medical, clinical, health CARE makes the notion of empowering the people in need (sick, ill, vulnerable) in idiosyncratic, health-related decision-making the only right option. Yet, many choose not to decide themselves and transfer the power of health-related decision making to healthcare professionals, usually doctors, presenting a kind of parallel empowerment.

The involvement in self-caring is strongly related to the level of health literacy and as such, can be shaped and modified with different initiatives.

I refrain from developing a universal model of empowerment (Empowerment for All-does it ring a bell?) as it’s something, I believe, that isn’t adequate for different types of social culture and societal developments. Would be a very good idea, though, to research and study/develop the frameworks for the optimal empowerment models, suitable for users with different levels of health literacy.

**Jim Phillips** (has over thirty years’ experience in the design, development and implementation of approaches that enable empowerment both in the UK and internationally. He has a background as psychotherapist and health coach- working both directly with patients and training clinicians).

People living with a long-term health condition have a unique set of experiences which enables them to support others through volunteering or paid employment and provide a different perspective to that of health professionals. Studies have shown that lay people are effective in providing self-management support. People with long term health conditions who are actively managing their own condition and have made positive life changes can act as effective role models and support to others to make positive life changes. Since we spend more than 99% of our life without health care professionals present, the potential in knowledge-sharing and peer support is nearly unlimited. Every person has experience and tools for handling numerous challenges. If this potential is structured so that people can learn from each other, the need to use health services will be reduced, leaving more time to discuss issues where the presence of health care professionals is needed.

People living with a long-term health condition are often regarded as a cost to health services and a drain on resources. In fact, people living with chronic disease can be a rich resource and an asset. Engaging with patients and seeing them as a resource is known as co-production. It is an acknowledgement that people’s needs are better met when they are involved in an equal and reciprocal relationship with professionals—working together to get things done. There are six core principles:

- Recognizing people as assets.
- Building on people’s capabilities.
- Promoting mutuality and reciprocity.
- Developing peer support networks.
- Breaking down barriers between professionals and users.
- Facilitating rather than delivering.

**Kaisa Immonen** (joined the European Medicines Agency in 2023 as patient and healthcare professionals’ liaison, having previously been Director of Policy at the European Patient’s Forum. She co-chaired the EMA Patients and Consumer Working party in 2016-2022, represented EPF on the OECD’s Healthcare Quality and Outcomes working party and participated in the CIOMS working group XI).

As an umbrella organization representing patient organizations, EPF (the European Patients Forum) refers to patients as being people living with chronic conditions. However, being a patient is also situational: many people may not be “patients” in the EPF sense, but whenever they interact with healthcare whether sitting in a GP’s consultation room, going to hospital for tests or acute treatment, or getting a prescription from a pharmacy they become (temporarily) patients.

Empowerment can be seen as a philosophy, vision, or goal as well as a strategy or process. Empowerment is a relational concept that manifests in the interactions between people, processes and structures in healthcare. The processes and structures of healthcare can be empowering or profoundly disempowering.

An EU-funded project, EMPATHIE, defined patient empowerment in 2014. Empowerment was seen as comprising three interlinked dimensions: health literacy, self-management and shared decision-making. EPF used a definition that focuses on persons gaining control over their own lives and being able to act on issues they define as important, both individually and collectively. This is closely enmeshed with the idea of “meaningful involvement”.

The Patient’s Charter on Empowerment (2015) sets out 10 principles of patient empowerment in favour of a definition. This was followed by a paper/ toolkit (2017) that includes a more conceptual discussion. EPF felt the need to define patient empowerment because the concept was increasingly used to drive agendas that were not, in fact, about empowering patients. Often, empowerment was equated with ‘choice’ to drive a market agenda in healthcare; patients’ participation in improving healthcare service quality, at the policy level, in co-designing research, and in developing practice recommendations remained and remains still, patchy and often contested.

Empowerment is still largely seen as an individual issue and something that can be “done to” patients even without their participation. Much research has been focused on self-management, with health literacy often treated as an instrument to support self-management by enabling patients to make the “right” choices rather than challenge the system. Shared decision making has become a more prominent research topic quite recently.

To shift the focus on the system and make real improvements, perhaps it is time to start speaking about participation and participatory healthcare systems and practices. Collaborative care and partnership have a nice ring, too.

To create a truly participatory system needs more than merely “open doors” to patients and citizens. Inviting participation without facilitating it, without accounting for the existing inequalities in society (who actually has the financial, social, emotional resources needed to make their voice heard? With whose backing?) will result in only reinforcing inequalities.

Probably we need to shift the focus away from the individual patient and start thinking more about:

- How different parts of the healthcare system, at different levels, hinder the empowerment and participation of patients,
- What needs to be done to eliminate those barriers, and

- How a more equitable and inclusive participation can be ensured.

In my view, participation needs to be built into the system at all levels. Perhaps the steps can look something like this:

1. Participatory research (the evidence) to ensure the right questions, the right design etc. to get the right evidence
2. Participatory knowledge (the policy, the guidelines) to ensure all relevant evidence is included, recommendations that matter, presented in a way that is understandable, disseminated
3. Participatory care (the performance) e.g. shared decision-making, service design, health-literacy friendly, provider-driven to dialogue-driven.
4. Participatory evaluation (the change) e.g. systematic quality improvement with patients, measuring patient-prioritised indicators, qualitative and quantitative, PROMs, PREMs and finally, action and a feedback loop back to all the other levels forming a virtuous cycle of knowledge, understanding and partnership.

Toolkit on Patient Empowerment (2017): <https://www.eu-patient.eu/globalassets/library/publications/patient-empowerment---tool-kit.pdf>

The Patient’s Charter on Patient Empowerment (2015): [https://www.eu-patient.eu/globalassets/campaign-patient-empowerment/charter/epf\\_charter\\_pe\\_2016.pdf](https://www.eu-patient.eu/globalassets/campaign-patient-empowerment/charter/epf_charter_pe_2016.pdf)

“An empowered patient has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behavior and to work in partnership with others where necessary, to achieve optimal well-being. Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to participate in decisions related to their condition to the extent that they wish to do so; to become “co-managers” of their condition in partnership with health professionals; and to develop self-confidence, self-esteem and coping skills to manage the physical, emotional and social impacts of illness in everyday life.” (From EMPATHIE. For a discussion please see the EPF Toolkit on Patient Empowerment, 2017, p. 6)

2 Empowerment is “a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important.” Collective empowerment is “a process through which individuals and communities are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.” (As

used in the PASQ project, adapted from Luttrell et al. 2009 and the Duque project.)

**Kristine Sorensen** (President of the International Health Literacy Association and Executive Chair of Health Literacy Europe. As the Founder of the Global Health Literacy Academy; she helps leaders implement health literacy by design in research, policy, and capacity building. She works for universities, governments, industry, NGOs and international organizations amongst others the Council of Europe and the World Health Organization. For more information: <https://www.kristinesorensen.net/>)

Health literacy-a key to social change and empowerment.

“Health is not everything but without health everything is nothing”. **Schopenhauer**

On top of the art museum AROS in Aarhus, Denmark, where I live, there is a gigantic circle-formed rainbow in which you can walk and look out at the city. The multi-colored glass makes you look at the world around us in a new way. Likewise, with health literacy. When you adopt the concept of health literacy and start applying it as a lens to the work we do within health care, disease prevention and health promotion; it becomes clear that we can do so much more to make people thrive, not only survive. During the COVID-19 pandemic, it was apparent how important health is for everything. The pandemic was threatening people’s lives, their health and well-being but also the societal infra-structure, even in well-functioning welfare societies. We needed to quickly adapt to new knowledge and practices to keep the illness at bay.

Health literacy entails the knowledge, motivation, and competencies to access, understand, appraise, and apply information to form judgement and make decisions concerning health care, disease prevention and health promotion in everyday life to maintain and promote quality of life during the life course, often with support of health providers. Amidst the pandemic, we needed to find new ways of keeping ourselves fit, changing the way we interacted with others in order not to get infected, keeping focus on hygiene and physical distances, following the new research that was shared about the virus and the disease, and yet, being aware of fake news and silo-thinking. At times, it has been tiresome and lonely to be part of the disruptive new ways of living; yet also a reminder about what really matters, namely the good life with work, family, and friends. Even before the pandemic, there were threats to the good life. The burden of non-communicable diseases was growing, the adherence to health education was lacking; and new digital habits hampered physical activity, particularly among children and adolescents.

Importantly, health literacy is developed during the life course. It is influenced by personal, situational, and cultural factors and impacts people’s health service use, health status and behavior,

engagement in health as well as enabling equity and sustainability. Research has revealed how people with higher education and higher socio-economic status have better opportunities than others. While much has happened in the past decades and especially in the last ten years in Europe; health literacy is still a neglected public health challenge in many countries.

Health literacy is content and context specific and can be measured in many ways. The European Health Literacy Survey from 2021 showed the state of the art related to general health literacy in 17 European countries. It confirms that health literacy leads to increased health status, decreased hospitalization, increased preventive measures, increased quality of care, and increased active participation in health and well-being. However, health literacy is also influenced by the way health is provided from a societal point of view. Some feel empowered when they interact with health systems; while others feel stupid and stressed. Mostly, health services are not designed to meet people’s health literacy needs. Instead, they provide standardized solutions that may benefit some but not all.

Health literacy can be a catalyst of change and act as an accelerator of the sustainable development goals by being recognized and promoted actively by all stakeholders involved in the provision of health. While people can be empowered by strengthening their health literacy to match the complexity of health systems today; it is also necessary to redesign health systems to fully comply with people’s needs. Many health systems today are compartmentalized and specialized leaving little opportunity for holistic and people-centered approaches to treatment and prevention. New thinking is needed to make a better match according to people’s needs. It means facilitating a new way of distributing resources where some seemingly receive different levels of services than others to cope and grow.

Health literacy can be improved by designing better visuals, signs, and forms. It can also be promoted through communication in clear language and focus on making patient journeys and access to services smoother and comforting. Lastly, it can be advanced through strategic planning and societal values embracing people-centered care. Health literacy is thus a political choice which requires strong leadership and a focus on what is needed. Examples of health literacy actions include health literacy policy goals, health literacy action plans, health literate organizations, and health literate workforces. Health literacy is a multi-sectoral empowering endeavor that includes e.g., building health literacy in schools, designing new health healthy cities and engaging people as co-creators when it comes to personal health and health of communities.

The capacity building needed to enhance health literacy is immense, however, if we succeed, we will be able to save time,



costs, and lives. The health literacy movement is constantly growing engaging champions from many fields and sectors. The International Health Literacy Association welcomes everyone to be part of the vibrant community to enhance local and national efforts. Health literacy champions face the challenge of health literacy gaps and strive to be the change to leave no one behind. Thanks for your commitment!

**Karolien van den Brekel** (works as a general practitioner in Utrecht, the Netherlands and applies Positive Health daily in her practice. Besides the patient care she contributes to innovation and health transformation as speaker, trainer, and educator in Positive Health and author of the Handbook ‘Positive Health in Primary Care’, the Dutch example. Since 2022, Director of Positive Health international. See: [www.positivehealth-international.com](http://www.positivehealth-international.com))

The founder of institute Positive Health in the Netherlands (iPH), Machteld Huber did research with her team about the definition of health. ‘Health as the ability to adapt and self-manage in the face of social, physical and emotional challenges’ (Huber et al. ‘how should we define health?’ *BMJ* 2011; 343) has been elaborated in the Netherlands as the concept of Positive Health. This innovative concept supports the transition from disease-oriented care to health-oriented and resilience care. It is a refreshing new concept, with a broad perspective on health. The practical applicability (with filling in the spider web) proves to be of added value for many professionals in health care and wellbeing. The lessons learned in the Netherlands and the countries that have already started working with Positive Health provide the starting points for a further expansion of the concept. Positive Health can be applied on both an individual and collective level. At first healthcare professionals have alternative ‘Positive Health ‘conversations with their patients/clients. It is about what really matters to the patients/clients and which steps they can take. This improves health outcomes for individuals and the patients and professionals are more satisfied (Jung 2018). With a good integrated community care network, the health care professional can easily refer and collaborate within this network. Secondly, in a community project ‘Indekerngezond’ (literally, ‘core healthy’) in Utrecht, based entirely on the Positive Health concept, local residents are challenged to live healthier lives and to take the initiative for this themselves. The community project is mainly for and by the local community. It is a meeting place where people can go to set up their own Positive Health projects, or to find something that will help them in their personal situation. All initiatives that arise there have one thing in common: citizen empowerment; they stimulate local residents to determine the course of their own meaningful and healthy life. They start from what people CAN do-instead of focusing on what they cannot. Indekerngezond’s mission is for local residents to take control of their own lives and contribute to the development of a healthy community. Due to more and more interest to expand the use of

Positive Health in care and wellbeing and in community projects outside the Netherlands, Positive Health international have been founded. The spiderweb is translated in English, German, French, Spanish, Icelandic and Japanese.

As a general practitioner working with Positive Health in daily practice, working together in the integrated network, we’re engaged in creating a coalition of the willing. With sharing good practices, giving lectures or workshops, have stories from our residents how Positive Health made a difference in their lives and how they empower others. It is an ongoing movement where more and more different colleagues from a variety of organizations get involved in the integrated and international network working with Positive Health.

Interested: look for more information:

[www.iph.nl/en](http://www.iph.nl/en) and [www.positivehealth-international.com](http://www.positivehealth-international.com)  
[www.positivehealth-international.com/dialogue-tools/](http://www.positivehealth-international.com/dialogue-tools/)  
[www.positivehealth-international.com/training/](http://www.positivehealth-international.com/training/)  
[www.positivehealth-international.com/handbook/](http://www.positivehealth-international.com/handbook/)

**Lars Kayser** (associate Professor at the University of Copenhagen. His research is focused on innovation in the digital service transformation of health care and digital health literacy, and how people can be served in order to better manage their health assisted by technology).

The focus of this short opinion paper is that the on-going digital transformation of health services introduces a new factor, which to some people, may be a disempowering factor like the white coat of the health professional. It is the requirement to actively engage with computers and smartphones which for GDPR reasons have log-in requirements and even sometimes with two-factor confirmation.

If we do not address this now, an inequity will arise amongst those who are able to use the technology and those who due to lack of education or experience or being physically or cognitive impaired cannot take part in this new community or landscape of the health services.

It is mandatory to address this rising problem. A way will be to educate health professionals to be aware of the potential challenges and barriers for the service users. These might be related to the service user’s knowledge and skills in relation to engage with information and technology or it may be due to mistrust or prior negative experiences [1]. It is also important to create a positive and including approach to the usage of technology amongst health professionals so they can serve as ambassadors and facilitators working with a positive attitude to the health services and technologies.

Here the eHealth literacy framework [1] and the two connected questionnaires, the eHealth Literacy Questionnaire (eHLQ) [2] for service users and the staff-eHLQ [3] for service providers may be effective tools to work with.

The coming years, we will need to discuss how those who want to take part in the management of their health, alone or together with their caregivers, can be assisted in a way that enables them to take advantage of technology, become more self-efficient and obtain a higher level of health literacy.

If done in a clever way, more can be included and less will be negatively influenced by the digital transformation. We should consider adding a sentence to the “Understanding of health related empowerment” [4]. It should be clearly stated that it is important to address the level of digital health literacy of both service providers and service users. A sufficient level of digital health literacy will facilitate the usage of digital services and technologies to empower older, disadvantaged persons. In this way, the digital services and technologies will not constitute a barrier that results in disconnected and disempowered individuals, but may help to include, engage and empower them [5].

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**Lars Munter** (a dedicated champion for self-care in Europe. Working both across Scandinavia and Europe for 20 years on knowledge sharing and joint platforms to promote health literacy, empowerment, and citizen action - including corporate social responsibility. As Director of International Projects in the Danish Committee for Health Education, he works for practical paths and systems leadership, and so acts also as Communications Lead for the Nordic Health 2030 Movement and the Wellbeing Alliance Denmark Hub to help deliver change).

Empowerment creeps into so many of my professional initiatives. I guess I once saw empowerment as “just” a tool in the toolbox—a component to enable the few, passive citizens/patients into action. That was then...

In health, originally, I worked to promote something simple. Hygiene. Good hygiene practices that enable people to protect themselves and their family. Or co-workers. Or community. And of course, I realized that a key element of this was also that I promoted a tool or a concept that gave them a method to have agency in respect to infectious or zoonotic diseases. So as a wider concept, I promoted self-care and information to boost their hygiene literacy and thus empowering them to better navigate the microbiological world around them.

But hygiene was actually just a start. Looking later at issues as diverse as social inclusion, mental health, school toilets, climate action, support for refugees, digital literacy, food safety—or at system level at the future of health in the Nordics or in Europe/ globally, I’ve seen again and again that a key component for needed action and/transformation of health systems is the component of empowerment. The recognition of people/citizens/patients—the target audience—as the primary active, capable actors in their own lives.

And obviously this is often not the case in a lot of current systems and policies. Investment in health literacy is low, self-care sometimes non-existent, prevention is struggling. We invest in cures, short-term techno-fixes, innovation (but not implementation). And while we get plenty of proof from initiatives like Frome, Somerset (see: <https://healthconnections.mendip.org>) self-organizing services during the pandemic, massive action in climate change from communities/cities (not states), or amazing mobilization of volunteers to help Ukraine (while States dither) it still seems that people are not really seen as worth trusting.

Despite the down-side I’ve outlined, I’ll also share a piece of hope, because I see a growing recognition also of the value of systems leadership. Of people, stakeholders, and organizations realizing that they do indeed have power and use it to push for change at micro or meso-level. We see a lot of great initiatives using the (positive) elements of a digital connectedness to work across bor-

ders and sectors to push and support others. The growth of WEAll (the Wellbeing Economy Alliance) is one. The emergence of the movement for a 4-day work week is another. So, from a start in hygiene and basic self-care, I now see empowerment happening and growing all around me. Perhaps – just perhaps—it will also be used and respected top-down in the future.

**Marie-Luise Dierks** (assistant Professor at the Hanover Medical School, Deputy Director at the Institute for Epidemiology, Social Medicine and Health System Research, Head of Masters’ Programme in Public Health at Hanover Medical School and Head and founder of the Patients’ University at Hanover Medical School (since 2006) (<https://www.patienten-universitaet.de/>))

Research topics: Empowerment and health literacy, patient satisfaction, quality of patient information and advice, empowerment, strengthening of self-management skills and digital competence in people with chronic diseases, Effects of patient participation in support groups.

**Marteka Swaby and Christine Francois** (joint statement: Marteka is a qualified psychotherapist who brings her clinical knowledge and experience, alongside her social media mastery to create bespoke and human digital content.

Christine a former banker with over 25 years of experience in the financial services industry, serving clients at national, regional, and international levels. She has extensive experience building and launching online communities and is a passionate advocate of self-care through optimized workplace well-being routines and wellness coach with Benevolent Health).

How can we improve health literacy and empower patients? This explores maternal vs paternal hierarchical structures across healthcare.

The idea of maternal healthcare being nurturing, giving, affectionate, kind and sympathetic. All things you associate with a mother. Perhaps, symbolic of chicken soup and kisses on the forehead. Paternal healthcare is probably the opposite of this and related more to authority, a protector or provider. Perhaps, more rigid in nature with more defined or fixed boundaries. From a health literacy perspective this is represented in traditional roles of nurses and doctors, or if thinking psychoanalytically the mother and father who care for the child or patient in healthcare.

To improve health literacy or empower patients we need to challenge these paternal vs maternal structures, which perhaps dictate or keep patients in a phase of adolescence, making it difficult to reach full maturity and feel fully empowered to take responsibility for one’s healthcare.

Perhaps, dismantling some of the systemic structures or traditional models of healthcare and the familial roles of mother and father could empower patients to increase health literacy.

### ***How does this look in reality?***

The Medical model has always been clinician led. The idea of the patient is passive in many ways. ‘A person receiving or registered to receive medical treatment or care’. Where you are told, which care or treatment is needed and this is provided. Similar to the authority of parents. It is something that is done to you within more defined or rigid and fixed boundaries. From a Eurocentric perspective, this model of ‘all knowing’ is also replicated in patriarchy or capitalist structures, the coloniser mindset. My way is right, and I have a successful model which everyone must follow.

### ***What about the role of caregivers, aunts, uncles or cousins?***

It takes a village to raise a family. To capture alternative inputs and allow the patient to lead we must accept that teenagers can make decisions. Sometimes this is hard to do especially when we feel we know best as a parent, and we prefer to protect, the experienced healthcare professional may also be more aware of any consequences.

True patient empowerment should allow patients to lead their own care with professionals supporting or guiding their decisions.

### ***Non-medicalized support and offerings need to also be considered in health literacy.***

Not necessarily gold standard, an obsession in the NHS which often defines the success or failure of individual treatment options.

For example, Eastern practices around mindfulness used to be ‘woo woo’ or ‘not evidence based’. However, new research understands Neuroplasticity and it is now deemed ‘bona-fide’.

But what would happen if we trusted patients to choose their own care or friends. Could our cousins or non-traditional practitioners who offer meditation, prayer, spirituality or religion, music, art, or mindfulness be considered as delivering health literacy and become the aunts or uncles to support the stretched parents to improve outcomes for patients?

This would certainly open up more opportunities in health literacy and diversify the workforce as we embrace choice in patient care.

**Matthijs Zwier** (an Independent Business Owner working as a Strategist, change agent and an experienced Transformational Catalyst, who stimulates and enhances transformations in society. Bottom line ‘nothing about me without me!’ starting with citizens, professionals, institutions/networks and (local) government to build capacity and target the ‘wicked problems’. Matthijs has a background in Social Constructionism, Health Sciences and Nursing).

A take on empowerment: We have to go back, back to the time when we sold out on public health. Just after the Second World War, when we had to rebuild society and health (care), healthcare was focused on infectious disease. This system never really changed over the years and yet diseases did. The system in place isn't fit for purpose. The key is that the future of health is outside the domain of healthcare. I describe four key elements.

### **Connect**

An important point of attention is ‘connect’, in the broadest sense of the word and especially connecting worlds (vertical and horizontal): Individual (patient, client, resident).

Community (neighbourhood, district, group of inhabitants).

(Formal and informal) organization/institutions/institutions and the professionals.

Policy organizations (including local and national governments, supervision, enforcement).

We should realize that in recent decades we neglected the power of the community and lost the experience and skills to cultivate community strength.

The emphasis is on connecting because we have to do it ‘together’ and polarization is constantly lurking, also in (public) health (care). To illustrate: ‘We’ residents can do it better than ‘them’ professionals and vice versa. Looking forward, the challenges are too great to feed or allow division, we will have to do it together.

### **Trust**

Something that often returns is the desire to restore trust in health (care), trust in professionals and their organisations, but also trust in the strength of patients, clients or residents. Trust is difficult to organize directly, trust arises. There are workable ingredients for building trust. Equality is a key word here. Co-creation, partnership and the creation of space and possibilities (e.g. continuous consultation during policy-making as opposed to one-off inquiries). Facilitating social strength that is already there. Rely on ownership, responsibility and (context-specific) expertise.

### **Twist**

Turn it around, shift the focus to the things that matter, show courage and decisiveness. Take a position: ‘we consider prevention and precaution to be important, we will invest heavily in this in policy and financing, and we will also disseminate this to health insurers, municipalities and other relevant stakeholders’. Shift the focus from illness and care to the focus on health and behaviour. Shift budgets from care to prevention. Turn disease-specific target groups into context-dependent focus, i.e. from the ‘diabetic’, the

‘COPD person’, the ‘frail older person’, the ‘patient’, to people. To unique individuals with a story, a background (past) and a future!

### **Tell**

Tell a story instead purely of accountability and control. This is also based on trust. Collect stories from the individual, community, organization and policy (government). Share stories with each other, tell, engage in dialogue and explore all perspectives. Find richness in stories and perspectives. Also use stories to identify problems, monitor, find solutions and determine impact, in short, enter into a continuous dialogue. Many examples are already available locally, regionally and nationally. Focusing on this much more emphatically is crucial, in order to increase trust, make connections possible and really disrupt health (care) in all its facets. Find a common ‘new’ language that fits the movement we want to initiate.

Nb: obviously the above is focused on qualitative data, logically we bring quantitative data (in all its forms) to the table as well, allowing us to take full advantage of the available knowledge. But, in a much more coherent way.

To conclude, I hope the above will enhance empowerment and empower individuals, communities etc. because I believe that just like trust, empowerment is very difficult to approach head on, it's something that is ‘cultivated’ over decades.

**Nicolaj Holm Faber** (Chief advisor at Steno Diabetes Center Zealand with 17 years' experience with operating evidence-based Self-Management programs in Denmark and other countries, targeting all NCDs. In addition, he is engaged in exploring the links between concepts of individual and community empowerment, and in the challenge of the dissemination of these concepts in society).

Empowerment is relevant in almost every aspect of human life. Versions of the question “Do I have the belief that I can succeed in creating a healthy, exciting and challenging life for myself?” is something everyone have asked themselves once or several times during life and that is a core question, when we are talking about empowerment. But even though the question about my personal beliefs is relevant, it is not the only reasonable question to ask! Does society support citizen empowerment? Does the health or social care system support patient empowerment? And what about schools, workplaces and so on. Disempowerment often starts with the feeling of losing control. And whether it is control regarding my health, employment, relationship or parenting, my curiosity is focused on how to reinstate that feeling of control or coherence in a person's life.

Empowerment is also a question about sustainability! A high level of empowerment will make citizens a more active partner in any aspect and that is a benefit to society. Active citizens contrib-



ute to creating solutions in society, e.g. about sustainability and prevent e.g. unnecessary waste, overuse of medicine and irresponsible behaviour.

**Lene Søvdal** (Clinical Psychologist, Mental Health Advisor and Independent Researcher based in Norway. Most of her work is focused on advocating, developing and delivering person-centered, health promoting, integrative and sustainable approaches and solutions within and beyond the healthcare system. She is a member of several international coalitions, committees, advisory boards and working groups concerning issues related to mental health, digital health, system change and sustainability).

Patient and citizen empowerment is both a process, and the aimed outcome of that process. Essentially it is about being able to identify, express and take action on one's health related concerns and needs and make informed decisions and choices regarding one's own health, and to engage in interventions and activities that are supporting one's own health. Patient and citizen empowerment needs to happen in a way that is truly empowering them. To enable and support empowerment and agency, patients can no longer be seen as passive receivers of a health service or intervention. They need to be seen and respected as equal co-creators and partners in all decisions, interventions and activities concerning their own health.

Within mental health care patient empowerment can happen through psychoeducation, patient involvement, co-production and collaboration. Promotion of ownership, self-efficacy, active engagement and empowerment is also embedded into most cognitive-behavioral therapy interventions and programs. These principles are often even more strengthened in digital health interventions, where patients might engage in self-guided stepped care programs or use app-based interventions from the comfort of their own homes and where they increasingly are more active in managing and improving their own health.

Health services and interventions that are centered around the service user, and where power is shared between clinicians and patients, are likely to not only improve the therapeutic relationship and the patient experience-but also the health outcomes of these services and interventions. Ultimately this can make a big difference for the service-users current and future health and well-being, as well as their sense of self, life satisfaction and quality of life.

Within schools, workplaces and communities, citizen empowerment can happen through mental health education and literacy, along with health promoting exercises and activities. This will also work as a preventive and protective mechanism when it comes to developing (mental) health issues, and help the person manage any existing or future (mental) health issues in a more proactive and empowered way.

In sum, patient and citizen empowerment is a process and a goal that benefits all stakeholders, and which potentially can reduce healthcare costs and increase the health and quality of life for people both within healthcare and in the overall society.

**Piera Poletti** (Deputy Director of the Masters in “Risk management”, Padua University, Italy and teaches in other programs in the same and other universities. Director of CEREF - Centro Ricerca e Formazione-Padua, Italy. Member of the Quality Assurance Scheme Development Group (QASDG) of the European Commission Initiative on Breast Cancer (ECIBC). She had been involved in many research projects and manuals' development related to Quality and Patient for the Italian Ministry of Health (2005-2012) and other National and European institutions).

Many aspects can explain variation in implementation of “Patient empowerment” around the world. How Patient empowerment is considered and carried out reflects countries' culture, that is, social structure and inequalities, healthcare service national model, healthcare institutions' culture and people attitude, professionals' education and so forth.

Therefore, as expected, there are different levels of understanding and diffusion of the concept and the practice of patient empowerment. Poor investment in research has provided limited findings on patient empowerment's impact on health outcomes so far, therefore some institutions have preferred not to invest in practices “not enough supported by evidence”.

Where a paternalistic culture is the regular approach to patients, or they themselves prefer not to be involved, to rely on professionals can be the preferred patients' behaviour: “I pay for the service, professionals have to take care of me”.

From an organizational point of view, it can be more convenient to have professionals delivering all the procedures, instead of spending time and efforts in teaching, educating, stimulating patients to learn, then supervise them, and manage possible unexpected consequences. Moreover, universities and other education agencies' programs preparing health professionals do not always include Patient empowerment as a theme to teach, thus professionals do not have the specific competence. As a consequence, often the focus during consultation and care delivery is only on communication, and empowering the patient is only a shadow in the background.

Media have not been involved properly in supporting patient empowerment in the last few years. The value of Person/Citizen/Patient empowerment is too high not to invest in, as much as possible.

Patient empowerment models have to be redesigned, in order to consider many factors, such as:

- The world socio-economic transformation, which is impacting people’s attitude and social relations very much.
- Healthcare evolutions, due not only to the traditional drivers, that is, technology and organization’s innovation, but also Sars-cov-2.
- Social media, which impacts in many ways, including doctor google.

In my opinion it is important to work together on a common basic framework on “Person/Citizen/Patient empowerment”, on which different silos can be develop, representing local applications. Implementations can provide systematic inputs to update the model, which can become more and more inclusive.

The “Knowledge to action framework” and the social movement strategies can offer insights to choose the best ways to impact not only the healthcare institutions, but also communities. Schools can be involved to cooperate in providing citizen with competence from the beginning. Universities can introduce seminars focused on empowerment. Patients’ associations play an essential role in supporting people in the empowerment process, however we have to consider the many persons who do not want to relate with organized networks and here social media can support their involvement. Professionals’ associations and scientific societies must be more involved in the “patient empowerment world”. Policy and implementation models can be offered to healthcare services: important also is to include measures of patient empowerment as service performance indicators and/or health outcome indicators.

**Justin Rautenberg** (holds a degree in business administration and has been with OptiMedis since 2018. He has a strong consulting background and has also worked as interim CIO for a regional hospital association. Over the past 23 years working in the healthcare field, he has built an in-depth knowledge of integrated care and population health management concepts. Besides his role as CFO of OptiMedis he is focusing on building outcome oriented and patient centric care solutions. Among others, he is currently responsible for the operations of the regional Health Network “Gesunder Schwalm-Eder-Kreis GmbH” founded in 2021).

Shared Decision-Making (SDM) in healthcare is considered a gold standard for supporting the cooperation of physicians and patients. SDM cultivates patient-centered care in which a healthcare provider and a patient jointly make a health decision after discussing different treatment options, their potential benefits and health risks, and considering the patient’s values and preferences. This process is challenging when patients lack information about their health problems and the pros and cons of various treatment options. Acknowledging and supporting the patient resolves this barrier and can help foster an informed, shared decision about the best disease management strategy and avoid unwanted treatment.

Despite various positive outcome-relevant effects, the practice of engaging patients in their healthcare decisions is infrequently implemented in routine care.

OptiMedis is working with other partners on COMPAR-EU, an interdisciplinary project funded by European Union. It aims to identify, compare, and rank the most effective and cost-effective Self-Management Interventions (SMIs) in Europe for adults with one of the four high-priority chronic diseases: type 2 diabetes, obesity, Chronic Obstructive Pulmonary Disease (COPD), and heart failure. SMIs are health care interventions that can help address the complex individual, social, and economic impacts of chronic conditions, improve outcomes and reduce healthcare costs.

The project facilitates SDM and supports implementation of best practices in different health care contexts through an interactive IT platform, featuring decision-making tools. The platform is adapted to the needs of different end users (<https://platform.self-management.eu/>)

The first tool is the “Patient Decision Aid”. It has been developed to help reach a shared decision between patients and Healthcare Professionals (HCP) on the best treatment. First, patients can choose from different outcomes they want to improve and give their preferences on the SMI. Second, the tool informs patients about the best suitable SMI based on their needs and preferences. Finally, patients can print the results, discuss them with their HCP and reach together a decision about the most promising SMI.

The second tool is the “Interactive Summary of Findings”. It helps HCP to find and understand the most important outcomes, the size of these effects and the certainty of the supporting evidence on SMI. HCP can use this tool when reviewing the evidence on the best course of action for SMI to support shared decision-making with their patients.

The IT platform supports both patients and HCP to improve their understanding of self-management options so that they are more likely to participate in SDM process.

**Vibeke Zoffmann** (Professor of translational empowerment at UCPH and Rigs Hospitalet, Copenhagen. Have developed Guided Self-Determination (GSD) to overcome barriers to empowerment, which is hosted by the Danish national health platform, [www.sundhed.dk](http://www.sundhed.dk). EMPOWER-UP is a generic PRO under development designed to measure empowerment in patient-provider relationships. It values clarification to improve health care professionals’ personal and professional identity as an approach to integrated care).

### **Relational empowerment**

Grounded theory research and participatory research have revealed a potential for change in relationships between users and

providers of healthcare. Getting access to this potential requires that the methods used in shared decision-making are empowerment-based. Guided Self-Determination (GSD) is such a method. It draws on reflective writing and drawing using GSD reflection sheets (1 to several GSD-sheets in accordance with the need and potential for change) as preparation to a flexible number of one-to-one or group-based dialogues with communication trained health professionals. GSD is designed to bridge the philosophy of empowerment and life skills as the goal of individual care (Figure 1).

### ***Empowerment as philosophy***

“The process of empowerment is the discovery and development of one’s inborn capacity to be responsible for one’s own life.”

### ***Decision-making method characterized by self-determination***

“Self-determination is a quality of human functioning that involves the experience of choice, in other words, an internal perceived locus of causality”. “Self-determination is the capacity to choose and to have those choices be the determinants of one’s actions”

### ***Developing Life skills is the goal***

“Those personal, social, cognitive and physical skills which enable people to control and direct their lives, and to develop the capacity to live with and produce change in their environment.”

“Balanced Self-Determined individuals are able to exercise their rights without denying the rights of others. Other-Determined individuals passively look to someone else (or to some institution) to make decisions on their behalf. Selfish-Determined individuals aggressively achieve their own goals at the expense of others”.

(Illustrations of the theoretical framework around Guided Self-Determination: see presentation on June 13 2022: <https://www.youtube.com/watch?v=b5tuW6c6DwA&abchannel=CentreforEmpoweringPatientsandCommunities>)

**David Somekh** (was a forensic psychiatrist, psychoanalyst and experienced clinician in management for many years who retired from the UK NHS more than fifteen years ago. He has been involved in healthcare quality since 1988. David and three colleagues set up EHFF, the European Health Futures Forum, as a not-for-profit network organization in 2013 looking at more sustainable models of healthcare than the current ones. He is currently Network Director. EHFF has engaged in a number of PE projects from 2014 to the present time).

This is more a historical review than anything else. In the later 1980’s when working as a young Consultant psychiatrist in the UK NHS I became interested in Quality Assurance, as it was then known, a new concept for NHS managers, imported from the USA. During the early 1990’s there were various initiatives to en-

gage patients and a constant change of labels, from indeed patient engagement to patient empowerment but also patient-centred care or patient involvement. Having kept an eye on this, although also actively engaged in supporting the use of patient advocates in local mental health practice, in 1998 I was part of a group of national Quality Society leaders who started the European Society for Quality in Healthcare. I was on the Board and eventually had my turn as President around 2004. At that time ESQH produced a template for EU quality going to 2010 which had five elements, patients as partners being the central component. At that time, there were powerful advocates for the patient being an active partner in their care. Harry Cayton was appointed as the Director for Public and Patient engagement by the UK Dept. of Health (his paper, ‘the flat-pack patient’ (2005) summed it up). Angela Coulter, indefatigable academic promoter of empowerment was very active (see her paper ‘the autonomous patient: ending paternalism in medical care’ Nuffield Trust, 2002) and we had a CMO, Dr Liam Donaldson, who in 2002 with his opposite number in Denmark, when the latter country had the EU Presidency, strongly supported the concept (but it wasn’t until 2012 that Jim Phillips and others started the ENOPE network).

While ESQH monitored how little seemed to be developing on patient empowerment between 2003 and 2013 (although the UK NHS had developed the Expert Patient project and Charan Nelander had started promoting the Stanford model in Denmark) when we set up EHFF in 2013 we were delighted to be able to join a consortium for a DGSANCO project on promoting patient empowerment, led by FAD and called ‘EMPATHiE’ (completed 2014/5). This involved old friends from EPF, DCHE and others. The importance of this project was that we’d been asked to help clarify what the concept meant, in order to answer concerns that supporting PE on a policy level wasn’t cost-effective. At that time also, the European Innovation Partnership on Active Healthy Agency had been set up (from 2012) and there was a patient empowerment subgroup in the B3 area, Integrated Care, and a number of the members of this group are now represented on the CEmPaC expert group, nearly ten years on.

A couple years later, Jim brought ENOPE under the umbrella of EHFF and joined the Advisory Board of EHFF, thus giving his organisation a more formal status. Jim and David were advisors to EPF in 2015/6 when they had a sponsored year promoting patient empowerment, supported by RBS and partly as a result, EHFF (with Jim playing a major role in the bid) successfully got funding for the CEmPaC project in 2017 from the Bosch Stiftung (RBS). This funding finished in March 2022.

Finally, last year EHFF and CEmPaC did a ‘quick and dirty’ questionnaire review of 14 European countries (25 responses) asking about locally used definitions and policy in this area. The vari-

ety of responses led us to feel that this Roundtable was necessary, partly because we have the good fortune of having such a network of experts to hand (really, only two major players were too busy to join us, NIVEL and FAD). The variation in responses led us to question whether the label of patient empowerment had outlived its usefulness, as it covered such a broad spectrum of activity. What we hoped to learn from the Roundtable exercise is whether a new benchmark definition was worth attempting, but either way, recording the event would, we believed, be a useful marker for others going forward.

**Susanne Melin** (is a Program Director at the Robert Bosch Foundation’s Bosch Health Campus where she is responsible for the philanthropic activities around health literacy. She is dedicated to improving health care for all by empowering patients and putting their needs at the centre. Recent and current funding activities include support for the German National Action Plan on Health Literacy and for selected research around health literacy as well as for the implementation of programs strengthening patients’ health literacy).

As an advocate for patients’ role and patients’ interests in health care, I support the European Patients’ Forum approach to Patient Empowerment. Patients’ perspectives and patients’ needs are at the core of Patient Empowerment and thus should also be at the core of defining what Patient Empowerment is. The EPF 2015-16 Patient Empowerment Campaign (funded by the Robert Bosch Stiftung) included a Charter and a Roadmap for Action. Both still provide very valuable insights into Patient Empowerment as well as guidance towards a truly patient-oriented perspective.

Patient Empowerment is, in my view, strongly linked to Health Literacy which focuses on the ability to process health related information and to make informed decisions about health related issues. This can mean information and decisions about the patients’ own health care as well as about health care institutions, the health care system, health education and health research. In all of these areas Health Literacy is the foundation that makes Patient Empowerment possible. Health Literacy is accomplished not just by patients’ abilities and competencies, but to an at least equal degree by the health environment around them the way accessible and understandable information is provided, shared decision-making is facilitated and patients are supported in acting upon their decisions. Again, this means not just decisions about a patient’s own health but also involvement and participation in health issues on meso and macro levels.

Health Literacy is needed not just for health care in the narrow sense but is interwoven with decisions in everyday life, e.g. around nutrition, mobility, family, work etc. Health Literacy therefore can and should be supported both from within the Health Care System itself and by policies beyond health care as such. For mea-

sures that aim at patients’ abilities and competencies, the attitude behind this support should be one of enabling and strengthening patients, not one of demanding and obligating. This becomes tangible in the EPF Charter: “...empowered to the extent [they] wish to be.”

However, Patient Empowerment goes beyond the ability to make informed decisions. It is also about a shift of power and has therefore social implications. Empowering patients may lead to changes that meet surprisingly strong levels of resistance. The leading question, in my view, should be whether these changes ultimately improve and enhance the well-being of patients-and if they do, they should be pushed forward accordingly.

**Tibbs Pereira** (is a founder member and former Chair of Patients for Patient Safety Ireland (PFPSI) <https://patientsforpatientsafety.ie/>. The group is formed of volunteers who work in collaboration with healthcare professionals and the health service in Ireland to improve patient safety across all aspects of healthcare in Ireland).

The concept and practice of Healthcare Empowerment clearly has universal buy-in. There are countless benefits of having empowered, literate patients with a strong voice. Patients for Patient Safety Ireland strives for patient empowerment in collaboration with healthcare professionals.

PFPS facilitates efforts to engage and empower patients, families and communities to play an active role in their own care; bring the voices of patients and people to the forefront of health care. Create an enabling environment for partnerships between patients, families, communities and health professionals. In Ireland, progress has been made in areas like Open Disclosure, however there are still stories in the news that prove that open disclosure has not been adopted and attitudes have not changed - factors like this discourage healthcare literacy and patient empowerment.

Time commitment for patients and healthcare professionals. Time is a precious commodity for everyone. There is a big gap in knowledge, skills and, most importantly, confidence among large sections of the population. Healthcare empowerment was not a consideration for me until a family member had a serious medical condition. Huge investment and the political will to set this up.

For us, progress is slow and there are several factors to consider, in our experience over the last nine years of our existence as a group. Our biggest challenge is to recruit new members to join the group. As a group of volunteers, it is difficult to set up structures and execute strategy, ensure that we operate to common standards as a group, training for members, etc. There are many questions to be asked and be answered, but the essential challenge is that healthcare empowerment requires a huge commitment and a culture change on a massive scale.



## Conclusions

These collected perspectives provide a rich and impressively diverse background to the actual Roundtable workshop, which took place on June 14th, 2022. There is a recording of the whole session that can be accessed via the CEmPaC team ([info@cempac.org](mailto:info@cempac.org)) but several papers have been drafted reviewing content of the

event. The first, ‘the concept of Patient Empowerment: is it possible to have a common and universal definition?’ has been submitted to the Eurohealth journal for publication and two others, on education in patient empowerment and on community empowerment are in preparation, prior to a second Roundtable is scheduled for December 2023.