

*“Improving the quality of healthcare using the experiences and competencies of patients: Are we ready?”*

## Central theme guidance

The HOPE Exchange Programme 2018 is asking its participants to work on patient involvement as a tool for improving healthcare. The participants are supposed to show how the quality and efficiency of healthcare can be improved by using the experiences and competencies of patients and their relatives, but also to point at both factors that stimulate this development and at any barriers to patient involvement that may exist such as attitudes, legislation, lack of resources etc.

There are many different perceptions in Europe of what “patient involvement” is. One of the key conclusions of a Eurobarometer<sup>1</sup> published by the European Commission in 2012, was that *“the term ‘patient involvement’ was not clearly understood by either patients or practitioners and often meant different things to different people. For many patients the term was a nebulous concept revolving around healthy living and being responsible for one’s own health. For both practitioners and patients it was often simply equated with medical compliance and following doctors’ orders. While patient involvement was often seen in terms of patients providing basic information on symptoms to a healthcare professional, it was less widely perceived to include a more interactive dialogue or opportunity for patient feedback.”*

However, many professionals and patients across the EU also did see the benefits of patient involvement, in the sense of having patients at the heart of the healthcare process. Many practitioners saw the benefits of having more motivated and engaged patients, with increased understanding. Correspondingly, many patients saw the advantages of having more information and options with regard to treatment, and a more open dialogue with practitioners.

Improving the quality of healthcare using the experiences and competencies of patients, requires a new approach towards the patients. Instead of being considered passive subjects or “recipients” of care, the patients hold the role of “co-creators”, being involved in development, implementation and follow-up of operations – both of their own care process and of the operations in general.

Patient involvement includes many different aspects and issues: communication between patients and the healthcare system, access to information, health literacy, preventive action and health promotion, the relationship between healthcare professionals and patients, self-diagnostics and self-monitoring, practicing of self-care, patients’ access to their own electronic medical records, possibilities for patients to choose provider and influence the choice of treatment etc.

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<sup>1</sup> Eurobarometer Qualitative Study: Patient Involvement, Aggregate Report published by the European Commission in May 2012.

Linked to patient involvement is the concept of person-centred care, in which the patient and its relatives take an active role and participate in planning and implementing care, and the patient is seen as more than just its medical condition.

Today's generally better educated patients tend to become experts on their own diseases. They want to make informed choices regarding treatments, lifestyles and healthcare providers and request information about accessibility and quality. But many people also would like to be involved in designing health services. The patients' own experiences and wishes are a source of knowledge to be weighed together with scientific knowledge and proven experiences.

In a recent report on the State of Health in the EU<sup>2</sup>, the European Commission states that *“truly capturing the quality of health care provision requires complementing already existing indicators with new, patient-centred data. These include patient-reported outcomes (such as whether a treatment reduced pain or enabled a person to live more independently), as well as patient-reported experiences (such as whether they felt involved in decisions about their care or whether a treatment was properly explained to them).”*

Patient empowerment goes hand in hand with the development of new digital technology, which offers new opportunities for prevention, detection, diagnosis, treatment, provision of information and communication. eHealth and mHealth systems can give people more influence over – and opportunities to take greater responsibility for – their own health and care, often increasing patient satisfaction.

Although false information may sometimes circulate, which requires efforts to provide citizens and patients with correct and scientific information, digital technology contributes to new fora of great importance for the patients. Already established patient organisations, are complemented by digital networks of engaged patients and online health communities where patients and their relatives can share knowledge, questions and concerns with other members.

Digitalisation also means that the approach to and organisation of care is undergoing a profound change, affecting among other things the balance of power between patients and staff. Many health professionals find it challenging to be a “co-creator” or “coach” fostering patient-centeredness and patient empowerment – a role requiring skills and competences that might not have been part of their formal professional education.

**Based on what they have encountered during their stay in their host country, the participants in the exchange programme are asked to**

- **give 1-3 practical examples of how the quality and efficiency of healthcare can be improved by using the experiences and competencies of patients and their relatives**
- **point at factors and initiatives (attitudes, legislation, projects, organizations, networks etc.) that stimulate and encourage the involvement of patients and their relatives, as well as at barriers to such an involvement that may exist (attitudes, legislation, lack of resources etc.).**

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<sup>2</sup> State of Health in the EU: Companion Report 2017. Report published by the European Commission in November 2017.

The practical examples of patient involvement may consist of methods to systematically visualize and take care of patients' knowledge, views and experiences at both individual and aggregated level (interviews, surveys, involvement in decision making etc). But they may also consist of methods and systems to create a relationship between healthcare professionals and patients that encourages feedback and patient responsibility for health prevention, medical treatment, diagnostics, monitoring, self-reporting of health data etc. These examples could be at national, regional or healthcare organisation level.

As there will, in most receiving countries, be participants of several different nationalities and professional backgrounds, the process of identifying and reaching consensus on practical examples, stimulating factors/initiatives and barriers to present at the final conference will be an important, if not the most important, element. The process of producing the end result is at least as important as the content of the PowerPoint presentation.

The participants are not supposed to start their presentations by a couple of slides presenting the health care system of the country in which they have stayed. Instead, they will all receive before the HOPE exchange programme a one-page presentation for each country participating. This collection of one-page documents will be prepared by the HOPE Office on the basis of the information available on the HOPE website. The PowerPoint presentation for each country should instead focus only on the practical examples, stimulating factors/initiatives and barriers that the participants have come across at national, regional, healthcare and/or ward levels.

Participants are not asked to give their opinion on the health system in the country in which they have stayed. The task is rather to identify elements in this system that they find inspiring or worth considering when looking at the challenges concerning patient involvement that they face at home in their own country. A question that the participants are supposed to bear in mind is what they would like to see implemented in their own country, region, institution or ward, or what they could learn from their host country when implementing a patient involvement approach. The task is oriented, as all the exchange is, on what to bring back home.

## Working process

### Step 1

Participants will individually identify examples, stimulating factors/initiatives and barriers during their stay.

### Step 2

They will exchange what they have found with other participants staying in the same country. If they do not meet before the end of the programme, national coordinators will organise this exchange by internet.

### Step 3

Participants will have to choose together up to three practical examples, as well as to agree on stimulating factors/initiatives and barriers.



## Step 4

Participants will prepare a PowerPoint presentation of up to three practical examples, as well as on stimulating factors/initiatives and barriers and their impact. The participants are also supposed to provide reasons for their choice.

## Presentations

- The presentations at the final conference are supposed to be 12 minutes long, and should be delivered to the organisers at the latest on Sunday evening. The presentation should not go below the time limit, nor exceed it.
- Presentations should be made in PowerPoint ONLY. Any sound effects and movies should be incorporated in the PowerPoint file.
- Diagrams and graphics are welcome where appropriate or necessary to explain an idea or to visualise a process.

## World café

The world café will take place on Tuesday before lunch.

## Copyright

**Presentations must stand alone (as a pdf-file) as they will be used for publishing on the website. This must be considered when using special effects or in respect to copyright restrictions.**

- Preferably, use only your own photographs as illustrations within the presentation.
- It is strongly recommended to only download images from websites that offer images free of royalties for commercial use (e.g. [www.pixabay.com](http://www.pixabay.com)).
- The absence of a copyright notice does not mean that an image or illustration may be freely used. If in doubt, assume you cannot use it.
- In case copyright images are being used within the presentation, proof of purchase stating the intended use of those images must be provided to HOPE.
- The names of all participants in a country should be mentioned on the presentation. They will personally be held responsible in case of copyright infringements.