

**Improving the quality of
healthcare using the
competencies and
experiences of patients.
Are we ready?**

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REPORT ON HOPE AGORA

STOCKHOLM, 3-5 JUNE 2018

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INTRODUCTION

The Swedish Association of Local Authorities and Regions (SALAR) hosted a HOPE Agora on patient involvement in improving health care between 3-5 June 2018 in Stockholm.

The conference featured high-level speakers who reported on good practices implemented in Sweden.

This HOPE Agora 2018 concluded the 37th edition of the HOPE Exchange Programme that involved 140 participants from 22 countries. During the event, the HOPE Exchange Programme participants reported on their 4-week stay abroad. They showed how the quality and efficiency of health care can be improved by using the experiences and competencies of patients and their relatives. They also looked at the factors helping or hindering patient involvement in health care.

There were numerous initiatives in a range of settings to be discovered, providing a significant scope for knowledge transfer.

The HOPE Exchange Programme is pivotal in achieving the HOPE objective of promoting knowledge and expertise sharing within the European Union and beyond. It offers a chance for participants to receive invaluable training and experience from hospital and healthcare professionals across Europe. It equips participants with a better understanding of how Europe's healthcare and hospital systems work. It also facilitates shared learning and the exchange of best practice.

CONFERENCE

The HOPE Agora 2018 started with a presentation by representatives of various key healthcare organisations from Sweden that are implementing good practices on patient involvement, thus paving the way for transforming the health system to meet future challenges.



Cristin Lind, Hans Lindqvist and Neha Sharma: Patient Partnership Facilitators at QRC Stockholm.

From *for* to *with* – Partnership with patients.

If knowledge from health professionals and patients is shared, health outcomes improve.

Today, we are facing a shifting landscape where patients, families and health professionals are adopting new roles. Patients and families have a lot to offer as they have knowledge about their illnesses and how the health systems could be improved.

Social media, big data, raising costs and demographic change are the new challenges to consider when shaping the provision of healthcare services. A complete cultural revolution is needed. Since 2012, things have started to happen.

The relationship between patient and healthcare provider is changing. It could be compared to a synchronised dance, which is not necessarily led by the healthcare provider.

Changes are occurring in the following fields.

From acute care (suffering) to chronic care (living). People with disabilities see themselves as playing an active role; instead of “suffering from”, they are “living with”.

From body parts to the person as a whole. Patients are asking to shift the emphasis from diagnosis to really seeing them as people.

From engagement to partnership. The speakers mentioned the [European Patients Forum \(EPF\) Charter on Patient Empowerment](#), highlighting what matters for patients and defining the principles of patient empowerment from the patients' perspective.

From “What’s the matter with you?” to “What matters to you?” Patients are asked what is important for them in the care process; they ask to be supported in their choice.

A partnership model based on patient involvement is required. This applies to all levels of care. They should be included in the care process as soon as possible and there are different ways and approaches to do so.

At this point, the speakers invited delegates to take a part in a survey on the challenges and gains of partnership. It was conducted with Mentimeter, a real time voting tool. Once the questions have been asked, the audience accessed the suggested link, entered the code provided and voted. The results were feedback displayed at the end of the vote.

Partnership is associated with improved patient outcomes, shorter hospital stays, fewer readmissions, improved functional status and reduced mortality. It contributes to enhanced decision-making, fewer medical errors and adverse events, improved adherence and optimised self-management, increased staff retention. The ownership is shared between professionals and patients.

Partnership and quality improvement need each other. Patient partnership helps quality improvement to:

- * Identify the unknown unknowns;
- * Shift the focus;
- * Discuss and define new quality indicators;
- * Challenge existing roles;
- * Reduce power differentials.

Quality improvement supports partnership to:

- * Act after listening;
- * Help patients get feedback after co-production;
- * Provide processes to partnership outcomes;
- * Increase curiosity.

To make partnership successful, a new culture is needed. As an example, the speakers shared how an adolescent unit's website was improved thanks to user feedback.

So how do we do it?

The speakers provided the example of patient partnership in Coachingakademin. During the first year, the team struggled to find an effective way to involve patients. It adopted several methods and tools, with some results in 2015 and 2016. There is no perfect method, and each has its own requirements and produces different results. Using more than one method gives a greater depth of understanding of patients and their needs.

The first method reported consists of shadowing the patient through a healthcare process by observing the environment and events from a patient perspective. It is the easiest method for beginners to learn about the patients' experience in healthcare processes. It has provided a lot of new ideas on how to improve a unit.

Love and Nuts aims at gaining patient insights and triggering conversations. Workshops and focus groups are ideal for this, but more structured methods will be included.

Patient/user-led audit drives at getting deeper insight of a unit itself and detecting issues that would not be otherwise recognised. Like Love and Nuts, it will include more structured methods. Patient interviews increase the understanding of experiences, needs and expectations as patients describe themselves and their experience in their own words.

When patients are part of improvement teams and considered as partners, this sends out a strong signal that patients' knowledge is valuable. Moreover, partnership allows thoughts and ideas to be constantly shared. Patient experience can offer unexpected insights to improvement teams, and those organisations that involve patients and their relatives tend to have higher levels of patient satisfaction.

Ida Björkman: Postdoctoral Fellow at University of Gothenburg Centre for Person-Centred Care (GPCC).

Benefits of person-centred care.

The challenges that Sweden is facing are: an ageing population; a high prevalence of chronic diseases; increasing healthcare costs; health inequities and increasing patients' expectations. Healthcare providers and health systems have to adapt to these expectations. Patients in Sweden have experienced problems with care coordination, which is now an issue. Resources have been wasted due to examinations being duplicated.

According to Ida Björkman, Person-Centred Care (PCC) is a new way of relating to patients. It represents an ethical obligation for healthcare providers to respect patient dignity and autonomy. Sweden has started several reforms to comply with this approach and several randomised controlled trials have been introduced in Göteborg.

PCC was introduced for patients with coronary acute syndrome, from hospital to primary care, to overcome the problem of care coordination. The trial showed improvements in the intervention group and that the change was driven by increased self-efficacy. The results show that patients with low levels of education benefit the most.

PCC for chronic heart failure patients reduced the length of stay by 2.5 days. Activities of Daily Living² (ADL) improved while no differences were reported in the rate of readmission and Health Related Quality of Life³ (HRQoL).

PCC physical therapy reduced general fatigue more in the intervention group than in the control group.

Among the lessons learned, the speaker stressed the need for participatory research designs and change at all levels; the need to evaluate complex interventions as such and to focus on outcomes.

Sofie Zetterström: Deputy CEO of Inera.

Digital solutions that support patient participation.

Inera is a company owned by SALAR along with the 21 county councils and the 290 local authorities in Sweden. It provides the shareholders with national digital services. These are for patients and citizens, healthcare, local government staff. Inera also supports the owners and their IT suppliers with infrastructures like networks, integration platforms, catalogues for master data, services for secure identification and managing the access to systems, along with the architectural frameworks that are needed to develop interoperability.

Inera's first mission was to develop a website to support patient empowerment. The company grew fast during the years and it is now responsible for more than forty national digital services. Service for patients and the general public are particularly well known and used by millions of people every month. This has really been a success story.

Digitalisation occurs at three levels. The first refers to the infrastructure to support interoperability between systems using national and international standards. The second relates to regulation and consists of supporting the owners with technical frameworks and guidelines, IT models and codes, security standards, legal guidelines and also guides to change workflows or develop the organisation as digital services are introduced. The third refers to e-services provision like web portals, secure personal services for the public, digital tools for healthcare staff.

Inera's goal is about changing perspective: from putting the patients at the centre to putting the patients' needs at the centre. Moreover, Inera's new approach consists of looking at the patients as active members of the healthcare team. *"A member who is well informed and has good knowledge of his or her condition, who takes part in making decisions on treatments and has the possibility to follow up results and take responsibility of his or her own health. This is a change we are trying to accomplish,"* stated Sofie Zetterström.

²[ADL definition](#)

³[HRQoL definition](#)

This shift is not easy due to lack of coordination among different care providers, which leads to fragmented processes. To mitigate this and to empower patients, Inera has developed a toolbox designed to navigate the care process. It contains patient portals with a lot of high-quality information; services to guide patients to the right level of care and to help them manage appointments; medication lists, and personal information or advice. There are also services for online treatments and for accessing medical records. All these tools are in use, but the involvement of the patients in the process depends on the interaction between the patient and the caregivers, which represents a challenge.

Sofie Zetterström mentioned three categories of services: health advice by phone, open web portals and personal e-services. The main trademark towards the public is 1177 Vårdguiden which is both a telephone number and the address of Inera's web domain. The information provided through these channels is evidence based and edited in cooperation with experts. All services are secure and accessible. This concept is extremely well known and popular among the Swedish people and used by millions of people each month.

The health advice by phone is a service provided by a nurse who guides the patient to the right level of care according to information on symptoms provided. Patients can be guided to primary care, emergency care or be referred to the ambulance service. Between 30%-40% of callers receive self-care advice. According to the evaluations, many patients would have gone to the emergency room if it was not for this advice. More than the 90% of patients follow the advice given. This leads to a double effect: it relieves both callers and the healthcare staff from unnecessary visits to healthcare settings. The aim is to ensure the right patient has the right level of care at the right time. The nurses of the service are employed by the county councils and Inera provides the infrastructure.

The system receives an average of 450,000 calls per month. The statistics collected are used to shape policy.

In addition to providing information about the Swedish health system, the open web portal collects information about diseases, symptoms and treatments. Every year 10,000 anonymous questions are answered by doctors. Through this service it is also possible to compare competences, waiting times and patient satisfaction across clinics.

A further example of a healthcare portal is UMO, consisting of an online youth clinic for 13-25-year-olds. At UMO, users can find all kinds of information about sex, contraception, relationships, equality, sexual orientation and many other embarrassing questions. UMO has been translated into 5 foreign languages as Sweden welcomes refugees. Statistics are showing that UMO is used by eastern countries. The main users come from Iran. This means that Inera is making an effort to promote gender equality and the possibility to make information about sex and contraceptives accessible all over the world.

The personal e-services cover booking an appointment, renewing a prescription, ordering home tests, listing medicines, reading test results and managing services for children. In particular, the schedule managing function has shown great results. Other positive effects include fewer late cancellations and patient no-shows.



Patients appreciate the service as they can schedule their appointments whenever they want. An analysis has shown that €700m could be saved every year once the service is in full use as it would relieve nursing staff from spending time on scheduling appointments by phone.

Not only is the service efficient and value for money, but it offers people better quality and independence. The platform is a flexible service for online treatment and health support, encouraging communication between patients and healthcare professionals. At the beginning, the development focused on cognitive behavioural therapy. Research has shown that online clinical treatment of cognitive problems is effective.

The online medical record service that allows patients to access their data has become more widely used despite the reluctance of the doctors and the patients themselves. It was first launched in Uppsala in 2012. Doctors were convinced that giving patients access to medical records and test results would only cause a lot of worrying and anxiety. They were also afraid that the patients would not understand the records and would burden healthcare professionals with a lot of questions and misunderstandings. But as the service grew, most doctors discovered its benefits. The service developed slowly, due to technical challenges and the need of the county councils to involve the professionals in the process. Policy makers are pushing for all medical records to be made available by 2020.

Research on patients who have accessed their medical records shows that they find the service useful. Patients heed what was said during the last appointment and consider themselves better prepared and well informed about their health conditions. They feel comfortable with the service and are not concerned about security issues. Most patients want more information than what is available today. Lastly, they feel frustrated when information is not readily available, e.g. unverified test results.

The next step consists in testing Artificial Intelligence (AI) solutions, but this will require more technological advancement. Sweden is ready to start on a small scale. The goal is to guide citizens to the right level of care while relying on automated services on the portal 1177.se. The service will be implemented by 2019 and used as a support system for nurses who provide advice by phone.

Hans Karlsson: Head of the Health and Social-Care Division at the Swedish Association of Local Authorities and Regions (SALAR).

Innovationsguiden – the use of design thinking to improve public services.

Patients and relatives have a lot of knowledge that could be used to enhance the health systems. Some patients do not want to take part in the decision-making process, but others do. Very few want to be recipients of a service; the majority want to be part of it. The co-creation process involving patients and professionals shifts the "balance of power" and we are not ready

Are we ready and do we want this change?

The Innovation Process aimed at public sector development based on user needs was inaugurated in 2016 and lasted for two years. The objective was to support municipalities, county councils and regions to work with user-driven innovations, developed through a co-creation process involving users and providers.

It is based on six steps, adapted to the working conditions in the public sector and designed to guide the development teams in a structured way.

A handbook called *Innovationsguide*, has been published with step-by-step instructions for setting up the innovation process. It provides for a development programme, including training and coaching.

An example of user-driven innovation is home-care services for senior citizens to support these people in their own homes while increasing their sense of safety and involvement in their daily lives. In-depth interviews with the user group were conducted. The users recorded their daily life in diaries. One of the findings was that people felt some distress when they did not know who would show up at the home care visits. An innovative prototype was created with user involvement and several home-care groups have now started using the solution that is being replicated in other municipalities.

Social services for youths living at family homes are another solution. Following interviews with these young people, it was found that they needed more information about. For this reason, a booklet has been published and adopted by all social services in the municipality.

Many development programmes have already been realised and have involved: 130 project teams totalling 700 people, 55 coaches, 220 course participants and 100 politicians and leaders.

With innovative programmes based on user involvement, it is important for project developers to turn off their professional brains and be ready to notice that the problem faced could well be different from what they expected at the beginning.

The innovation processes mentioned have led to some ripple effects. The biggest university hospital in the country has started to employ service designers as well as training the current staff in a bid to lead service design projects and teach the method to others. Several organisations have started to use the support tool set out in the *Innovationsguiden* independently, creating their own courses and development programmes. Lastly, Göteborg municipality has adopted a policy of always using this service design perspective for developing projects.

Åsa Steinsaphir: User Involvement Coordinator at North Stockholm Psychiatry.

Patient experience as a competence.

Everybody thinks that user experience is important for quality improvements in a health organisation, yet few resources are allocated to user involvement. In a healthcare organisation many competencies have to be connected, included those of patients. However, involving patients in a more structured way is often complicated. According to the speaker, this is due to distance. Often, patients are involved on a voluntary basis, but it is not possible to rely only on enthusiasm alone. At North Stockholm Psychiatry, they moved inside the organisation and started to employ people with user experience as a mandatory requirement. The user involvement coordinator is a person regularly hired, who becomes part of the organisation. Such coordinators help to break the stigma associated with psychiatric care.

“User experience is not for everybody,” stated Åsa Steinsaphir. She regularly meets hospitalised patients in forums to collect their feedback. This is gathered and discussed every six months to see if improvements are possible. An example she reported was about the need for patients to talk more often with the nursing staff. Following this, daily talks were organised, and patients were more satisfied. This has resulted in daily talks with nurses being extended to the whole clinic. This action was implemented without drawing on further resources, but patient satisfaction increased. The rest of the staff was informed about the patient forum results. Lastly, the user involvement coordinator liaises with the patients’ organisations.

It is important to define a job description and to clarify what it is expected from the person, who has to be seen as a co-worker and not as a patient. It is also necessary to avoid discrimination and to have the same expectations toward the user involvement coordinator than for the rest of the staff.

Short movie viewing⁴.

Dialysis on the patient’s own terms: Unit for self-dialysis at Ryhov Hospital,

Jönköping.

At the regional Ryhov Hospital in Jönköping, there was a self-dialysis unit for several years. A new wing was opened with 12 stations, 8 more than before, and 14 patients are using the stations at present.

The patients could arrive at the hospital earlier than the staff, accessing the station through a card and entirely managing their care.

The dialysis ward needed an extension to cater for demand, but the hospital did not have enough resources. The idea of self-dialysis emerged as a solution.

⁴To watch the short movie, click on the following [link](#).

Self-dialysis is something patients can do entirely on their own. *“The first thing I do is run the self-test, set the machine up, put on the tubes and filters. It takes 20 minutes to set it all up before I can stick the needles in. I run all the operations by myself, from first to last. The dialysis itself takes 4 hours a day, plus preparation and cleaning time. In total 25 hours per week,”* stated Patrik Blomqvist, Patient Supporter at the Ryhov Hospital self-dialysis unit.

“Usually the dialysis runs your life. We would like life to run the dialysis. You must have your dialysis, but you could have it suited to your day as it stands,” says Britt-Mari Banck, Operations Manager at Ryhov Hospital.

Self-dialysis could be a good alternative to home dialysis since patients feel at home and have the chance of mixing with other people with the same condition. Self-dialysis is not only about the patients running their own dialysis but also about the patients being informed about all the aspects of the treatment. Britt-Mari Banck says that the staff wants patients to participate in the entire process. Doctors, nurses and patients discuss together how to solve problems and patients are informed about what is happening.

“Since my illness is such a big part of my life, it is good to know what is going on,” says Patrik Blomqvist.

“When the ward was set up, the machines were new both to us and the patients. We were exactly at the same level, with our manuals out, no-one better than another,” confirmed Britt-Mari Banck.

The self-dialysis unit is so successful because patients have the chance of scheduling their treatments according to what suits them better. Moreover, patients share their experiences with other and provide mutual support and information about treatment.

Self-dialysis service is also a way to save resources.

WORLD CAFÉ

HOPE organised for the third time a World Café during its agora. Participants were invited to share the most interesting good examples they found during the HOPE Exchange Programme as well as other practices they were aware of. They were asked for their opinions about the factors that encourage patient involvement as a way to improve quality in healthcare and about the barriers.



Drawing on five to seven design principles, the World Café methodology is a simple, effective, and flexible format for group dialogue. It aims at harnessing collective wisdom and not at reaching a resolution that involves trade-offs. The process began with the first of three 20 to 30-minute rounds of conversation for the group seated around a table. At the end of the round, each group member moved to a different table. Staying behind on each table was the “table host” for the next round, who welcomed the following group and briefly filled them in on what happened in the previous round. Each round had been prefaced with a question designed for the specific context and desired purpose of the session. Afterwards the individual group members were invited to share the insights of other results from their conversations with the rest of the large group.

World Café participants reported many good examples learned during the country presentations session and the conference. However, the most common were: the Patient Champion (the United Kingdom); the expert by experience (Finland and Serbia); the company Inera (Sweden); the listening groups for oncologic patients (Estonia) and elderly people (Sweden); the patient council (Slovenia and the Netherlands); the peer support (Spain and the Netherlands); the quality survey (France); the remote monitoring (Slovenia); the provision of health advice by telephone (Portugal and Sweden); the user involvement coordinator (Sweden); the virtual hospital (Finland); the volunteers (Italy, Slovenia, Switzerland and the United Kingdom).

Participants also mentioned the participation of relatives in the care path definition; the presence of patient representatives and the possibility for patients to have remote consultations on their conditions.

Table 1: Factors encouraging and hindering patient involvement. Source: World Café results, HOPE Agora 2018.

Encouraging factors	Hindering factors
Change of attitude	Bureaucracy
Communication	Digital exclusion
Culture	Education
Education	Lack of interdisciplinary teams
Education & training	Lack of resources
High health literacy	Lack of staff
Impact measurement	Lack of time
Patient self-monitoring	Lack of trust of professionals toward patients
Policy makers engagement	Legislation
Positive attitude of professionals	Medical language
Resources availability	No indicators
Results comparison	Organisational structure
Strategy	Patient attitude not willing to participate
Strong leadership	Traditional role of professionals
Teamwork	Valid evidence-based information

COUNTRY INFORMATION

AUSTRIA

HOPE National Coordinator: Gertrud Fritz

Exchange Participants 2018: Christy Carolan (Ireland)

Mette Harboesgaard (Denmark)

María Amparo Martínez Assucena (Spain)

Hanne Nafei (Denmark)

Josselyn Oldewarris (The Netherlands)

Jukka Paso (Finland)

Anu Poikala (Finland)

Milorad Spanovic (Serbia)

Ingrida Urboniene (Lithuania)

Christian Dietrich (Germany)

Patient-centred care in Austria has been developed by implementing three practices: *patient and family wellbeing*, *health literacy* and *communication*.

Patient and family wellbeing is aimed at child care at Graz University Hospital and consists in showing short informative films, involving families along their children's care pathway and providing information on how to cook healthy food.

Health literacy is possible through digitalisation of the healthcare system, which supports patients in obtaining information on their own health status.



The graphic features the title "Health Literacy Electronic Health Records" in red. On the left, a list of "Health care services" includes ELGA, Early detection, Free dental braces, Free vaccinations, Medicines subsidy, Mother-child pass, and Preventive check-ups, with a URL https://www.bmgf.gv.at/home/EN/Health_care_services. The ELGA logo is in the center. On the right, a cartoon shows three men in a discussion; one says "There are too many players & a lack of coordination," another replies "You're wrong!", and a third says "You're right! I'm hungry!". Below the text is a circular diagram of medical icons like a microscope, heart, stethoscope, and pills.



Digitalisation of the healthcare system relies on the Electronic Health Record called ELGA⁵, which provides information to patients and health professionals on patients' health status and care pathway. ELGA is a tool for enhancing the coordination of care among different health professionals, since they all access the same information. Health literacy is also the consequence of using self-care apps, supporting patients with COPD. The app provides medication reminders, training, illness diary, calendar, practical information on daily life and useful addresses. A further example of health literacy solutions implemented at Graz Geriatric Health Centre is training centre services where professionals simulate critical situations. Patients and families can attend the training and learn how to provide care when such events occur.

High quality communication is a key point of patient-centred healthcare. This is possible by training health professionals on how to talk to their patients. The HOPE Exchange Programme participants also reported the example of shared decision-making in primary and palliative care and of specialised outpatient clinics for patients with hearing impairments that have adopted alternative communication methods.

⁵For more information on [ELGA](#).

DENMARK

HOPE National Coordinator: Bertil Selde Krogh

Exchange Participants 2018: Renata Bozikovova (United Kingdom)

Maria João Dallot (Portugal)

Joanne Dowds (Ireland)

Leena Koulu (Finland)

Catherine Lechot Roethlisberger (Switzerland)

Ana Pilar Martínez (Spain)

Maria Ntara (Greece)

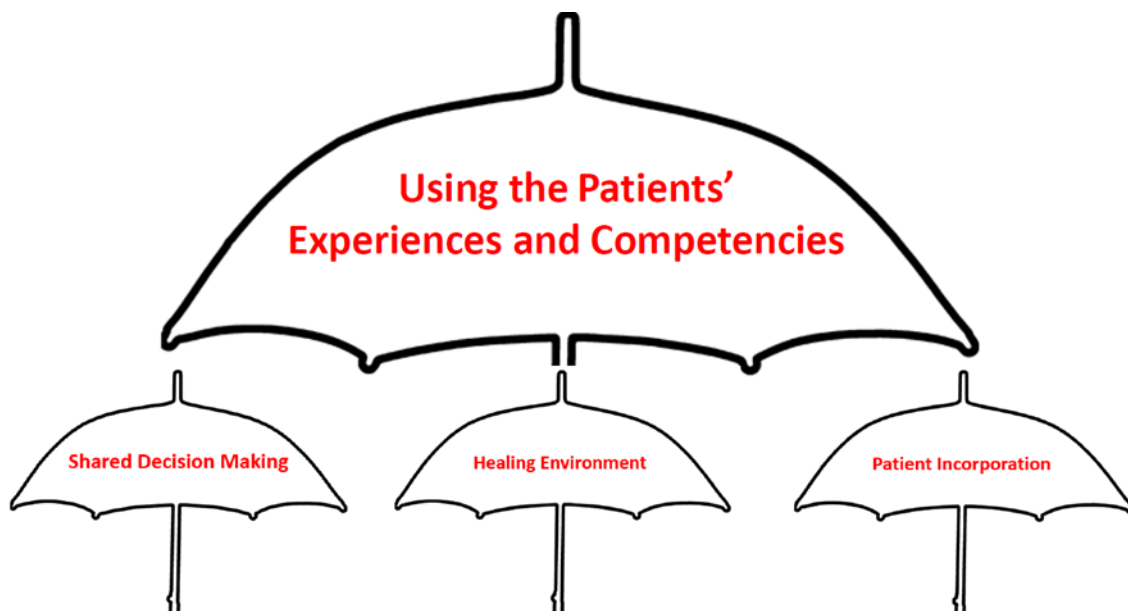
Christian Queckenberg (Germany)

Sabine Sramek (Austria)

Astra Zviedre (Latvia)

In Denmark, patient involvement is a means for Danish policy makers to achieve the national goals of better quality, continuity of care and geographical equality in the healthcare system.

Patients' experiences and competencies are used in shared decision-making, in shaping the architecture/environment of health settings and are incorporated in care pathways.



An example of shared decision-making is VIBIS, the Danish Knowledge Centre for Patient Involvement in Healthcare established in 2011 by the Danish Patients Organization (*Danske Patienter*). The goals of VIBIS are: sharing knowledge and providing training to Danish health professionals on patient involvement, including shared decision-making and patient-reported outcomes; developing manuals and providing consultancy to hospitals for the implementation of local patient involvement interventions; providing courses on becoming "Shared Decision-Making Ambassador". A further example of shared decision-making has been reported at Kolding Hospital where patients and physicians agree on common treatment plans.

Patients are experts about their own lives while physicians are experts about the illness. At Aarhus University Hospital patients could choose to have haemodialysis, peritoneal dialysis or dialysis at home, just by filling in a form. Patients with chronic kidney disease usually need dialysis before a kidney transplant, in some cases waiting times are up to a year or more. Previously, patients needed to see two nurses specialised in different types of dialysis. Now, they are invited to a *Kidney School*, consisting of two-day programme run by nurses for a group of 12 – 15 patients and their relatives. There are three meetings in total about: 1. Choice, 2. Options, 3. Decision. A “Dialysis Choice” document was developed in collaboration with patients. It turned out that the 80% of the patients chose dialysis at home, reflecting an increase of 23% in starting dialysis at home. Patient feedback shows that they like this decision-making process.

Further examples of patient involvement at Kolding Hospital and Randers Regional Hospital refer to healing environment. At Kolding Hospital, children and parents have been involved in developing RUMLE, a game-based app aimed at informing, entertaining and preparing children for what happens in connection with an MRI. At Randers Regional Hospital, the post-anaesthesia care unit, parents and professionals have been involved in creating a safe and non-clinical environment for children to reduce their anxiety.

The Danish concept of Hygge was considered in the development of the healing environment. The relationships between families and professionals improved while maintaining a safe non-clinical environment. Each post-surgery child received a toy from a foundation.

Patient incorporation in North Denmark Region is the last example reported by HOPE Exchange Programme participants, consisting of including patients in diverse discussions to enhance the organisation. They talked about a peer board with young adults suffering from chronic diseases, focusing the discussion on how to improve relationships.

Denmark has been actively working on patient involvement. The taking home messages are:

- * Communication between all actors concerned is crucial;
- * Simple changes – like art or a calming environment make a huge difference to how patients feel and heal;
- * Listening is crucial for improving.

ESTONIA

HOPE National Coordinator: Hedy Eeriksoo

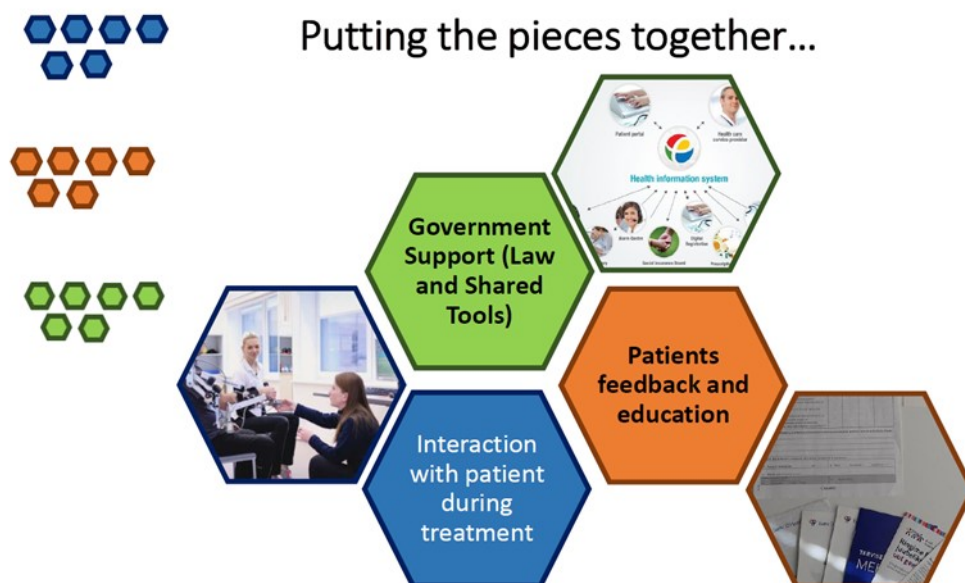
Exchange Participants 2018: Ana Filipa Coelho (Portugal)

Graham Smith (United Kingdom)

HOPE Exchange Programme participants reported the example of a Health and Welfare Information Systems Centre, which provides patients' data in one accessible and secure place. Furthermore, the Estonian Government has sponsored the eHealth Patients Portal, developed by hospitals and IT teams. Several projects have been run on automation and easily readable data.

In the Regional Hospital (Regionaalhaigla) and East Tallinn Hospital (Ida-Tallinna Keskhaigla), a good practice was communication with patients using signs, screens, leaflets and other tools. In the Southern Estonian Hospital (Lõuna-Eesti Haigla AS) in Varu, a nationwide satisfaction survey is conducted every year.

The same tool has also been implemented at Tartu University Hospital (Tartu Ülikooli Kliinikum) and a results analysis is included in the annual report to improve patient satisfaction. Patient feedback is collected by the Patients' Information Office, promoting among the activities the follow-up of patients' complaints and suggestions; the production of patient leaflets about procedures and; session groups for oncologic patients to listen to their experiences. Participants also mentioned the Picture Archive Communication System (PACS), an image bank available to all doctors in the country including GPs. In conjunction with the Cancer League, PACS promoted the "Mammography Bus", for breast cancer screening all over Estonia.



At Haapsalu Neurological Rehabilitation Centre (Haapsalu Neuroloogiline Rehabilitatsioonikeskus), strong leadership and governance have been recognised as supporting patient-centred care. *“The team works with the patient, not for the patient”* quoted the HOPE Exchange Programme participants. At the same centre, patients are involved through neuro-robotics as well as analysis of bio-feedback and neuroplasticity.

At Pärnu Hospital (Pärnu Haigla) healthy lifestyle initiatives are promoted in collaboration with organisations with similar goals. These are advertised through social media.

At West Tallinn Hospital (Lääne-Tallinna Keskhaigla) patient surveys are conducted every year as well as the follow-up on complaints and suggestions received from patients. Information is shared among professionals through the eHealth portal. This hospital specifically addresses infectious disease such as HIV and promotes initiatives that engage patients and doctors to collaborate with start-ups.

Examples of applications that use patients' experience and competence are: Monitoring of HIV patients and interaction with healthcare professionals; monitoring of multiple sclerosis patients at home and hypertension advice based on monitoring findings.

According to the HOPE Exchange Programme participants in Estonia, patients' experience and competence are:

- * Patients' ability to look after their own health (either to prevent health problems or to manage them);
- * Patient centeredness: *“No decision about me without me”*;
- * Patients' feelings, lessons learned from their life experience with the health problems;
- * Patients' expectations and desires towards healthcare.

How to measure quality of healthcare?

- * Patients' satisfaction (expectations met);
- * Stable or improved health;
- * Traditional healthcare quality indicators (e.g. average life expectancy, readmissions, mortality rate);
- * Decrease in avoidable chronic diseases (diabetes, hypertension, obesity).

The following box shows potential barriers to improvement and possible solutions.

Table 2: Potential barriers for improvements and possible solutions. Source: HOPE Agora 2018.

Barrier	Solution
Patient literacy	Investing in patient education; Working on health language.
Gathering patient feedback	Timely surveys; Promoting session-groups.
Financial resources	Investing in prevention policies; Developing more efficient processes.
Effective communication to patient	Developing visual information.

FINLAND

HOPE National Coordinator: Hannele Häkkinen

Exchange Participants 2018: Caroline Baya (United Kingdom)
Zakir Bickhan (United Kingdom)
Isabel María Díaz Martínez (Spain)
Anabela Ferreira da Costa (Portugal)
Mariska Huslwit-Verweij (The Netherlands)
Ainoha Iceta (Spain)
Dragica Karadzic (Slovenia)
Sarah Lambrecht (Germany)
Niki Lamprou (Greece)
Thuc Le Minh (France)
Maria José Maia (Portugal)
Carlotta Mantoan (Italy)
Lorentyna Mikulska (Poland)
Miriam Preiser (Switzerland)
Mary Quinn (Ireland)
Anneliese Raab (Austria)
Ursula Sprincnik (Austria)
Inger Marie Taagaard (Denmark)
Baris Ulucan (Switzerland)
Natalia Zieba (Austria)

The HOPE Exchange Programme participants in Finland quoted the following stimulating factors as means to improve quality of care using the experiences and competencies of patients:

- * A nation of trust;
- * Highly educated healthcare professionals;
- * Digitalised, innovative society;
- * High educational level;
- * Welfare society.

They identified the long distances and the low population density as future challenges for the health and social-care system.

The participants reported the example of Sarah, a 30-year-old patient suffering from depression and fatigue. Sarah's pathway involves three strands: *virtual hospital*, *personalised care plan* and *expert by experience*.

The *virtual hospital* is a hub developed with patients, which Sarah could access through the care system. Sarah is active and able to manage her care pathway: she finds out about symptoms, logs onto healthvillage.fi, specifies symptoms; books an appointment and sees the doctor. The virtual hospital is a system used every day by health professionals and allows for resources to be fine-tuned. During treatment she uses eHealth tools and in the follow-up phase she collaborates with the health professionals. Above all, the hub empowers Sarah to manage her healthcare.

She has access to her data and can reflect on her condition. Lastly, she is confident that her data will be used properly.

Personalised care plans target patients suffering from chronic diseases. Patients fill out a self-care form beforehand and participate in the decision-making process. This results in improved health outcomes, health literacy and cost effectiveness.

Sarah decided to be an *expert by experience*. To become an expert by experience, people can either make an application or be asked by a health professional. They are trained for 8-10 months and may collaborate in primary and specialised health care, municipalities and social services.

Experts by experience:

- * Know what it is to be ill and to be a patient receiving treatment;
- * Know the factors that have helped in their recovery;
- * Are trained for their tasks and to help other patients.

Patients feel emotionally supported and professionals gain insights for better services and understanding of the patients' needs and possible challenges. In addition, experts by experience contribute to better patient-centred planning of care.

Is Finland Ready?

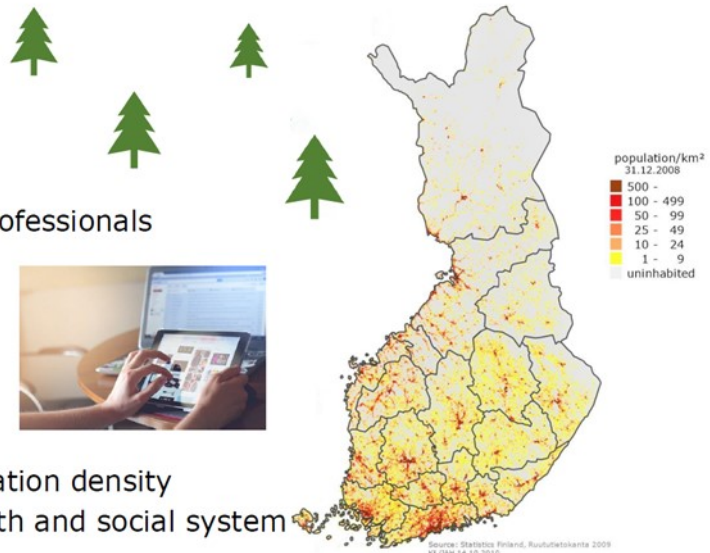
Stimulating Factors:

- A nation of trust
- Highly educated healthcare professionals
- Digitised, innovative society
- High educational level
- Welfare society



Barriers:

- Long distances and low population density
- Future challenges for the health and social system



FRANCE

HOPE National Coordinator: Antoine Malone

Exchange Participants 2018: Ana Aroca Tanarro (Spain)

Carlo Alberto Camuccio (Italy)

Begoña Frades García (Spain)

Nadeem Hussein (United Kingdom)

Cathy Phelan (Ireland)

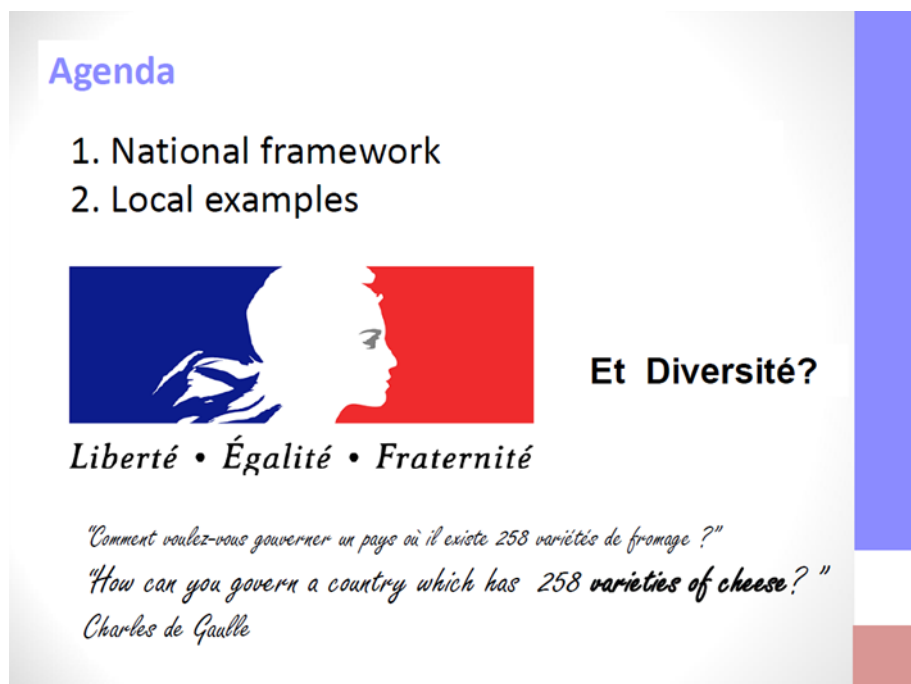
Mathias Oliver Rechsteiner (Switzerland)

Paulina Sarbinowska (Sweden)

Mariya Sharkova (Bulgaria)


Zorica Tasic Stojanovic (Serbia)

María Carmen Zabala Ortiz De Zárate (Spain)



Agenda

1. National framework
2. Local examples



Et Diversité?

Liberté • Égalité • Fraternité

"Comment voulez-vous gouverner un pays où il existe 258 variétés de fromage?"
"How can you govern a country which has 258 varieties of cheese?"
Charles de Gaulle

The HOPE Exchange Programme participants in France reported initiatives for enhancing the quality of healthcare services by using experiences and competencies of patients at the national and hospital level.

The French National Health Strategy 2018-2022⁶ represents the country's health policy framework. It is set out by the Government following assessment by the High Council of Public Health of the state of health of the population, its main determinants, as well as on possible strategies for action. The strategy suggests that users should be involved in improving quality and safety of care, thus redefining their role in the healthcare system.

⁶Stratégie nationale de santé 2018-2022, page 52.

A further initiative at the national level is the release of a joint document⁷ providing a list of elements, encouraging hospitals to initiate local projects with patient involvement. The stakeholders who took part at this initiative are: France Assos Santé, the Ministry of Health, and the High Authority for Health and federations of health providers.

The French Patient Experience Institute (*Institut Français de l'Expérience Patient*) is a non-profit organisation whose mission is to contribute to making the patient experience a means of transforming the health system.

With regards to the hospital sector, it is mandatory to include a patient representative in the development and implementation of healthcare strategy. To make patient involvement effective, the institute works on involvement methodologies with a federation of patient representatives. According to the HOPE Exchange Programme participants, it is important to educate clinicians across the organisation about techniques and the importance of patient-centred care. For this, the French Patient Experience Institute provides consultancy with emphasis on listening. Progress has been made but there is still room for improvement.

The role of patients has also been crucial in the national certification process adopted by the High Authority for Health (Haute Autorité de Santé – HAS) to assess the level of quality in hospitals and clinics throughout the country. This information is available on the website www.scopesante.fr. Patients who have been hospitalised for more than 48 hours can take part in a survey and contribute to the assessment process. The indicators assess the process or the outcome of care and hospitals could be ranked and benchmarked. The HOPE Exchange Programme participants reported the case of Centre Leon Bernard in Lyon, where the 83% of patients who took part in a survey recommended this organisation to family and friends.

The HAS elaborated a survey for patients admitted at hospitals at least for 48 hours. The survey provides patient feedback on the support provided by health professionals (doctors, surgeons, nurses and care assistants), the quality of meals provided, the room and the organisation of discharge.

Some examples of strategies adopted in hospitals are: user commissions, patient groups, innovative software & questionnaires, patient therapeutic education.

User commissions were introduced by law in 2016 and since then they have been mandatory in every healthcare-related institution. They ensure that patients' rights are respected, play an important role in enhancing the quality of care and ensure the involvement of patients and relatives in the health system. In each commission there should be a legal representative of the institution, a doctor (clinical mediator), a non-medical mediator, two patient representatives and the quality manager. Optionally nurses, personnel and other clinical representatives may sit on the commission. The aim of these commissions is:

- * Develop the policy on reception, care, information about the patient's rights and relationships between medical staff and patients;
- * Make the connection with the quality and security programmes of each institution and make proposals;

⁷[Construire et faire vivre le projet des usagers en établissements de santé.](#)

- * Receive details about complaints and adverse events in the institution and ensure that corrective action is taken;
- * Mediate in hospital complaints;
- * Propose action after consultation with the patients' associations.

Patient groups represent an innovative good practice as they use patient experience to improve quality. Such groups are not mandatory but may be useful for the certification process. They consist of 10-12 patients and their relatives chosen by the patients' doctors. They meet on a voluntary basis with three members of the institution. Their objective is to develop more democratic care, while listening to the patient experiences, main problems and opinions regarding different programmes implemented in the institution. They aim to provide education to patients and form a group of *patient experts* to guide the institution in the patient experience.

An example of patient group has been promoted in Strasbourg to support children suffering from language impairments. At Léon Bernard Centre, two software programs are being used – MyHOP and MyCLB – to allow full access to medical records, direct communication with health professionals and patient surveys. Patients are asked to take part in a questionnaire to follow up ambulatory surgery. Since it started, around 5,000 patients have used this platform. The centre receives 12,000 connections through the platform. In addition, they are asked to provide information about any social problems relating to their condition.

Through therapeutic education, patients acquire the necessary skills to manage their long-term illnesses and enhance their quality of life (HAS, 2018). The HAS evaluated the following aspects of patients' experiences:

- * Coordination, continuity and effectiveness;
- * Comfort and listening;
- * Respect of their wishes;
- * Involvement.

Patient Education Groups are a further example worth mentioning. They focus on patients suffering from chronic conditions. The patients learn how to cope with their daily problems with the support of multidisciplinary teams composed of patients and professionals.

An example of professional and therapeutic education (ETP) has been implemented at the University Hospital of Nantes, where the Reference Centre in Therapeutic Education and Cognitive Remediation (*Centre de référence en Soins d'Éducation thérapeutique et de Remédiation Cognitive - CreSERC*) provides services to people suffering from mental illness through cognitive remediation, personalised education and peer-to-peer training to potential peer to peer, the latter involving former patients to advise others.

Primary care plays a relevant role in improving efficacy of care by educating patients. The participants of the HOPE Exchange Programme reported the good example they discovered in Royat, Auvergne. The practice was developed to inform parents about which type of care is the most appropriate for their child, to avoid unnecessary hospitalisation.



In conclusion, French people tend to seek care but do not generally take active part in their care.

Nowadays some changes are taking place to increase efficiency by highlighting prevention and decreasing the length of hospital stays. In parallel, it is a worldwide objective to personalise medicine and to include patients' needs in the care process. The big challenge is to move from paternalistic medicine to humane medicine. Basically, healthcare providers need to involve patients more while patients need to take more responsibility for managing their condition and care. There are lots of interesting projects going on, most of them in their early phases. Projects in hospitals are now driving change. It seems likely that in 5 years' time, after a few pilot projects have been tested, the way to involve patients will be much more structured at all levels. It is necessary to wait and see if the changes taking place in the hospital will also be implemented in remote areas of the system.

GERMANY

HOPE National Coordinator: Peer Köpf

Exchange Participants 2018: M^a Del Carmen Carcedo Barrio (Spain)

Cristina Carriedo Scher (Spain)

Sandra Eismann (United Kingdom)

Inga Frismane (Latvia)

Joke Habben (Denmark)

Martin Kaiser (Austria)

Jan Kjaersgaard (Denmark)

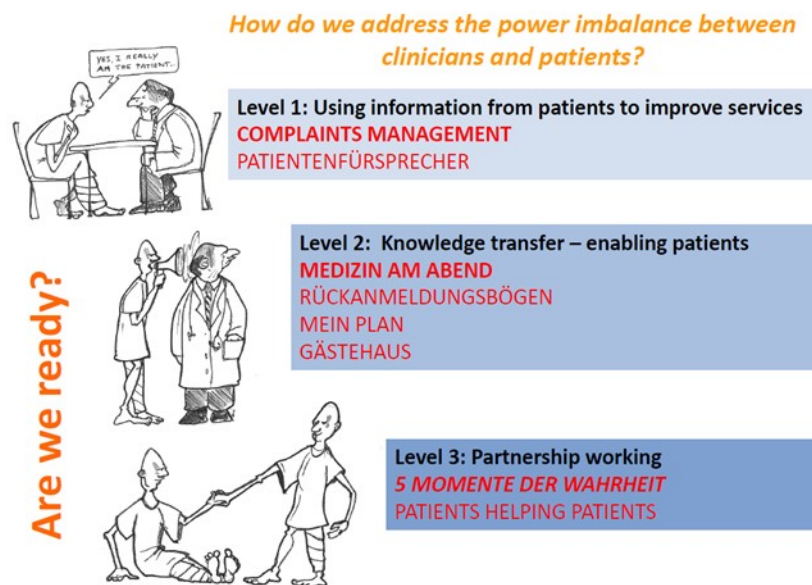
Marianne Prica (Switzerland)

Benjamin Schaffer (Austria)

Piotr Szykiewicz (Poland)

Hanna Tolonen (Finland)

The feedback by HOPE Exchange Programme participants in Germany answers the question, “*How to address the power imbalance between clinicians and patients?*” This could happen in three ways: using information from patients to improve services; enabling patients through knowledge transfer and through partnerships.



Complaints management systems are widespread in hospitals throughout the country and are used as a source of information for improvement.

An example is waiting times at outpatient clinics preventing patients requesting appointments. Information collected through the complaints management system has been combined with other available data and actions have been promoted accordingly.

A further initiative reported is the so-called “Medicine in the Evening” (*Medizin Am Abend*) consisting of public lectures by clinicians every 5 weeks, the aim being to discuss scientific themes with the general public using plain language. These lectures are free and represent a good example of contact between patient and professional.

“5 Moments of Truth” (*5 Momente der Wahrheit*) is an example of a practical quality system. Patients helped design a booklet about ambulatory care. Patients know what information they need and professionals know what information to provide.

A “Feedback Form” (*Rückmeldungsbogen*) is given to all patients who are asked to comment on and rate their experience. The results are centrally analysed and patients can leave their contact details if they agree to be contacted again.

The enabling factors are:

- * Legal framework;
- * Resources;
- * Education;
- * Value of data;
- * Open-minded attitude.

The barriers are:

- * Culture;
- * Expectations of patients;
- * Communication;
- * Bureaucracy.

HUNGARY

HOPE National Coordinator: Zsuzsanna Boros

Exchange Participants 2018: Fanny During (France)

Catherine Greffier (France)

Christoph Scherer (Germany)

Anna Vesper (Estonia)

Three good practices have been reported by HOPE Exchange participants in Hungary: *Integrated Legal Protection Service, Patients' Rights Act and patient education.*

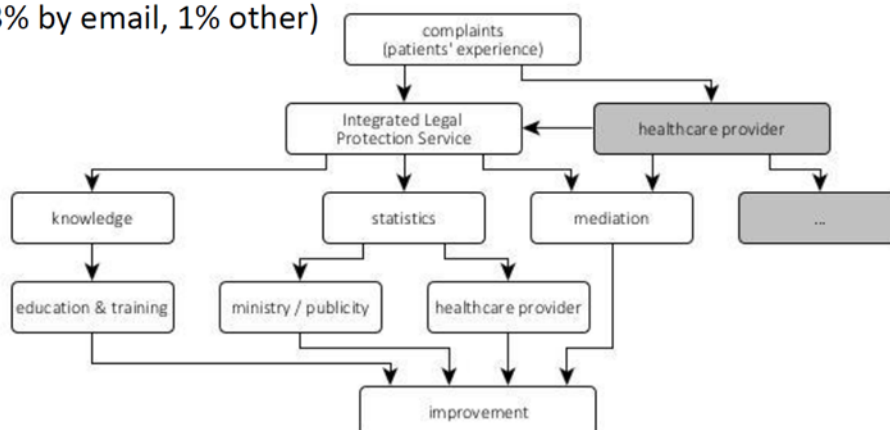
The Integrated Legal Protection Service was founded in 1999 and involves multidisciplinary staff members, regional offices and information centres. Its task consists in protecting the rights of patients; organising the work of rights representatives; providing information about health, social-care and welfare services; publishing the availability of the rights representatives at the service provider; training; performing tasks relating to integrated legal protection and intervening where necessary (requesting information, making suggestions and/or recommendations). In 2017, the Integrated Legal Protection Service reached 14,622 contacts (69% by phone, 17% by personal contact, 13% by email, 1% other).

The *Patients' Rights Act* was promulgated in 1997. With a universal and plain language text, it states patients' rights and health professionals' obligations. The Act states that patients are entitled to receive healthcare services and to be informed about their medical record and to privacy. Health professionals' obligations are to provide care and information, to keep record and to remain confidential.

Patients' rights

Integrated Legal Protection Service: Results

- In 2017, 14.622 contacts (69% by phone, 17% by personal contact, 13% by email, 1% other)



Ref.: <http://www.ijsz.hu/menupontok-2-5.html>



The first example of patient education was observed at Törökbálint Pulmonology Hospital. It involves improving the quality of life and self-care competencies of patients with respiratory diseases and improving socio-psychological competencies of patients and their relatives. The patient education is based on clear and repeated explanations in appropriate language. The aim is to involve patients and their families in the decision-making process.

A multidisciplinary team together with a patient education coordinator elaborated different programmes for inpatients and outpatients. Inpatients admitted to rehabilitation follow a 3-week programme of 50 minutes per day to improve self-care and healthy lifestyle. The sessions address illness-related knowledge, treatment management while providing psychological support, dietary support and promoting physical activity. Moreover, interactive training for using devices has been planned. The sessions may be individual or collective according to the patients' needs.

In addition, art therapy has been used as patient education tool: a 4-day programme including 2-hour workshop per day, a 2-hour of voice training and respiratory gymnastic session. Lessons are provided by a music professional.

Patient education projects result in better relationships between patients and health professionals, higher self-confidence on both sides and added value for patients and relatives.

The barriers to the involvement of patients in the country are: strong hierarchy; lack of human resources; resources unevenly distributed across regions; quality strategy and standards not fully implemented, and little national uptake of the prevention programme.

The factors that stimulate the involvement of patients are: strong motivation of health professionals; willingness of health professionals to work in interdisciplinary teams and readiness of patients to be more involved.

IRELAND

HOPE National Coordinator: Eamonn Fitzgerald

Exchange Participants 2018: Jasmin Hribar (Austria)

Anne Kanto-Ronkanen (Finland)

Gunilla Nordström (Sweden)

Grzegorz Piotrowski (Poland)

Sean Ritschard (Switzerland)

The initiatives that focus on patient involvement in Ireland reported by HOPE Exchange Programme participants were the *National Patient Experience Survey* and *Self-Management Programme for Chronic Diseases*.

Initiatives that focus on patients involvement

- ▶ National Patient Experience Survey
- ▶ Self Management Programme for Chronic Diseases
- ▶ ...and many more



The *National Patient Experience Survey* is aimed at collecting patient experiences of acute care in 40 hospitals across the country. The response rate was 50% and the results were used by the Health Information and Quality Authority (HIQA) for monitoring purposes. The initiative was duly promoted among patients, two weeks after their discharge.

Patients provided good feedback on: admission; care in the ward; examinations, diagnoses and treatments. Poor feedback was collected on discharge and transfer.

The fact that this initiative is nationwide shows great focus on patients' needs. The survey is not a tool to benchmark the outcomes of hospitals.

The *Self-Management Programme for Chronic Disease* was launched in 2017 and consists of an individual plan addressing the needs of the patients suffering from chronic diseases. Patients and their carers are at the centre of a network and their needs are addressed by GPs, health professionals or members of the community.

Our conclusion

- + nationwide
- + high focus on patients needs
- + not a benchmarking or comparing system for hospitals
- + feedback to hospital is easy because there is a certain distance

**«from what is the matter,
to discovering what matters to the patient»**

ITALY

HOPE National Coordinator: Amleto Cattarin

Exchange Participants 2018: Juan Manuel Gavala Arjona (Spain)

Dino Sarpi (United Kingdom)

Sabrina Wadel (France)

Cittadinanzattiva is the first good practice reported by HOPE Exchange Programme participants in Italy. Its main objectives are the promotion of civic participation and the protection of citizens' rights in Italy and in Europe. Composed of volunteers, lawyers and doctors, *Cittadinanzattiva* aims at enhancing patient empowerment and participation in decisions, has strong connections with Public Relations Offices (*Uffici Relazioni con il Pubblico - URP*) at the hospital level and is a member of Mixed Conciliatory Committee (*Commissione Mista Conciliativa*). The organisation promotes the [European Charter of Patients' Rights](#), agreed among diverse European Member States and stating 14 fundamental rights for patients. Moreover, it has a strong political influence on the public health agenda, since it takes part in national negotiations.

The second example reported is about [VaccinarSi](#), a campaign supported by the Italian Ministry of Health and developed with universities and medical councils, aimed at providing medical and scientific information on vaccines. The campaign was certified by the [Vaccine Safety Net](#) (WHO) and implemented to rebuild trust in vaccination programmes among the Italian population.

The participants also talked about the importance of volunteer associations working with hospitals in paediatric oncology wards. Further examples of this kind include patient associations participating in patient care and supporting families. They perform diverse activities such as: purchasing medical devices or financing hospital workforce by providing specific services (e.g.: psychologists, physiotherapists, social workers, etc.). Moreover, these associations support patients while they experience their conditions. An example of this kind is ANDOS, providing information to breast cancer patients on how to handle all aspects of their condition. Funds come from donations, contributions from members and state support.

The participants reported the example of long-term care settings (*Residenze Sanitarie Assistenziali - RSA*), where patients needing health and social care are admitted for longer stays. Patients, their families and health professionals all have online access to patient records.

The last example is telemedicine, which, in the Veneto region is based on the active participation of patients. More specifically, participants mentioned the day-hospital chemotherapy service which operates a home telemonitoring system provided by the "Breast Unit", a multidisciplinary department in the Integrated University Hospital of Verona.

LATVIA

HOPE National Coordinator: Evija Palceja

Exchange Participants 2018: Verónica García González (Spain)

Rainer Oberguggenberger (Spain)

Boris Selan (Slovenia)

Christina Simfeld (Germany)

Tula Maria Van De Sanden (The Netherlands)

PALDIES!



Veselības ministrija



In Latvia, the first solution reported by the HOPE Exchange Programme participants is the *healthcare chaplaincy*, a service provided by chaplains to ensure support to patients and families at delivery and maternity wards. This service was created to provide information that is owned only by clinicians. The chaplain represents the parents during meetings with multidisciplinary teams. He/she receives clinical practical training lasting from 3 to 6 months and holds a bachelor's degree in theology or religion. He/she takes care of patients' spiritual wellbeing, focusing on the experience of patients and family and contributing to improved treatment.

The *Parents' Board* is in charge of connecting families experiencing the same situation using a database. Information for other parents is provided on Facebook. The *Parents' Board* offers a consultancy service. This initiative has been strongly supported by the Communication Department, which also promoted the use of the *Paldies card* – allowing anybody to provide feedback, and the *Doctor Form* – allowing parents to enquire about their child's care pathway.

Through this interaction, parents' feedback has been taken into consideration to improve the website.

LITHUANIA

HOPE National Coordinator: Daiva Zagurskiene

Exchange Participants 2018: Isabel Casado Montañes (Spain)

María Isabel Romo Valdivieso (Spain)



The Lithuanian Diabetes Association (LDA) was founded in 1989 by Vida Augustinienė, President of the LDA and Board Member of the International Diabetes Federation in Europe. It participates in health policy making, ensuring that the voice of patients is heard. This is the first good examples reported by the participants at the programme.

“Society lacked information about diabetes, the disease frightened people. Nobody was defending the rights of the sufferers. Diabetes expanded unrestrictedly,” said Vida Augustinienė.

LDA was the first entity to talk about the impact of diabetes on society, allowing the Health Department to increase awareness about how patients cope with this disease. The association took part in the legislative process aimed at changing the law on patients’ rights; unifies the interests of diverse diabetes stakeholders (patients, families and health professionals) and seeks to improve diabetes monitoring; disseminates information to targeted audiences and general public; provides patients with social and psychological assistance.

The LDA's main achievements have been:

- * Obtaining funding for some conditions and medicines;
- * Increasing budget for regional hospitals;

- * Reducing GP waiting lists;
- * Obtaining funding for organising educational summer camps for diabetic children;
- * Organising training sessions for the World Diabetes Day.

The main barrier is related to the fact that common objectives and strategies shall be independent from political leadership.

LDA claims to increase funding for education programmes addressing people with diabetes; increasing salaries of health professionals and introducing insurance for patients who experience adverse events.

The second example is *Integrated Home Care* (IHC) covering both health and social care. The first pilot project was introduced in Birstonas and then extended to 39 municipalities. The project dealt with disabled and elderly people, their relatives and/or carers. IHC consists in providing social care for a certain number of hours and days a week, by a multidisciplinary team which is composed of a nurse, a nurse assistant and social workers. The initiative is funded by the European Social Fund, municipalities and national grants.

IHC strengths are preventing isolation; offering daily support to both patients and families/carers; preventing burnout in families/carers; providing additional services such as shopping, laundry, hairdressing.

The main barrier is the scarce dialogue between health and social care services that should become more patient-centric. Moreover, patients are often reluctant at first to adopt this new way of delivery care and they need time to adjust. To ensure affective uptake of this solution more staff, equipment, devices and digitalisation are required.

The Exchange Programme participants reported as a last example the case of Vilija Mirimavicienė, a patient who uses a wheelchair after a car accident. Vilija decided to share her experience with other people in the same condition, as she knew, that this would empower patients and help them to better adapt to their new situation. She collaborates with Palanga Rehabilitation Hospital as a patient expert, in a team composed of doctors, nurses, physiotherapists and occupational therapists. The service lasts 6 hours a day, for 5 days. The initiative is successful because the messages from the patient expert are more powerful for patients. She helps them to overcome the first reaction to the new situation, leading people towards independence and teaching wheelchair management. Vilija is in charge of organising leisure activities for the group twice a week and is a key support person for the rest of the healthcare staff.

POLAND

HOPE National Coordinator: Bogusław Budziński

Exchange Participants 2018: Pascale Demilecamps (France)

Pablo Garmilla Esquerria (Spain)

Liga Ose (Latvia)

Sussi Vestergaard (Denmark)

When patients and professionals are asked about how to improve healthcare, the answers provided will be different.

Is patient involvement about technological tools or human communication? The HOPE Exchange Programme participants state that patients' knowledge should be used to improve technology.

The three greatest advances in medicine correspond to antibiotics, anaesthesia and new technologies. The advantages of new technologies rely on their accessibility, efficiency and quality. Medicine would be more effective if technology were used since it represents a means to overcome barriers. The greater use of technology has its drawbacks: possible user dependence, resistance to change, low education levels in users, law, implementation costs and depersonalisation and security.

In Poland, a patient database exists at the local level, but it is not integrated nor enough accessible to patients. According to the HOPE Exchange Programme participants, patients and professionals have to be educated in the use of IT for better access. To achieve this, time and resources are needed.



hope
European Hospital and
Healthcare Federation



Lodz, Poland

Patient's involvement:

- Technologic tools?
- Human Communication?

Poland's team / Hope Agora 2018



A good example reported by the HOPE Exchange Programme participants is the *Dedicated Coordinator of Individual Cancer Care*. Patients holding the so-called oncological card are assigned a coordinator who takes care of all aspects of patient management, allowing the patient to focus on the most important thing – getting better. The coordinator schedules appointments for the patient, collects the medical documentation necessary for commencing therapy and oversees the schedule of treatments and additional tests.

Participants also mentioned a patient association dealing with patients who experienced laryngectomy and the effort made in establishing relations between patients and professionals. Furthermore, the association promoted the information sharing among patients suffering from the same illness. In Poland there are several patient associations that communicate directly with policy makers and professionals working at the hospital. In addition, regular meetings are organised to ensure equality and communication between patients and health professionals.

Communication between medical and non-medical/management staff and patients is key to patient involvement.

PORTUGAL

HOPE National Coordinator: Francisco Antonio Matoso

Exchange Participants 2018: Dejan Dobersek (Slovenia)

Vicente Guadaño Salvadores (Spain)

Petra Lindstedt (Sweden)

Erikka Mannila (Finland)

Christina Oestergaard (Denmark)

Vicki Turner (United Kingdom)

Sjoerd Van Huffelen (The Netherlands)

Bernhard Vester (Switzerland)

The HOPE Exchange Programme participants in Portugal reported two examples of patient participation, namely *integrated care for ventilated patients (CAI)* and *integrated care for premature babies*.

The CAI solution enables shared responsibilities among the professionals involved in the patient care pathway (physiotherapists, primary care and social-care professionals). Integrated care is based on three pillars: telemonitoring, telephone and home visits. Patient participation is facilitated by self-care at home, shared decision-making involving the hospital and community as well as proactive care planning. This combination reduces hospital stays and emergency admissions and increases social integration.

The second example reported consists of integrated family care for children aged 0-3 years by Os *Francisquinhos*, an association based on intradisciplinary teams providing home care to premature babies and their families. The association ensures connection with the community and the health system. The child's family environment is the most appropriate for an intervention, given the possibility of controlling a variety of fundamental factors in the process of child development, promoting the autonomy of the family which is actively involved in the decision-making process. The results include increased personalised care plans and integrated care; increased wellbeing of families and children; increased social integration.

The factors enabling the participation of patients and families are closely related to education and culture. Patients and families have to be motivated to take part in the decision-making process and information should be shared among clinicians, patients and families.

SERBIA

HOPE National Coordinator: Milos Bozovic

Exchange Participant 2018: Ksenija Kadic (United Kingdom)

In Serbia, the first good practice is an organisation providing support to people with alcohol addiction, where these people could share their experience. The focus is on strengthening the experience of the person as a way to overcome the problem. Further examples provided are patient associations where the so-called *experts by experience* support patients suffering from diabetes and cancer and their families and patient umbrella organisation. The National Association of Rare Diseases (NORBS) deals with challenges in diagnostic and quality of treatment.

NORBS – NATIONAL ORGANISATION FOR RARE DISEASES IN SERBIA

CHALLENGES

- Diagnostics
- Quality of Treatment
- Not being included in Healthcare



SOLUTIONS

- Rare disease Centres of Expertise
- Rare diseases registry
- Informing patients
- National strategy for rare diseases in Serbia



TO IMPROVE HEALTH AND QUALITY OF LIFE FOR PEOPLE WITH RARE DISEASES

The *House of Good Health* provides preventive services and free health checks. Moreover, patients and health professionals work together to organise educational courses aimed at promoting healthy lifestyles. Services have been set up in remote areas and interactive courses organised for the whole community. The *House of Good Health* also promotes discussion to define the public healthcare strategy, whose priorities focus on patient rights, strengthening community-based activities, developing personalised solutions and adopting an integrated approach to care.

An example of community health care is long-term care for people with mental illness. In Serbia, this has led to a reduction in hospital admissions where most patients are still treated.

The last good practice refers to *experts by experience* who define recovery programmes for people with addiction, which involve them, their families and the community. This is a key factor of success.

SLOVENIA

HOPE National Coordinator: Maja Zdolsek

Exchange Participants 2018: Irene Cubells Asensio (Spain)

Susan Jensen (United Kingdom)

Sofja Tomase (Latvia)

The HOPE Exchange Programme participants reported EkoSmart as main good practice – an EU-funded programme to develop a smart city ecosystem in three domains: health, active living and mobility. Emphasis is placed on electronic and mobile health as one of the pillars of smart cities.

EkoSmart uses technology as part of Internet of Things with a focus on patient-centred care. The programme has introduced an initiative to promote the use of telemedicine for patients suffering from chronic conditions. The service is based on remote diagnostics monitoring involving a community nurse who communicates with the patients through e-care services. It empowers patients through enhanced self-care; applies integrated care models for chronic patients and reduces or avoids hospital stays. Through ICT infrastructures, EkoSmart supports all-round communication among health professionals, patients and social care professionals.

Patients' experience is used in *patient councils* and *volunteer organisations*. With the introduction of patient councils, admissions to outpatient facilities have increased while volunteer organisations provide support services to patients and families.

Patient education has been introduced in diverse fields. In gerontology, multidisciplinary teams of experts organise workshops or social events to train attendees on fall prevention, ageing without addiction, chronic disease and violence prevention. A further example of patient education regards cystic fibrosis. Once diagnosed, parents are taught how to manage the disease and adapt the family lifestyle. Regular meetings with patients, families and clinicians are organised until the patient reaches the age of 19. Postnatal family education is aimed at recognising when problems could be solved at home or care provided by a doctor is required.

Patient involvement in treatment requires two-way information: from patient to clinician and from clinician to patient. Two such examples regard patients at a psychiatric hospital, actively participating in their rehabilitation and patients managing their chronic conditions through the EkoSmart programme.

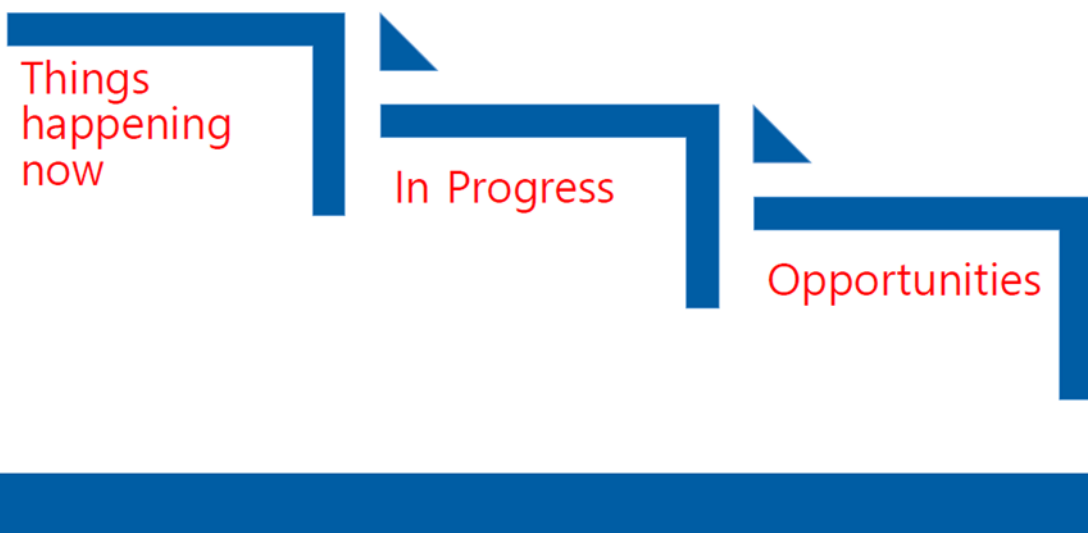
The following are further initiatives are in progress:

- * Model practice (community nurse focused on promotion and prevention);
- * National diabetes plan development;
- * A traumatic care development in paediatric departments;
- * Prems & Proms (national repository of patient-reported experiences and outcomes, for proactively identifying vulnerable patients).

In Slovenia there is room for improvement, according to the HOPE Exchange Programme participants. To date, patients are not motivated in engaging in their own health care. Furthermore, patients' satisfaction is monitored by central government, limiting direct patient feedback and the legislation on long-term care is still ongoing.

"Small things can be changed with big impact on patient experience and where possible, the patient's life stays bigger than the disease."

Outline



SPAIN

HOPE National Coordinator: Asunción Ruiz de la Sierra

Exchange Participants 2018: Hélder Amorim (Portugal)

Marco Artico (Italy)

Harold Astre (France)

Ida Agnete Dalsjö (Denmark)

Miguel Fausto Da Costa (Portugal)

Ieva Lejniece (Latvia)

Teresa Luciano (Portugal)

Nikoleta Mougolia (Greece)

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Nicola Seanor (United Kingdom)

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In Spain, the HOPE Exchange Programme participants found three good practices in patient involvement.

- Three themes explored around patient experience in healthcare in Spain:
 - ▣ Hospital at home
 - ▣ Active Patient
 - ▣ Co-production of service with the patient

- Key conclusions (and are we ready...?)

The first is *hospital at home*, an outpatient service performed by a hospital team. In this model, the family competencies are used to enhance patient care, in the comfort of their home. This is a patient-centred care service, representing a sustainable alternative to inpatient care. The patients are very satisfied as they receive the same health service as they were in hospital.

However, not every patient can receive such services; some patients live too far away from the hospital and caregivers may lack specific competencies.



The second example reported is the *Active Patient Programme*, whose objectives are to create an equal collaboration between patients and professionals and to support patients in sharing knowledge and learning from each other. The programme is based on the Stanford/Albert Bandura model. It consists of a self-management group education programme and peer support and is aimed at supporting patients in effectively managing their own care. Different approaches adapted to different settings have been implemented in the diverse autonomous communities.

Despite a global strategy, the initiative has not been fully implemented. Moreover, the programme requires strong coordination between agency and a strong motivation on the patient side.

The third good practice is a project started in 2018 called “Let’s Have a Coffee” (*Vamos a tomar un café*), involving the inpatient department director, chief nurse and patient. The objective is to promote an informal discussion and to learn about the patient experience in order to improve and develop the delivery of care. To make this project successful, a new mindset is needed. Limitations are patient selection and preparation.

According to HOPE Exchange Programme participants, Spain is not yet ready, but the country is moving in the right direction. Patient collaboration and improvements to patient experience should be a core focus for projects. This kind of practice should be rolled out nationally; and monitored, evaluated and researched centrally.

SWEDEN

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The three good practices implemented in Sweden and reported by HOPE Exchange Programme participants are: *patient-centred care in cardiac ward*; *improving life for elderly* and *patient self-dialysis*. The first two have been implemented in the Region of Kronoberg and the third in the Region of Gävleborg.

ARE WE READY...

...LET'S TALK ABOUT

1. PATIENT CENTERED CARE IN CARDIAC WARD
2. IMPROVING LIFE FOR THE ELDERLY
3. PATIENT SELF DIALYSIS
4. TAKE HOME MESSAGE

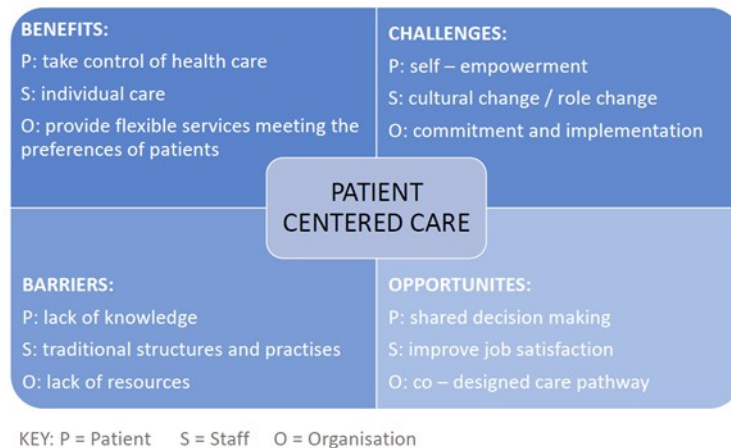
Patient-centred care in the cardiac ward is performed through pulse and collaborative meetings. Pulse meetings are held every day to ensure effective communication between professionals and patients while collaborative meetings, which take place in a collaborative room, involve patients in setting out their care pathway. These are patient-centred solutions where patients become decision makers. The focus is on patients' needs, not only on the diagnosis. This partnership increases autonomy and supports patients in coping with their condition at home, while reducing hospital readmissions.

The evaluation methodology of patient-centred care in the cardiac ward is based on patient surveys and focus groups with professionals. Patient surveys showed an improvement rate in their satisfaction, ranging from 5.18 to 5.55. Focus groups showed an improvement in terms of coherence, affinity, long-term planning, patient enrolment and satisfaction. The challenges relate to traditional structures, organisational and educational factors.

The practice *life improvement of elderly people* focuses on the fact that elderly people have different problems and needs. It consists in listening to them and involving health and social-care professionals. The needs of the individual precede the obstacles in the organisation, and the contribution of social and health care professionals is coordinated to create added value for the person. Professionals meet patients individually to ensure that they feel safe and involved. In this way, the elderly are able to access tailored and flexible care, while feeling involved.

Patient self-dialysis relies on an agreement by the patient to undertake the treatment by himself/herself. The practice is subject to a continuous evaluation process. According to what has been observed by HOPE Exchange Programme participants, it has led to ownership, control, more responsibility and improved quality of care.

The conclusions on patient-centred care practices in Sweden are shown below.



SWITZERLAND

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The HOPE Exchange Programme participants in Switzerland stated that the healthcare professionals involved in the process of care shall put the patient at the centre. They also stated that in Switzerland this happens. Patients are seen as clients. They also observed that between professionals and patients there is respect. Wishes are not always easy to handle, but patients are allowed to have a say in their treatment. A practical example consists of *palliative care*.

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2002).

The HOPE Exchange Programme participants reported the example of the ABC concept (Advance care planning, Best care for dying, Community involvement) introduced at the Hospital of Bern. This is based on providing support to patients who have decided to end their life and is based on anticipation, reducing fears and increasing competencies of professionals. Patients are asked what makes them suffer the most and what competencies are needed for which problem. Professionals are trained to handle this critical situation.

A further example reported is the *SENS approach* (Symptom management; End of life decision/preferences; Network/emergency organisation; Support of the carers) also adopted at the Hospital of Bern. The unit that introduced this approach uses a multidisciplinary team providing healthcare services but also counselling, pastoral care, physiotherapy and music therapy. The team is supported by volunteers who create a link with the professionals involved in the care process and who help create warmth and humanity in the ward.

The barriers to implementing these practices include: the system, which in Switzerland is fragmented into regions, the community and the hospital; a lack of resources; the attitude of families, the politicians, society and professionals' ideas toward this topic; the family network.

The conclusion is that patients and relatives' empowerment would save resources, increase quality of life, put more focus on patients and increase health professionals' satisfaction.

THE NETHERLANDS

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Anne Herbrich (Germany)

Lea Kalda (Estonia)

Fiona Langworthy (United Kingdom)

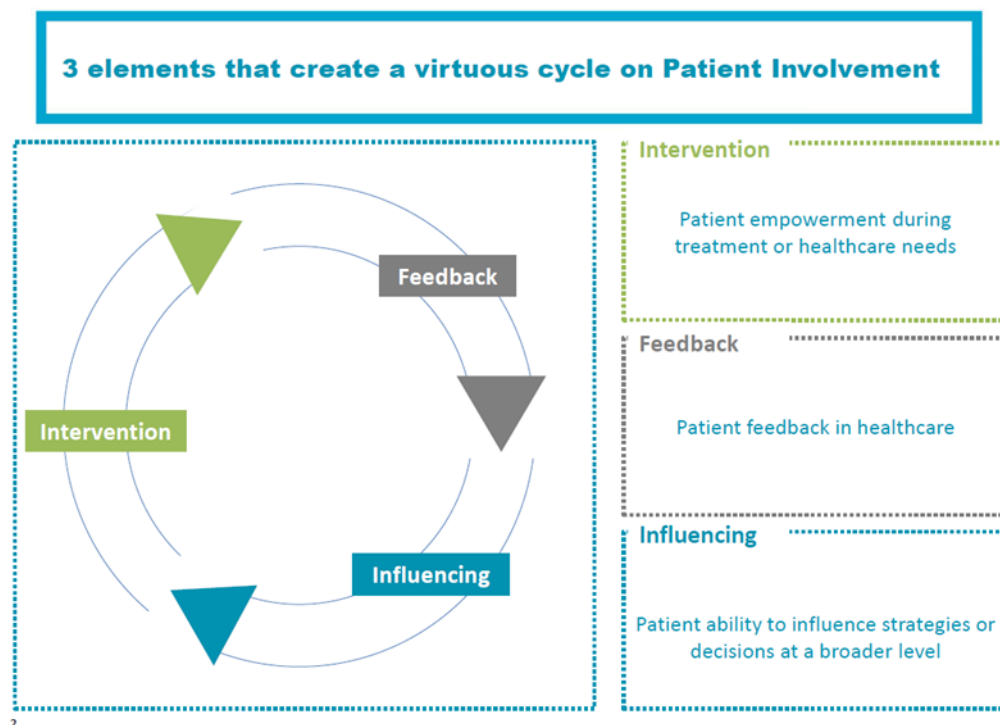
Pirjo Lehtomäki (Finland)

Cecilie Heerdegen Leth (Denmark)

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Patient involvement can be defined several ways, but a common definition is the involvement of the patient in decision-making or expressing opinions about different treatment methods, which includes sharing information, feelings and signs and accepting health team instructions.

The HOPE Exchange Programme participants in the Netherlands stated that there are three elements creating a virtuous cycle on patient involvement. These are: patient empowerment during the treatment or during the identification of healthcare needs; patient's feedback and patient ability to influence strategies or decisions at a broader level.





The first good practice reported was the *peer support* for patients undergoing surgery. As part of the patient pathway a meeting is organised with a former patient before and after the surgery, at the patient's home. This practice has improved the recovery phase.

The second example is the *mirror conversation*, consisting of appointments with discharged patients and professionals to identify action plans for improving departments. Professionals are asked to put themselves in the patients' shoes.

Lastly, the example of *patient councils* was reported. Since 1996, every hospital has had one, and they advise care providers on budgets, policy and quality. A council meets the board regularly, which must follow the council's advice unless for justified reason. The council engages with patients' organisations and is based on voluntary membership.

The participants took the example of a patient council participating in the design of a new and more comfortable waiting area at a breast cancer unit. Further examples include: relocating some care from one hospital to the other; developing nutrition plans with patients; rescheduling visiting hours.

The so-called *Low Literacy Programmes* have been introduced to deal with low literacy, which leads to low health skills. These programmes help patients to be better informed and more able to be involved in the decision-making process. Some hospitals have improved their websites and brochures with plain language and more illustrations. Other examples are communication training by experts and awareness campaigns to detect low-literacy.

According to the HOPE Exchange Programme participants, the Netherlands is ready to improve the quality of healthcare using the experiences and competencies of patients.

UNITED KINGDOM

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Andrea Wenighofer (Austria)

The first example reported by the HOPE Exchange Programme participants in the United Kingdom was the *co-designed pathway*. Clinicians, nurses, managers and patients come together around a table and discuss every single step a patient has to take when they go for their treatment. It starts at home. When the patient gets to the hospital, they have to find the right room at the right time, they have to receive their treatment and after that they have to go back home safely. The co-designed pathway is a very patient-centred process. By asking specific patient groups about their experience during treatment, patients can co-design new pathways to ensure safe procedures. Sometimes there are patient experience teams which make sure that the hospital staff focuses on the patient's view because in the end the resulting pathway has to be as convenient for the patient as the financial and clinical restrictions allow. The co-designed pathway of care allowed the hospital to acquire useful information to better organise the provision of healthcare services and the patient to be closer to home.

The second good practice presented was the *Friends and Family Test (FFT)*, aimed at collecting feedback through a survey after the patient is treated at the hospital. The FFT has produced 45 million pieces of feedback so far. Every month this figure rises by 1.2 million, which makes it the biggest source of patients' opinions in the world, according to the HOPE Exchange Programme participants. The FFT reports that 9/10 people in England would recommend the services they receive by the NHS to their loved ones. The FFT gives the hospital the opportunity to identify areas of improvement and to improve healthcare together.

The *Patient Champion* was the third good practice identified by the HOPE Exchange participants. The Patient Champion is appointed by the department of health with the aim of building meaningful and continuous relationship with the staff, the patients and the public. The main objective is to shape services and to make improvements together. A concrete example is a campaign to promote hand hygiene among health professionals and in turn to reduce MRSA.

A further example reported is the *volunteers*, who are mainly former patients willing to provide different unpaid services within an acute care trust. The hospitals visited by the HOPE Exchange participants have treated 300 and 700 volunteers respectively. Volunteers can take up different roles: they feed patients, they listen to them, they provide fun activities for children and they may even ask the patients if they can pick them up from home.

The *Older People Emergency Department* is rather innovative and was created thanks to patients' feedback. The approach is holistic and the patient gets in touch not only with clinicians and nurses but also with other professionals such as physiotherapists, occupational therapists and pharmacists. The process is patient-centred and when a patient gets to the emergency department, they get a comprehensive geriatric assessment. This has led to 15% fewer hospitalisations.

According to the HOPE Exchange Programme participants, the United Kingdom is ready to improve the quality of healthcare using the experiences and competencies of patients.

Patient Involvement

The NHS Belongs to the People



'No decision about me without me'





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HOPE represents national public and private hospitals and healthcare associations, national federations of local and regional authorities and national health services from 30 European countries.

HOPE mission is to promote improvements in the health of citizens throughout Europe, high standard of hospital care and to foster efficiency with humanity in the organisation and operation of hospital and healthcare services.