EPF CONFERENCE "PATIENT AND FAMILY EMPOWEREMENT FOR BETTER PATIENT SAFETY"

Conference Report

08-09 November 2016
Hotel Bloom, Brussels

10/01/2017

Contents

1 Introduction 3

2 Setting the scene 4

2.1 Welcoming words 4

2.2 Why patient empowerment matters in patient safety 5

2.3 Key points from the discussion 6

3 Challenges to patient empowerment in patient safety 7

3.1 Overview of main issues and Challenges 7

3.2 Case study: patients advocating for safety 8

3.3 Key points from the discussion 9

4 Parallel workshop sessions 9

4.1 Workshop 1: Patient empowerment in acute settings 9

4.2 Workshop 2: Patient-professional communication as a critical safety factor 12

4.3 Workshop 3: Patient and family involvement in the aftermath of incidents 14

5 Developing core competences for patient and family empowerment 16

6 Closing plenary: Looking forward 18

6.1 Patient safety should remain an ongoing priority at eu and national levels 18

6.2 A perspective from the oecd 19

6.3 Closing of the conference 20

1 Introduction

Patient safety has been a priority for EPF since the founding of our organisation. Patients have a fundamental right to expect their care to be safe. The topic is at the heart of our advocacy work for equitable access to high-quality, patient-centred healthcare across EU.

EPF has for many years participated actively in policy-making and initiatives at European level. We have been members of the European Commission's Expert Group on Patient Safety and Quality of Care since 2008, we contributed a patient perspective to the Commission Communication in 2008 and the subsequent Council Recommendation in 2009 – which still remains the main reference point for EU policy. The latter contains a special chapter that requires Member States to inform and empower patients and citizens, and to involve patient organisations in the development of policies and actions at national level. The EU directive on cross-border healthcare has more recently introduced specific requirements for patients to have access to information about the safety and quality of care.

However, despite this activity, improving the safety of healthcare remains a formidable challenge: healthcare-related adverse events occur in around 8-12% of hospitalisations, and a 2006 Eurobarometer survey showed that 23% of respondents had been directly affected by medical error, 18% had experienced a serious error in a hospital, and 11% had been prescribed the wrong medication.[1]

Could patient and family empowerment help improve these figures? Little attention has been paid to date to the role of patients' and families' involvement and empowerment in patient safety. To ensure care services are designed around patients' needs, meaningful patient involvement is necessary at all levels in the system. At the same time, in the area of safety, there are specific challenges that need to be addressed.

The objectives of the conference were therefore to:

- raise awareness across the EU Institutions, Member States and stakeholders about the link between patient safety and patient empowerment;
- provide a platform for discussion of specific issues regarding patient empowerment in the context of safety from a number of different viewpoints;

[1] Special EUROBAROMETER 241, "medical errors", European Commission, January 2006: http://ec.europa.eu/health/ph_information/documents/eb_64_en.pdf

- identify knowledge gaps and opportunities for further study;
- take the first steps towards developing a set of 'core competencies' for patients and families in the area of patient safety, thus supporting the implementation of the EU Council recommendation on patient safety (2009).

The multi-stakeholder conference took place over one and a half days and was conducted in English. It was structured around thematic plenary sessions and debates with the audience, as well as parallel workshops, followed by a closing plenary which presented the key conclusions and proposals on the way forward.

This report compiles the presentations and debates made during the conference in a summary form. The full versions of the various presentations can be found on the EPF website at http://www.eu-patient.eu/Events/past-events/epf-conference-on-patient-and-family-empowerment-for-better-patient-safety2/

2 Setting the scene

2.1 WELCOMING WORDS

Robert Johnstone, EPF Board member, welcomed the conference participants, stepping in for EPF President Marco Greco who was unable to attend. He started by giving an overview of the data on medical errors and other adverse events. A Eurobarometer survey in 2014 showed almost one third of respondents had experienced an adverse event while receiving healthcare. Almost half of those people had reported the incident. Unfortunately, the most common response was that nothing happened; only one in five had received an apology; fewer still had received an explanation.

Clearly, such figures can seriously undermine patients' trust in the healthcare system.

Robert also referred to a literature review done as part of the EU Joint Action PaSQ[2] , which estimated that 44% of complications due to adverse events in hospitals may be preventable. Preventable adverse events are leading causes of illness and death worldwide, and translated into money would account for a cost of about €13.7 billion.

He then went on to show how patient safety fits into EPF's priorities and work plans.

Patient safety is at the heart of our work plan 2015-17, closely linked to quality of healthcare. Quality of healthcare is a 'hot topic' at the moment, as the European Commissioner for Health has been mandated to set up a framework for assessing the performance of EU health systems. EPF is closely following these debates and calling for a patient's perspective to be at the centre of EU policies on quality of care.

Without specific focus on patient safety, aside from asserting the patients' fundamental right to safe care, EPF wanted to take the opportunity of our autumn thematic conference 2016 to remind policymakers of the vital role that patients and families can play in improving safety.

[2] www.pasq.eu

2.2 WHY PATIENT EMPOWERMENT MATTERS IN PATIENT SAFETY

Robert Johnstone, EPF Board member

Robert Johnstone then proceeded to give the keynote speech of the session. He started by reminding participants that the Alma Ata Declaration issued by the World Health Organisation (WHO) in 1978 stated that: "*The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare.*" The EU member states declared in 2006[3] that they regarded patient involvement as a common operating principle in the health systems of the European Union. However, Robert reminded the audience that today this is still not the patient's experience on a daily basis as the patient role is still in a transformative phase.

There is a need to change attitudes and move healthcare systems towards making patient empowerment a practical reality for all.

Patient empowerment is "*the right thing to do*". But it also brings concrete benefits. Healthcare systems face challenges relating to chronic disease, ageing and technology, and there are also financial constraints – the so-called sustainability challenge. Far from being cost drivers, evidence shows that empowered patients are part of the solution for sustainable, patient-centred healthcare systems.

Aspects of empowerment

Patients' organisations see patients as "co-producers" of well-being, not just of better health. The notion of well-being (which is reflected in the WHO's definition of health[4]) also encompasses self-awareness, confidence, health literacy and the coping skills to manage the impact of illness in everyday life. Therefore, empowerment can also increase the patient's capacity to act on life issues outside the health arena. It implies being recognised by health professionals as a key partner in care, but it does not mean shifting responsibility onto the patient inappropriately.

Patients can help improve safety

Patient safety is at the heart of healthcare. Patients, as primary users of the system and the ones experiencing the "whole journey", should be involved in the assessment of the system as their contribution would prove to be very valuable to identify gaps, failures and merits, and to design services that meet their real needs. Patient experience is not limited to patient satisfaction surveys, and it serves as a signal to realise what is actually occurring (both good and bad) in the system. So there is realisable value in involving patients in the assessment, planning, designing, implementation, continuous evaluation and improvement of healthcare systems.

In order to achieve this involvement, patients need support and empowerment. In this regard, health literacy is a key aspect of empowerment. Health literacy is not just about information but also about an individual's capacity to access, understand and evaluate information, and take meaningful decisions concerning their health. Health literate patients, in turn, need professionals with the right

[3] Council Conclusions on Common values and principles in European Union Health Systems, 2006 (2006/C 146/01): http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF

[4] "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (Preamble to the Constitution of the WHO)

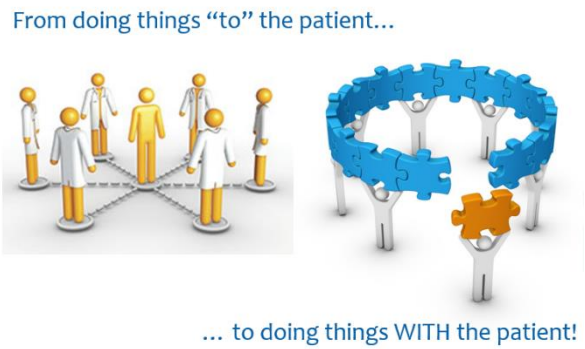
skills and attitudes to support their decision-making. Patient organisations could play a distinctive role by informing and educating both patients and health professionals.

What more needs to happen

Robert reiterated EPF's view that patient safety must remain a specific priority area within the European health policy. Studies show that on average more than 50% of EU citizens think that patients could be harmed by hospital care, and 91% of stakeholders think patient safety is an issue[5]. That means that there is still much to be done and EPF will keep working with the European Commission and other international organisations and stakeholders towards continuous improvement.

On a fundamental level, a culture change is needed so that healthcare is designed around patients' needs and with their active involvement. Empowered patients are still seen as a threat by some health professionals and they are not recognised as experts in their care.

> *"To make empowerment and safety a reality, care has to be designed around patients' needs, as only the patient sees it as it really is."*
> Robert Johnstone, EPF Board Member



2.3 KEY POINTS FROM THE DISCUSSION

- **How to empower patients to deal with the large amount of information available online?** Some of the participants considered the large amount of information an important barrier in that patients can find it difficult to judge what is good quality and trustworthy information. For others, the internet is a crucial resource in their daily lives, as sometimes they can get there more information than from a clinician, and it also gives patients access to first-hand experiences from other patients with a similar condition. Patients need tools and resources to sort good information from bad. Some participants considered this a promising area for collaboration between patients and healthcare professionals.

[5] European Commission infographic, 2014

3 Challenges to patient empowerment in patient safety

3.1 OVERVIEW OF MAIN ISSUES AND CHALLENGES

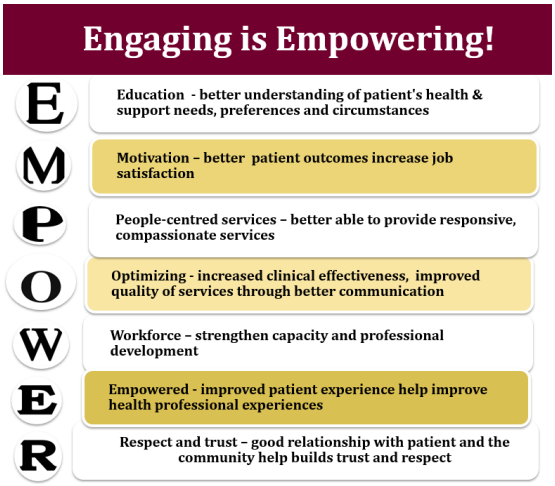
Nittita Prasopa-Plaizier, WHO Patient Safety Programme

In her presentation, Dr Prasopa-Plaizier emphasised that while there are several challenges in this area, there are also many opportunities.

In 2004, patient safety and the need for improving it appeared for the first time on the global agenda. This led first to efforts to analyse and estimate the actual burden of patient safety. Studies and reports showed different results, but on average it can be said that 1 in 10 hospitalised people are harmed by the system.

She also recognised that empowered patients can make a difference in reducing the above-mentioned burden, and their involvement will not only improve health and individual outcomes but will also help to lower healthcare costs.

> *"Patient safety is not only about being at the hospital. We should also engage not sick people and those who leave the hospital and go to the community."*



Regarding the challenges of patient safety, Dr Prasopa-Plaizier structured them as follows:

- Health literacy, which involves both rights and responsibilities of patients, is about awareness, knowledge and perception; three skills that can change health-seeking behaviours, improve the access and use of care and services, and involve patients in decision-making and self-management processes.
- Capacity and skills for engaging: from patients to tell their story, from health professionals to involve patients and families in their own care, from the community to raise awareness about how the health system works.
- Healthcare systems face new challenges: emerging demands (unhealthy lifestyles, aging populations, multimorbidity, increasing wish of patients to self-manage their care), system constraints (finances, lack of engagement, hierarchical workforce, weak delivery models) and a slow pace towards universal health coverage.

- Creating an enabling environment for engagement: cultural and societal barriers influence health literacy and people's ability to engage. Institutions and organisations have the means to facilitate the engagement and empowerment of patients, families and communities. Through training, good practices and cultural change, a proper environment could be created in order to improve the effectiveness and responsiveness of the systems.

How to improve Universal Health Coverage

According to the WHO, Universal Health Coverage means "*ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.*"[6]

A strong primary healthcare is key for achieving quality universal health coverage, and engaging the community can also help. The community plays a crucial role in raising awareness, reaching vulnerable populations, helping the system to better understand people's situations and needs, and to adapt services to cultural preferences.

3.2 CASE STUDY: PATIENTS ADVOCATING FOR SAFETY

Antonio Ciaglia, Policy Manager, International Alliance of Patients' Organizations (IAPO)

Antonio, representing IAPO – which is EPF's "sister organisation" working on a global level–, highlighted that to improve patient safety, it is very important to promote patient-centred healthcare around the world and engage with international institutions.

Patient safety is at the core of the healthcare system and the key challenge is to make sure that patients can take ownership of their condition. In this regard, patient organisations have a crucial role to play in empowering patient communities two enable them to act as equal partners in decision-making processes. One of the ways to do so is by developing an ability to critically evaluate the quality of information they get, as this is a starting point to take the right health decisions.

Pursuing patient engagement at institutional level

Institutional engagement and capacity-building are very important to improve patients' and patient organisations' ability to play a leading role.

IAPO has been active in the WHO programme Patients for Patient Safety (PFPS), launched in 2005. Guided by an advisory group made up of patients, the programme aimed to incorporate the patient, family and community voice into all levels of healthcare through engagement and empowerment. It uses patient experiences as a learning tool, and their stories have become an invaluable resource for learning.

[6] http://www.who.int/health_financing/universal_coverage_definition/en/

"Patient Safety Champions", active in the WHO programme, are able to represent the patient voice before relevant stakeholders and organisations. They can be powerful advocates, using the specific skills and expertise developed through the experience of being patients.

The challenges for patient organisations are to build credibility; to bridge the gap between representing a plurality of voices of patient communities and speaking with one, strong voice; and to unify the way in which patient safety is defined, measured and evaluated.

Patient organisations – and in particular umbrella organisations – can do a lot to identify areas of action and to enable and facilitate interaction among individual patients, patient safety champions, and institutions.

3.3 KEY POINTS FROM THE DISCUSSION

- **Definition of "patient champion":** a patient champion, or patient advocate, can be a patient or someone familiar with the situation and condition of patients. The champion does not need to be a professional, but s/he should have specific skills, including the ability to communicate and drive the credibility of the cause s/he is defending. It is also important to realise that s/he is representing a whole community and not only her/his own interest or disease. A patient advocate representing a patient organisation is mandated by her/his membership to represent patients. Patient organisations have an important role in providing training to patients interested in doing advocacy work.

4 Parallel workshop sessions

The afternoon of the first day of the conference closed with three parallel workshops, which addressed key aspects of patient and family empowerment and involvement in patient safety. The topics for these workshops were selected based on discussions in the EPF working group on patient empowerment and the fact that they have been little discussed in the past.

4.1 WORKSHOP 1: PATIENT EMPOWERMENT IN ACUTE SETTINGS

Facilitator: Dr Nicola Mackintosh, King's College London
Rapporteur: Tessa Richards, Senior Editor/Patient Partnership, BMJ

The workshop started with an overview about the Patient Partnership initiative launched by the British Medical Journal (BMJ) in 2014. The initiative has seen the journal move to co-produce its content with patients and advancing international debate on how to embed meaningful partnership with patients in clinical practice, service delivery, research, education, and policy. Tessa Richards highlighted that patients' comments are very insightful and helpful for the authors to widen their views on safety and care.

Nicola Mackintosh presented key findings from a UK research project examining care of acutely ill patients in medical and maternity settings. (See presentation.) She emphasised that lay expertise could be the backbone of patient safety, especially in acute illness: patients often sense intuitively that something is wrong before physical or clinical markers manifest themselves. However, their concerns are often not taken seriously or they are afraid to speak up. This disconnect is problematic.

The group then split into small groups of 3 to 4 persons to discuss. Questions included the following:

- What changes are needed at system level to enable staff to be responsive to patients' concerns? What are the barriers?
- How can we support patients to freely voice concerns in a meaningful and supportive way?
- What tools, including digital interventions, can aid sell surveillance and self-diagnosis? How might they address power differences?
- Any other issues.

Language was identified as a major barrier. Aside from the gap between medical and lay language, different languages are a concrete issue in many cases, even if translators are sometimes available, especially in cross-border healthcare contexts. Lack of clarity or explicit policy in communicating with patients on the part of the healthcare organisation, and staff members' fear of blame, were also identified as barriers to engagement.

Resources are a perennial problem: there is a lack of sufficient staff, who at the same time often have poor morale. On the organisational side, it was noted that there are few incentives to promote continuity of care; and on the legal side, professionals often fear blame and litigation as a result of errors. Feedback is not currently embedded into the system, and the "blame culture" needs to be opened up. Transparency, the group felt, is conducive to trust.

Culturally, patients and carers are still not seen as a resource for improving the quality, safety and sustainability of health care. Health professionals are not trained to work in partnership with patients. Technology is often not well used, for example in hospitals where health records are not integrated and the system is still paper-based.

Information for patients is usually focused on warning signs that patients should be looking out for, but in real life symptoms often manifest themselves in a different way. Thus, focusing on warning signs could paradoxically hamper proper communication. Patients often do not want to disturb border healthcare staff, especially knowing that staff are under pressure.

Responsiveness of the system is not routinely measured: there needs to be a reflection on what kind of measures would be appropriate. For example, patients could be asked: "did you feel safe?" Or "what happened if you raised concerns?". In terms of prevention, it's important that patients and families know that they may have an intuitive feeling that something is wrong and in that case it is okay, and even welcomed, that they speak up. Health professionals inter need to also know about this and respect that patient intuition.

The issue of health professionals' empowerment was also raised – professionals should feel confident that they can speak up on their concerns and tell others for example if they do not feel safe working in a certain way, without fear of reprisal.

Patients can be supported to voice their concerns by making it easier for them (by providing accessible tools they can use). In Bulgaria there is an online patients and doctors' platform that functions as an open space for feedback and dialogue. It must be possible to give feedback anonymously, and the environment surrounding the patient should be conducive for providing feedback.

Education and training should be reviewed to integrate a greater focus on ethics and emotional intelligence. Health professionals should also get training on how to communicate with patients in a clear and understandable way, and on how to empathise with patients and their concerns.

Fundamentally, a cultural change is needed so patients are seen as "part of the team" and as a valuable resource in healthcare.

Regarding technology, the group felt that observational devices and remote monitoring technology could be helpful, for instance for diabetic children, allowing them to "still be kids". The electronic health record that patients can carry with them and update in real-time, is a key tool to support empowerment. This could be available as an app. Other portable digital tools that the patient can update in real time could be useful to support continuity of care, for example when transitioning between chronic and acute care.

The idea of creating a paid job-role for patients with chronic conditions with experience of navigating the system was proposed. They could act as informal coaches/advisers for patients providing peer support as part of the primary care team. This is already being done quite successfully in some hospitals in the US.

The group's key recommendations were as follows:

- Co-produce new metrics and performance indicators of quality of care with patients, including timely and appropriate response to patients' concerns.
- Use the potential of technology (such as integration of medical records, shared digital platforms, patient hotlines for timely exchange). Full electronic medical records should be shared with patients.
- Hospital boards, medical meetings and committees which determine policy and practice on patient safety should include patients.
- Medical education programmes need to include a focus on how to listen to patients, empathise and work in partnership with them.
- It was suggested that all hospitals should have a patient ombudsman. This is the case in some hospitals in some countries, but not yet fully implemented.
- Patients also welcomed a way to report their experiences, both positive and negative, for example through a "hotline". This could be a valuable learning resource.

- Encourage and support patient-led innovations, such as #hellomynameis.[7]

4.2 WORKSHOP 2: PATIENT-PROFESSIONAL COMMUNICATION AS A CRITICAL SAFETY FACTOR

Facilitator: Ove Gaardboe, Danish Patient Safety Association
Rapporteur: Katharine Wheeler, Lupus Europe

Ove Gaardboe kicked off with a presentation on the project "Hello healthcare", a Danish example about how to improve patient safety through engaging patients and family and by breaking down structural barriers. Within the project, a toolkit has been developed with suggestions and questions for patients to be used during their healthcare experience. The toolkit is given by health professionals to patients and shows the willingness of the staff to be evaluated and, above all, invites patients to engage with them.

Good communication between staff and patient – besides being the decent and right thing to do – improves safety due to fewer ordinary errors, such as incorrect medication, but also fewer "silent misdiagnoses"[8]. The latter is particularly an issue at the end of life: Ove showed that a third of patients are given treatments that are not beneficial for them, and according to one study close to 70% of physicians' orders of highly interventionist treatment such as intubation and administering CPR were not concordant with the patients' wishes. (See presentation.)

Katharine Wheeler then shared her own story with the workshop participants. She explained her experience living with a collection of auto-immune diseases and how long it took for her to have the right diagnosis. In short, she shared a message about the importance of patients speaking up about their symptoms, and the need for healthcare professionals to listen to the patient and think out of the box. (You can read the whole Katharine's testimonial here, on EPF Blog.)

The group then moved on to discussion. They focused on the following questions: Are there some situations where patient-professional communication is particularly critical to ensure safety? What are the current barriers to effective patient-professional communication? What is the role of different actors such as healthcare professionals' organisations and patient organisations?

[7] The #hellomynameis campaign started in 2013 by Kate Granger, a patient with cancer, to encourage healthcare staff to introduce themselves to patients after she observed that many healthcare professionals did not introduce themselves to her. More information at http://hellomynameis.org.uk/

[8] The silent misdiagnosis refers to the fact that patients' preferences are often not taken into account in treatment decisions; and whilst medical misdiagnosis is error recognised safety issue, preference misdiagnosis is not. The authors of a 2012 paper on this topic argue that if patients had their preferences taken into account, based on full information and weighing of the treatment options and their evidence-base, likely outcomes for the individual, etc. they would not only be more empowered and happy, but would also contribute to the sustainability of healthcare because patients, when involved fully, have been shown to prefer less interventionist approaches. ("Patients preferences matter. Stop the silent misdiagnosis" by Al Mulley, Chris Trimble and Glyn Elwyn, The King's Fund, 2012)

The participants felt that perhaps the primary question should be turned on its head: are there any situations where patient-professional communication is *not* critical? This neatly encapsulated the importance of communication for a safe healthcare environment. Participants noted the importance of effective communication between the members of the healthcare team, but felt the patient/family should be included in the concept of "the team".

"Are there any situations where patient-professional communication is not critical?"

However, certain critical points can be identified: point of transition or handover from one healthcare environment to another (for example between hospital and primary care, between specialists, discharged to home care or rehabilitation…); any points where decisions need to be made, such as diagnostics, decisions on treatment (or non-treatment); and when the patient instinctively knows something is wrong ("an invisible problem"). The latter point, interestingly, also came up in workshop 1.

Barriers identified in this group were rather similar to workshop 1. Being sensitive to safety situations is a kind of situational awareness, needed by both patients and professionals with the security that they can raise issues without adverse consequences. Effective communication requires openness and trust and a genuine "no blame" culture.

Health professionals need to be willing and able to listen, and recognise patients as experts on themselves. Conversely, patients and family members should also be able to listen. An equal partnership requires an attitude change on both sides, and a willingness to situate oneself in the other's shoes.

Medical culture and tradition was called into question: "Why is it so hard to talk to God?" Professionals – and society at large – do not see the patient as 'competent', and patients can fear talking openly, for example about side-effects or if they are taking a complementary treatment that they feel the doctor will not approve of, but which may present a safety issue if it interacts with other treatments.

Time and resources where identified as a barrier, as professionals are sometimes too busy and stressed to take time to listen and talk to patients. However, it was noted that they are at times also cited as an excuse not to address the real problems.

"The pressures on healthcare staff are there, but are they sometimes used as an excuse not to communicate well?"

Financial and legal issues – risks for the professionals to communicate openly – were also identified as a barrier in this group, as in others.

The group felt that there is a need to look more closely at the content of professional training when it comes to communication. In principle, communication skills are included in most types of professional training, but there are still too many gaps with what patients experience in reality. This raises the question of how effective the communication training is, and to what extent medical or healthcare organisation culture might undermine what graduates have learned during their education. Someone commented that professionals tend to distance

themselves from a holistic view of the patient, the longer they practice and the more they specialise in the specific condition.

Patient organisations can support professional training either by getting patient representatives involved in training provided by universities or other institutions, but also by training professionals themselves – several patients said their organisations were already active, usually with professionals from the disease area.

The recommendations from this group were:

- Multi-stakeholder collaboration to put communication strategies in place – there are existing tools that can be shared and implemented in different contexts. Willingness to learn and "do better" is essential.
- Involve patient organisations in developing communication training for professional education, whether in university settings or in continuing professional education.
- Professionals should be encouraged to attend events organised by patient organisations by giving them credits for continuing professional education from such activities. This might need a readjustment of the criteria for CPE credits in some cases (non-medical skills and knowledge).
- Encourage the "What matters to you?" approach from healthcare professionals towards patients to encourage good communication – this should be part of the everyday structure of medical training.
- Develop patient-driven tools for good communication for special needs, low health literacy, and so on to support patients' interaction with healthcare professionals.

4.3 WORKSHOP 3: PATIENT AND FAMILY INVOLVEMENT IN THE AFTERMATH OF INCIDENTS

Facilitator: Solvejg Kristensen, Denmark
Rapporteur: Momchil Baev, National Patient Organisation, Bulgaria

The session started with the projection of a video presenting the story of Josie King, a girl who died in hospital due to a preventable medical error (link), where the underlying cause was inadequate communication among healthcare staff. Her mother subsequently partnered with the healthcare organisation concerned to set up a patient safety unit, as well as with a university to create a patient and family hotline for patients to raise their concerns and get information.

With this true story as a background example, Solvejg Kristensen explained that whenever a patient safety incident occurs, there can be three types of victims: the patient, family and friends (the first victim); the healthcare professional(s) concerned (the second victim); and the healthcare organisation as institution (the third victim). Whilst the first victim is harmed – injured or at worst killed – as a result of the incident, the second victim is often traumatised by it, as no healthcare professional deliberately sets out to harm

patients.[9] Professionals often feel personally responsible for the event and feel as though they have failed the patient, doubting their own clinical skills and knowledge base.

The group brainstormed in pairs what the implications of an adverse event could be for the three different types of victims. Afterwards they shared their thoughts with the rest of the group.

- For the patient, family/friends: trauma, anger, grief, loss and pain, feeling that somebody has to pay, mistrust toward the professionals.
- For the healthcare professional: suffering, litigation, media interest on individual level, the system was not optimal, peer pressure, mistrust towards the system they are working for.
- For the healthcare organisation as institution: loss of reputation, cost, media attention, legal issues, but also an opportunity for learning and improvement.

After an adverse event, what does the patient want/need?
One existing recommendation is to use the "five As":

1. Acknowledgement
2. Apology
3. All the facts
4. Assurance
5. Appropriate compensation

The group suggested some needs: for empathy, honesty, compassion, as well as the availability, means and strength to turn a negative into a positive. It should be realised that there is not "one model which fits all" in these cases.
The session ended with a reflection about the kind of activities that participants could imagine in the long-term for improvements in patient safety. Ideas shared included involving patients and families in the shaping of new policies, creating networks of people who have experienced /our experiencing similar situations, and changing the attitude of health workers towards patients.

The key recommendations from this group were as follows:

The group felt that the essential attitudes of healthcare staff – particularly in the acute phase of handling an adverse event – to make the patient/family feel safe and well cared for are:

- Empathy.
- Honesty and respect: "Be real." "Look me in the eyes."
- Wise and grounded: "An apology with all the facts." "A need for closure."

In the subsequent discussion, the issue of litigation/the legal framework around adverse events was raised as it can be a barrier to creating a blame-free culture, to optimal reporting, and to the kind of open and honest communication that patients and families want and need. This should be further explored and addressed.

[9] The discussion here focused on human errors, not deliberate wrong-doing.

5 Developing core competences for patient and family empowerment

On the morning of the second day, participants first gathered in plenary session to hear the reports from the workshops (reported above). The morning then continued with plenary session 4 on developing core competencies for patient and family empowerment.

Kaisa Immonen, EPF Director of Policy, introduced the session by explaining the rationale and background. The 2009 Council recommendation includes under paragraph 2(c) a specific provision for the development of "core competencies" in patient safety for patients, which refers to "the core knowledge, attitudes and skills required to achieve safer care". However, to date this provision has never been implemented. EPF felt that it was now up to the patient community to take this forward and reflect on what such core competencies could be for patients and families.

> **2. Empower and inform citizens and patients by:**
>
> (a) **involving** patient organisations and representatives in the development of policies and programmes on patient safety at all appropriate levels;
>
> (b) disseminating **information** to patients on:
>
> (i) patient safety standards which are in place;
>
> (ii) risk, safety measures which are in place to reduce or prevent errors and harm, including best practices, and the right to informed consent to treatment, to facilitate patient choice and decision-making;
>
> (iii) complaints procedures and available remedies and redress and the terms and conditions applicable;
>
> (c) considering the possibilities of development of **core competencies** in patient safety namely, the core knowledge, attitudes and skills required to achieve safer care, for patients.

The objective of the session was to conduct a first exploration of the topic, which would then be further developed by EPF in the next year towards some concrete recommendations.

After the introduction, the participants were divided into groups to brainstorm on skills, knowledge and attitudes but also on what external factors would need to be changed, given that patient safety is not only or primarily the patients' responsibility. They then shared their thoughts with the rest of the group, and the following knowledge and skills were identified:

- Knowing how the system works and how to "navigate" it, understanding the procedures.
- Knowing how to communicate with healthcare professionals to better understand one's condition and get the answers needed.
- Knowing how to ask questions, how and where to look for information.

- Knowing the rights and responsibilities of a patient.
- Understanding one's own disease/condition.
- Attitudes of perseverance, sense of responsibility, openness to hear other perspectives (listening to the professionals was mentioned in one of the workshops).
- One group suggested a check-list of questions for patients to ask, such as: "Who are you?", "That's not me", "Do you have my record?", "What medication is this?", "It's not clean here," "Why is this different to what I was told before?"

External factors:

- Clear and simple information that is easily accessible when the patient needs it through various channels and formats, including information to take home.
- Openness of the staff towards patients, to listen and hear their concerns.
- Openness within healthcare organisations, such as hospitals, to discuss adverse events and risks openly with patients.
- Transparency of the healthcare system (e.g., on infection rates, resistance, what risks there are and what is being done to manage risks and prevent adverse events).
- Advocacy networks of patients are needed to provide peer support.
- Capacity-building is needed for patients to improve their knowledge and skills. Patient organisations can play an important role here.

Should reporting be considered a critical attitude or even a responsibility? Some in the groups felt that the patient has a responsibility to speak up on situations they are not happy with. This needs to be further explored.

Interestingly, it was said that patients and family members should also be able to listen; "equal partnership is an attitude" and also implies certain knowledge.

Communication was at the centre of this session. The ability to express oneself is a skill, but it was recognised that training patients and families so that everyone can communicate optimally is not a realistic prospect, and furthermore patients are vulnerable, ill, often scared. Therefore, the healthcare environment needs to better support all patients' ability to express themselves regardless of the patient's skills or background. This may have resource implications for the healthcare organisation, for example if interpreters need to be available. Focus in the training of healthcare professionals should be on their human skills and attitudes, such as empathy, a sense of dignity, and their interaction skills. This could be done effectively in collaboration with real (skilled) patients.

6 Closing plenary: Looking forward

The final plenary session placed patient safety within the wider EU health policy and related initiatives, particularly the health system performance assessment (HSPA) framework and the collection of healthcare quality indicators.

The question about the role that patient safety occupies in EU health policy is currently unclear; whilst there have been several Council Conclusions on the topic in the recent years, and two reports from the European Parliament, with a clear request for a solution for a follow-up action to the PaSQ Joint Action and the question of a permanent collaboration at EU level by end 2016, to date there has been no progress.

The Council under the Italian presidency in 2014 noted that "*patient empowerment and involvement are recognised as an essential part of good quality and safety of care and require an effort by Member States to exchange cross-country knowledge and effective tools*," and asked Member States to encourage this particularly "*through evidence-based and unbiased provision of information and education, and promote patients' participation in decision-making in the healthcare process in order to contribute to the prevention of adverse events*".

A 2015 own-initiative report by MEP Pedicini, similarly recognise that patients and their organisations play a key role in advocating for safer care, which should be promoted through empowerment and participation at all levels. This report also called on member states to "*develop EU guidance for patients' involvement in patient safety strategies and actions in collaboration with stakeholders, particularly patient organisations*", and to provide patient organisations with support to carry out safety activities.

For this session, invited speakers included the representation of doctors at the European level and the OECD, whose importance is growing with the increasing emphasis in EU policy on collection of indicators and data on healthcare quality in health system performance.

6.1 PATIENT SAFETY SHOULD REMAIN AN ONGOING PRIORITY AT EU AND NATIONAL LEVELS

Dr Bernard Maillet, Vice-President, Standing Committee of European Doctors (CPME)

The first speaker was Dr Bernard Maillet, representing CPME the European-level organisation of doctors, with whom EPF enjoys a longstanding collaboration on many aspects of EU health policy.

Dr Maillet started by introducing the CPME, which represents national medical associations of 28 countries in Europe. Like EPF, the CPME believes that access to the best possible quality of healthcare should be a reality for everyone, and sees the

patient-doctor relationship as fundamental in achieving this objective.

The EU mandate in health is limited as it leaves most of the responsibilities to the Member States. That said, there have been a number of EU level actions on patient safety, namely the Council Recommendation of 9 June 2009 (about prevention and control of healthcare associated infections) and the Council Conclusions on 1 December 2014, which invite Member States to finalise a framework for a sustainable EU collaboration of patient safety by 2016 and to intensify efforts and improve strategies in the field.

Dr Maillet emphasised that to implement the Council Conclusions, patient safety must remain an ongoing priority at EU and national levels, and it should therefore continue being a distinct priority element of the EU Health Programme. Further actions are needed to ensure protection of patient safety and to continue to foster exchange of good practices in the field, as so successfully done by the Joint Action "PasQ". He also stressed that the Commission's Patient Safety and Quality of Care Expert Group would be crucial to develop and implement the Member States and stakeholders' collaborative work in this area.

6.2 A PERSPECTIVE FROM THE OECD

Niek Klazinga, Head of Health Care Quality Indicators (HCQI) Project, OECD Health Division

Dr Klazinga stressed that "*healthcare does not produce health, people produce it*", and it is healthcare that supports people in realising their potential health.

He gave an overview of the indicators work of the Organisation for Economic Co-operation and Development (OECD). A core set of measures has been developed that are continuously being refined for better international comparability. Among them, the OECD analyses mortality and life-expectancy, prevalence and incidence of diseases, patient-reported outcomes (PROMs) and patient experience through a specific set of questions. The OECD also examines patient experiences in relation to safety along three dimensions: prevention, incidents and incident management. (See presentation.)

The OECD aims to develop a comparable set of patient-reported outcomes and experience indicators by disease, sector, service and system level; to extend data collection to challenging and neglected areas; and to focus on enabling international comparability.

In January 2017, during the Policy Forum on the Future of Health with the theme 'People at the centre', the OECD is organising a conference to discuss how to realise person-centred care, how to care for people with complex needs, and the potential of measuring outcomes and patient experiences as a catalyst for change. Several Health Minister will attend to engage in the debate. EPF will be among the stakeholder participants and will take that opportunity to engage with the OECD's indicators agenda.

6.3 CLOSING OF THE CONFERENCE

At the end of the plenary session, Kaisa Immonen, EPF Director of Policy, took the floor to thank all the speakers, facilitators, operators and participants, and to explain the next steps from EPF.

The conference fulfilled its purpose in that it identified a number of new issues and opportunities to advocate for better patient safety from the patient perspective. This was the first EPF conference on the links between empowerment and safety, and for many participants it was also their first event on the topic. During the rich discussions over two and a half days, patient representatives showed they want to actively engage in safety. Patients want to see a real culture change and a recognition that they, and their families, are equal and valued partners in care.

Many participants felt that patient organisations play a potentially very important role in triggering improvements in patient safety, for example through sharing information and good practices, coaching individual patients to become effective advocates, advocating for more involvement in their own national or disease context, and training healthcare professionals on how to work in partnership with patients. Too often, they do not have the capacity or resources to carry out such activities.

The conference outcomes will contribute to the future policy and advocacy work of EPF on this topic. Next year, EPF will set up a task force to reflect on the development of a set of 'core competencies' for patients and families aiming to involve them in the area of patient safety – this will address a key provision of the 2009 Council recommendation which has today not been implemented.

Our task force will have to reflect on the broader role of patients and families in healthcare and how the system needs to change to accommodate and welcome them. A "knowledge deficit" on the part of patients may sometimes be the issue, but equally often it may be something fundamental at system level, such as a lack of responsiveness to patients, or unintended ethical consequences of efforts to increase patient involvement, if empowerment/power issues are not addressed.

EPF will pick up the key recommendations and outcomes of the conference and use them actively in our advocacy towards the European Commission, Members of the European Parliament, and other health stakeholders highlight the need to keep patient safety as a specific priority of European health policy. We have already started by highlighting the importance of patient empowerment in the draft call for action launched at a meeting of the European Health Policy Platform on 5 December. This will also inform our response to the mid-term evaluation of the third EU Health Programme, in February 2017.

Next year, EPF will also develop a position paper on the quality of care from a patient perspective, based on a survey conducted during 2016, which will inform our advocacy in a broader way around quality of healthcare and health system performance. Patient safety will continue to be a key aspect.

Annex: conference agenda

ANNEX

EPF CONFERENCE ON PATIENT AND FAMILY EMPOWERMENT FOR BETTER PATIENT SAFETY

Programme

8-9 November 2016, Hotel Bloom, Brussels

	Day 1: 8 November 2016
9.00	**Registration and coffee**
10.00	**Plenary session 1: Setting the scene** *This session will give participants an understanding of patient empowerment in the context of patient safety* *The conference will be moderated by Gurmit Sandhu* **Welcoming words** • Marco Greco, EPF President
10.30	**Why patient empowerment matters in patient safety** • Robert Johnstone, patient representative and EPF Board member
10.50	**Q&A**
11.30	Coffee Break
12.00	**Plenary session 2** **Challenges to patient empowerment in patient safety** *This session will explore the specific challenges to patient involvement in the area of safety, e.g. ethics – is it a welcome responsibility or an unwelcome burden?* **Presentation outlining the main issues and challenges** • Nittita Prasopa Plaizier, WHO Patient Safety Programme **Case study: patients advocating for safety** • Antonio Ciaglia, Policy Manager, International Alliance of Patients' Organizations **Q&A**
13.30	**Networking lunch**
15.00	**Parallel workshop sessions** *The parallel workshops address key aspects of patient and family empowerment and involvement in patient safety.* **WS 1: Patient empowerment in acute settings** Facilitator/presentation: Dr Nicola Mackintosh, King's College London Rapporteur: Tessa Richards, Senior Editor/Patient Partnership, BMJ **WS 2: Patient-professional communication as a critical safety factor** Facilitator/presentation: Ove Gaardboe, Danish Patient Safety Association Rapporteur: Katharine Wheeler, Lupus Europe

	WS 3: Patient and family involvement in aftermath of incidents Facilitator/presentation: Solvejg Kristensen, Denmark Rapporteur : Momchil Baev, National Patient Organisation, Bulgaria
15.45	**Coffee Break**
16.15	**Second session of the parallel workshops** *(repeated)*
17.00	Close of first day and rest break
19.00	**Conference dinner**

Day 2: 9 November 2016

10.00	**Plenary session 3** **Feedback from the workshops** • Rapporteurs of the workshops *Rapporteurs will present the key outcomes from their workshops.*
11.00	**Plenary session 4** **Developing core competences for patient and family empowerment** Facilitator: Gurmit Sandhu *Interactive session with the audience*
12.00	**Coffee break**
12.30	**Closing plenary: Looking forward** **Patient safety should remain an ongoing priority at EU and national levels** • Dr Bernard Maillet, Vice-President, Standing Committee of European Doctors (CPME)
12.50	**A perspective from the OECD** • Niek Klazinga, Head of the Health Care Quality Indicators (HCQI) Project, OECD Health Division
13.05	**Q&A**
13.20	**Closing of the conference** • Marco Greco, EPF President
13.30	**Good-bye networking lunch**

This document received funding under an operating grant from the European Union's Health Programme (2014-2020). The content of this document represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.