Proposal Regarding the Development of Key Competencies for Patients, Families and Carers in Patient Safety

Contents

1. Introduction and background

The 2009 Council recommendation on patient safety 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".

More recently, the Council under the Italian EU 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.

To date, the 2009 provision referred to above has not been implemented. EPF decided that the patient community should take this forward and reflect on what such core competencies could be for patients and families.

In the EPF work plan 2017, provision was made for a Task Force that would reflect on the question of "core competences for patients and families to contribute to better patient safety" and put forward recommendations by end of the year.

The present document is based on the work of this Task Force. It includes proposals to implement the provision of the 2009 Council recommendation regarding the core competencies of patients and families, as well as a wider reflection on the systemic issues that need to be addressed in order to empower patients and family members in the healthcare environment.

1.1 METHODOLOGY

The primary objective of the Task Force was to develop a proposal for a set of "core competencies" for patients and families", including but not limited to:

- Knowledge, skills and attitudes that patients and families need in order to take an active role;
- External factors in the healthcare environment that needs to change to enable patients and family members to take a more active role;
- Reflections and/or recommendations concerning implementation.

In this the Task Force took account of previous work, including the outcomes of the EPF conference on patient safety on 8-9 November 2016. The Task Force met twice during 2017 and developed a draft document. The document was subsequently circulated for consultation with EPF's membership,

although it is not an official EPF position paper. It does, however, build extensively upon EPF's previous work in the area of patient safety, patient empowerment and meaningful patient involvement.

1.2   WHO IS THIS DOCUMENT FOR?

This document is meant primarily as inspiration and guidance for policymakers and practitioners who wish to implement the Council recommendations in their own country, region or locality. It can also be useful for patients, informal or family carers, and their representative organisations for advocacy purposes. Ultimately, we recommend it for anyone interested in the patient perspective on patient safety.

During the work process we realised, referring back to the simple wording of the Council recommendation, that the task was in fact far from simple. It was not possible to come up with a short list of competencies which all patients/family members in all healthcare settings "should" have. We also realised that against an inherent imbalance of power, knowledge and information in the healthcare context, such a list of competencies would not be appropriate from a patient empowerment perspective. For this reason, we adopted a much wider approach.

The key competencies we have identified are many – and they are complex. Thus, they will not be easily implementable in the sense of providing a quick educational intervention, for example. However, we hope they will provide food for thought for the different actors in the healthcare system who wish to drive change, and potentially form a basis of a more concrete project.

This paper is intended to be updated in due course, particularly as EPF's initiative on systematic, structured and meaningful patient involvement evolves post-2018. Good practices, resources and tools can in future be annexed to updated versions of this paper or integrated in the relevant EPF webpage. These can include checklists, leaflets, websites, courses and disease-specific tools. EPF will reserve the right to evaluate and select the practices, based on our evaluation criteria for meaningful patient involvement, which will be developed in the next years.

1.3   A NOTE ON TERMINOLOGY

In this document, the term "patient" is sometimes used for brevity, but a patient is not isolated from her/his family and social network, so it should be understood that informal carers, friends and family members are included. Informal carers are persons who provide care (usually unpaid) to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal employment framework.[1] Whenever necessary we do refer explicitly or specifically to families and informal carers.

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[1] Definition courtesy of Eurocarers

2. The role of patients/carers in patient safety

The European Commission's second report on patient safety (2014) recognised that the experiential knowledge of patients and families is a valuable resource for health professionals and that this experience should be gathered as an element of quality improvement systems. Patients' involvement is also vital for instilling a *patient safety culture* in the healthcare system.[2]

EPF would like to see patient organisations take a more active stance on patient safety at policy level. Nevertheless, we acknowledge the challenges related to individual patients' involvement in this area and the need for empowerment.

2.1 PATIENT EMPOWERMENT AND INVOLVEMENT IN THE CONTEXT OF SAFETY: BRIEF BACKGROUND

Patients play a vital role in the management of chronic conditions. They live with their condition every day and become experts through lived experience, on the condition itself and its impact on their life, the impact of treatments, and the positive aspects as well as failures of the healthcare system, which they rely on a regular basis. Supporting and promoting the *meaningful involvement of patients*, both individually and collectively in improving patient safety, is one of the priorities for EPF.[3]

Similarly, informal carers have concrete knowledge of the conditions of the patients. They play a key role in the daily life of patient and in the management of their situation, whether care is delivered in an institution or at home.

Literature indicates that patients' willingness to get involved varies, for example people in an acute situation or facing a very severe illness are less willing and able to be involved in decision-making, whereas patients who are managing chronic conditions routinely are more willing and able to do so even in a hospital environment, which can often be profoundly disempowering for patients. Other factors include characteristics of patients, such as demographic characteristics, and the attitude of health professionals.

According to a recent UK research project presented at the EPF Conference, lay expertise could be the backbone of patient safety, especially in acute illness, but there are barriers. Patients often "sense intuitively" that something is wrong before physical or clinical markers manifest themselves. However, their concerns are often not taken seriously. Key findings included that most patients were informed and engaged in self-monitoring and asked for help; patients' confidence and ability to contribute were influenced by the nature of their illness, age, experience of the health system and models of care; patients had concerns about overloading the system, upsetting staff and compromising their own care if speaking up; and that response from staff was variable. Some perceived attributes of patients made it even harder to speak up: ethnic minority background, level of education, stigma, being seen as a

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[2] Reports of sub-groups of the PSQC WG on education in patient safety and reporting-learning systems, April 2014. Available at http://ec.europa.eu/health/patient_safety/policy/package_en.htm

[3] For more information about patients' role in patient safety, see EPF Briefing Paper (2016), available here: http://www.eu-patient.eu/globalassets/policy/patientssafety/patient-safety-briefing-paper.pdf

'difficult patient' for example if having mental health or substance abuse issues, (lack of) ability to speak English, and being alone.[4]

Thus, when thinking about this topic it is vital to *consider the context*. Depending, for example, on the social-economic, including educational, background of the patient, the healthcare environment, and the patient's degree of vulnerability (e.g. routine chronic vs. acute care), different possibilities and degrees of involvement can be envisaged. We cannot stress enough the importance of an *enabling, empowering environment* – which will require fundamental cultural and systems change, not only actions aimed at patients and families.

3. Key competences for patients, families and carers

Below, we present a list of **possible core competences that found broad agreement** within the Task Force. In order to follow the wording of the Council recommendation, these were divided into *knowledge, skills and attitudes*, although we recognise that those categories are complementary and to some extent overlapping. In addition, many of the identified points overlap across the document. For example, patients' rights will be found under the healthcare system, as they should exist within a legislative framework and be implemented; but also under the competences of patients and professionals, as the latter need to be aware of them and apply them in daily life and professional practice.

The discussion around patient *empowerment* and the *competences* of patients and their supporting persons – be it family or other (informal) carers – always needs to find the right balance between enabling patients to take control without placing too much of a burden on them.[5] This mean that patients and carers should indeed be regarded as part of the caring team and experts through lived experience, and those who wish to take further steps in becoming actively involved in their care should be given the right support, while at the same time bearing in mind that all patients are to some extent vulnerable and need appropriate help and support in dealing with their condition. The specific support needs of carers should also be recognised.

Knowledge refers to the information that patients should have and be able to apply in their daily life when navigating through the healthcare system. First and foremost, patients should be aware of their rights – as patients specifically, and as citizens. Other information, such as common standards, also concerns patients as this often distinguishes authorised and safe practices, products or organisations (an example is the common EU logo for online pharmacies). Basic information about the specific medicine or medical device a patient is using, and related knowledge such as understanding the use

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[4] Presentation by Dr Nicola Macintosh and Jane Sandall, "Patient empowerment in acute settings" given at the EPF Conference, 8-9 November 2016; the slides are available at http://www.eu-patient.eu/Events/past-events/epf-conference-on-patient-and-family-empowerment-for-better-patient-safety2/

[5] The Patient's Charter on Patient Empowerment (EPF, 2016) makes this clear under point 2: "**I am empowered to the extent I wish to be.** No-one is beyond empowerment, though some people may need more support. The right strategies should be adopted for specific needs, particularly to encourage the voices of those who may be in a vulnerable or marginalised situation … If patients wish to delegate a decision to someone else, this should be respected." The Charter is available at http://www.eu-patient.eu/campaign/PatientsprescribE/charter-on-patient-empowerment/

of generics and knowing about antibiotic resistance, is of great importance. Knowing what peer support and patient organisations exist in one's disease-area is very helpful.

Being able to find this information or being aware of it is not the goal in itself – rather, patients should be able to find, understand and appraise information and then apply it effectively in order to make meaningful choices in their own life. This is called *health literacy*.[6] Health literacy, including digital health literacy, is gaining in importance particularly with the availability of vast amounts of online information of varying quality.

Patients seek *information on the Internet.* This is often presented as a threat, but appropriate online information can be an effective way of engaging people in taking an active role in their health. At the same time, there is an overwhelming amount of information online, often of dubious quality, which does not contribute towards empowerment. Likewise, many patients do not discuss such information with their health professionals – sometimes out of apprehension – and they are still likely to trust the information given by a healthcare professional. Health professionals should have the right skills to have conversations about online information with patients, talking them through the information and providing explanations and context in a non-judgemental way.

The above underlines the importance of *communication* – for the patient, understanding of one's needs and the ability to communicate them effectively to health professionals is equally important as for professionals to be able to communicate well with the patient and carers/family members, as well as among themselves. As the EPF conference workshop of November 2016 concluded: are there any situations where patient-professional communication is *not* critical?

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[6] For a definition and extensive discussion of health literacy, see WHO (2013) *Health Literacy. The Solid Facts*. Available at http://www.euro.who.int/en/publications/abstracts/health-literacy.-the-solid-facts

Table: Key knowledge skills and attitudes for patients to contribute to safer care

Knowledge	✓ About your rights as a patient (and citizen) ✓ About your condition, prognosis and any relevant issues, e.g. genetic or lifestyle factors (including exercise and diet) ✓ About your own goals, values and priorities for your health, life and well-being – to support discussions on benefits and risks of treatments and generally in the planning of your care ✓ About your medicines, whether or not they are branded or generics, prescription or over-the-counter, including information on adherence (e.g. avoiding over-dosing and what to do in case a dose is accidentally skipped), possible side-effects, and changing situations (e.g. a woman becoming pregnant while on long-term medication) ✓ About other therapies you may be taking, e.g. herbal remedies or supplements, and how they might interact with medicines ✓ About antibiotic resistance where relevant and how to use antibiotics correctly ✓ About your medical device(s) and how to use them ✓ About the healthcare system and how it works ✓ About the safety and quality standards applied in your healthcare facility, e.g. hospital ✓ About quality marks, such as the common EU logo for legal online pharmacies ✓ About where to find peer support or a patient organisation in your disease-area/locality ✓ Specific knowledge relevant for carers includes: knowledge of the healthcare and social protection system and how they work, knowledge about the condition of the person cared for, practical knowledge about how to care, knowing what support is available, where to find a carers' support organisation ✓ Knowing what to do in an emergency (both patient and carer)
Skills	✓ How to find information online and how to appraise (judge) its quality and trustworthiness ✓ How to communicate effectively in different situations, e.g. during consultation or in an emergency ✓ Strategies for dealing with different situations, e.g. preparing for consultations, follow up on consultations, whom to address with queries, how to counter paternalistic attitudes ✓ Specific skills relevant for carers include: transversal skills such as communication, time management, priorities management, stress management
Attitudes	✓ Realistic ✓ Curious ✓ "Full disclosure", i.e. tell your health professional everything that is relevant, including what medicines or any other therapies you are taking ✓ Challenging paternalist culture ✓ Understanding the limits of your knowledge ✓ Sense of responsibility and agency ✓ Co-operative and listening to the perspective of health professionals ✓ Specific attitudes relevant for informal carers: being aware of the specificities and the challenges attached to the role of carer, managing one's own (physical and mental) health, asking proactively for information and support

4. An empowering healthcare environment

We asserted in the beginning that the burden of safety must not be placed on patients inappropriately, and that patients face barriers to getting involved, some of which are structural, relating to the healthcare setting, but many of which have to do with human relationships. We also stressed the importance of an *enabling environment*, which empowers the person *vis a vis* the system. For this reason, it would not be appropriate to present a mere check-list of competences for patients, families and carers; we must also address healthcare professionals and beyond that, the wider healthcare system.

4.1 KEY COMPETENCES FOR HEALTHCARE PROFESSIONALS

Equipping patients with the capacity to take active part in their care and creating an enabling environment for this to happen – *patient empowerment* – requires committed efforts to upgrade the skills of healthcare professionals, as well as a change in attitudes regarding the "proper role" of patients as well as informal carers.

These measures are part of building a *patient safety culture* (see box, right). Building a patient safety culture might require changing the attitudes of professionals, developing teamwork[7], translating research evidence into practice, considering patients as partners in the healthcare process (to the extent they can and wish to participate) and ensuring that expectations for outcomes are realistic and in the best interest of patients. Safety culture starts with recognising the possibility of error and ensuring continuous learning and improvement processes are in place. Senior leadership accountability is very important to build a culture of safety in any organisation.[8]

> "A safety culture is where staff within an organisation have a constant and active awareness of the potential for things to go wrong. Both the staff and the organisation are able to acknowledge mistakes, learn from them, and take action to put things right ... patient safety needs to be addressed at an institutional level, 'from trust board to ward', as well as by designing out errors in processes and equipment."
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> - Source: NHS, UK

The knowledge and skills referred to in this section are linked to the broader function of the healthcare system, and rather than the medical/scientific expertise that the professional is expected and assumed to have. Knowledge of the broader healthcare system includes having links with patient organisations, social care and other support groups. Professionals should take into account their broader social context of patients, such as family, friends, and work. For them to be able to provide patients with the holistic care that they require, they need to know about the different actors that can participate in the care of the patient, often based in the community.

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[7] For an example of positive effects of interprofessional collaboration see: Ann Pharmacother. 2007 Feb;41(2):319-24. Epub 2007 Jan 23; https://www.ncbi.nlm.nih.gov/pubmed/17244644

[8] Sammer CE1, Lykens K, Singh KP, Mains DA, Lackan NA. What is patient safety culture? A review of the literature. J Nurs Scholarsh. 2010

In addition, we place high importance on *"soft skills" and attitudes*. Identifying the reasons behind the lack of such skills and attitudes as perceived by patients[9] is not within the scope of this document. Nevertheless, the majority of the input into this document related to the skills and attitudes of professionals. Adopting a genuine team-work approach each patient is integral to care that is well-coordinated from the patient's and family's viewpoint. This can be a structural or organisational question, but it also requires a willingness to work as a team, potentially relinquish some "power" and also to accept the patient and their carer as an equal member of "the team".

Table 2. Key competencies for healthcare professionals

Knowledge	- Understanding what patients want and need (generally) - Understanding of conditions they are treating and the common safety issues related to the condition - Understanding of the individual patient's needs, values, priorities and preferences regarding treatment and care - Understanding the patient's social, family and work context - Having an up-to-date professional knowledge - Having knowledge of patients' rights and human rights - Knowing where to refer the patient for support, including patient organisations - Utilise carers knowledge and experience of supporting the patient - Understanding the key role of informal carers, their specific needs and the challenges they face - Knowledge of the support available for informal carers
Skills	- Being able to communicate effectively with patients, families and informal carers, including problem-skills where necessary - Being able to discuss potential benefits and risks of treatment options as well as the uncertainties or lack of evidence-base in a way patients can easily understand - Active listening - Being able to deal with "informed patients" in a constructive way - Being able to employ (innovative or digital) strategies and tools of meaningful patient involvement and participatory practice in order to involve all patients to the extent they feel comfortable with - Coaching and guiding appropriately, tailored to each patient's circumstances - Team working skills - Stress management skills

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[9] For example, the patient survey and focus groups conducted as part of the EMPATHiE study ("Empowering patients in the management of chronic diseases," 2014) found that health professionals' attitudes and views of the patient were a key barrier as well (in the converse) a key facilitator of patient empowerment. Final report, http://www.eu-patient.eu/whatwedo/Projects/EMPATHiE/

Attitudes	✓ Seeing the patient as a whole person rather than a diagnosis ✓ Acknowledging the role and needs of informal carers ✓ Welcoming the patient's and carers' active involvement ✓ Co-operative and empathetic ✓ Avoiding disempowerment and paternalism ✓ Helpful, polite, respectful, appropriate, inclusive and open-minded, "the human face" ✓ Educative and guiding mindset ✓ Understanding the limits of your knowledge and accepting uncertainty ✓ Efforts to reassure patients and build trust in professionals and the system

4.2 ORGANISATIONAL AND SYSTEM BARRIERS / ENABLERS

Patients and carers interact with individual health professionals, but often there are significant systemic constraints on these interactions. A prime example is the often perceived (by patients, but also by professionals) lack of time to have a meaningful discussion during a consultation. The Task Force discussed potential barriers to, as well as enablers of, patient involvement and empowerment in the context of safety, recalling the conclusions of the EMPATHIE study (2014), which found that the same factors can be either barriers or enablers.[10]

Below, we outline some of the systemic issues that need attention if patients and families are to be genuinely empowered and if professionals are equally to be empowered so that each can make the most of the human interactions that make up "care".

Health literacy

The first group of topics is closely interrelated: health literacy, information and communication. Health literacy is an aspect of empowerment (EMPATHiE, 2014) and a critical strategy for people to cope with the overwhelming amount of information often available online, and to navigate an often confusing healthcare environment.[11] *Health literacy* entails the knowledge, motivation and competencies needed to access, understand, appraise, and importantly *apply* health-related information in daily life to make judgments and take decisions concerning one's health, in order to maintain or improve quality of life during the life course.[12] Health literacy is highly relevant to patient safety, given that low health literacy is associated with less frequent use of preventive services, poorer management of chronic conditions, and higher mortality.[13] It has also been associated with medication errors, misdiagnosis due to poor communication between providers and patients, low rates of adherence, and more hospital readmissions.[14] Knowledge of safety issues and processes, the standards that should be applied for quality of care, and so on would form part of patient safety-

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[10] EMPATHIE final summary report, cited above.

[11] See EPF paper on patient empowerment (2014) available at www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/Background-papers/

[12] Sorensen K et al., "Health literacy and public health: A systematic review and integration of definitions and models," *BMC Public Health,* 2012.

[13] Berkman ND et al., Literacy and Health Outcomes; AHRQ; Rockville, MD, 2004

[14] Nielsen-Bohlman L, Panzer AM, Kindig DA (2004), A Prescription to End Confusion. Project brief; Vernon JA, Trujillo A, Rosenbaum S, DeBuono B (2007). Low health literacy: Implications for national policy. http://publichealth.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10_4_07.pdf

related health literacy. Often it is not feasible to require patients to know about these, but better information for lay people can contribute to health literacy and to the transparency of the system in general. Patient organisations can play an important role in this as information they produce is usually presented simply and co-produced with patients.

Information for patients and transparency of the system

The availability of information is one of the recurring issues raised by patients and the key challenge for healthcare systems. Patients are increasingly interested in becoming active in their own care, in engaging in advocacy and becoming active citizens; thus they reasonably expect the healthcare system to be transparent and easily navigable for its users. There are many aspects of the healthcare system that patients want to be better informed about, ranging from questions about what their rights are, how the insurance and reimbursement system works, what the evidence-base is for different treatments or what exactly biosimilar medicines are; to questions about which online pharmacies patients can trust and which patient organisations they can address for support. Having effective legislation in place to protect the public and patients is not enough if this is not well communicated to the public and the patients. The question of transparency is of course linked to the accountability of the system and good governance. Lack of transparency in the healthcare system is a barrier, whereas transparency and openness of the system towards its users and beneficiaries is conducive to trust.

In a safety context one specific issue is that information for patients is often focused on "warning signs" that patients should be looking out for, but in real life symptoms often manifest themselves in a different way. As noted by the speakers at our conference session acute care, focusing exclusively on specific warning signs could paradoxically *hamper communication*, because patients often do not want to disturb healthcare staff with "trivial" matters if they are not flagged as warning signs.

Communication

Good communication between the members of the healthcare team[15] as well as between healthcare staff and patients is a safety concern. Patients facing communication barriers are more exposed to errors[16] but also to "silent misdiagnoses".[17] Patients often perceive a gap in understanding when trying to make sense of medical jargon; and quite concretely patients and professionals sometimes speak a different language, especially in cross-border healthcare and multi-cultural contexts.

The ability to express oneself is a skill, but training patients and families so that everyone can communicate optimally is not realistic; furthermore, patients can be vulnerable, ill, and are 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 has training implications for healthcare professionals and resource implications for organisations.

Although effective communication is indispensable at all times, certain critical points may be identified during a patient's journey: these can be transitions or handovers from one healthcare environment to

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[16] Kingston-Riechers J, Ospina M, Jonsson E, Childs P, McLeod L, Maxted J. Patient Safety in Primary Care. Edmonton, Alberta: Canadian Patient Safety Institute & BC Patient Safety and Quality Council; 2009.

[17] The silent misdiagnosis refers to the fact that patients' preferences are often not taken into account in treatment decisions. Whilst medical misdiagnosis is a recognised safety issue, preference misdiagnosis is not. "Patients preferences matter. Stop the silent misdiagnosis" by Al Mulley, Chris Trimble and Glyn Elwyn, The King's Fund, 2012.

another (e.g., between hospital and primary care, between specialists, hospital to home or rehabilitation); any point where a decision needs to be made (e.g., diagnostic test, decision on whether to choose treatment and which treatment); or situations when the patient instinctively knows something is wrong, where listening and taking the patient seriously might have serious safety implications, as referred to earlier in this paper.

Cultural change

The burden of improving communication between the different actors in the system cannot solely be put on the actors themselves. A systemic approach that enables and encourages those actors to effectively communicate with each other is needed. Cultural aspects of medicine need to be considered, such as the roles of "professional" and "patient" that are deemed acceptable in a certain healthcare context. Patients and carers are still not seen as a resource for improving the quality, safety and sustainability of health care. From this perspective, hierarchical medical culture where "lower-status" employees (e.g. nurses) are discouraged from challenging "higher-status" employees (e.g. specialist doctors) is also a clear patient safety issue, and reiterates the need to shift to a genuine patient safety culture.

Opportunities to speak up or give feedback

Practical opportunities to give feedback, for example via supporting services at the hospital or helplines, maybe helpful, and we recommend that patient feedback should be systematically collected and not only focus on negative feedback but also on what is positive. It is also important that *in the healthcare environment*, patients, families and informal carers know that they may have an intuitive feeling that something is wrong and in that case it is welcomed and valued that they speak up. Health professionals need to respect the patients' and carers' intuition. Similarly, professionals themselves should be able to raise any issues and should have appropriate channels for doing so.

Taking responsibility

Notwithstanding the caveat expressed above, attitudinal barriers may also exist on the part of patients and carers, often related to a medical culture that treats patients as passive recipients rather than active participants. Some individuals may not, for example, accept it when professionals admit they do not know the answer or cannot provide a solution. There may be differences across geographical regions of the EU in how the role of patient is perceived. Specific advocacy by patient organisations, particularly through training and awareness-raising and working together with healthcare providers to drive culture change and patient empowerment, can be helpful.

Training and education

Health professionals are still not appropriately trained to work in genuine partnership with patients, although the content of education is evolving. In principle communication skills, for example, 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 training provided is, and to what extent (organisational) culture might be undermining what graduates had learned during their education. Patient safety, and partnering with patients (including such skills as shared decision-making and active listening) should be more embedded in both academic education and continuing professional development (CPD). Patients' participation (either by individual patient-experts or by

patient organisations) in the training of healthcare professionals and in developing educational curricula is a promising but still under-used resource.

Lack of recognition of informal carers

The role of informal carers is worth emphasising, given that involving them in care is beneficial for the quality of care of the patient, and yet their role and contribution is often under-recognised. Valuing and supporting informal carers also has an important preventative effect, as it contributes to maintain the well-being and mental health of carers themselves.

Resources

Resources are a perennial problem in healthcare. There is sometimes a lack of sufficient healthcare staff, who then have poor morale or suffer from burnout – a recognised patient safety factor but also a barrier to effective interactions with patients and families. However, innovation – in the sense of doing things differently, and better – need not be costly, and there is accumulating evidence that "low-level" innovation involving users can significantly improve a service at negligible cost.[18] For patient organisations, in turn, perennial lack of funding and staff resources are barriers in the way of these non-profit non-governmental organisations playing their role effectively in (for example) building patients' capacity and contributing to better health policy making.

(Dis)integration of care

For patients fragmentation in care – the opposite of integration – is a formidable barrier: Fragmentation translates as lack of continuity or co-ordination in care, and it includes for example patients seeing different doctors or nurses every time, sometimes not knowing who is responsible for their care and safety. "Integrated care" is often addressed from a system perspective, but better co-ordination from the patient/family perspective is an essential aspect of quality of care.

Legal barriers

Professionals often fear blame and litigation as a result of errors, which makes them reluctant to speak out.[19] Feedback is not currently embedded into the system, and the "blame culture" needs to be opened up. Patients need a legal framework to ensure redress if something does go wrong, but often they also say that if provided with an honest and open explanation and apology, they would feel less inclined to resort to legal measures.[20] An important aspect of EPF's future work in patient safety will be to formulate a patient perspective on how the system should interact with patients and families when adverse events do happen.

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[18] Committee on the Learning Health Care System in America; Institute of Medicine; Smith M, Saunders R, Stuckhardt L, et al., editors. Best Care at Lower Cost: The Path to Continuously Learning Health Care in America. Washington (DC): National Academies Press (US); 2013 May 10. 9, Creating a New Culture of Care. Available from: https://www.ncbi.nlm.nih.gov/books/NBK207217/?

[19] Report of the Reporting and learning subgroup of the European Commission Patient Safety and Quality of Care Working Group (PSQCWG), *Key findings and recommendations on Reporting and learning systems for patient safety incidents across Europe,* May 2014. Available from: https://ec.europa.eu/health//sites/health/files/patient_safety/docs/guidelines_psqcwg_reporting_learningsystems_en.pdf

[20] Robbennolt, J. K. (2009). Apologies and Medical Error. Clinical Orthopaedics and Related Research, 467(2), 376–382. http://doi.org/10.1007/s11999-008-0580-1

Technology

Technology holds promise but is often not well used, for example in hospitals where health records are not integrated and systems are still paper-based. Patients often do not have access to their own (electronic) healthcare records, even though that is a basic patient's right. Given the extensive scope of the question of technology in healthcare, we do not make specific recommendations here but EPF will address this in more detail in its work on digital health.

Lack of evaluation

Responsiveness of the system to its users is not routinely measured. There needs to be a reflection on what kind of measures would be appropriate in the context of patient safety. There is a current project by the OECD to develop a survey instrument for patient-reported (safety) incident measures (PRIMs), and in parallel the OECD Patient-Reported Indicators Survey (PARiS) launched in January 2017 hopes to develop cross-country comparable indicators for measuring patient experience, which may also be relevant to the patient safety context.

5. Discussion and caveats

Caveats

There are some caveats to be borne in mind when considering the development of "competencies" for patients and families in this area of safety in particular. Patients are *already burdened* with having a disease and having to cope with treatment, being in hospital, etc. In addition, there are risks in *over-emphasising individual patients' involvement as the change agent* when it comes to safety improvement. In addition to being vulnerable and burdened, patients are not usually in a position where they have the power to change things. Some patients may be too unwell or cognitively unable to speak up; they may not feel equipped to speak up or even if they do they may not actually be listened to. Therefore, some process/guidance needs to be developed around how any patient speaking up is acted on and this could be referenced in the professionals' key competencies. Another risk is that the *burden of responsibility* may be inappropriately shifted from professionals to the patient, even as an unintended consequence. This should never the case. Finally, according to EPF's fundamental values *each patient's individual circumstances and preferences* must always be considered. Patient involvement is something positive that should be facilitated and encouraged, but patients should not be pressured into "being involved".

A note concerning access barriers

Patients' access to care has been a frequently occurring theme in the Task Force, particularly in relation to the patient's right to a timely and accurate diagnosis – something which many patients with chronic conditions find difficulties with.[21] Although access to healthcare is out of scope of the

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[21] EPF survey report "Patients' perceptions of quality in healthcare", published in February 2017 and available at http://www.eu-patient.eu/globalassets/policy/quality-of-care/quality-survey-report.pdf

present paper, this is a reminder of the necessity of EPF's 2017 Campaign "Universal Health Coverage for All", which aims to put equity of access at the centre of political debates. [22]

6. Towards implementation / Recommendations

The 2009 Council recommendation does not suggest how core competencies for patients (and carers) might be implemented. This document stresses the crucial importance of involving representative organisations of patients at whichever level of the healthcare system such competencies are being considered. Civil society organisations, in particular carers' organisations play a key role in offering support and training to informal carers.[23] Development of a set of core competencies and their implementation in the system should be done as a co-production, following the principles of meaningful patient involvement (EPF, 2009).[24]

Training initiatives developed in partnership with other stakeholders, including health and long-term care professionals and institutions, are particularly relevant in this context. Against this backdrop, the involvement of carers' organisations is particularly helpful for ensuring a participatory approach for the design of training, likely to meet carers' needs. Carers' organisations play also a key role in reaching out to carers, and flank training opportunities with relevant support such as respite care, allowing carers to engage in training.

The recommendations below stemming from EPF's previous work are relevant in this context.

Embed patient empowerment, safety and quality in health system performance assessment

- Existing performance indicators and their relevant to patients' priorities should be reviewed;
- New performance indicators for quality of care should be co-designed with patients, including timely and appropriate response to patients' concerns;
- Whilst recognising the great value of initiatives such as PaRIS (OECD), indicators alone will not be sufficient to embed a patient perspective in healthcare performance assessment. Systematic, structured and meaningful user involvement, including structured channels for providing feedback and mechanisms to act on this feedback, must be installed.

Use the potential of technology for the purposes of real patient empowerment

- Implement integrated electronic healthcare records, which should be interactive and shared/co-managed with patients;
- Implement shared digital platforms for easier patient/family-professional/provider interactions (also accessible to patient with certain disabilities);
- Implement patient hotlines or e-platforms for easy feedback/complaints;

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[22] http://www.eu-patient.eu/campaign/access-to-healthcare/

[23] See the Baseline study on support services for carers across the EU, coordinated by Eurocarers in the framework of the Erasmus+ project TRACK: www.eurocarers.org/track/publications

[24] See EPF Value+ Toolkit, available at http://www.eu-patient.eu/whatwedo/Projects/ValuePlus/

- Ensure that online platforms for medicines safety monitoring and submission of patients' reports of suspected adverse reactions (now mandated by EU legislation) are genuinely user-friendly and easy to use, provide feedback and engage in continuing improvement with the involvement of users' organisations.

Hospitals and other care organisations

- Hospital boards, medical meetings and committees that determine policy and practice on patient safety should always include at least two representatives of patients/healthcare users, with equal rights to any other members;
- Hospitals should have someone, such as a patient liaison and/or ombudsman, who is independent and responsible for looking after the patient's interest (including but not only for patient safety issues).

Professional education

- Healthcare education programmes should include a specific focus on how to listen to patients, empathise and work in partnership with them, co-designed with patients, family members and patient organisations;
- Professionals should be encouraged to attend events organised by patient organisations as part of their continuing professional education, by giving them credits for such activities. Criteria for CPE credits should be readjusted to allow for this kind of collection of credits for vital non-medical skills and knowledge;
- Patient organisations should be involved in developing training curricula, in all training from basic to continuing professional education.

Communication

- Communication strategies should be put in place with multi-disciplinary expertise – existing tools can be shared and implemented in different contexts, willingness to learn and "do better" is essential;
- Patient-driven tools should be developed and shared to facilitate good communication for special needs, e.g. low health literacy, cognitive and other disabilities, to support interaction between patients and healthcare professionals.

Recognition of informal carers

- Awareness-raising and information is needed to tackle the stigma attached to caring; policymakers and professionals should engage with carers' organisations as a matter of course;
- Support services should be made available and their existence communicated to carers;
- legal frameworks.

Annex: Participants of the EPF Task Force

EPF would like to sincerely thank the following individuals for participating in the ad hoc Task Force and bringing their valuable expertise, perspective and input to enrich the draft document (in alphabetical order):

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