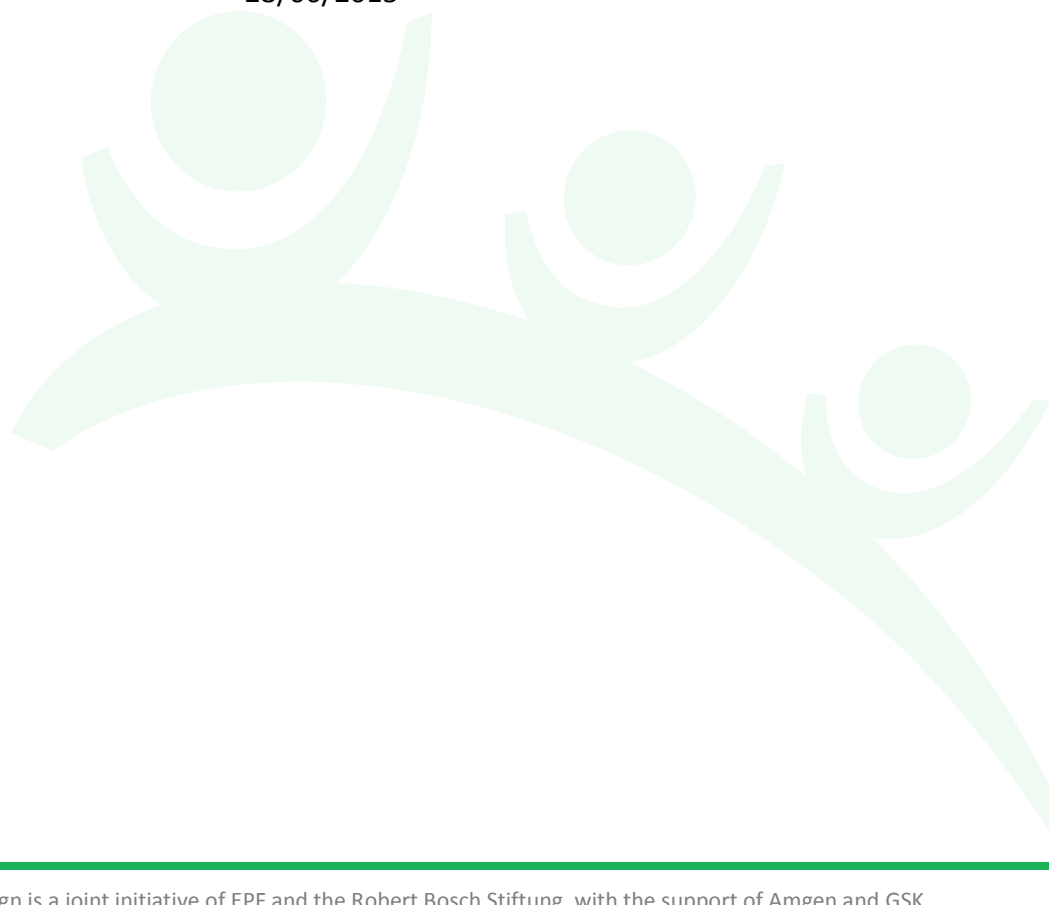


“EMPOWERED PATIENTS ARE AN ASSET TO SOCIETY”

Conference Report

20-21 May 2015
Thon EU Hotel, Brussels

28/06/2015



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1 Introduction

Patient empowerment can be defined in subtly different ways that reflect different perspectives – for example, those of policy-makers, health professionals and patients – and thus can lead to differently-weighted priorities and outcomes.

Patient empowerment is one of EPF’s fundamental aims, as reflected in its Strategic Plan 2014-2020:

“To promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition according to their preference, whilst raising awareness about their rights and responsibilities.”

The way in which chronic diseases are generally addressed is a good example of the way different perspectives on patient empowerment can lead to differently-weighted priorities and outcomes.

From the point of view of politicians and policy-makers, chronic diseases are seen as a sustainability challenge for European health systems. This is usually presented in terms of funding – “our health systems cannot cope financially with chronic conditions and the ageing population”.

But from a patient’s perspective, health systems are often unable to cope well with chronic conditions *because they do not meet patients’ needs*.¹ The systemic challenge is to overcome fragmentation of care, which often means that patients have to “fight the system” just to get the care they need.

Tackling chronic diseases effectively requires a fundamental shift from a disease-centred approach to a patient-centred approach², combining self-management in the community with well-integrated professional support through the life course. This implies the empowerment of patients and their involvement at every level in the healthcare system, ensuring active patient involvement in policy-making and in co-designing of care services to meet their needs more effectively.

Patients living with chronic conditions are sometimes referred to as “the most under-used resource in the healthcare system”. Patient-centred care models are already showing a contribution to higher quality of care, a better patient experience, as well as potentially lowering costs in the long term.

For several years, EPF has advocated strongly for patient empowerment to feature centrally in EU health policy-making. This is why EPF participated as a key partner in the EMPATHiE (Empowering Patients in their Health Management in Europe) Consortium, which delivered its final report on a mapping study of patient empowerment across the European Union, entitled “[Empowering patients in the management of chronic diseases](#)”, to the European Commission at the end of September 2014.

The report addressed the concept of empowerment as well as existing good practices, barriers and facilitators, and produced a number of recommendations regarding the key facets of patient



¹ See, for example, the EPF papers on [chronic diseases](#) (2012) and [healthy and active ageing](#) (2011).

² The terms “patient” and “patients” as used in this report should be taken to include the whole family.

empowerment, models of best practices and scenarios of future collaboration in the European Union.

The objectives of the Conference were therefore to:

- Explore the concept of empowerment, including key aspects identified in the EMPATHiE study: information to patients and health literacy; the new patient-health professional relationship and shared decision-making; and self-management, including the potential of technology;
- Explore existing good practices, challenges and pitfalls related to empowerment from the perspectives of different stakeholders;
- Reflect on approaches to operationalising and measuring patient empowerment;
- Outline and illustrate the current evidence-base and identify gaps and opportunities in relation to further research; and
- Launch the EPF Campaign on Patient Empowerment, with its slogan: “Patients Prescribe E⁵ for Sustainable Health Systems”.

The Conference – which brought together policy-makers from the EU Institutions and national levels, health professionals, health managers, patient representatives, non-governmental organisations and academics – lasted one and a half days and was conducted in English. It was structured around thematic plenary sessions and interactive debates with the audience, as well as parallel working groups, followed by a closing plenary which presented the key conclusions and proposals on the way forward.

This report presents the contributions made during the Conference in an edited and/or 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-june-2015/conference-on-patient-empowerment/>.



2 Setting the scene

2.1 WELCOME AND OFFICIAL LAUNCH OF THE CAMPAIGN

Anders Olauson, EPF President

Supporting patients to become empowered and actively involved at all levels was one of EPF's fundamental aims when it was first set up 12 years ago, and since then it has become an inherent part of the organisation's strategy. A very clear signal emerged from EPF's work on the EMPATHiE project regarding the need – and indeed the appetite – for a European strategy on patient empowerment. The importance of this Conference lies in stimulating fresh commitment and fresh ideas on how to take the outcomes of the EMPATHiE project forward in a concrete way.



Of course, a single conference – however good – will not change hearts and minds. This is why EPF is launching a major year-long campaign on patient empowerment; the first one ever at EU level. EPF believes the time is right to make patient empowerment known and understood in every part of Europe; but more, to make sure that it is seen as integral to ensuring high-quality, patient-centred sustainable health systems of the future. The campaign slogan says it all: “Patients Prescribe E⁵ for Sustainable Health Systems”. Patients are no longer passive – they are active, decisive, and assertive, ready to play their rightful role at both the collective and individual level, and if supported, they can make a difference to the sustainability of healthcare systems.



The five “Es” of Empowerment stand for:

Education: We can make informed decisions about our health if we have the appropriate education and information tools;

Expertise: We self-manage our condition every day, so we have a unique expertise and experience to contribute to the design and reform of health systems;

Equality: We can make decisions about our health in equal partnership with health professionals;

Experience: We are part of patients' organisations that represent us and channel our experience and our collective voice;

Engagement: We need to be engaged in co-designing more effective services and in research into new treatments – but we also need the engagement of wider society.

By the end of the campaign in June 2016, EPF hopes this will represent the beginning of a new era, with political buy-in for patient empowerment at all levels: recognition that patient empowerment is inherent to ensuring that health systems work for patients and for society as a whole.

“If this sounds ambitious, that is because it is – it has to be. This is our mandate for the Conference and indeed for the coming years. I am confident that every Conference participant will embrace this unique opportunity not only to share and deliberate on the huge challenges facing patients and our health systems today, but also to work together to orchestrate real change”

2.2 OPENING REMARKS³

Vytienis P Andriukaitis, European Commissioner for Health

How patient empowerment can be made functional and effective is no easy question. First of all, we need a change of mindset by both clinicians and patients themselves. While we have a lot to gain by involving patients in a joint decision-making process, decisions on final treatment belong to doctors. The success of the medical treatment they choose relates most of all to building trust, which begins with building partnerships with patients. This means making consultations matter, rather than making them longer.



Secondly, patient empowerment is very much related to the development of information and communication technologies in medicine such as eHealth and mHealth. The use of modern technologies is already driving patients to engage more actively, to maintain a healthy state, to manage a chronic disease or to change their lifestyle on receiving a diagnosis. More needs to be done to improve interoperability and standardisation of telemedicine and mHealth. The digital Single Market strategy for a digital European Union, which was launched in May 2015, will help us make progress.

Patient empowerment is a key aspect for the sustainability of healthcare systems. The Commission has launched a number of projects on the topic of patient empowerment, and EPF has been part of many of them. The EMPATHiE study analysed an area of critical importance: chronic diseases are associated with premature morbidity, loss of healthy life years and are responsible for 86 per cent of all deaths. Therefore, patient empowerment needs to be promoted in this context.

“I believe that engaged patients can change the quality of their health, but they can also influence how medical care is delivered in the future.”

2.3 WHY PATIENT EMPOWERMENT?

Robert Johnstone, Chair of Access Matters and Board Member of EPF and International Alliance of Patients’ Organizations (IAPO)

The [Alma Ata Declaration](#) issued by the World Health Organisation (WHO) as far back as 1978 stated that: “The people have *the right and duty* to participate individually and collectively in the planning and implementation of their healthcare”. It was declared in 2006⁴ that patient involvement is a common operating principle in the health systems of the European Union. However, today this is still not the patient’s experience on a daily basis.



There is a need to change attitudes and move healthcare systems towards making patient empowerment a practical reality for all. Patient empowerment also brings wider benefits. Healthcare systems face challenges

³ The Commissioner’s speech (video) can be found at: <https://www.youtube.com/watch?v=fj1QThwrApY>

⁴ 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>

relating to chronic disease, ageing and technology, and there are also financial constraints – the “sustainability challenge”. But today, healthcare systems are largely *not working for patients*; all too often, the patient is a passive recipient of care rather than an active and equal partner. Far from being cost drivers, 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 health⁵) 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 means being recognised by health professionals as a key partner in care, but it does not mean shifting responsibility onto patients inappropriately.

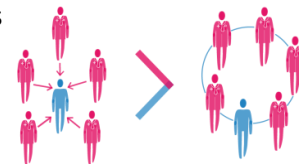
Choice of definition shapes the realisation

EPF’s definition refers to a non-binary, non-linear process:

“Patient empowerment is a process that helps patients gain control over their lives, increasing their *capacity to act* on issues that *they themselves* define as important... a process through which patients *individually and collectively* are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take action to meet those needs.”⁶

This cannot be imposed from the top down, nor will it involve a revolution from the bottom up – change needs to be effected at all levels, through both individual and collective action by patients.

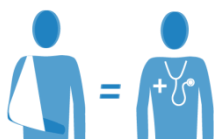
EMPATHiE’s working definition⁷ shows how empowerment manifests itself in concrete action. An important element of this definition is that healthcare systems should “*aim to equip patients...with the capacity to: participate in decisions related to their condition to the extent that they wish to do so; [and] become “co-managers” of their condition in partnership with health professionals*”. Experience shows repeatedly that patients have practical coping skills for specific aspects of their condition, but currently healthcare systems do not give patients permission – and certainly do not encourage them – to use those skills to make certain decisions.



A culture change is needed in order to design healthcare around patients’ needs

Empowered patients can be seen as a threat by some health professionals, but what patients seek – and what health professionals need to accept – is simply a change in the balance of power to recognise chronic patients as experts in their own care *by experience*. This change can be achieved by focusing on education and training for health professionals.

Only the patient sees his/her whole journey through the healthcare system, so involving patients in the designing of healthcare systems results in services that meet the real needs of patients. The right methodology is crucial: **patient experience is not limited to patient satisfaction surveys**, and it serves as a signal to what is occurring (both good and bad) in the system. So there is realisable value in involving



⁵ “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)

⁶ Adapted from the EU’s Joint Action for [Patient Safety and Quality of Care](#) (2012).

⁷ See “Empowering patients in the management of chronic diseases”, p.7.

patients in the assessment, planning, designing, implementation, continuous evaluation and improvement of healthcare systems. In practical terms, this means involving patients' organisations (repositories of multiple individual patient experiences) at the policy and provider levels. Continuity is also vital: one-off consultations are unlikely to achieve the necessary systemic changes.

2.4 THE CASE FOR PATIENT EMPOWERMENT

Angela Coulter, Nuffield Department of Population Health, University of Oxford



Much of the way healthcare is delivered at the moment assumes that health professionals have all the answers and that the patient's role is entirely passive. Once we stop disempowering patients, they can begin to empower themselves.

Of the many ways in which patients can be empowered and engaged in their own healthcare, here it would be useful to focus on just three: health literacy, shared decision-making, and strengthening self-management of chronic conditions.



Health literacy

Health literacy is very important; there is a huge thirst for information about health. At least 80% of patients in the UK actively seek information via the Internet about coping with health problems. Information on its own can be empowering, but patients need access to reliable answers to their questions at the time when they need it. "Health literacy is not just about the passive absorption of information; by my preferred definition ('The capacity to obtain, process and understand health information and *to use it* to make decisions about health and healthcare') it is a dynamic, interactive process. This is why I disagree with the Health Commissioner when he says that the final decision on treatment rests with the doctor – we must persuade him and many others that it must be a shared decision by the patient and the doctor."



A recent survey⁸ showed that people with better health literacy also seem to experience better health. Although this is not a definitive view, it does point to the importance of health literacy in terms of patients' perceptions and their real situation. This benefit to society has also been highlighted by the WHO⁹: limited health literacy negatively affects health, reinforces health inequalities, especially among poorer populations, and leads to higher healthcare system costs. Health literacy is affected by context, culture and setting, and building personal health literacy skills is a lifelong process.

Shared decision-making

“Shared decision-making is a very important concept, but we should clarify what it is exactly and when it is appropriate. My preferred definition of this is: 'Clinicians and patients working together to select tests, treatments, management or support strategies, based on clinical evidence and the patient's informed preferences.'”

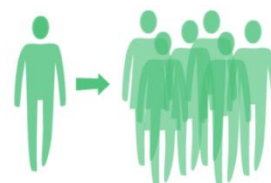
⁸ Produced by the European Health Literacy Project (HLS-EU), 2009-2012.

⁹ "Health Literacy: The Solid Facts", WHO Europe, 2013:
www.euro.who.int/_data/assets/pdf_file/0008/190655/e96854.pdf

It is appropriate in a variety of contexts: one-time decisions for tests or treatments; chronic care-management decisions; and wellness and health-promotion decisions.

The key to understanding this concept is to recognise that in every medical or health decision, there are at least two sources of expertise for making a good choice. The clinician has had lengthy and extensive medical training; but only the patient knows his/her attitude to risk, how the illness is experienced in his/her particular social circumstances, and his/her values and preferences.

One of the problems is that information which supports the process of shared decision-making, especially when obtained via the Internet, is often unbalanced. It tends to give an exaggerated view of the benefits of a medical intervention and rarely talks about risks or uncertainties, and so is biased in favour of more treatment. One source of unbiased information is Patient Decision Aids, which are evidence-based and designed to give the facts on options and outcomes, but also to encourage the patient to think about what matters to him/her, to facilitate the process of deliberation.



Patient Decision Aids can help to address the significant gap that often emerges between the patient’s own goals and concerns regarding a treatment decision and the clinician’s assumptions regarding the patient’s goals and concerns¹⁰. One of the largest systematic reviews¹¹ in the [Cochrane Library](#) shows that use of Patient Decision Aids led to: greater knowledge for the patient; more accurate risk perceptions; greater patient comfort with decisions; increased patient participation in decision-making; better agreement between values and choice; and fewer patients choosing major surgery.

Managing chronic conditions

If one makes the generous assumption that a health professional will spend on average 3 hours per year (one 15-minute consultation per month) in direct contact with a patient living with a chronic condition, that leaves 8,757 hours per year during which the patient must manage his/her own condition. Therefore, **self-management support is central to dealing with the biggest problem for every healthcare system in the EU: how best to manage chronic conditions.**

Personalised care planning can address this problem. Recognising that the patient’s goals (e.g. “to better manage my pain relief so I don’t wake up at night”, “to have the same person caring for me from 9am to 3pm so my parents can go to work”, etc.) may differ from the clinician’s goals, it encourages a conversation between the patient and the clinician to jointly agree goals and actions for managing the patient’s health problems. This process must be planned/proactive, anticipatory, collaborative, targeted, holistic and must be regularly reviewed.



There is good evidence¹² that this collaborative and much more empowering approach is effective, leading to better physical and emotional health and better capabilities for self-management.

¹⁰ See, for example, Sepucha K et al., Developing instruments to measure the quality of decisions: Early results for a set of symptom-driven decisions, *Patient Education and Counseling* 2008 73:504-510.

¹¹ Stacey D et al., Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 2014.

¹² Coulter A et al., Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database of Systematic Reviews*, 2015.

Traditional practice styles create dependency, discourage self-care, ignore the patient’s preferences, undermine the patient’s confidence, do not encourage healthy behaviours and lead to fragmented care.

2.5 KEY POINTS FROM THE DISCUSSION

- **Low levels of general literacy, language problems and other barriers to access** among specific populations must be addressed. Evidence shows that when such groups are targeted with the right strategies, they benefit most from health literacy campaigns. The health literacy process also needs to be personalised at the point of delivery.
- There is a strong argument for **formalising the function of expert patient advocates** within healthcare systems: patients with extensive experience in self-management could be employed as “health navigators” for the newly-diagnosed, tasked with guiding the new patient through the symptoms, possible treatment regimes, potential/actual social issues and other aspects of living with a chronic condition. Evidence shows that peer education is often more effective than institutional channels. Organising the training of expert patient advocates through patients’ organisations could also facilitate economic activity by patients who might otherwise be excluded from working.
- **eHealth and mHealth** offer huge potential for patient empowerment, but there is a need for real political will by Member States to engage with all stakeholders to ensure that eHealth and mHealth projects result in systems that are genuinely user-driven and widely interoperable. Also, the development of mHealth must include a harmonised certification process, to ensure that data uploaded to the thousands of mobile applications is not misappropriated or misused.

The results of a number of eHealth and mHealth evaluations are now emerging, and they are largely disappointing. One of the basic problems is that investors and developers are taking technological innovation as their starting-point rather than identifying problems from the patient perspective and then devising solutions. The result is that we have a lot of very clever kit in search of a problem to solve. This gap must be closed: we need more engagement with the patient experience in order to realise the enormous potential for eHealth and mHealth to empower patients.



- **The pressure for real change** towards patient empowerment is coming from the patients’ organisations; they are becoming much more focused in terms of what they are asking for, and the politicians are starting to listen. There are plentiful references to patient-centred care, shared decision-making and health literacy in policy documents, but costs are increasingly driving government decisions on health. What has not been tried so far is to embrace patient empowerment on a scale that will produce significant cost savings and other benefits. Given today’s new situation, there could soon be a cultural revolution in healthcare delivery.



Talking positively is easy; making it happen on the ground is the real challenge.

3 Patient empowerment in real life

3.1 ARE YOU THE PATIENT’S PARTNER? DANISH INITIATIVES IN EMPOWERMENT

Dr Camilla Noelle Ratchke, President of Junior Doctors’ Association (JDA), Denmark

It is true that some doctors can appear to “block” patient empowerment, so it is very important to bring them on board. Current initiatives¹³ that involve the JDA – which is a trade union, hence a stakeholder in the Danish healthcare system – are proof that doctors can be active in promoting patient empowerment on the ground.

The “Hello Healthcare” initiative

Launched by the Danish Society for Patient Safety (DSPS), the “Hello Healthcare” initiative to increase patient safety has been driven by the recognition that, although standards generally are high in the Danish healthcare system, the quality of care *as experienced by the patient* poses some problems. A September 2014 study of the patient experience sponsored by the JDA has shown that – despite receiving treatment delivered in a professional, respectful and friendly way – one in four patients had unanswered questions, usually relating to what their particular condition meant to them, their lifestyle and their future. Typically, from the patient’s perspective the barriers involved: a strong perception that staff were too busy to answer questions; the fear of being a burden on the system; and the feeling that it was inappropriate to question the information given by health professionals.



The findings of this study say something about communicating information, but also about attitudes among health professionals to inviting patients into a dialogue. Printed material and advice to patients as part of health literacy campaigns only go so far; what makes a real difference is health professionals encouraging patients to pose any question they may have as part of an exchange. The “Hello Healthcare” initiative has produced and widely distributed a leaflet entitled “Thanks for Asking”, which gathered together a number of questions which patients and their families have found relevant to ask during various stages of treatment. The leaflet also encourages patients to ask their own questions. A November 2012 patient survey co-sponsored by the DSPS showed that by using this leaflet, 40 per cent of patients felt they had a more active dialogue, 86 per cent felt they had a positive outcome in the exchange, and 56 per cent would recommend the leaflet to other patients. So, patient empowerment begins where disempowerment ends – with dialogue.

“Patient empowerment begins where disempowerment ends – with dialogue.”

“We treat human beings – not just diseases”

The JDA policy paper on patient empowerment involved asking a range of patients’ organisations what they need from the healthcare system and what they want from clinicians. One important thing to remember is that no clinician is trained to raise barriers to patient empowerment – the

¹³ The JDA prefers to use the term “initiative”, which implies a series of beginnings, rather than “campaign”, which tends to suggest a beginning and an end.

patient is the reason people become doctors. The issue is one of changing the culture and attitudes among health professionals.

However, achieving this requires a dual approach: professional organisations must aim to raise awareness and educate their members, but there is also a need for structural and organisational changes decided at the policy level. It is unfair to simply accuse a clinician of communicating badly when the system allows him/her just 10 minutes from the time the patient enters the surgery to the time the next patient enters.

The JDA carried out a survey of just under 3,000 of its members (around 25 per cent of the total) in March 2014 regarding attitudes to contact with the patient. This showed that:

- 9 out of 10 members thought that patient contact suffered because of too much focus on efficacy and production (the term widely used to refer to the processing of patients through the system);
- 9 out of 10 members wanted more co-operation with patients;
- 7 out of 10 members felt they did not have enough time with the individual patient; and
- 7 out of 10 members thought organising delivery of care differently would improve contact with patients, leading to a rise in patient-experienced quality – and were willing to change the way they work in order to achieve this.

3.2 EQUIPPING PATIENTS WITH THE SKILLS AND KNOWLEDGE TO TAKE AN ACTIVE ROLE: THE “PATIENTS’ UNIVERSITY” IN BULGARIA

Roza Cheglajska, National Patients’ Association, Bulgaria

The “Patients’ University” programme was started in Bulgaria by the National Patients’ Association (NPO) in 2012, having been developed first by the Spanish Patients’ Forum. This long-term project aims to deliver information to patients with chronic diseases, who very rarely receive the education they need about their condition and how to manage it. Patients in Bulgaria also often struggle to access medication.

The aims of the programme are: achieving an effective dialogue with the patient; offering patients the opportunity to be trained by a fellow patient with a similar condition; integrating various professionals involved in the treatment; and improving patients’ self-control and discipline in managing their condition, thus leading to improved adherence to treatment.

Currently, there are more than 8,500 patients with chronic diseases and over 370 medical specialists in the programme, which uses outpatient facilities, hospitals, schools, universities and other locations.

Training in the 11 disease faculties/modules currently available takes three forms over the course of one month: individual meetings and seminars (using educational materials), followed up with telephone consultations via a call-centre staffed by trained medical professionals; the dedicated website created by the NPO is an additional channel of information and support. Each disease module is personalised as much as possible – typically this element is missing from the everyday patient experience, which is why clinicians lose their connection with the patient.

Three months after the training, the NPO follows up with him/her for feedback on the progress in treatment, the patient-doctor relationship and any issue relating to the treatment process. The NPO then maintains contact with each participating patient on a six-monthly basis, supporting the empowered patient-doctor relationship.

3.3 PATIENT EMPOWERMENT “IN REAL LIFE”: CHALLENGES, RISKS, SOLUTIONS? – PANEL DISCUSSION

Hilary Doxford, Vice-Chair of the European Working Group of People with Dementia (EWGPWD)

Aneela Ahmed, young patient

Michele LeVoy, Director, Platform for International Cooperation on Undocumented Migrants (PICUM)

Dr Camilla Noelle Ratchke, President of Junior Doctors’ Association (JDA), Denmark

Hilary Doxford: I was diagnosed with early-onset Alzheimer’s in 2012, a full seven years after I first sought medical advice on an emerging problem. Those seven years were marked by frustration at



my declining cognitive abilities and memory, but also by disempowerment due to a systemic failure to engage with me. On my first visit, after giving my GP a clear and concise view – with examples – of my problems, he replied: “What do you want me to do about it?”. My empowerment began with a correct diagnosis – I understood what my problems were, I felt relief and was able to begin to take control of my disease rather than letting it rule me. In my experience as an informed patient in the early stages of my disease, clinicians involved in research are much more open to

discussing the patient’s own ideas for treatment, hence to patient empowerment. Patient empowerment has a very specific aspect for dementia patients, as generally they need more time to formulate and express their thoughts; in the later disease stages, when the ability to receive and assimilate information and then act on it is continuously declining, patient empowerment is far more problematic. There is another issue specific to dementia patients: carers can often pose a barrier to patient empowerment by speaking for the patient *to the exclusion of the patient*.

Aneela Ahmed: My journey as a type 1 diabetes patient began when I was a child and actually disempowered – it was my mother’s insistence on a blood test that led to a timely diagnosis of my condition. From that start, we built a good relationship with the paediatric team, and everything went well for six months, until it was decided to begin my transition

from paediatric to adult care. For young patients, the biggest issue is that this transition dismantles or removes relationships that are specifically tailored to engage effectively with them, replacing them with a patient experience that tends to be less engaging. The burden then shifts onto a still-maturing person to become an informed patient and to seek patient empowerment on the same terms as fully-developed adult patients. Patient empowerment should therefore be started at an early age – in schools and universities, i.e. when



young people are already being educated in other things. Constantly learning, changing and questioning their healthcare is the best thing young patients can do for themselves.

Michele LeVoy: The majority of undocumented migrants are healthy when they come to the EU, but their particular living and working conditions often contribute to their general need to seek medical treatment. The experience of the migrant journey itself and fear of deportation can also generate mental health problems. However, the lack of ID and fear of deportation together form the greatest barrier to access to medical treatment; so the patient empowerment agenda for undocumented people is intrinsically linked to the equity of access to healthcare agenda. For undocumented migrants and their children, legal entitlements to healthcare and payment requirements vary widely across the 28 Member States, but in practice there are other barriers to access: lack of awareness, complex rules, communication/language issues, prejudice, etc. Even when a legal entitlement exists, access is governed more by fear of contact with authorities, so a high percentage of undocumented migrants will not seek medical care or will only do so when seriously ill, favouring emergency systems or parallel systems provided by NGOs. Other issues include: a worsening of health status because of poor living conditions and delay in seeking care; the lack of continuous care; and problems in access to specialist care. What needs to change includes, first and foremost, providing equal access, changing national legislation on entitlement if necessary; introducing a “firewall”, i.e. no transfer of personal data between healthcare providers and immigration authorities; ensuring access to information about entitlements; and changing the way we talk about and to irregular/undocumented migrants, moving away from stigmatising people through terminology.



“There is no such thing as ‘an illegal patient’ – a patient is a patient.”



3.4 KEY POINTS FROM THE DISCUSSION

- **The perception of a lack of communication by doctors** tends to ignore the time-constraints and other pressures under which clinicians are obliged to work: e.g. doctors in Slovenia, The Netherlands and parts of Spain only have seven minutes per patient. In Denmark, for example, the learning of communication skills is integrated into early medical training and revisited during professional development. However, although clinicians can regard themselves as the patient’s partner, time-constraints and other pressures tend to promote a different culture. Doctors are human beings; if they are put in a difficult situation then the outcome for the patient is likely to be less satisfactory. Patients’ organisations must work with professional organisations to promote positive change in the environment for healthcare delivery; expert patients, nurses and pharmacists could play a more formal ancillary role. Better use of existing technology and best practice could also improve the exchange and distribution of information as a way to maximise the benefit of face-to-face consultations.
- The specific reality of **treatment for some patients involves multiple visits to many different specialist providers** as necessary, so the starting-point for patient empowerment in such cases has to be good co-ordination of patient information between professionals within the healthcare system. Resource-allocation can also be a determinant: for example, in Estonia, where doctors are very interested in working with the relatively few patients with spina bifida and hydrocephalus, the authorities’ refusal to fund one administrative assistant post has shifted onto the patient the burden of identifying potential providers and then arranging and co-ordinating appointments.

4 Parallel workshop sessions

The afternoon of the first day of the Conference featured three parallel workshops over two sessions, which aimed to address three key aspects of the EMPATHiE study in more depth. The outcomes of the workshops form an initial contribution to the development of a Charter of Patient Empowerment and a Multi-Stakeholder Roadmap over the next 12-18 months.

4.1 WORKSHOP 1: HEALTH LITERACY AND THE INFORMED PATIENT

Health literacy was identified in the EMPATHiE study as a fundamental aspect of empowerment. Access to high-quality information is a key facilitator of empowerment, just as lack of access is a key barrier.

Fundamental principles of empowerment

- Information is accessible: The right information must be available in the right amount and at the right time. A graduated approach should be applied: from the most basic information to the most complex.
- Communication is tailored: Both the content *and* the communication approach should be appropriate to different needs (of individuals, groups, etc.).
- Information is of high quality – accurate, comprehensive, understandable, consistent, transparent and evidence-based...



- ... and developed with meaningful patient involvement: Information is a patient’s right which needs to be implemented, applying a partnership approach involving all stakeholders – nothing about patients without patient involvement.

Key action areas

- Assess patients’ needs: Opinion polls and consumer surveys are not always reliable, so ask the patients! This can be done through patients’ organisations, for example.
- Develop and implement quality guidelines at both the EU and national level. These should be developed *with* patients’ organisations, based on existing good practice and evaluation of their usefulness. Online resources and mobile apps should be subject to a “quality seal”.
- Implement health literacy education in schools, applying a life course approach that includes skills to appraise information critically and media literacy, as well as basic science literacy.
- Educate health professionals to communicate with patients: Start by assessing the current level and process of education, then develop a core set of (soft) skills to be integrated into curricula.

4.2 WORKSHOP 2: THE NEW PATIENT-PROFESSIONAL RELATIONSHIP

Ensuring that health professionals have the right skills, knowledge and attitudes to practise patient-centred healthcare is a key factor in patient empowerment. Training needs to be oriented towards patient-centred values and patient involvement, including shared decision-making and soft skills such as communication, empathy and partnership. This also involves a culture change and a shift in the perceived roles of patients and professionals. This workshop explored what is needed to drive that culture change, and what professionals and patients can do within that process.

Fundamental principles of empowerment

- Empowerment is a principle regardless of age and ability. Some patients may need more encouragement or a different approach.
- Patients must participate as co-designers of programmes and principles (policy-making): This must be done with sensitivity to context (particular countries/regions, themes), as there are many national and social issues which carry particular importance, but it is also an excellent opportunity to share experiences and best practice between Member States. Positive examples must be taken into consideration when strategies are formulated.
- “Nothing about me without me”: Patients and healthcare professionals should show mutual respect of their respective competencies. Applying the concept of managing risk through informed choice, all healthcare professionals must be well-prepared to exchange information with patients, who should also prepare before a consultation. Both sides of the dialogue should identify and express desired outcomes – shared knowledge reduces the risk of the “silent misdiagnosis”¹⁴.



¹⁴ See, for example: Mulley A, Trimble C, Elwyn G., “Patients' preferences matter: stop the silent misdiagnosis”, London: The King's Fund, 2012.

Key action areas

- Introduce patient empowerment campaigns as soon as possible, e.g. using EPF's E⁵: The aim should be to equip patients with tools that are recognisable by healthcare professionals, e.g. by ensuring that there is significant overlap between Decision Aids for patients and healthcare professionals. The emphasis should be on local, bottom-up initiatives, using existing networks more effectively.
- Agree what should be a matter for legislation and what for motivation regarding patient participation in the co-design of programmes and policy making – charters might be a compromise solution. Indicators for healthcare performance and healthcare evaluation must be more flexible; the training of healthcare professionals should be patient-centred rather than disease-centred, and should involve patient input.
- Mutual respect between patients and healthcare professionals is a long-term goal and cannot be legislated; human rights in healthcare must be emphasised throughout the EU. Promote more sociological research on shared decision-making.

4.3 WORKSHOP 3: THE ROLE OF SELF-MANAGEMENT IN CHRONIC DISEASE

Self-management is a key aspect of patient empowerment, and overall there is positive evidence on self-management support programmes. Patients with chronic conditions have many common needs, such as building confidence and self-efficacy, interacting effectively with healthcare providers and navigating the healthcare system. Technology can help, but is it the answer? This workshop looked at the potential of self-management education, including the use of innovative tools such as eHealth and mHealth in supporting patients as they manage chronic conditions in daily life.

Fundamental principles of empowerment

- The starting-point of empowerment is an individual patient's need to self-manage his/her care in the context of personal goals, values and situation.
- The process of empowerment is very dynamic and needs can vary significantly from time to time, so the support environment should take this into account and be adaptable.
- Empowerment depends on the quality of interaction within an optimal facilitating environment; this applies both to human interaction and sources of information.
- Empowerment is a highly information-driven process which could benefit from developments in technology; currently, solutions are lagging behind technological developments.
- Empowerment is a matter of building confidence, knowledge and learning skills...together. This process can begin before the onset of a disease, and as early as school-age.



Key action areas

- Stakeholders, led by patients' organisations, should work together on disseminating best practices at different levels (local to EU).

- Develop competencies for professionals to support self-management; adapt the relevant technology (eHealth) for the same purpose.
- Ensure patient access to tailored/personalised health information and communication tools.
- Ensure that patients are educated and kept informed throughout their journey;
- Services, information and technology should be made functional across the system from the patient’s perspective. This requires that both systems and surface processes should be interoperable, using patient input as the starting-point.

5 Developing an evaluation and research agenda

5.1 CAN PATIENT EMPOWERMENT BE MEASURED?

Dr Julia Röttger, Department of Health Care Management, Technische Universität Berlin

Today there is no clear answer to the headline question, but one can obtain an overview of indicators to assess patient empowerment, and focus on particular indicators used in large-scale studies and/or healthcare system comparisons (by the WHO, OECD, Commonwealth Fund, Health Consumer Powerhouse, etc.). This can generate a discussion regarding existing gaps and whether we are measuring the right things.



One can cluster indicators that apply at the individual level and the system level in a matrix (figure 1), and then assess each of these indicators in terms of the extent to which they are process-oriented (facilitators/barriers for patient empowerment) or outcome-oriented (producing a level of achieved empowerment) at each of the two levels.

Since patient empowerment is not included currently as an indicator for healthcare system assessment, to what extent is it captured by the existing indicators? In relation to the aims of a healthcare system, the WHO includes the level and distribution of “responsiveness”, whilst the OECD refers to the level and distribution of “responsiveness/patient-centredness” and “access”.

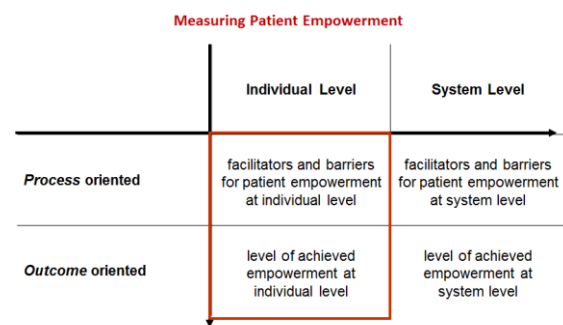


Figure 1

The process followed in large-scale surveys divides and then sub-divides a country’s whole population to derive a subset of people who enter into direct interaction with the healthcare provider. The experience of this final subset can then be measured in terms of four main categories: respectful treatment, autonomy/shared decision-making, communication and confidentiality. For patients living with chronic conditions, coordination/continuity of care can also be included.

In terms of access to healthcare, the WHO’s World Health Survey (2002-3) focused on choice of provider and waiting times compared to costs/co-payments, and then featured results measured by unmet need/foregone care and all four of the main measures for direct interaction with the provider. On the other hand, the Commonwealth Fund (2006) surveyed sicker adults (i.e. included patients living with chronic diseases), which resulted in greater focus on waiting times and costs rather than choice in terms of access to healthcare, and greater focus on the first three of the four

main categories for measuring the direct interaction with the provider (more on shared decision-making, less on confidentiality), plus greater focus on coordination/continuity of care.

If we apply the matrix devised earlier to these findings, we see that certain indicators (respectful treatment, choice, communication and autonomy/shared decision-making) allow us to say that we are measuring patient empowerment *to some extent* in terms of *process-oriented indicators* at the individual level. However we do not yet have the indicators that would allow a genuine measurement of patient empowerment *as an outcome*.



At the individual level, there are large-scale/comparative studies (e.g. the Patient Activation Measure, the Empowerment Scale, the Patient Enablement Instrument) which use mainly indicators related to facilitating patient empowerment, but such indicators were not really designed to *measure* patient empowerment.

At the system level, we know of three organisations (the European Observatory on Health Systems and Policies, the OECD and the Health Consumer Powerhouse) that try to set levels/indicators for patient empowerment at the European system level in a comparative way. It is possible to cluster the indicators used by these organisations under five headings:

- patients' rights (example of indicators used: healthcare law based on patients' rights);
- complaints procedures (e.g. no-fault malpractice insurance);
- choice (e.g. right to a second opinion; cross-border healthcare);
- public participation (e.g. patients' organisations involved in decision-making; an active role for patients' organisations in decision-making in health technology assessment, hospital planning); and
- information (e.g. access to own medical record; availability of information via Internet or 24/7 telephone line; provision of list of providers with quality ranking).

Certain indicators (complaints procedures, patients' rights, information and choice) are *mostly process-oriented* in terms of measuring patient empowerment, whilst *public participation indicators are outcome-oriented* to an extent that could allow the measuring of achieved patient empowerment at the system level.

In conclusion, a wide range of indicators to assess facilitators/barriers for patient empowerment exist and are being used, and several scales to assess patient empowerment *indirectly* also exist. However, patient empowerment and related concepts are hardly measured *widely and directly as an outcome* in comparative studies; instead, all of the measures tend to focus on the direct patient-doctor interaction (process). There is a wide range of possible indicators to measure patient empowerment at the system level, and some of these are already being used for comparative studies; but the availability of national data varies considerably (e.g. plentiful data for Germany, negligible data for Croatia), which can negatively impact international comparative studies and prevent any attempt to establish a reliable baseline measure. Finally, it is very important to *measure inequality* in all of the assessments that are conducted – *are all patients empowered, or only certain individuals* (e.g. those with a strong educational background)?

5.2 KEY POINTS FROM THE DISCUSSION

- There is **no common basis for international-level comparison** because different bodies of data are derived differently (e.g. OECD versus the European Observatory), in terms of classifying professional activity, performance, etc. from one country to another. Also, the way the available data is presented in international-level assessment frameworks tends to oversimplify/flatten or even exclude some national features, so for a useful comparison one would have to dig deeper for the underlying determinants of the data.
- Another important factor is **the way a question is framed**: this can to some extent predetermine the resulting data and thus prevent a good degree of comparison. So, certain indicators may be useful at the regional or international level, but others may only be useful for national comparison.
- **Health includes mental health**, which is also a social issue. Therefore, for a meaningful assessment/ comparison of its impact we would need to collate data from all relevant assessment frameworks (e.g. social security systems), not just health-related frameworks.
- The **Patient Reported Outcome Measures (PROMs) approach** used in the UK to assess the quality of care for certain procedures from the patient perspective might provide a useful starting-point for examining how best to produce data from the patient perspective in order to measure patient empowerment. A further step might be to devise **patient-defined** outcome measures rather than PROMS, because then we would be measuring the things that matter directly to patients.
- One challenge is that **many important aspects of patient empowerment are qualitative**, and so do not lend themselves easily to a quantitative data-measuring approach. Qualitative data certainly offer a better insight into what is really happening, but comparing them is difficult, because important facets can be flattened or obscured in the process of aggregating results for comparison purposes. Broadly speaking, **qualitative research can help identify the right questions to ask in order to produce quantitative data, and can then help towards a better understanding of that data.**
- **A single index** is neither desirable nor attainable; the key is to interpret the available data correctly within a clearly defined context.



6 Where do we go from here?

6.1 PATIENT EMPOWERMENT: THE POLICY CHALLENGE

Dr David Somekh, European Health Futures Forum and EMPATHiE Consortium

Every now and then a project has the good fortune to serve as a catalyst for progress in a policy area. Building on years of advocacy by organisations like EPF and EHFF, the EMPATHiE project in conjunction with EPF's campaign on patient empowerment has ensured that this very important aspect of health policy is firmly on the European policy agenda.



Currently, the burden on our healthcare systems is a key issue in policy-making circles. The concern is that healthcare systems are not sustainable, so radical action is needed to ensure high-quality healthcare in the future. It is no accident that the EU Health Commissioner is referring positively to the beneficial outcomes (including cost savings) which patient empowerment can bring. Up to now, lip-service has been paid to patient empowerment, so perhaps the opportunity to change things for the better in practice has arrived.

Resistance to change: the problem of culture

As well as being large and complex, healthcare systems are very resistant to change. Innovative improvements appear regularly in a scattered way across systems, but one of the reasons they are unlikely to be generalised and sustained over time is the very slow progress in changing attitudes and behaviours among healthcare professionals and patients. The most obvious barrier relates to vested interest, coupled with the more familiar anxiety related to any kind of change of the status quo.

eHealth has potential, but the real challenge is not to be found in technology, it is in human interaction. Sending our data electronically to a clinician or having an exchange via the Internet does not automatically equal good communication; paradoxically, it may prevent us from communicating what we would really want to say in a face-to-face consultation.

The evolution of the policy agenda

To take an example from the past, patient safety had been talked about for some years but only appeared on the European Commission's agenda around 2003, when a particular set of circumstances allowed the issue to be raised prominently. Just like with patient empowerment, there was a strong financial argument which convinced the politicians to take action – but it took another five years before there was a Council Recommendation on patient safety (in 2009). Since then, there has been steady acceptance by Member States that strategies should be implemented at national level, and the Commission has been monitoring progress on implementation. Nevertheless, progress and outcomes have been very patchy.

This experience shows that getting patient empowerment on the policy agenda is just the start. One cannot ignore the fact that healthcare systems are very slow to change, mainly due to the complex cultural changes that are required, so the pressure must be maintained.

Change over time

Once the principle of patient empowerment is fully accepted politically at different levels, two key elements are needed:

- Better health literacy, so that citizens are better informed about the health aspects of lifestyle choices and patients better understand the problems healthcare professionals may have in meeting the new roles they are expected to undertake; and
- Education of healthcare professionals to have a holistic approach to the patient – training them to see him/her as a person rather than a collection of symptoms to be “managed”.

These two elements can be addressed immediately through the systematic introduction of programmes, but they will only become embedded in the healthcare system as attitudes change over time.

What positive action can we take right now?

- Seize the moment – there is a genuine window of opportunity to get patient empowerment onto the policy agenda in a more meaningful way;
- Build on recent research initiatives in the area of health literacy and self-management of chronic conditions to convince the doubters with data;
- Seek to bring about a Council Recommendation on quality in general, or patient empowerment specifically, including support from the European Parliament;
- Start practical exploration of the policy scenarios for European co-operation identified in the EMPATHiE project; and
- Support the year-long campaign, led by EPF!

6.2 THE EUROPEAN COMMISSION’S PERSPECTIVE

Maria Iglesia Gomez, DG SANTE, Head of Unit D2 (Healthcare systems)

Everyone agrees that patient empowerment is a good thing, but it is also a complex issue requiring cultural changes over time. Patient empowerment cannot be legislated; it will take the involvement of a whole range of actors, working on a co-ordinated basis as they each take different steps. The EPF campaign on patient empowerment is one of those important steps.



The Commission is currently engaged in helping the Member States to reform their healthcare systems to make them more effective, more accessible to patients and more resilient. Each of these three pillars of the Commission’s agenda has implications for patient empowerment.

Strengthening effectiveness

The effectiveness of healthcare systems depends on reliable performance assessment frameworks. The current task is to help Member States devise common methodologies, indicators and models to measure and compare reliable data together. The Commission has set up an expert group on Health System Performance Assessment (HSPA) with Member State representatives as part of the reflection process on sustainability of health systems.

The first of two priorities is to find a common approach to defining quality and the indicators for measuring it, including effectiveness and patient experience (empowerment, satisfaction, safety and patient involvement). The expert group will deliver its report on quality at the end of 2015 or in early 2016.

The second priority identified is integrated care, integrating social and health services at national level, which is a difficult challenge. The report of the expert group on integrated care will be delivered in 2016.

Increasing accessibility

The Commission has identified three main initiatives to improve access and coverage for all citizens.

Planning of EU health workforce: Ensuring sufficient levels of properly-qualified staff involves addressing mobility. The Commission has a Joint Action that deals with planning, skills and the “brain drain” from some countries, and is identifying recommendations for action.

Cost-effective use of medicines: When addressing innovation in medicines and medical devices, the key question is “who pays?” The question becomes especially challenging when a country is facing budget cuts. The Italian Presidency’s Conclusions adopted in December 2014 said that innovation should be for the benefit of patients. The Commission is currently consulting the Presidency trio on their preferred policy topics – the participation of patients’ organisations is very important.



Optimal implementation of the Cross-border Healthcare Directive: Member States have to reform their healthcare systems in order to fulfil their obligations under this law, including greater transparency of the healthcare systems. The Commission is currently monitoring compliance with the Directive; it wants to launch measures to accompany the Member States to make what is contained in the legislation a reality.

Improving resilience

Resilience means making efficient use of the instruments available to each healthcare system to be able to continue to get its work done. The Commission has identified two areas for action: collecting data in order to be able to work on the HSPA, including an initiative to improve collection of patient data at national level; and eHealth, addressing the differences between Member States in terms of the size and scope of their technological resources to ensure common standards and interoperability.

Next steps

Patients are the central element in every part of the EU health agenda, which is why the Commission is paying particular attention to patient safety and quality of care. It is committed to developing a framework for EU collaboration to facilitate the exchange of practices between the Member States and to co-ordinate different policies. What underpins the current agenda is the determination by DG SANTE to help Member States go from policies to implementation. This will involve inviting all actors to join a common process with the Member States and the Commission in its patient safety and quality of care initiative.



6.3 THE WAY FORWARD: PRESENTATION OF THE EPF THEMATIC CAMPAIGN

Cynthia Bonsignore, EPF Communications Officer

It is time for patients to seize the EU health agenda, to take the European discussion on patient empowerment a crucial next step forward. This is why EPF is launching the “Patients Prescribe E⁵ for Sustainable Health Systems” campaign on patient empowerment, as a way to continue the discussion and to show the imperative to move from words to concrete action.



The campaign has two main objectives:

- Everyone understands patient empowerment differently, so the campaign needs to promote a common understanding of health literacy, patient empowerment and patient involvement to make them more concrete;
- There is activity around patient empowerment, but there is no strategy at European level on this important policy element. With this campaign and as a result of this event, we want to call for active engagement on patient empowerment by decision-makers and healthcare professionals.

Promoting understanding and good practices

In addition to the EPF briefing paper and toolkit, the campaign leaflet will be central to spreading the word. This is why it will be translated into the 24 EU languages, so that EPF member organisations can use it at the national level. The participants in this Conference can act as ambassadors, using word-of-mouth and social media to engage more people in the campaign.

Many local and regional health institutes, universities, patients’ organisations and industries have developed and implemented initiatives on patient empowerment and involvement. EPF will set up a repository to gather and share interesting genuinely patient-centred initiatives from across Europe.

Tools for advocacy

The Conference has taken the first steps towards formulating a powerful “Charter of Patient Empowerment”. The aim is to build on the fundamental principles identified in the workshops and the other outcomes of the Conference to arrive at a common set of principles of patient empowerment expressed in the 10 points of the Charter. EPF will consult all of its member organisations to ensure broad agreement on its content. The work on the Charter will feed into the drafting of a “Roadmap to Patient Empowerment” that will outline the critical journey we need to take. The Roadmap will provide the basis of proposals for concrete actions to be taken by European policy-makers and healthcare stakeholders.

Action in the coming months

A number of events and actions are already planned, beginning with the preparation of a campaign toolkit, which will be made available to Conference participants and others as soon as possible. Another idea for engaging with policy-makers is “co-mentoring”: patients will be encouraged to put questions to Members of the European Parliament, who will then be encouraged to provide detailed answers that can take patient empowerment forward.

Later in the year will see the launch of the Ambassadors initiative, involving patients and healthcare professionals who will talk about the campaign at national and European level. There will be a

dedicated meeting with members of the European Parliament to engage them in policy actions. The campaign will close in June 2016 with an exhibition at the European Parliament, drawing on all the outcomes which will have been created over the course of the campaign.

7 Closing remarks

Nicola Bedlington, EPF Secretary General



"I am delighted at the progress we have made over the last two days. For EPF, patient empowerment has become part of our DNA as an organisation and inherent to our strategy over the years. I see this conference and campaign as a real "break-through" in moving faster and further on patient empowerment as a key response to ensuring sustainable, patient-centred healthcare systems in Europe.

Earlier we heard Maria Iglesia Gomez of DG SANTE describe to us the EU's strategy for making healthcare systems more effective, more accessible to patients and more resilient. I believe there is no contradiction between these views.

I also heard a couple of people talking over coffee about empowerment versus access. Again, there is no contradiction between the two – they are intrinsically linked.

Overall, we have heard many powerful and insightful contributions that teased out the various threads of patient empowerment. What we need now is more coherence and more political commitment at all levels to really make it work for everybody."

"What we need now is more coherence and more political commitment at all levels to really make it work for everybody."