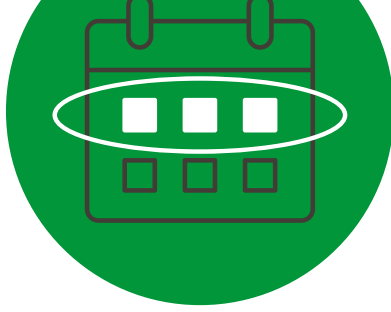


2019 **EPF**
Congress

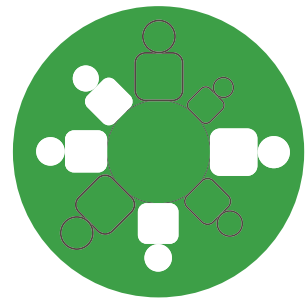
Advancing *meaningful*
patient **involvement**

A path to more effective health systems

Summary report



*The first ever
European Congress
on patient
involvement driven
by the **European**
patient community*



INTRODUCTION

Why This Congress, Why Now?

Patient involvement is an underused resource in the development of equitable and sustainable healthcare systems, an indispensable element of delivering effective high-quality, person-centred care efficiently. European policy-makers recognise the importance of patient empowerment and involvement, but real action is lacking.

As the only European-level cross-disease patient organisation, EPF has the unique position of linking patient communities across the Union with developments in EU policy. This Congress, the first large-scale European event exploring patient involvement, was an opportunity for stakeholders to join forces to push for policies that support positive change.

The EPF Congress was different – because it was organised by and for patients; because it addressed patient involvement at different levels and in different contexts; and because it opened a reflection on how to move forward realise meaningful patient involvement in practice.

Congress presentations are available here:

eu-patient.eu/News/News/epfcongress-presentations

Biographies of speakers, moderators and Congress ambassadors are available at www.epfcongress.eu



Marco Greco, EPF President



Grand Opening

Two Masters of Ceremonies were at hand to open the Congress, welcome the participants and to introduce each session, picking up on various themes that emerged in the presentations for stimulating discussion with the audience. They were **Mair Elliott**, a young patient activist and **Albert Aszalos**, Project Manager at Semmelweis University, Hungary.



Mair Elliott,
Young Patient
Activist



Albert Aszalos,
Semmelweis
University

The first speaker, **Marco Greco**, EPF President, welcomed participants and introduced the Congress. He spoke about his own journey as a patient advocate, and the evolution he has witnessed when it comes to the concept of patient involvement. This is largely due to the activism of patients and their organisations who have insisted for more involvement in decisions that concern them. The formal way in which patients are currently engaged with and in the European Medicines Agency, for example, would have been unthinkable 20 years ago. Still, despite increasing recognition of its importance, patient involvement is not happening as "a matter of course" and is not being realised to its full potential. "It is like we have decided to travel to the moon; but now that we have arrived, we are not getting out of our space capsule," he said. Now is the time to turn concept into reality – and it is possible.



Marco Greco, EPF

He then gave the floor to **Anne Bucher**, Director-General of Health and Food Safety at the European Commission, who said the emphasis on patient involvement is one of the radical changes healthcare systems have undergone in recent years. Patients are rightly claiming more ownership of their healthcare, including their data, and while there is still a long way to go, it is the right direction. She reminded the audience of the 24 European Reference Networks that deal with rare and complex diseases, bringing together 900 hospital units. These networks have benefitted from patient involvement at a practical as well as at a management level. She then went on to describe the Commission's



Anne Bucher,
European Commission

"Beating Cancer Plan", which aims to address the full cycle from prevention to treatment to palliative care. Digitalisation of healthcare is another key area where developments offer opportunities for better access to care and stronger patient involvement. However, it is a very complex field and particularly discussions on health data, its ownership and use require more reflection. Governance frameworks for data sharing, built on trust and ethical standards, will be indispensable. Lastly, access to and affordability of medicines is a vital priority. Ms Bucher said a balance will need to be found between ensuring incentives for innovation and the availability and affordability of treatment.

On behalf of the European Parliament, **David Lega**, MEP from Sweden and former Paralympic swimming champion, welcomed the participants and said that as a patient living with a rare disease, he is well aware of EPF's advocacy. For Mr Lega, it is important that patients see themselves as more than patients. Speaking from his personal experience, he said that since childhood he kept forgetting that he is a patient; even though he had a medical condition, he did not have to feel ill. He actively took up sports and twenty years later became a triple world champion in swimming; he also participated in two Paralympic Games. In other words, his identity changed from patient to athlete; after that, it changed to public speaker, entrepreneur and, now, politician. Being a patient does not have to be a person's only identity; however, this is only possible if the "patient part" gets the supports it needs. Mr Lega's main message was that in order to contribute actively to their surroundings and to society, patients need to work to become more than their illness.



MEP David Lega



FIRST PLENARY SESSION AND KEYNOTE PRESENTATION:

Why patient involvement?

The opening session gave way to the first plenary session, dedicated to the patient experience. To answer the question, "Why patient involvement?", two inspirational patient speakers took the floor.

Cees Smit, Patient advocate from the Dutch Patient Alliance for Rare and Genetic Diseases (VSOP) spoke first. In a personal testimonial he described his journey as a person with severe haemophilia. At the time of his birth, treatment did not exist and life expectancy was low. Fortunately, this changed over the years and medical advances have improved patients' quality of life and life expectancy. Mr Smit described himself as a complex patient with a lot of co-morbidity, and showed the many contacts with healthcare providers that are part of his care. Importantly, he manages his care mostly himself. Mr Smit said he is fortunate to be able to do this; but for many patients who have less strong health literacy skills, the healthcare system can be like a "black box"; it is organized in silos that do not reflect the real patient journey.

Mr Smit described his patient activism throughout his life, including his involvement in research. He participated in a study on haemophilia in the Netherlands, which collected data from men over 50 years. The research showed men with haemophilia had substantial shorter life expectancies. Today, due to medical developments, patients can live a normal life, and life expectancy is almost normal. Still, in his own life, while certain elements of the condition have improved, there are new associated threats such as kidney failure.

In a chronic health condition, co-morbidity¹ presents three main issues: the co-morbidity itself, the related multiple medications and their risks, and the lack of coordination between various healthcare providers the patient needs. This requires a high level of self-management, and with increasing age, patients worry: who will take over when a patient can no longer manage their care? Who will see this need? In this context Mr Smit also questioned whether there are too many disease-specific organisations.



Cees Smit, Dutch Patient Alliance for Rare and Genetic Diseases



Sara Riggare, Karolinska Institutet

An organisation for patients with multiple health problems might be more useful.

Mr Smit also sees access to treatment and affordability as a challenge today. Debates about price transparency are intense. Could patients play a mediating role in polarised discussions? The sustainability of healthcare systems is another important topic, as are issues beyond healthcare such as nutrition and lifestyle, where patients also have a role to play. A sustainable healthcare environment, more healthy life years, and equity in health are important objectives linked to the 2030 agenda on Sustainable Development Goals.

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“In a chronic health condition, co-morbidity presents three main issues: the co-morbidity itself, the related multiple medications and their risks, and the lack of coordination between various healthcare providers the patient needs”
.....

The next speaker, **Sara Riggare**, patient advocate and advisor at Karolinska Institute in Sweden, spoke of her patient journey. Having experienced the first symptoms of Parkinson's Disease at 13, she was finally diagnosed with the condition at 32. To cope with the diagnosis, she started informing and educating herself about her condition, connected with people in similar situations, and slowly came out of what she described as a "black hole." Some 10 years ago she started to combine her patient experience with her engineering skills to improve the situation of people living with chronic disease,

1 Comorbidity: having more than one health condition at the same time

and obtained a degree in health informatics at the Karolinska Institute. An important finding was the link between the medication she took and the effect on her functioning at various times during the day, which she measured through a finger-tapping test. She has published her findings as part of her PhD.

Ms Riggare emphasised the huge importance of self-care for patients living with chronic conditions. To manage her condition, she spends one hour with a neurologist and 8,765 hours in selfcare per year. She does not want more "red dots" - instead the healthcare that is provided should be as meaningful as

possible, with sharing and respect for each partner's experience and knowledge. Ms Riggare closed by presenting a "patient competence framework" she has developed. Apart from being self-care experts, patients can be many things - mentors, communicators, activists, innovators and entrepreneurs, supported by technology and monitoring; healthcare partners and coordinators, as well as patient researchers. The dynamic framework can be used in discussions between healthcare providers, patient organisations and policy-makers to support a more equal relationship.

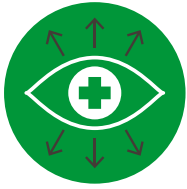
Key points from the Q&A

Advocacy can be beneficial to a patient's well-being; being "more than just a patient" can increase self-confidence. Support from loved ones is indispensable. Patients should lead the patient journey, not the object, because they know their condition and how it affects them at every stage of the journey.

One barrier is that patients are often thought of as "only" patients and no longer recognised as experts in their own field. Sara Riggare was questioned about why she, a patient, wanted to do research on her condition. Such views are deeply engrained in society and need to be challenged and changed.

Coordination of care is important for continuity and for safety. While GPs and family doctors could play more of a role to ensure that different "strands" of care are well-aligned for an individual patient, patients do not see their GP often. Pharmacists, also, can play a stronger role, for example in making sure that medicines prescribed by various healthcare professionals can be safely combined.

Young patients often have other issues on their minds, such as education or career, which can make it difficult to combine activism with other life goals. Patient organisations should commit to creating the pathways and structures for including young patients.



KEYNOTE PRESENTATION:

Patient Involvement – Presenting the Evidence

The second part of the plenary focused on showing the evidence why patient involvement is not only "the right thing to do", but a real added value. **Professor Alf Collins**, Clinical Director of the Personalised Care Group of the NHS in the UK, gave the keynote presentation.

Most improvements that can be made to healthcare systems are low-cost, such as peer support. It is critical to ensure that investments will be beneficial – because the more is invested, the more harm can be done. The benefit-harm balance is fragile; so is the balance between under- and overtreatment. To get to the optimal balance can be only be done by shared decision-making. Patients share their circumstances, values and preferences; clinicians share the possible treatment options with their benefits and harms. Decisions can then be taken informed both by the evidence and the patient's personal preferences. This is a way to maximise value in the system.

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“To improve the conversations between patients and clinicians, everything needs to be changed”

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Evidence-based medicine comprises three elements: clinical expertise, best evidence, and *individual patient preferences*. This way of working brings multiple value: for the person (improving the outcomes that matter to them), for the population (investing resources more wisely), social and technical value (outcome vs. cost). Value can be maximised by maximising options at the point of care (biological, social and psychological). Unless decisions are shared, the worlds of patients and healthcare professionals will never meet: healthcare providers and policy-makers want to discuss disease management, while patients want to discuss the impact of a disease and treatments. "Shared decision making is the only way to avoid poor decision quality," according to Professor Collins.

Professor Alf Collins, NHS England

Of course, costs have to be managed; this is complex given technological advances, ageing populations, and citizens' expectations. The international response to the need for cost containment is to focus on population health, prevention, personalised care and integrated systems. But patient involvement is critical – this concept has to be moved "from the margins to the mainstream". The chasm between those who accept the vital importance of patient involvement and those lagging behind needs to be overcome.

To improve the conversations between patients and clinicians, everything needs to be changed – from how professionals are taught to how health systems are designed.

To take things forward, in Professor Collins 's view requires "conceptual stability". It has to be clear what we mean when we speak of "patient-centredness", "patient involvement" or "patient engagement." We also need a clear, precise and concise argument and a theory of change.





PANEL DISCUSSION:

Different Perspectives – One Vision



Hans Kluge, WHO

Usman Khan, former EPF Director introduced the panel discussion. The aim of this session was to build on the presentations and make a "business case" for patient involvement; each panellist briefly shared their vision.

Starting with an international organisation perspective, **Hans Henri Kluge**, Regional Director nominee for Europe of the World Health Organization and a medical doctor, stressed his conviction of the need to put the patient at the centre of healthcare. His key campaigning messages included empowering people, and raising health literacy to create enabling environments for people to make healthy choices. He described four action points for the WHO: advising governments and health professionals on how to communicate health messages to the public; fostering digital health literacy, drawing on latest research on social media and other technologies; engaging with partners to identify and act on most effective strategies to empower communities; and establishing a unit within WHO to advise governments on behavioural change as a powerful determinant of prevention of infectious disease.

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**“Primary care represents
the natural setting to engage
patients and citizens”**

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Dr Kluge stressed the need for an inspiring vision for change, shared across the WHO European Region. The challenge is not the "what" but to move to the "how": tools and instruments need to be developed; disruptive thinking and transformative action will be required. Policies that concern patients should be co-created with them to ensure their relevance. Dr Kluge also stressed equity: no-one should be left behind. Studies show almost 50% of people have low health literacy, and digitalisation risks widening the gap. Access to medicines is also at the top of the WHO's agenda – aiming for fair prices, which incentives for innovation on the one hand and equitable access for patients on the other.

Jean-Christophe Tellier, President of EFPIA, the EU pharmaceutical trade association, said

fragmentation in healthcare systems is an issue; all stakeholders must realise they are working for the benefit of patients. No stakeholder can do this alone; the aim should be to co-construct solutions. Stakeholders' ability to communicate with each other seems to be lost, and "we have to radically change the way we work together." There needs to be a shift from population to individual; personalised medicine and optimising resource allocation, taking into consideration all the costs involved, can be a useful approach.

Patient involvement in industry has evolved over the years, Mr Tellier said, for example regarding informed consent in research, which has evolved into more of a partnership notion. In clinical trials, the patient's unique perspective, circumstances and views on a certain treatment should be taken more into account. The aim should be the best possible patient experience. Lastly, each patient should have access to the medicines they need. Responding to a question about prices, he said the value of a treatment that cures a patient with one injection for the rest of their life is much harder to define than that of a pill taken once a day. That conversation needs to take place.

Elena Petelos, Advisory Board Member at the European Forum for Primary Care, raised the issue of professionals' working conditions, which pose a risk to patients. She argued that high-quality primary care is vital for improved outcomes; that evidence generation needs to capture the needs, preferences and wishes of patients; and that policies need to support prevention and health promotion but also interdisciplinary training and primary care research. She said: "Patients and professionals must sit at the same table; shared-decision making needs to extend beyond clinical settings." Participation requires appropriate governance structures across the board.

Primary care represents the natural setting to engage patients and citizens; both kinds of input are needed for societal relevance and deliberative

process legitimacy, but their perspectives differ. Pockets of such activity already exist; living labs could join forces to exchange experiences and thus foster innovation. Primary care professionals are strongly invested in real-world evidence, but ensuring data protection and the interests of patients is paramount. New study designs could generate comprehensive evidence for optimal interventions and better resource allocation. Patient-reported outcomes despite their usefulness cannot capture the lived experiences of patients and carers over a longer period of time and across the continuum of care. Co-designing care and research with patients could promote a person-centred, evidence-based practice. Narratives from professionals and from patients may have an important role to play in this regard.

Jan-Philipp Beck, CEO of EIT Health, the largest public-private partnership to deliver health innovation in Europe, spoke next. EIT Health involves some 150 partners from all areas of healthcare and over 400 small companies, focusing on education, research-driven innovation and business creation. The key challenge is to connect patients with the innovation process, so that an understanding of the needs can lead to outcomes that really matter.

The key to success is the involvement of different partners that will support the uptake of solutions developed in "living labs", where clinicians, technicians and patients work on new technologies in a home care environment. One

of his motivations for attending the Congress was to look for effective and efficient models of partnership. He also mentioned the inclusion of patient organisations in his organisation's annual conference, and a new patient innovation award, which has been received with enthusiasm. There is a move towards outcome-based approaches, applying a common framework and using single language around that. Many good examples exist already to share and compare.

Sara Riggare welcomed the visions and said that in any effort to define a theory and model for change, the goal must be clearly defined. The need for cultural change is becoming apparent; healthcare systems should not exist for their own sake but should support patients in reaching their health goals, including by supporting self-care. A similar shift needs to happen in patients, too, particularly with respect to self-care and engagement with healthcare choices. Patients may not all be sufficiently health-literate to engage in advanced healthcare discussions, but they know their personal situation, needs and aspirations and have a contribution to make.

Cees Smit also agreed with the statements. In relation to self-care, he said he taught himself how to best care for himself in the early seventies, for example by administering intravenous injections himself. This self-care approach "rolled over" to the entire haematology community and to other conditions as well. He also stressed the tremendous potential of "citizen science" related to self-care, which could be translated into evidence-based medicine.





DAY 2 KEYNOTE PRESENTATION:

Ensuring equity, inclusivity and diversity of the patients' voice

Session chair **Nicola Bedlington**, EPF Special Advisor and previous Secretary-General, explained that the session's topic has always been at the core of EPF. The organisation has been working with European civil society NGOs and its own members exploring inclusivity; the main outcome of this work was the Inclusivity Roadmap published in 2018.²

The UN Sustainable Development Goals³ are a major point of reference, particularly Goal 3 on health, which includes universal health coverage based on the principle that nobody should be left behind. The essence of this plenary session would be, therefore, to explore how societal groups vulnerable to stigma and exclusion can be part of the patient movement.

Ms Bedlington then introduced the keynote speaker, **Professor Jan De Maeseneer**, Professor Emeritus in Family Medicine and Primary Healthcare at Ghent University, to set the scene for the discussion. Professor De Maeseneer presented equity, inclusivity and diversity from four perspectives: nano (a person's direct interaction with a healthcare provider), micro (dealing with a team of healthcare providers), meso (population level) and macro (policy and government decisions).



Professor Jan De Maeseneer, EFPC

At nano-level, equity relates to access to quality services and providers; inclusivity relates to nobody being left behind; and diversity is linked to human rights and an ethno-sensitive approach. The opinion of the European Commission's Expert Panel on Effective Ways of Investing Health (EXPH) on access to healthcare lists multiple factors that come into play,

including coverage and affordability issues, and the timely availability of services. In patients' interaction with healthcare providers a number of elements will determine the quality of the encounter: the connection between patient and provider, the provider's clinical and cultural competence, and the extent to which the context of the patient is taken into account. Discussing the potential role of patient organisations, Professor De Maeseneer underlined the importance of advocacy, of stimulating increasing health literacy, and working on empowerment. The patient experience is crucial, and the patient narrative is a powerful tool.

Moving to the micro level, he said equity at this level relates to access to integrated inter-professional primary care teams; inclusivity and diversity relate to a shift from disease-oriented to goal-oriented care. The EXPH's definition of primary care stresses the need for partnership with patients and caregivers. One main challenge is that as populations age, multimorbidity increases - this will characterise the future of care. Though efforts are made to develop integrated, patient-centred services, in reality systems often do not cater for what truly matters to patients. The real shift needs to start from the patient's life goals, relating to the quality and quantity of life as defined by each individual rather than the absence of disease. The measure of success should be the achievement of the individual person's goals rather than the accuracy of diagnosis, appropriateness of treatment, eradication of disease, or prevention of death. This is a crucial paradigm shift.⁴ The evolution from "chronic disease management" to "participatory patient management" rightly puts the patient at the core. Integration of services is of the utmost importance to improve efficiency and to avoid

² Find out more about our Roadmap here: https://www.eu-patient.eu/globalassets/campaign-patient-empowerment/roadmap/roadmap_patient-empowerment_epf_2017.pdf

³ Find out more about the UN's SDGs here: <https://sustainabledevelopment.un.org/>

⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3381278/>

duplication. Personal electronic health records should also reflect this paradigm change and start from the patient's own life goals. These should be shared between patient and providers to determine how they can be achieved and how different providers are involved.⁵ The role of patient organisations at micro level according to Professor de Maeseneer is participation in the organisation of the care process, advocating outreach to vulnerable groups, putting the patient in the "driving seat" of their care coordination; and mobilising citizens to provide support in care (informal carers).

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“The evolution from "chronic disease management" to "participatory patient management" rightly puts the patient at the core”

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At meso level, Professor De Maeseneer said that, in terms of equity, there should be system accountability for a defined population. In many countries primary care zones are being developed. Inclusivity in turn relates to community-oriented primary care and intersectoral action for health, taking into account social determinants; and diversity links to addressing social determinants of health according to the principle of "proportionate universalism."⁶ Decentralised organisation of primary care, for example in primary care zones, can improve its visibility. Defining a clear relationship between a population that accesses a certain network of services and the providers can increase providers' accountability for outcomes, access and quality. In this effort nobody should be left behind. In such interdisciplinary primary care networks patients have an active voice and choice; they can participate in the way these networks are organised. The role of patient organisations at meso level should be to voice the needs of the population, for example regarding access and quality, in the context of intersectoral cooperation.

5 <https://www.tandfonline.com/doi/full/10.1080/13814788.2017.1374367>

6 This concept relates to a need for action across the whole of society, focusing on those factors that determine health outcomes and addressing health inequity, the strategies that should be given priority are those that are universal but are resourced and delivered with an intensity that is related to the level of social need (Sir Michael Marmot)

Nicola Bedlington, EPF

Turning to the macro level, Professor De Maeseneer stressed the importance of a "health in all policies" approach for equity, inclusivity and diversity. It is about human rights, advocacy and solidarity; about social justice and democracy. Important challenges remain, such as the affordability of innovative medicines. He thought it would be desirable for prices of medicines to be negotiated and set at EU rather than national level. Co-payments should be reduced or eliminated. Separation of research & development on the one side and production & sales on the other has to be explored in order to ensure affordability of innovative medicines. He said patients have an important role in this debate.

Health is also global. In a brainstorming document (April 2019) the EXPH argues the EU should launch a new dialogue with African countries. There is no future for health in Europe if we do not take Africa and the important developments there into account. Migration, food production, climate change – all these elements are interrelated, and the EU could address them in an integrated and comprehensive way. The patient voice will be essential in these discussions. Special attention is required for the representation of people affected by mental ill health. At macro level, patient organisations could work towards policy participation, together with academics and civil society organisations. They could be involved in defining and designing the research agenda, as they know what the priorities are. Patients are important partners and can contribute at different levels in order to achieve equity, inclusivity and diversity that will make our societies healthy and sustainable.





PANEL DISCUSSION: *Perspectives on inclusivity*



Tamás Bereczky, EUPATI

Ms Bedlington chaired a panel discussion with a range of different perspectives on inclusivity.

Christopher Roberts, Vice-Chair of the European Working Group of People with Dementia, Alzheimer Europe, spoke about how the voice of people living with dementia is heard in his organisation and presented the working group, which is entirely composed of patients.

Alzheimer Europe supports patients coming together, as this helps ensure that its activities reflect patients' priorities. The working group is run with the support of Alzheimer Europe staff and aims to look for solutions rather than dwelling on problems. Its chair sits on the board of Alzheimer Europe and members actively participate in the annual conference as session chairs and speakers. Many presentations have been made in the European Parliament, and several projects are ongoing across Europe. The members of the working group are true experts by experience. People are not defined by their condition; current stigma and lack of understanding needs to be addressed. Mr Roberts's message was there is a life after diagnosis; this can inspire people with dementia to speak out and to change the lives of others. He felt this model should be replicated across other patient groups.

Freek Spinnewijn, Director of the European Federation of National Organisations Working with the Homeless (FEANTSA), reflected on how to better channel the voice of homeless people in the patient movement. At least 700,000 people are homeless in the EU on any given day. Almost all suffer from health problems, multimorbidity is common. Average life expectancy of chronically homeless people is around 50 – some 30 years less than the general population. Despite this, the patient movement does not really include homeless people. There are several reasons for this. Homelessness is seen as an undeserving cause; policy-makers and society as a whole tend to avoid the issue; in addition, homeless people

are usually not organised in representative structures such as advocacy networks (but the experience of the patient movement concerning advocacy and empowerment could be a valuable resource); homelessness as a health problem cannot be linked to a single disease, whilst the patient movement tends to be organised around specific diseases. Regarding universal coverage, out of pocket payments – even if small, even if reimbursed – can be an unsurmountable obstacle to a homeless person to access primary healthcare. Finally, many health issues that concern homeless people fall outside the health sector. Social determinants of health are of key importance for homeless people. One could argue that the best "medicine" to address the bad health of people who are homeless is housing. Mr Spinnewijn suggested it might be useful for EPF to grant membership to organisations such as FEANTSA to foster cooperation across sectors and improve access to health for some of the most vulnerable people.

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“Patient movement should reflect on how to bring excluded people in and ensure that their voice is heard”
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Tamás Bereczky, EUPATI⁷ Director of Communications and Course Design, spoke about his experience in the HIV community and echoed Cees Smit's earlier point concerning the



⁷ EUPATI (the European Patients Academy) is a pan-European project implemented as a public-private partnership by a collaborative multi-stakeholder consortium, led by the European Patients' Forum. EUPATI has already trained 96 patient experts on medicines development, clinical trials, medicines regulations, health technology assessment. More information: www.eupati.eu

current lack of activism. He said the patient movement should reflect on how to bring excluded people in and ensure that their voice is heard. Solidarity is a key issue: in this his Congress and similar events there is a strong sense of solidarity, but it is easily forgotten when organisations are bidding for the same resources. Funders and governments should not pit health conditions against each other; we have to stand up and work together across disease areas; and it is the responsibility of the patient community to reach out to those that are left behind and invisible. Mr Bereczky stressed the importance of talking to the people concerned when building a patient organisation on a specific condition. Social media can be a useful tool. A robust strategy is required, which resonates with the target audience and which will help build a community. Evidence-based advocacy is important. It is important for governments to invest in patient organisations; this avoids relying on membership fees (which excludes those who cannot afford them) or on industry funding.



Alyna Smith, PICUM

Alyna Smith, Advocacy Officer at the Platform for International Cooperation on Undocumented Migrants (PICUM) talked about the difficulties undocumented migrants face in accessing care. These include limited entitlements. Moreover, even when care is available, there is a risk of being reported to authorities. The right to care is in many countries limited to urgent care only, unless one can pay – but for undocumented migrants that is not really an option. It is often forgotten that undocumented migrants are rooted in and contribute to the communities where they live. They have families and they work – but they face many forms of social exclusion and run the constant risk of arrest and deportation. Restrictions to their access to health care are often justified based on misleading claims that are not grounded in evidence, but in fear. Such exclusionary narratives should be resisted. The equity, inclusiveness and resilience of our healthcare systems is at stake, and our commitment to leave nobody behind. Ms Smith underlined the need to protect access to healthcare systems and strive towards truly universal health care. The needs and realities of people who are marginalised from our health systems must be systematically

addressed, working collaboratively to demand a more inclusive health system.

Alain Cornet, patient representative at ePAG/ ReCONNECT⁸ shared his views on how it can be ensured that people with rare disorders are not left behind. There are some 6,000 rare disorders, some of which are extremely rare. How can they make their voice heard? Setting up the European Reference Networks, mentioned by Ms Anne Bucher earlier, has been very useful. EURORDIS – Rare Diseases Europe has worked to include patients in these networks from the start. A next step will be for the larger organisations to help smaller ones to have access. In the ERNs, experienced patient advocates are linked to patients that do not have that experience; they act as mentors. We should broaden this practice. Ways should be found to establish the real needs; patient organisations can help design patient pathways. Patient advocates' skills need to be developed. Most patient advocates speak English, have a university education, have enough money – Mr Cornet questioned how representative this is if the voice of other groups is not included. EUPATI is a wonderful programme, but it only reaches a few. There is a need for programmes that are available to as many people as possible, starting from a low level of knowledge. Congresses like this one are learning opportunities, and learnings should be shared with vulnerable and invisible groups. Mr Cornet emphasised the need to start with ourselves in order to implement change. Ask yourself, he said, "What can I concretely change in my organisation and life to make a difference to include rarer patients?"



8 More information here: <https://reconnet.ern-net.eu/patients-our-epags/>

Parallel working sessions in summary

The moderators, speakers and agenda of all sessions can be found [here](#).

1. Measuring Impact of Patient Involvement



The principle of patient involvement in healthcare, from research to service co-design, is increasingly accepted.



To gain more support for and investment in systematic patient involvement, it needs to be measured and its impact made visible to policymakers. The principle of patient involvement in healthcare, from research to service co-design, is increasingly accepted, but at the moment impact is not evaluated in a consistent manner. This workshop explored several case studies showing the potential of patient involvement to achieve accurate value assessment in healthcare, attempting to address the barriers in the way of more systematic evaluation.

Key conclusions

- Measurement matters because accumulating the evidence base can help develop more person-centred health systems and democratise healthcare.

- Impact of patient involvement can manifest in processes and budgets, but sometimes it can be challenging and complex to capture. Depending on the case, quantitative or qualitative indicators can be more appropriate.
- Partnerships need to set common goals and objectives as well as align on concepts, processes, methods and expected outcomes for long-term impact.
- Patients should be involved as early as possible in the process and their roles and those of other partners should be clarified in advance to ensure meaningful involvement.
- Existing tools and practices should be mapped and shared to allow learning and efficient use of resources.

2. How patients' perspective can improve healthcare performance assessment



This session examined the value of looking at healthcare "through the patient's eyes" when shaping quality improvement policies and actions.



There is value in looking at healthcare "through the patient's eyes" when shaping quality improvement policies and actions.

The perspective chosen affects both what is measured, and how, but few health systems routinely ask patients about their outcomes and experiences of care. Systematic measurement of what matters to patients can improve care on many levels: by improving the dialogue between patients and healthcare professionals; by improving organisational processes, leading to better benchmarking and transparency; and by improving resource allocation at systems level.

Key conclusions

- Patients' descriptions of quality do not fully align with widely used definitions. Therefore, the most

relevant indicators for patients may not be those traditionally used in healthcare.

- Instruments and collection methods for quality are diverse and system-wide implementation is rare; many existing measures were not developed with patients. Co-design methodologies should be improved, and this calls for specific expertise.
- Transparency and accountability are vital for building and maintaining trust. But it is important to consider caveats, such as risk adjustment, when publishing results.
- Given the importance to patients of social aspects, standardised measurement should consider including social care as well as healthcare.
- Patients should be involved not only in developing and validating measures, but also in policy-making.

3. Patients as partners in research: making co-production "the new normal"



This session was developed in collaboration with The BMJ in recognition that patients are increasingly not only research "subjects" but also partners and co-researchers, even drivers of research.



Patients are increasingly not only research "subjects" but also partners and co-researchers, even drivers of research. Research with patients, driven by patients' real-life unmet needs and priorities, can deliver high-value, sustainable solutions. This session, developed in collaboration with The BMJ, looked at innovative examples from therapeutic r&d and the wider context of health as well as setting research priorities with patients.

Key conclusions

- Building blocks for meaningful involvement include being treated as an equal partner; agreeing terms of engagement; recognition of what the patients bring into the research; investment of both time and resources; and maintaining a relationship of support, feedback and reciprocity.
- Leadership from the top is essential to create a fertile environment for a sustained patient engagement culture.
- Managing conflicts of interest is needed at individual and organisational level.
- Patient representatives should be remunerated, but currently there is no broad agreement as to level of remuneration. Participants felt it should be linked to the complexity of the activity, the skills and experience needed, and the time commitment.
- Existing tools should be applied to the European context to arrive at fair and consistent principles for remuneration.



4. Designing better healthcare services with patients



This workshop included role-plays by the EPF Youth Group as well as case studies from Slovenia and Denmark that illustrated different approaches to co-design.



Co-creation is not about saving money – it is about investing energy and emotion into doing things better. This workshop included role-plays by the EPF Youth Group as well as case studies illustrating different approaches to co-design. The group explored domains where co-creation is needed; the pressure points that can be solved with co-creation; barriers; and potential solutions. Interaction between systems is vital as healthcare takes care of part of patients' wellbeing, but other sectors also contribute. This is especially important as lifestyle modification is part of care of many chronic conditions. Mental and physical health should be addressed in a holistic way.

Key conclusions

- Co-creation is not about feedback, it is about involvement from the start.
- Social care and health care should not be separated. Horizontal integration is key to removing fragmentation barriers to patients' access to and experience of care.
- Families need support to support patients with selfcare. They should be also included in the co-creation process.
- There is a need for champions who will be change-makers, both from the patient community and among healthcare professionals and other involved actors such as administration and financing.

5. How to ensure digital health brings real-life benefits for patients?



Opportunities for digitalisation include improving healthcare practice and services, developing guidelines, and better research – important but under-used potential, given the huge amounts of data collected every day.



Opportunities for digitalisation include improving healthcare practice and services, developing guidelines, and better research. Nevertheless, countries still face issues regarding the uptake of electronic health records, lack of guidelines and resulting interoperability problems. Moreover, patients still do not have routine access to their health records. A case study of patients being involved in development of hospital services showed value and cost-effectiveness, in line with an increasing body of literature. The EmERGE project showcased in the session demonstrated how patient involvement can drive innovation when community involvement is embedded from the start.

Key conclusions

- All relevant information should be fed into the EHRs and they should be linked to other services, such

as medication overviews and appointment booking systems. Including care information in addition to health data would be an opportunity to provide more person-centred care.

- Reimbursement for patients and payment of healthcare professionals need to be clarified, as currently there are divergences depending on whether a consultation is physical or virtual.
- Models should be developed for who should have access to what part of the patient's data and why.
- The right legislation needs to be in place to prevent discrimination, together with public awareness campaigns and sanctions for breaches.
- In development of innovative solutions, patients' involvement should be an obligatory condition for EU funding. To avoid tokenism and push good practice, patient involvement guidelines should be developed with patient organisations.

6. Patient safety – how can patients and families help improve it?



This session focused on healthcare environments. It began with a personal story of one family showing how trust can be damaged when there is no support following medical error.



This session showed how a personal tragedy can result in positive change, albeit at a heavy price. The story of one family showed how trust is damaged when there is no support following medical error. For the parents, re-telling their story was traumatic and burdensome, and they lost their privacy. Nevertheless, seven years of advocacy resulted in real policy change at the health system level. Participants agreed that patient involvement and patient safety are inextricably connected and there is a need for a wholesale culture change, which affects everyone involved, from patients and families to healthcare staff.

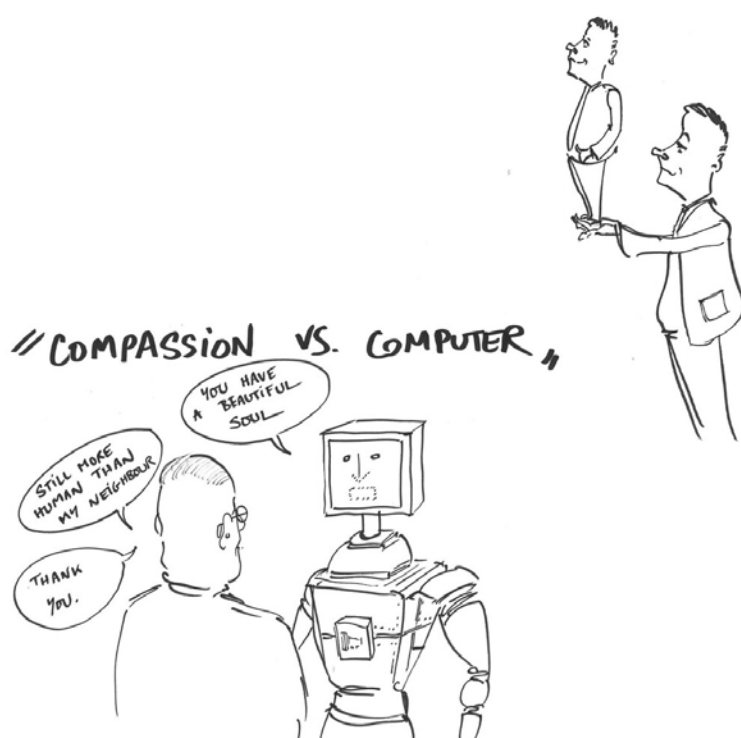
Key conclusions

- Patients' involvement is hampered by an imbalance of power. Patients who question their care can be labelled as "complainants", initiating a legal process in some cases, when all they want is answers.
- The "See it, say it, sorted!" slogan used in the UK by transport police was used as an example. Everyone should be able to signal a safety issue they spot, and the "sorted" aspect needs to be clarified.
- Good practices flagged by the group included the "Hello, my name is" campaign and having patient safety officers in healthcare organisations.
- Healthcare professionals or organisations should also be rewarded for doing things right. This requires systematic channels for feedback to be in place for everyone.

"(...)HOW HARD WE MAKE IT FOR PATIENTS TO NAVIGATE OUR SYSTEMS,"



THE IMPORTANCE OF SELF-CAKE..



Cartoon art by Thomas Duval



AFTERNOON KEYNOTE PRESENTATION

Culture change and leadership

The keynote speaker in the short afternoon plenary following the parallel working sessions was **Marc Boutin**, Chief Executive Officer of the National Health Council, United States. Mr Boutin started by describing his personal journey in patient advocacy.

As a volunteer he had witnessed how difficult it was for patients and their organisations to make their voices heard among the paternalistic attitudes of healthcare professionals. He had also seen relatives die due to lack of treatment – even where treatments existed, patients could not always access them. Mr Boutin has now been active in the patient movement for over 25 years, and is currently managing the National Health Council, a national umbrella patient organisation created by patients for patients. The NHC solely addresses systemic changes, driving meaningful and affordable access to healthcare and innovation. When first starting in this job, Mr Boutin met with many CEOs of patient groups, listening to what they saw as the biggest challenges. Time and time again, the lack of affordable access to care was mentioned. A system that was originally designed to help promote high-value care has evolved into a mechanism that shifts the cost of healthcare to people with chronic conditions. In the US, lower-middle class people with a chronic condition can expect to pay 20–22% of their annual income to get a first prescription or to see first specialist.

This means choices have to be made, and

that many people do not get the care that they need. These are huge challenges. It also means that there is a huge opportunity to think differently, and change the culture.

Changing culture is hard to do – whether at organisational or societal level. After all, health is big business, related to 20% of the economy, and there are many vested interests. People tend to look at others to make the required changes as they are entrenched in their roles. However, some trends and factors can help drive culture change around health, such as the explosion of chronic conditions. This is not just a US phenomenon; people live longer everywhere, with more chronic conditions. But in many cases, people with chronic conditions remain invisible. Mr Boutin said: "We do not see each other; and as a society, we do not talk about it." This needs to change; patients have to "come out of our closet". The sheer magnitude of the issue is driving change in healthcare systems and provides an opportunity for cultural transformation.

A second important element is science. An increasing number of conditions previously thought incurable can now be treated. Some therapies even cure for life – but this raises a lot of questions. What is the value of being cured, and having those extra years of life? These developments create pressure on how we value health and specific interventions. How are we going to pay for that? How can future innovation be encouraged in the present? This forces us to take a long-time perspective – and in turn challenges our system and creates opportunities for culture change.

A third element relates to data. There are data points on each and every one of us, which are already being used to influence behaviour – what people buy, what people watch. Data is being collected

Marc Boutin, US National Health Council



on a massive scale. Interestingly, the biggest disruption is not coming from the health sector but from the retail sector; companies like Amazon are increasingly buying into insurance companies and such, combining the data of those companies with health data, running these through algorithms and getting into the personalised healthcare space. It is impossible to know whether companies like Facebook and Google use data responsibly; this is one of the big questions. What is the appropriate use of non-health data that will impact on health outcomes? There are huge opportunities here – but also a huge risk with respect to the management of these data from a patient perspective. Should patients own their data? Mr Boutin disagreed: he said while the data is about us, there are others involved that need to create the systems and storage. There are expenses associated with that. However, patients should have rights as to how the data is used. Data is a commodity, which is being monetised – and right now we have no control over it. It should be used to the benefit of people and society.

These four elements undermine traditional ways of organising and delivering healthcare – and can help in creating culture change.

It will also be very important to debunk the persistent myth that "patients want everything". The reality is that patients do not want everything – they want what works for them. Healthcare professionals have good intentions and aim to support patients. However, paternalistic assumptions about what patients want get in the way. Patients focus on quality of life and functioning; we need to engage with healthcare professionals to make sure they understand this.

A three-step approach will be required: inspiration, information, and intimidation. As patients, we need to make use of our stories to explain why personalised healthcare matters to us. As policy advocates, we need to think about aligning the incentives and removing barriers, working with all the players involved. There should not be tension between patients and healthcare providers; providers are our closest allies, and they are in a difficult situation too. The system is not designed to allow them time for shared decision-making, for example. We need charismatic leaders, creating compelling stories, creating the infrastructure and putting the intimidation in place.

.....

“An increasing number of conditions previously thought incurable can now be treated. Some therapies even cure for life”

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Mr Boutin called on the audience to partner with their umbrella organisations and with EPF, and to develop a clear strategy for change. Change is already happening, and we can shift culture – but the vision has to be clear, and cooperation is required. It will be important to dissect specific issues rather than talk in general terms. Specific problems require specific solutions. We need to prioritise and develop a road map. This is happening already, but it needs to be accelerated. As patients, we are the least resourced, but the most important – and most passionate.





DAY 3 MORNING PLENARY:

Patients as teachers – what can patients teach professionals?

Kaisa Immonen, EPF Director of Policy, chaired this session. In her introduction she said that if healthcare systems are serious about changing culture into one that places people and patients at the centre, it should look at the training of its healthcare professionals.



Tessa Richards, BMJ

This is where change is required, not least because of the ongoing technological and demographic changes which require health professionals to obtain and maintain new skills. There is an emerging movement and incorporating patients into medical education. This is happening gradually, unevenly, and stepwise: patients’ stories are increasingly used as learning material; sometimes role play is used. However, advanced roles such as shaping teaching curricula are still rare. How can we make sure that training curricula can benefit from the involvement of patients as a matter of course? This is what the session would try to answer.

Kaisa then gave the floor to the first keynote speaker: **Stijntje Dijk**, final year medical student at the Erasmus University of Rotterdam. Stijntje stated that every medical student should be equipped with the proper skills to serve communities; and teaching these skills at undergraduate level is the most effective way. Inserting the crucial notions of

patient engagement and patient-centredness into that level will have a lasting impact.

There are many different ways to involve patients. Stijntje described the findings of a recent research project she was involved in. A systematic review of the literature regarding patient involvement found that there are four ways to engage patients in medical education – as teachers, as assessors, as curriculum developers, and as selection committee members.

.....
“Embedding patient partnership in medical education is a movement that is undeniably on its way”

Tessa Richards, BMJ
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The research showed that the motivation for patients to get engaged in professional education relates to a sense of responsibility to the community, wanting to change healthcare for the better, and as a contribution to personal fulfilment and growth. The institutions’ perspective focused on a desire to improve education by teaching patient-centred, interprofessional care, social accountability, and making education engaging, powerful and transformative.

Patients are found through existing university partnerships, social media, posters in health faculties, personal connections of the health professionals and through patient organisations. Selection criteria vary, but on the whole, anybody wishing to participate can do so. Communication

Stijntje Dijk, Erasmus University Medical Center



skills, teaching affinity and representatives' physical signs are important. How patients are prepared for engagement in teaching varies: training programmes, in line with the intended learning outcomes, can help build confidence and prepare for challenges.

Patients see a number of benefits of getting involved, such as making an active contribution in an important domain, networking, and having medical check-ups. Drawbacks – both potential and preventable – are also identified, such as feeling vulnerable, confronting stigma, and non-appreciative reactions from the professionals' side.

While medical faculties generally view engaging patients in positive terms, some concerns were mentioned, such as patients' stories potentially being traumatising for students, the political motives of the patient organisation concerned, and fears of tokenism in cases of structural involvement. Students' concerns related to feeling pressured when patients asked them for information and advice, and feared that getting the perspective of only one patient could lead to bias.

Stijntje Dijk also provided some advice for patient organisations when starting to work with teaching institutions. The first step is to find your way through the "university jungle" and check if there is framework for integrated involvement or a commitment that the university has made. Are there champions in the medical school a patient organisation can work with? She especially encouraged patient organisations to collaborate with student organisations, who are already involved with medical education. The next step would be to create interest within their own organisations, facilitating peer support and networks, and calling for significant and meaningful roles thinking beyond only the role of a teacher.

She referred to ongoing discussions in this field related to "preparation vs authenticity" of patients. In addition, there are open questions as to who should take the teaching role, patient representatives or individual patients? What should be the level of commitment? Are patients volunteers or employees? The study is undergoing peer-review and will be submitted for publication in the near future.

The next speaker, **Tessa Richards**, Senior Editor in charge of the Patient and Public Partnership initiative at The BMJ, addressed

the topic of medical journals as "trailblazers" for promoting patient and public involvement in medical education, clinical care, research and policy making. Today's medical students, young doctors and other health professionals will play a key part in influencing the future shape of healthcare. The medical journals they read – and publish in – arguably have a role and responsibility to help advance the partnership agenda. The BMJ is in strong position to do so, having taken innovative steps over the past five years to involve patients and the public in its editorial processes.

Healthcare delivery systems are complex and, in many cases, designed for those that work in these systems rather than those that use them. As a community we need together to analyse where changes can be made, not least to how services are provided to make them more person-centred. Currently, health systems are poorly integrated and often difficult to navigate. Co-designing services with those who use them is increasingly being advocated as a way forward. Assessment of the value of healthcare must also take much greater account of where value lies in patients eyes; more medical care, in terms of tests, treatment and interventions, does not guarantee better care. Patients need to be supported to make informed choices and decisions about their care and treatment which take account of their individual goals, priorities and preferences. There are several positive developments towards establishing "value-based" healthcare, where "value" takes account of patient and public views. One is the OECD's PaRIS initiative, a move to develop comparable metrics of patient-reported outcomes and experience as a way to assess and compare health systems' performance.

The BMJ is seeking to advance partnership with patients and the public in healthcare through a dedicated strategy, co-developed with the International Patient Advisory Panel five years ago. The Panel continues to steer its work.

The BMJ's strategy promotes co-production of content. There are different ways in which this is done: authors who submit research papers are asked to complete a statement on if and how they involved patients or the public in their study. Making a statement of patient and public involvement mandatory and included in the methods section of papers will hopefully encourage more researchers to do their research with patients. At some point in the future it is possible that the BMJ will adopt a policy to only accept co-produced clinical research papers.

The BMJ also works with patient reviewers, who comment on the usefulness and relevance of papers to people like them, alongside conventional peer review. It publishes two patient-led series: "What your patient is thinking" and a lively online series "Patient Perspectives" in its BMJ Opinion section. These provide valuable insight and learning on what matters to patients and communities. It is a tangible way in which patients can help influence the mindset of healthcare professionals and medical culture. "Partnership in Practice", a series dedicated to showcasing examples of how health professionals and patients are coming together

to jointly develop new services or educational initiatives, also seeks to spread learning.

Other specialist health journals published by the BMJ company are beginning to adopt elements of the BMJ's strategy. The movement towards co-production of medical journals has only just begun. Working in partnership with patients is challenging, for it is a new way of working. Sharing examples, challenges, and lessons learnt can over time help advance both the science and the art of partnership in healthcare. Embedding patient partnership in healthcare systems and medical education is a slow social movement, but it's undeniably on its way.





PANEL DISCUSSION

Different perspectives – patients teaching professionals

Kaisa Immonen then introduced the panel and invited all panellists to briefly state their perspectives on the topic of patients teaching healthcare professionals.

Alice Casagrande, Director of the Fédération des Etablissements Hospitaliers et d'Aide à la Personne, Privés Non Lucratifs (FEHAP), an employer's federation representing non-profit organisations, presented a project called "Partners in Knowledge" and its commitment to involve patients and service users in the professional education in social services.

Inspired by the Vancouver statement on professional education (2015) and the interprofessional health mentor programme of the University of British Columbia, she underlined the role of other healthcare professionals, including nurses, midwives, occupational therapists, dentists and so on, in the continuum of health and social care provision. Interprofessional education entails that students should learn around, or with the help of, a patient, a disabled person or informal carer. Involving the broader spectrum of healthcare providers will also improve communication and team working in person-centred care.

The project has been ongoing for five years and has collected information on innovative programmes in healthcare and social services involving patients and service users. The Swedish "gap-mending model", where training involves was one of these; it has found that interprofessional learning substantially reduces the distance between health/social care providers and the service users. The work has led to the formulation of the "Partners in Knowledge" statement on involving patients

and social services users in continuous education. The statement has already been signed by the French health minister as well as by major students' unions. Responding to a question about how to make sure "invisible", disadvantaged or marginalised groups can be involved, Alice stressed that these groups have specific expertise to offer and initiatives need to be inclusive of all voices.

.....
“We need to shift and start thinking about inter-professional education, and not medical education. This way we can ensure continuous professional development for patient involvement”

Alice Casagrande, FEHAP
.....

Katherine Capperella, Global Head and Patient Engagement Leader at Janssen, provided her individual perspective from the vantage point of industry, strongly agreeing that patients should be involved in training medical students. Some teaching institutions and medical schools are already doing so, such as the "Walk with me" classes at Stanford University. It might be useful for teaching institutions to get together and develop this concept. However, as in industry, these institutions are competitive, which is not conducive to cooperation.

As a company, Janssen has involved patients for a while now, for example in doing clinical trial simulations. Involving patients at this stage, doing dry-runs, significantly improved the actual trials. A video was produced with patients in a specific condition who described how the condition affects them and how they would like to be treated – to be viewed as a person rather than as a trial subject. Training the investigators was very helpful, and a



clear demonstration of how partnering with patients can truly change methodologies and outcomes. Good practice examples in this area need to be disseminated and replicated. Responding to questions, she agreed that it would be very important to also include marginalised groups in these partnerships; this involvement needs to be proactively planned.

Michel Ballieu, Executive Director of the Biomedical Alliance in Europe and representing medical associations at European level, briefly introduced his organisation and mentioned that the Alliance recently set up a permanent CME Expert committee, composed of health practitioners and of staff specialized in education. Its mission is to improve the quality of continuing and unbiased medical education. When the committee started its work, it was felt that patient input was lacking, and that is why EPF was invited to join as permanent committee member to provide the perspective of patients.

He raised the issue that doctors sometimes find it difficult to work with patients on medical education because of the emotions involved when working directly with patients, echoing somewhat Stijntje Dijk's findings. EPF is an appropriate intermediary to feed patient perspectives into such work which centres around policy. Doctors also often have misgivings about the Internet, where patients find information about their condition and sometimes become experts in their own disease. On the other hand, information found online, e.g. on appropriate treatment, is not always correct.

In view of patient involvement in CME/CPD it would be useful to teach patients about how to best address their experience and recommendations; while the authenticity of patients is important, training can help to make their input and involvement more

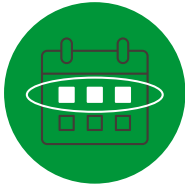
fruitful. Replying to questions about how to make sure that education is truly unbiased from the interests of the healthcare industry, he agreed this is an important issue and ways have to be identified to protect unbiased, high-quality education. That is the mission of BioMed Alliance's CME Experts Committee.

“Doctors sometimes find it difficult to work with patients on medical education because of the emotions involved”

Nathalie Bere, Patient Engagement Liaison at the European Medicines Agency (EMA), shared EMA's strategy to engage with patients. In the beginning, there was a lack of awareness of how patients could participate, but when they were brought into EMA scientific discussions, they demonstrated the valuable of their contributions. Patients are experts in their condition, their unmet needs, desired outcomes and risk acceptance – key information for regulatory discussions. Patients contribute to decision-making in a tangible way, and their involvement is now an integral part of EMA's work.

EMA established a formal Patient and Consumers Working Party in 2006. The group meets four times a year on a broad range of topics. In parallel, there is a Healthcare Professionals Working Party. Initially they convened as single groups, however as both groups were curious about each other's views, so joint meetings were piloted. Today most meetings are held jointly as both groups have experienced the benefit of what they can learn from each other.





CLOSING PLENARY:

Why health systems must start delivering for and with patients

Instead of a presentation, the closing plenary featured a conversation between **Susanna Palkonen**, President of the Patient Access Partnership (PACT), and **Mark Pearson**, Deputy Director of Employment, Labour and Social Affairs at OECD.

How can meaningful patient involvement help healthcare delivery become more patient-centred, participatory and efficient?

Mr Pearson said that as a patient he had experienced the frustrations of bureaucratic, rigid, inflexible and impersonal healthcare. Individual "micro stories" add up to a one massive issue – the lack of efficiency in healthcare systems. Studies have shown that one in five euros spent on healthcare is a waste of money: it will not improve health, and may even lead to worse outcomes. Duplication, lack of safety, and limited access to available data as well-known inefficiencies. Implementing systems that truly put patients at the heart of healthcare would help resolve many of them. Improving the involvement of patients is a goal in itself, but also a response to the bigger questions related to our healthcare systems.

What is the role of the OECD in patient involvement?

Mr Pearson first introduced the work of the OECD, which provides economic policy advice to the 36 participating governments. As health corresponds to high levels of spending (10% of GDP on average), and as health is linked to a variety of other policy areas, such as labour and employment, improving the value and effectiveness of health systems is of paramount concern to OECD member governments.

In 2017, the OECD Secretariat and health ministers agreed that the central objective for healthcare should be the delivery of people-centred healthcare. Ensuring people-centred healthcare is the principle that guides all of the OECD's work in health. The OECD's people-centred healthcare strategy continues to be developed, in cooperation with the countries involved. One of the key activities is the creation of the Patient-Reported Indicator Surveys (PaRIS), which will develop indicators to measure

Mark Pearson, OECD & Susanna Palkonen, PACT

patient-reported outcomes and patients' experience of care. PaRIS aims to counter the tendency of looking at healthcare as a cost item.

The EU participates in OECD activities in the same manner as country delegates and is an important partner. The Commission supports the OECD's work on "Health at a Glance" and related country profiles, which compare countries' performance on a number of indicators and provide detailed reviews describing the challenges faced by each national health system.

Mr Pearson explained that the initiative includes one strand of work which looks at particular conditions (initially hip/knee replacement, mental health and breast cancer). Patients are active participants in the working groups and contribute to the development of the measurement methodologies. The other strand looks at how health systems can best serve people living with chronic conditions; what are their interactions with the health system and to what extent do patients see improvement as a result? A formal patient advisory panel will be set up to provide strategic oversight of the survey, in particular to help ensure the survey design and implementation is appropriate and the survey findings are meaningful from a patient perspective. By means of a



wider online portal, feedback will also be solicited from a broader group of patient stakeholders.

How do OECD activities influence financial decisions on healthcare at country level?

Mr Pearson mentioned the progress made in mental health. Often it is easier to begin a meaningful conversation on mental health issues with labour ministers, rather than health ministers. The OECD focused on the systemic underinvestment and poor quality of mental health services – a particularly striking example in the generally underfunded area of chronic healthcare. Of Between 40% and 50% of people receiving benefits in the EU have a mental health issues. Training programmes set up by employment ministries to get people back to

work are not effective if the underlying a mental health issues are not being addressed. Another subject where OECD has put great emphasis is prevention: total spending on prevention across OECD countries averages below 3% of all spending on health. Thanks to OECD, most health ministers are now aware of that number.

What messages would OECD have for governments regarding patient involvement?

Mr Pearson stated that nobody would disagree with the notion that we need to put patients at the centre of healthcare. But agreeing with this is not sufficient; more progress must be made. It has traditionally been easier for health systems to focus on hard, "measurable" clinical outcomes and statistics rather than talk about how to involving patients in decision-making, promoting co-production, and ensuring choice. In order to make progress we will need find new ways to measure these important outcomes and characteristics. Initiatives like PaRIS show that these are not just a "soft" notion – they can be measured. Disruptive thinking and partnerships, though difficult, are needed if true and meaningful change is to be made.

**Congress
spotlight**



Vytenis Andriukaitis, former European Commissioner for Health and Food Safety



Concluding reflections

Reflecting on the discussions during the Congress, **Usman Khan** found **Sara Riggare's** concepts to be insightful. Her notions were that “red dots” represent a patient’s interaction with clinicians while ‘white dots’ represent the vast majority of a patient’s life, that is, self-care.

Framed in this way the importance of a patient’s lived experience is brought to the fore whilst not diminishing the value and importance of well-structured treatment and care. Transformation of healthcare systems from a paternalistic model to one shaped and owned by patients will require meaningful dialogue between patients and healthcare; this is a significant challenge. Mr Khan referred back to Marco Greco’s metaphor about the patient movement having reached the moon; he asked whether the challenge now is to create a new universe. The patient community will build on the conversation that began at the EPF Congress. We need to move from transactional improvements to transformational ones, taking patient involvement to the next level.

Before the formal closing of the conference, young patients took the stage. First, Master of Ceremonies **Mair Elliott** reflected that for her, the main take-away was ensuring that those who currently do not have a voice are included in the patient movement. It will also be crucial that any research on healthcare provision starts from the perspective of patients and includes patients from the start. A major problem in driving change is that people generally do not want to admit they are mistaken. Everyone should be open to admitting errors, and be prepared to look for and see solutions.

Ms Elliott then handed the stage over to **Elisabeth Kasilingam** (EPF Board Member) and **Borislava Ananieva** (President of the EPF Youth Group), who invited participants to reflect on their personal take-home message and how they would embed that into their own work and that of their organisations. Everyone was then invited to share their plans with their neighbour. Following this, participants were transported in time to November 2020 and asked what they had done in reality to implement their take-home messages, and what the key component of their success was, again sharing this with their neighbour. The exercise was a fun way to wake up the audience and get some concrete commitments for action.

In his closing address, EPF President **Marco Greco** recalled the warm support to EPF from

the outgoing EU Commissioner for Health, Dr Vytenis Andriukaitis, who had delivered a speech at the Congress gala dinner. Our community will continue to foster such positive relationships also with the new Commission. Reflecting on the previous days’ events, Mr Greco said for a patient it is crucial to find a healthcare professional who is empathic. However, empathy and understanding require a scarce resource – namely, time. Health systems are not designed for this, and we have to work together to secure that time in order to have better, more meaningful exchanges between patients and professionals.

Peer support is indispensable in this respect; patients can be friends and mentors. Patients need and benefit from the help of others fighting the same battles. Building on this solidarity will benefit everybody. Emotions were mentioned several times during the Congress. There are emotions involved when patients are involved in the care process. But these emotions are actually useful; through understanding patients’ emotions, regulators for example can better address the risk/benefit of different treatments, and gauge patients’ acceptance of risk.

Despite the huge challenge of organising a large event like this, a first European-level Congress on patient involvement, for and about patients, by patients – Mr Greco felt it fair to say that the event had been successful. EPF will reflect on all the outcomes in the coming months and ensure there is follow-up, which may take the form of a second congress homing in on a particular theme. The Congress also aimed to inspire participants to take what they have learnt home and make useful changes to their daily work. He asked: “What will you do to make a difference?”

Mr Greco formally closed the Congress, warmly thanking the EPF team, the EPF Board as well as the sponsors who all together made this event possible.



EPF would like to thank our partners and our generous donors for the sponsorship received.

Partners



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