EUROPEAN
PATIENT
INNOVATION
SUMMIT

CREATING
CONNECTIONS

MEETING REPORT

EUROPEAN PATIENT INNOVATION SUMMIT (EPIS) 2016

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VIEW REPORT

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Foreword

First and foremost, Novartis and the Steering Committee would like to take this opportunity to thank everyone who worked tirelessly behind the scenes over the past few months to help develop and deliver an outstanding programme at the Summit. To the speakers and moderators who dedicated large amounts of time and effort to generate exciting and interesting content for the meeting, and everyone who attended the Summit – your active involvement was key to the success of this interactive, informative and productive meeting. We hope the Summit offered a great opportunity for you to share your experiences with others and raise awareness of important issues within the patient community. This report summarises the Summit and captures the key messages and recommendations from plenary and workshop sessions. A recap of each disease forum can be found at the end of this report.

The Summit Steering Committee

Introduction

Introduction to the Summit

Unlocking the Potential of Digital Technologies: the Pharmaceutical Industry's Perspective

INTRODUCTION TO THE SUMMIT

The summit began with a welcome to the first European Patient Innovation Summit (EPIS) from representatives of the Summit Steering Committee: Raj Mahapatra (an Executive Committee Member of the Ankylosing Spondylitis International Federation [ASIF]), Neil Johnson (Chief Executive of Croí [the West of Ireland Cardiac Foundation]) and Sanja Njegic (Head of Region Europe Patient Advocacy and Relations, Novartis Pharmaceuticals). Raj Mahapatra and Neil Johnson presented the evolution of the concept and co-creation process behind the Summit which shaped the meeting specifically for patient organisations. The co-created theme, main objectives and scope of the meeting, including activities that would be taking place throughout the Summit, were outlined to highlight the wide range of topics being covered and the opportunities to interact with one another in a collaborative setting. The scale of the meeting was also presented, with over a hundred European and international patient organisation representatives spanning several disease communities in attendance.

Creating Connections

Over the past 2 years, Novartis Pharmaceuticals Region Europe has organised patient forums on several chronic diseases. Discussions at these patient forums revealed that many of the issues and areas of interest raised were common to the different disease communities, and thus, there was an obvious need for a platform for advocacy leaders to network, share practical wisdom and identify workable solutions to problems.

The stage was set for a new approach and the idea for a European Patient Innovation Summit emerged to take on a leading role in creating connections across patient organisations and disease communities.

The Summit Steering Committee was established, which included a number of leading EU and international patient organisation representatives alongside Novartis, to lead the co-creation of the Summit. The Summit Steering Committee shaped the meeting theme and objectives, agenda, post-meeting materials and agreed on the next steps with the aim to inspire the patient advocate community regarding the potential of digital technologies for transforming practice, expanding networks and best serving the patients they advocate for.

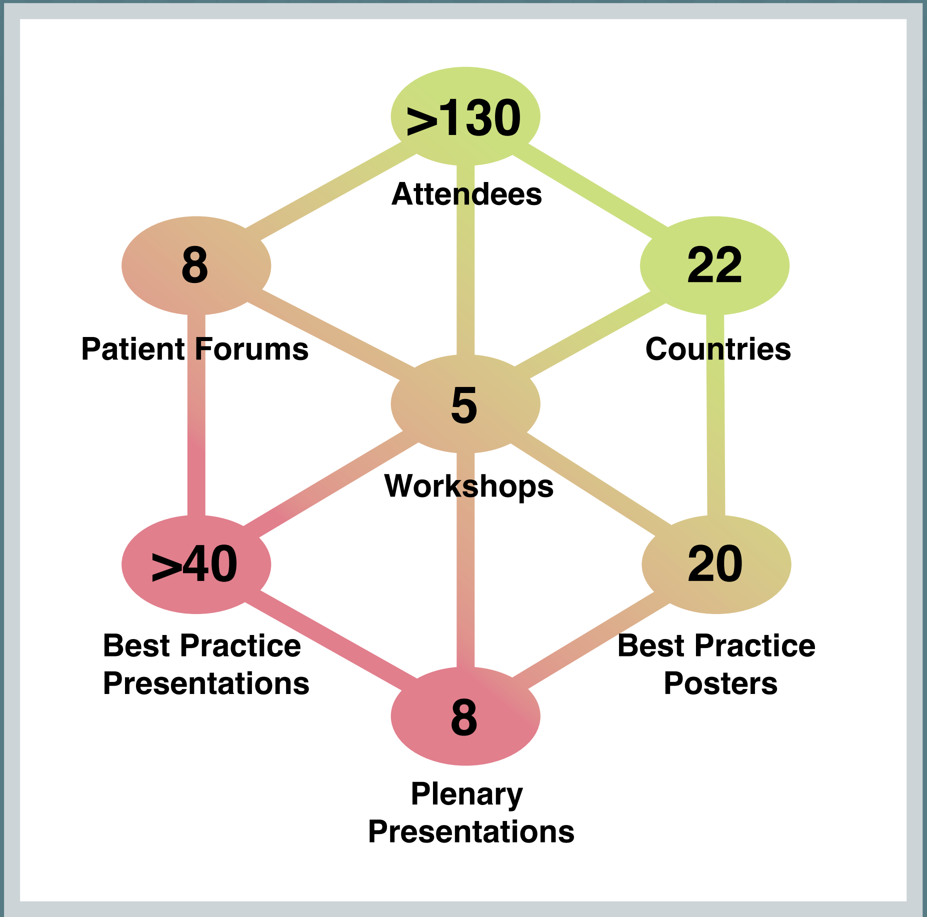
INTRODUCTION TO THE SUMMIT

We All Live in a Digital World

New technologies and innovations are already enriching the way in which we manage our health, and will continue to lead the way forward with innovative ways to access, process and exchange information, communicate with each other and share knowledge and experiences. The EPIS patient-centric programme centred around the vision of healthcare in the digital era, exploring how digital technologies can revolutionise patients' lives and increase the reach and effectiveness of patient organisations, as well as how patient groups can make the best use of available technologies to yield solutions to commonly identified problems.

Summit in Numbers

The 2-day Summit, attended by patient organisations from 22 countries, consisted of a mixture of plenary presentations, workshop sessions and disease forums, specific to each disease community. Eight different disease communities were represented at the meeting, including: ankylosing spondylitis, asthma, heart failure, migraine, multiple sclerosis, psoriasis and psoriatic arthritis, rare auto-inflammatory conditions and retinal diseases. More than 40 presentations in the disease forums and 20 posters were presented during the Summit, describing novel initiatives and demonstrating best practice from various global patient organisations.



>130 Attendees

8 Patient Forums

22 Countries

5 Workshops

>40 Best Practice Presentations

20 Best Practice Posters

8 Plenary Presentations

UNLOCKING THE POTENTIAL OF DIGITAL TECHNOLOGIES: THE PHARMACEUTICAL INDUSTRY'S PERSPECTIVE

While welcoming attendees to the Summit on behalf of Novartis, Sanja Njegic (Head of Region Europe Patient Advocacy and Relations, Novartis Pharmaceuticals) gave an insightful presentation into Novartis' commitment to patients. Within this, she shared its vision for redesigning the way healthcare is delivered to benefit patients, by adapting key processes to best suit patient needs through the use of novel digital technologies.

Learning and being inspired by patients should guide the pharmaceutical industry to develop better products and ultimately achieve better outcomes for patients. Indeed, Novartis' strategy to focus on the patient perspective in a digital environment aligns with its core values to experiment and deliver better solutions for patients through innovation and collaboration with patients. Additionally, it falls in line with the Novartis Patient Declaration – a public statement detailing exactly what patients can expect from Novartis in five key areas, ranging from clinical trials to access to medicines, demonstrating a strong commitment to the patients they serve. A collaborative approach with patient organisations to accomplish this goal has been embraced by Novartis, who have a vast network of patient advocacy managers across Europe acting as key points of contact for patient organisations.

Novartis works in partnership with key stakeholders, such as patient organisations and experts in the digital field, to develop novel technologies that can be used in a variety of settings across disease communities. The digital tools being developed should help expand research and understanding into different disease areas that will improve patients' journeys, experiences and outcomes. Novartis' digital activities range from raising awareness and improving patient engagement, to planned and rolled-out outcome-focused initiatives.

The Niji™ platform is one of the outcome-focused initiatives under development in the cardio-metabolic field which aims to enable doctors to quantify biomarkers in their offices. Such technologies can speed up the processes of diagnosis and treatment for patients. Digital technologies can also be used in clinical studies; wearable devices have been used in the outstep-HF study to measure activity and sleep when reviewing whether certain treatments can improve daily physical activity.

UNLOCKING THE POTENTIAL OF DIGITAL TECHNOLOGIES: THE PHARMACEUTICAL INDUSTRY'S PERSPECTIVE

Various outcome-focused apps are in the pipeline which either stand alone: such as ViaOptaDaily, an app that helps support daily life, or work in connection with other devices: such as the Air Smart Spirometer, which is a portable spirometer that can be used with iPhone or android devices.

Many breakthrough activities led by Novartis, including outcome-focused patient monitoring apps such as SymTrac MS, or large awareness campaigns with digital components like the European Psoriasis Patient Activation Campaign, were co-created with patients and patient organisations; this will continue for future projects. Collaboration is vital to Novartis' commitment to a patient-centric culture, helping to guide the advancement of innovations in technology and high-quality products that help people live longer, with a better quality of life, thus giving them more time to do the things that matter to them.

Day 1 Plenary Sessions

Healthcare in the Digital Era

The Patient Group Experience of Digital Technologies

HEALTHCARE IN THE DIGITAL ERA

Over the past 20 years, the growth of new technologies and the worldwide web has completely transformed all aspects of our lives. The computing power of the modern smartphone is now greater than the entire NASA organisation in 1969, with processing power a million times greater. It is hard to imagine that before 1998, the multinational technology company, Google, did not exist. Yet, today, Google is an easily identified word associated with connectivity worldwide and its search engine an integral part of everyday, modern life.

During Session 2, we heard from Sam Dickinson (Head of Behavioural Innovation at the Google Digital Academy) and Professor Esther Rodriguez-Villegas (Chair in Low Power Electronics in the Department of Electrical and Electronic Engineering at Imperial College London) regarding the future potential of digital technologies in a healthcare setting and how they will help patients develop mastery over their condition. This was followed by a panel discussion with these speakers and Jan Geissler (Co-founder of the CML Advocates Network). The discussion was moderated by Christina Fasser (President of Retina International) and Kathy Redmond (Consultant at Redmond Consulting).

HEALTHCARE IN THE DIGITAL ERA

Professor Esther Rodriguez-Villegas holds the Chair in Low Power Electronics in the Department of Electrical and Electronic Engineering at Imperial College London. She leads a wearable technologies lab, where her multidisciplinary team works on all aspects of creating novel wearable electronic systems, with a special focus on improving the diagnosis and management of chronic health conditions. In her presentation, Esther provided insight into how novel devices, like wearable technologies, can help patients gain mastery over their condition.

Sam Dickinson (Head of Behavioural Innovation at The Google Digital Academy) works closely with teams around the world to help them make best use of modern digital technologies, maintaining focus on the user experience at every stage of any innovation project. During the meeting, Sam fittingly shed light not only on how patients can get the most out of digital technologies, but also provided a glimpse of the future of digital technologies and how these could potentially revolutionise patient lives.

KEY LESSONS FROM SESSION 2

> “Innovation is a human contact sport” *Unlocking the potential of digital technologies in the healthcare setting: a look into the future*
> *Sam Dickinson, Google*

People are the fundamental drivers of innovation. It may seem that money or technology are limiting factors in realising innovative concepts and ideas, and it can often be hard to fight against the Semmelweis reflex when adopting new and different approaches in healthcare, particularly in an intensely regulated environment.

However, the best innovation happens when people from a range of disciplines partner and share their experiences to think differently and against ‘the norm’, even with limited money or technologies, to achieve one goal or mission.

> “The Semmelweis reflex or ‘Semmelweis effect’ is a metaphor for the reflex-like tendency to reject new evidence or new knowledge because it contradicts established norms, beliefs or paradigms.”

> “We are committed to spending 10 percent of our time in what we call ‘the weird places’” *Panel discussion – Unlocking the potential of digital technologies: challenges and considerations for patient groups*
> *Sam Dickinson, Google*

Finding inspiration from unusual places can play an important role in helping people engage with new and different ideas. Sam provided an example of this during the panel discussion where inspiration for a new design of dental floss arose from spending time with zoologists tasked with cleaning hippopotamuses’ teeth.

Patient advocacy groups having the freedom to innovate through expanding networks outside of their fields of expertise and not being restricted by traditional methods, will be important in unlocking the potential of digital technologies to find fresh answers to difficult challenges.

HEALTHCARE IN THE DIGITAL ERA

> "Every health problem is a journey" *Sensing technology: helping patients develop mastery over their condition*
> *Esther Rodriguez-Villegas, Imperial College*

Often we consider ourselves healthy until we are diagnosed with a condition, but health is really a continuum; changes in our health often occur long before symptoms are noticed and there is a visit to the doctor.

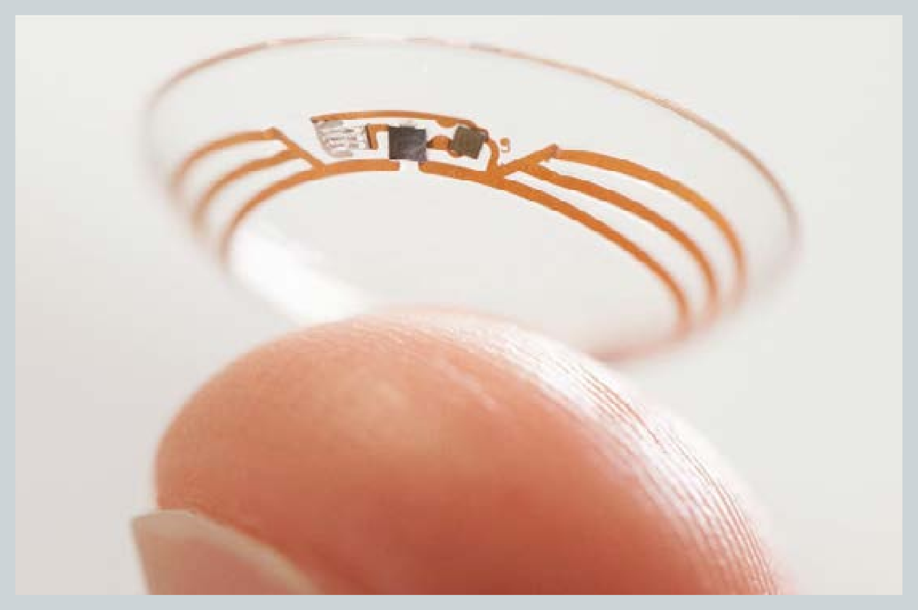
> "Rather than episodic reactive healthcare, we should promote preventative and proactive healthcare" *Unlocking the potential of digital technologies in the healthcare setting: a look into the future*
> *Video from Google*

The advent of new technologies, coupled with devices, allows us to understand and monitor what is taking place in our bodies and observe any changes before seeing a doctor, thus moving towards making healthcare fit-for-purpose in the future and overcoming the current lack of resource in healthcare systems.

With increasing numbers of people analysing their own health and seeking proactive healthcare, there will inevitably be associated healthcare costs. How to manage these costs should be addressed if technologies assessing personal health status are to be promoted and widely adopted by the general public.

Technologies will also allow the collection and analysis of vast amounts of data which will provide detailed insights and aid research into disease progression. These data will also open the door to hyper-personalised medicine by giving doctors a glimpse into each patient's individual experiences and how the condition specifically impacts their lives.

HEALTHCARE IN THE DIGITAL ERA



Sam and Esther presented examples of the types of technologies under development. Esther described AcuPebble, a device the size of a Euro coin that acts like a stethoscope, recording and interpreting the sounds within the body, which can provide an accurate, real-time diagnosis of sleep apnoea. Novartis and Google have teamed up to create a 'smart' contact lens that allows patients with diabetes to measure glucose levels in their tears using a tiny sensor and microchip.

Both speakers agreed that for patients and patient organisations, finding a partner to help innovate and develop new technology is crucial to encourage patient self-care through the use of digital technologies.

> "I am worried about the power of my devices" *Sensing technology: helping patients develop mastery over their condition, overheard on public transport*
> *Esther Rodriguez-Villegas, Imperial College*

Collecting hard data, such as survey results or information from wearable devices, is one of the best ways to deepen universal understanding of a disease for a variety of different stakeholders. Data can also provide objective evidence, identifying problems that need to be resolved and supporting new ideas to solve these challenges. Even so, there are concerns about using personal data, some of which were expressed by the audience during the panel discussion. Data privacy and data protection are hot topics in the healthcare industry, as regulations have not kept up with advances in technology. Finding the balance between sharing and analysing data, as well as ensuring data privacy and protection, will be a focus of the healthcare industry in the digital era.

HEALTHCARE IN THE DIGITAL ERA

As new technologies and devices exist in a largely unregulated environment, their accuracy, reliability and safety is often not validated, making it difficult to identify credible devices from those that are not. It is important to try and create an environment where products are validated and their accuracy is guaranteed so that patients are reassured when they use technologies and devices.

> “Experiment with the quantified self” *Unlocking the potential of digital technologies in the healthcare setting: a look into the future*
> *Sam Dickinson, Google*

Despite the challenges ahead, experimenting with ways in which technology can be used to assess and analyse our own health is central to understanding and developing the digital realm of healthcare.

THE PATIENT GROUP EXPERIENCE OF DIGITAL TECHNOLOGIES

Before the Internet, access to medical information was reserved for a limited number of groups, such as doctors and industry. Patient organisations had to act locally on a small travel allowance and with limited access to medical information to circulate to their patients. Now, the Internet and social networks allow a global reach for patient organisations. It is possible for them to serve patients anywhere, at any time; have access to medical journals; join forces with other global patient groups and mobilise activists; run instant campaigns and reach out to policymakers and media.

During Session 3, we heard from Jan Geissler, Denis Costello and Caitríona Dunne about their respective patient advocacy group (CML Advocates Network, RareConnect and Fighting Blindness) experiences with digital technologies. We also heard from Birgit Bauer, a social media expert, journalist and speaker about her experiences and knowledge on the use of digital technologies in healthcare. A number of key learnings came out of this session.

The CML Advocates Network

During a conference in 2005 for Chronic Myelogenous Leukaemia (CML) advocacy groups, an idea was fostered by four leaders of such groups for a larger network to connect hundreds of leaders of national patient organisations across the globe. Today, the network includes 109 patient organisations from 82 countries. Not only does the CML Advocates Network connect organisations, but it also helps individual organisations build their own capacity and serve their patients locally.

Everything related to the development of the CML Advocates Network has been done online. An online platform provides information and a place to connect to other patient advocacy group leaders. 'Close-to-zero cost' platforms such as Facebook, Google Docs, SlideShare and Twitter walls at annual meetings have also been used to foster connectivity between patient advocacy groups.

THE PATIENT GROUP EXPERIENCE OF DIGITAL TECHNOLOGIES

RareConnect

Patients with rare diseases commonly experience the feeling of isolation. www.rareconnect.org – a EURORDIS initiative that is a patient-led social network for people living with rare diseases – was launched in 2010; it is run by patients in partnership with patient organisations. This platform now hosts 90 disease-specific communities, 800 patient partner organisations and a network of 350 volunteer moderators. RareConnect hosts disease-specific communities for many rare diseases to ensure the patient voice is heard. One example is a community for people with a gene mutation (FOXP1) that has yet to be defined as a disease but with the phenotype well described in literature. Regardless of its rarity, a community of 70 families are now starting a research project after connecting with each other on RareConnect.

Fighting Blindness

The main goals of Fighting Blindness are to fund research into treatments for rare, genetic, age-related and degenerative conditions associated with visual impairment and blindness, support people living with sight loss and empower patients. To embrace and grow with the changing landscape of digital technologies and reach key stakeholders, Fighting Blindness redesigned their website in 2012. The website has a number of useful features; such as news and events, avenues to sign up and register for events, active challenges, newsletters and membership, a flexible donation system and the integration of social networks.

KEY LESSONS FROM SESSION 3

There is a substantial need and desire from patients for easily accessible information online relating to their disease; be this information on the condition itself, the various treatments available or information from other patients regarding their own personal experiences with the condition.

In order to meet the needs of and best serve their patients, it is imperative that patient organisations...

Go where your audience is . . . and serve them there

It is important to know and serve your audience where they are active; using analytics and metrics from online platforms can support with this. It is important to effectively use one online platform to host high quality content, rather than separating out content over multiple platforms at the cost of its quality and regularity. However, if end-users are engaging in a particular form of social media, it is imperative to have a presence on that channel. Information could be hosted on this channel, or instead, it could be used to drive interest and navigate to another online platform, ensuring that the target audience is reached. Newsletters, advertising and links from other websites can help drive traffic to a main website; this is a successful strategy to engage with patients.

Think about the different identities that patients have

Some patients wish to remain anonymous online and many patients often wish to separate their social media identity from their patient identity. When using social media as an online outreach tool, it is important to think carefully about the 2 different identities of individuals and how this may affect the social media strategy.

Utilise the free technologies available

Using Google Docs instead of developing a website, or using SlideShare or AuthorSTREAM rather than paying for webinars, is a great way to take advantage of easy-to-use, free technologies to ensure activities and information reach a wider audience. Already, video conferencing and real-time messaging are cost-effective consumer realities.

THE PATIENT GROUP EXPERIENCE OF DIGITAL TECHNOLOGIES

> “Be the standard bearers of good practice and good information”
> *Unlocking the potential of digital technologies: lessons learnt to date*
> *Denis Costello, RareConnect/EURORDIS*

Although there are great benefits to sharing and accessing information online, there are also pitfalls; incorrect information can be accessed and shared with similar ease. It can be difficult to distinguish bad information from good. Additionally, as highlighted during Birgit Bauer’s talk, the information needs of a patient will differ throughout the course of their disease, for example the needs of patients with long-standing disease will differ from patients newly diagnosed with a condition. It is therefore imperative to ensure patients can easily access information appropriate and specific to them at each stage of their patient journey.

Patient organisations and their associated online platforms must therefore represent the ‘gold standard’ for good practice and information. This involves regular moderation and review of content posted online so that patients can trust that the information provided will be accurate, reliable, appropriate to them, and easy to understand. One of the main goals when the Fighting Blindness online platform was redesigned was to ensure better control over the content distributed.

Use the collective intelligence of the community

Global access to the Internet and online platforms have allowed patient organisations to gather input and insights from the collective patient community to aid advocacy. This information can be collected through SurveyMonkey or through viral feedback within social networks. Indeed, with the advent of numerous social media platforms, for example Instagram and Snapchat, as well as video-hosting websites and blogs, patients are now more than ever able to tell their stories to the wider public, and provide invaluable insights into the patient experience.

Data from the patient communities can be presented in a new way to inform and engage stakeholders such as politicians, decision makers and journalists. Patient organisations can also use these data to improve their services for patients.

The CML Advocates Network have used this approach to collect patient-generated evidence worldwide through connected patient organisations. Information gathered by the collection of these data led to the development of an app, ‘CML Today’, to improve patient outcomes.

THE PATIENT GROUP EXPERIENCE OF DIGITAL TECHNOLOGIES

> "Patients are and should be recognised as the experts in their disease"
> *Unlocking the potential of digital technologies: lessons learnt to date*
> *Denis Costello, RareConnect/EURORDIS*

Advances in our digital capabilities have allowed patient experts, or 'influencers' to emerge; Birgit Bauer is an influencer in social media and is part of this burgeoning movement. Blogs, video blogs, TED Talks and podcasts have all provided a stage for patients to voice and demonstrate their disease expertise. This has added weight to the idea that there is equal importance to patient knowledge and experts' input.

RareConnect, an online social network, engages with this concept by providing webinars that aid dialogue between patients and physicians, allowing shared learning to occur.

Understand and meet the needs of your target audience

The target audience should dictate the design and content of any online platform; Fighting Blindness provides an example of this with their new website, which aims to increase accessibility, especially for visually impaired people.

An online platform may also be accessed by key stakeholders (fundraisers, industry, policymakers and the general public) and, due to the global nature of digital technologies, individuals with different languages, educational status and internet literacy. These are key considerations to reflect upon when developing online resources for a platform.

Online platforms should also be designed to be accessible through multiple channels, such as laptops, phones or tablets, as the use of portable devices to access information is becoming increasingly more common.

People can't always attend live events, particularly patients who may be restricted by demanding treatments, who may find excessive travel challenging, or patients who wish to remain anonymous, so platforms like Facebook livestreaming or Twitter can compensate by providing information from conferences and congresses, and allowing global participation. Twitter was used successfully to share information from the European Committee for Treatment and Research in Multiple Sclerosis congress in London, using the hashtag #ECTRIMS2016, and a Twitter wall has been used successfully by the CML Advocates Network at their annual conferences.

Workshop Sessions

Giving Patients a Voice in the Drug Development Process

Improving Organisational Effectiveness

Enhancing Fundraising Efforts

Achieving Success When Lobbying and Campaigning

Facilitating Patient-Doctor Communication

GIVING PATIENTS A VOICE IN THE DRUG DEVELOPMENT PROCESS

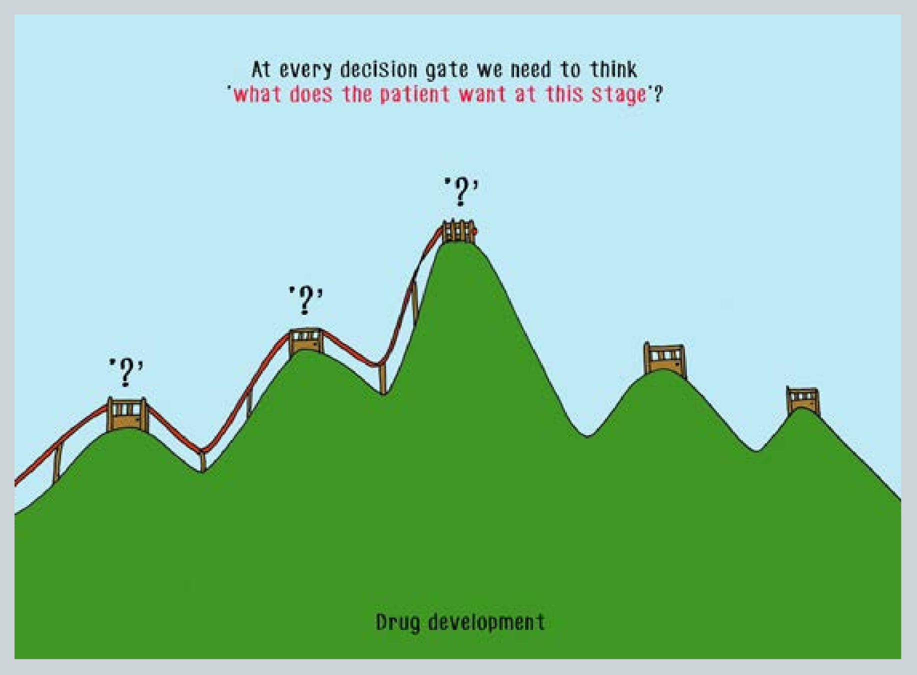
WHY?

Aside from clinical trial participation, there are a number of opportunities for patient involvement at each step of the drug development process which should be, but are not, currently being used. Their use of prescribed medication should mean that their needs are represented at every decision point.

Drug discovery and development is a complex, lengthy and expensive process; only approximately 2% of substances evaluated in the early research stage make it to market and this can take more than 12 years. The large investment involved means that the right questions should be asked and outcomes assessed so that they make a meaningful difference to patients and clinicians. Patients should be involved early on in setting research priorities and agendas to prevent large research waste occurring, which can often happen when the wrong questions and outcomes are addressed.

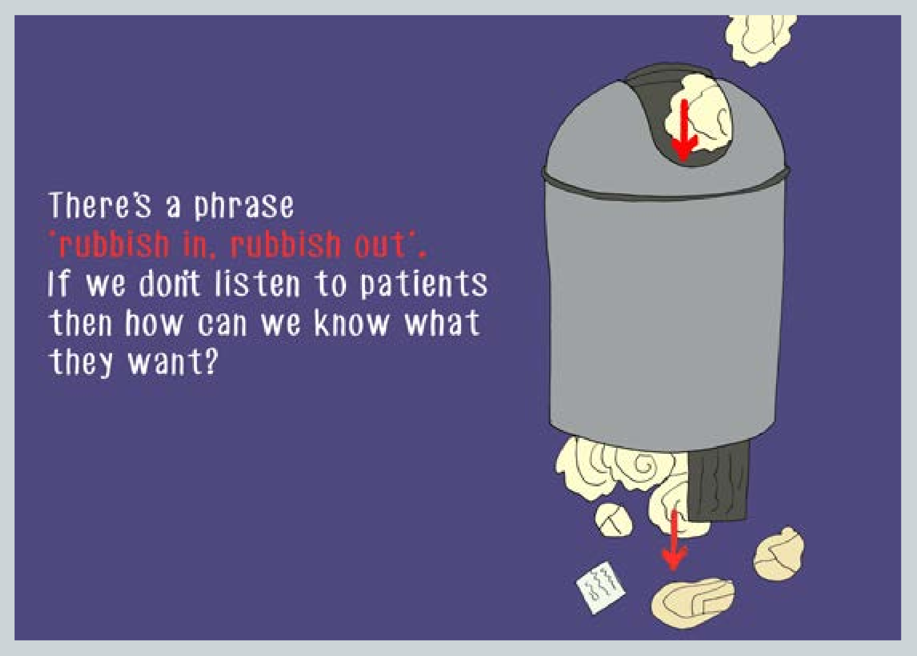
There is great potential to harness patient knowledge and experience for decision-making in the drug development process. One workshop attendee suggested that the term: 'a patient's voice' did not do justice to patient input in this situation and preferred the terms: 'a patient's knowledge' or 'a patient's expertise'.

> "We would not refer to 'the clinician's voice', but rather to 'the clinician's knowledge'; so why is this not the same for the patient?"
> *Workshop attendee*



GIVING PATIENTS A VOICE IN THE DRUG DEVELOPMENT PROCESS

During this workshop, Jan Geissler (Director of European Patients' Academy on Therapeutic Innovation [EUPATI]), Joan Jordan (Blogger for MS Ireland) and Caitríona Dunne (Communications and Advocacy Executive for Fighting Blindness), both of whom are EUPATI fellows, moderated discussions on how patients can contribute to the drug development process, and how patient organisations can help facilitate this contribution, particularly through use of digital technologies.



GIVING PATIENTS A VOICE IN THE DRUG DEVELOPMENT PROCESS

HOW?

One of the major challenges that patient organisations face is how to ensure that the patients they serve gain access and involvement in the drug development process at all stages. Some recommendations were discussed, but for many steps of the process, the answers remain unclear.

Demystify the drug development process

The first step to ensure patients are involved in the drug development process, from clinical trial participation to input into research design, is to help patients understand the process. Online training could present a valuable way for patient organisations to unlock the potential of digital technologies, in order to increase understanding of the drug development process. EUPATI have created an online training toolbox that can be adapted by national organisations to tailor information for patients on all aspects of drug discovery and development.

EUPATI toolbox: www.eupati.eu

GIVING PATIENTS A VOICE IN THE DRUG DEVELOPMENT PROCESS

Facilitate patient recruitment in clinical trials

Patient registries are of enormous benefit to collect and provide information on the nature, dynamics, disease and treatment outcomes, and quality of life for patients; they are also crucial in enabling patients to stay informed about trials and be contacted to register and participate in trials more easily.

Public awareness campaigns on how clinical trials are run or on clinical trial recruitment, which could have a digital component, may also help engage patients in actively seeking out and participating in clinical trials.

A further issue reported during the workshop, with no clear solution, was the challenge that both patients and patient groups encounter in finding information on trials that are being recruited for and those that will be available in disease areas in future. Further discussions between key stakeholders are needed on the best way to resolve this problem.

Reach the ‘hard-to-reach’

Reaching patients that are considered ‘hard-to-reach’ is key to improving trial participation and gaining patient insights into the drug development process as ideally all patients should be represented in this process, rather than just a small group of the wider patient population.

To do this, it is vital that you...

Tailor to your audience

For patient registries, one interesting workshop outcome was the clear difference between countries in the information that patients are prepared to disclose to patient registries, as well as the preferred communication method, e.g. traditional offline questionnaires versus web-based surveys. Tailoring patient registries so that they accommodate these differences will be important in engaging patients worldwide.

To engage all types of patients in the drug development process and clinical trials, adapting information so that is fit for each specific audience is vital; this may mean adapting information for different countries, patient groups (such as patients in/out of clinical trials), age groups, disease areas and levels of education.

Gather feedback

Digital technologies can be valuable for getting patient feedback on how they would like to be involved in the drug development process and the challenges they face when participating in clinical trials. Patients can also define through digital feedback tools (such as SurveyMonkey or Facebook) the ideal format that they would like when receiving information on the drug development process.

Technological advances, such as video conferencing, have extended global reach with well-networked organisations. They strengthen how patient organisations work with staff, volunteers, board members and other individuals involved with the organisation.

George Pepper (Co-founder of shift.ms, a social network for people recently diagnosed with MS) and Denis Costello (Online Communications Manager at the European Organisation for Rare Diseases [EURORDIS], a non-governmental patient-driven alliance of patient organisations across Europe and beyond) moderated discussions on the challenges faced in this new social networking realm and potential solutions.

CHALLENGES FOR IMPROVING ORGANISATIONAL EFFECTIVENESS IN A NEW DIGITAL NETWORKED REALITY

Communication

Often communicating with volunteers that may not be as digitally aware as others can present a challenge when trying to implement a digital communication strategy internationally. Lack of digital knowledge and training in digital communications can be an obstacle to improvements in organisational effectiveness for patient organisations. There is a need for clear communications pathways, be it digitally or otherwise, within and between organisations.

Patient organisations now operate in a globally-connected setting, but issues such as language barriers can reduce the effectiveness of international networking. Difficulties when communicating with members from different countries can make coordinated activities worldwide a challenge.

Resources

Lack of resources represent a huge problem for patient organisations in the digital sphere. Both financial resources, such as a lack of funding to help train staff or volunteers with new digital technologies, and human resources, such as a shortage of staff or committed volunteers – particularly those that are 'digitally savvy' – impact on fulfilling the objectives of the organisation. They can reduce the likelihood of patient organisations attracting, retaining and training new members through digital technologies, who could later help to maintain an active and up-to-date online presence, as well as safeguard information provided online.

Retaining engagement and networking after meetings run by patient organisations is problematic; solutions to this issue, as well as that of resourcing and communication were outlined by each organisation in the workshop.

SOLUTIONS BY SUCCESSFUL RESOURCING

Getting 'tech savvy'

There are a number of avenues that patient organisations can take to improve their technological capability and increase their organisational effectiveness through online networking.

The first steps are identifying the key skills that are required to action the use of digital technologies and those who need training in these skills, whilst also evaluating the risks associated with these digital technologies. For example, social media training may not be needed for all volunteers in an organisation if their digital strategy focuses on developing a website.

Using existing resources is a great way to improve networking through digital means without additional expense. This can encompass free online resources for digital training, such as tutorials for using digital networking tools or tapping into the existing digital technology experience of the membership community.

Involving young people through recruiting patients with social media skills, or contacting universities or specialist education programmes for interested students who have some social media interest/expertise, can also help reduce costs and improve a patient organisation's digital presence.

Getting alignment and buy-in from distributed branches of the network

Sharing resources through partnering with other organisations in a network can reduce the financial burden often experienced by patient organisations. This can be via an equal partnership, or a large organisation may partner with a smaller organisation to offer additional resources to the smaller organisation. An example of this may be the sharing of a social media package for simultaneous upload.

Getting, and keeping, new members

To attract new members, it must be easy for those potential new members to access information about the patient organisation. Strategies that support this include the optimisation of webpages (Search Engine Optimisation), using open groups on Facebook and Twitter to direct potential members to closed groups or online platforms for patient organisations, and using traditional print items and text messaging to direct individuals to the online network.

Relevant content plays an essential part in appealing to new members; making the content unique and specific helps it reach the right audience. Refining the patient organisation image so that it seems exciting, positive and fun, and designing specific tools or services for a younger audience, can engage the next generation.

The above points also apply to the retention of existing members, as engaging existing members is crucial to ensure their continued support, to help elevate the standing of the patient organisation within the patient community. Mixing face-to-face interactions with digital interactions can maintain interest in certain topics and provide follow-up opportunities, as well as preserve the ethos of the networked group.

Building a community of people who do things together and happen to have the same disease, rather than just a community of 'sick people', was a key take-home message from the workshop. Gathering feedback from members and taking action can ensure the needs of the patient community are met and should trigger more active contributions from them.

WHAT IS AVAILABLE?

Digital technologies have provided many new opportunities to enhance fundraising efforts for patient advocacy groups. Websites, emails, social media and paid media channels (such as text messages) are all used to help increase donations and raise awareness of fundraising activities. Online fundraising platforms have dramatically improved levels of donation through their ease of use; tools like PayPal and Google are very popular.

Online fundraising presents an opportunity to gather metrics on fundraising patterns across many disciplines. Online benchmark reports can provide insights into the donating behaviours of various non-profit organisations.

During this workshop, Neil Johnson (Chief Executive of Croí) and Maria Serena Porcari (CEO of the Dynamo Foundation) moderated discussions on how patient groups can use digital technologies and overcome any challenges to increase the amount of funds raised.

HOW DO WE APPLY WHAT IS AVAILABLE TO OVERCOME CHALLENGES AND ENHANCE FUNDRAISING?

‘Strategy is king’

Having a fundraising strategy, which does not have to be purely a digital strategy but should incorporate a digital component, is vital for improving fundraising efforts of patient organisations.

Ask the right questions

There are a number of key questions that should inform any fundraising strategy:

> “How much do we need to raise, who from, how will we achieve this and where are our donors online?”

ENHANCING FUNDRAISING EFFORTS

Challenges may become apparent after asking these questions, such as finding the resource to maintain a successful online presence on a platform where donors are most active; these issues should be considered before moving forwards with a strategy.

Understand your donor base and donor behaviour

Identification of the target audience, the frequency of appeals, access points for the target audience and the life cycle of the donor process need review before any fundraising campaigns or activities are started. Collecting metrics and using online benchmarks can provide valuable insights into fundraising techniques for patient organisations. It is often the case that web traffic does not always lead to increased donation, so collecting metrics on why people donate and where they are coming from can help optimise fundraising strategies. Patient organisations should not shy away from communicating with their donor base; building a relationship with prospective donors can prove beneficial in increasing funds.

Utilise online channels

Workshop attendees agreed that having a website with a facility that enables users to donate, is a good way to raise money, as getting online traffic can lead to donations. Having a fixed amount to donate at the top of a webpage, which people can change if they wish to, is a useful strategy to enhance fundraising. Coupling online fundraising channels, such as fundraising emails, with traditional offline techniques, may also lead to a better response rate.

Invest money to raise money

It can be easily forgotten that online fundraising needs to be actively managed and that costs for doing so need to be factored into budgets. Budgeting for targeted online appeals (for example, paid channels such as YouTube adverts or using an online platform that is usually top of a Google search) should be part of the fundraising strategy; the value of investing money to raise money should not be underestimated.

ACHIEVING SUCCESS WHEN LOBBYING AND CAMPAIGNING

Lobbying and campaigning can be complex, but underpin the activities of all patient advocacy groups. A successful lobbying strategy includes a pool of tactics, such as applying public pressure, as well as actions, such as face-to-face meetings and planned activities for the general public.

As digital technologies have become integrated into everyday life and the activities of patient organisations worldwide, their use as lobbying and campaigning tools have been widely embraced. There are some late adopters due to 'a fear of the unknown' or a lack of understanding of the benefits of digital technologies and social media networks for campaigning and lobbying.

During the workshop, Avril Daly (CEO of Retina International) and Stanimir Hasurdjiev (Chairperson of the Bulgarian National Patients' Organization and Board Member of the European Patients Forum) moderated a group exercise where attendees were divided into working groups and asked to identify the challenges faced when using digital technologies and discuss potential solutions, to support the introduction of a new patients' rights law in their respective countries.

ORCHESTRATING A CAMPAIGN TO GET POLICYMAKERS TO VOTE FOR A NEW PATIENTS' RIGHTS LAW

IDENTIFY A CLEAR ISSUE AND MESSAGE TO BE SHARED

Patient stories are our strongest asset

When lobbying or developing a campaign, patient organisations should focus on issues, using the context of patient stories and how they affect parts of everyday life. Illustrating a patient's story can help advocate and demonstrate a need, in addition to generating support from the public for a change in policy.

ACHIEVING SUCCESS WHEN LOBBYING AND CAMPAIGNING

To do this effectively, various digital tools can be used to collect patient stories and subsequently tell them to chosen target audiences. Using online communities, such as closed Facebook groups, can help to collate the patient perspective. Videos on social media, email alerts and newsletters are also communication channels used to get patient stories to the target audience, based on where they are most active online.

Every problem needs a solution

Presenting a clear goal with supporting evidence to policymakers is a high priority to outline the need for a change in policy. Achieving legislative change is more likely when well-thought through solutions are presented to policymakers. Highlighting the economic benefit of proposed changes may also help to positively influence politicians.

Develop a strategy with digital components

As for fundraising strategies, having a lobbying and campaigning strategy with clear goals and tactics for digital components is vital. Technologies can further the reach of an agreed strategy but should be considered part of an overall campaign. A strategy should promote targeted and consistent messages across all campaign platforms – aligning online and offline channels.

Match the message to the target

The fundamental steps in developing a campaign strategy include setting clear objectives and consistent messages to share, as well as establishing the digital or other communication channels to use in order to reach the target audience. Knowing the strengths and weaknesses of each online platform and their mode of action needs evaluation for strategic success.

Setting clear timelines for your campaign has a far-reaching impact and keeping timelines short helps maintain momentum.

Digital technology is only effective if it can be managed

Finally, a recurring theme from the workshops involves assessing resource use to incorporate digital technologies into patient organisation activities. Using resources wisely may mean prioritising the digital channels used; instead of accessing a wide range of digital platforms, building upon already established online networks or engaging with ‘influencers’ with a strong social media presence, will help to maximise exposure with limited resources.

EMBRACE THE ‘DIGITAL-PHYSICAL WORLD’

Even in the digital era, the goal remains the same: time with key decision-makers

Many politically active individuals have heightened activity on social media. Patient organisations that use social media networks to lobby or run a campaign can reach these individuals successfully, paving the way for future face-to-face interactions. Direct and indirect contact can be easier in an online space.

Don’t be afraid...

Don’t be afraid of the digital-physical world. Combining digital and traditional tactics can be a powerful way to maximise campaigning and lobbying efforts – technologies can help give longevity to traditional events. Livestreams on Facebook and Twitter hashtags can all improve the interactivity and participation at an event, while opening up a platform for ongoing discussions post-meeting and capturing key meeting outcomes. Similarly, hosting traditional events can help generate content for a digital campaign. The digital and physical world can complement each other in a campaign strategy.

It’s crowded – collaborate!

There are many groups with shared needs and desired outcomes, so there is added value in campaigning, using a multi-stakeholder approach. Stakeholders, such as other patient organisations, clinical experts and patients, can be reached through social media and may have a strong online presence themselves which can aid campaigns. Celebrities can also play a role in increasing the reach of a campaign as they can often be contacted via social media. Using existing digital communities in this way for lobbying and campaigning has been tremendously successful.

FACILITATING PATIENT-DOCTOR COMMUNICATION

Identifying how digital technologies can facilitate patient-doctor communication, and any potential hurdles to adopting digital technologies, were the main focus of this final workshop, moderated by Raj Mahapatra (an Executive Committee Member of the Ankylosing Spondylitis International Federation [ASIF]) and Dr Raj Sengupta (a Consultant Rheumatologist at the Royal National Hospital for Rheumatic Diseases).

HOW?

The collection and storage of patient data has dramatically evolved with digital transformation, affecting everyday life. Sophisticated technology can be used to transmit data from patient to doctor; the number of devices with these features is growing. Apps, online platforms and wearable devices serve as a hub for new diagnostic and treatment technologies; they can also provide doctors with essential information about whether a condition is being managed effectively with optimal treatment. Questionnaires available via online platforms prior to initial doctor consultations can aid early diagnosis, alongside websites that provide information on the condition and related symptoms.

Each consultation has a short window of opportunity to gather information from patients to guide diagnosis and treatment, so provision of 'real-time' data to doctors outside of the consultation helps optimise face-to-face time. This freedom from collecting data could give doctors time to better understand the treatment priorities of the patient and provide reassurance on disease management and therapeutic options.

Digital technologies also offer the advantage of gaining an insight into the disease course of individual patients. Personalised and targeted treatments specific for each individual are a primary goal in disease management; digital tools that can collect accurate data and enable this should be embraced in future clinical practice.

Dr Sengupta offered a practical example of how this could be done in ankylosing spondylitis (AS). Firstly, collecting data prior to a consultation enables more in-depth conversations between the doctor and patient on the patient's treatment goals during the consultation, allowing doctors to ask questions, such as:

> "If there's one thing we could help you do, what would it be?"

FACILITATING PATIENT-DOCTOR COMMUNICATION

Many patients with AS experience difficulties sleeping, therefore this may be a key treatment priority expressed by a patient with AS during these conversations. Apps or wearable devices that record sleep could be used following the consultation to assess whether the treatment is improving sleep and thus serving the patient optimally.

Understanding the patient, not just the disease, was often highlighted during the workshop. Several online patient-driven platforms yield large datasets and real-world patient experiences; doctors should be engaging with these to understand the patient perspective on the condition and thus improve dialogue with patients. Webinars between groups of patients and a doctor, and Skype patient-doctor interactions outside of regular consultations, can further support patients in dealing with their condition. By supplying links to useful and informative websites in referral letters, doctors can help patients gain a more comprehensive understanding of their condition.

BUT...

Remember, human contact is key

Digital technologies present huge opportunities for our healthcare system but should not replace the human touch. There is still an important role for patient-doctor conversations as outlined above and there shouldn't be a move towards diagnoses in isolation without relevant support from healthcare professionals. Digital disease monitoring should be used by patients to record changes in their condition, which if observed, lead them to seek help from healthcare professionals and not solely from a digital community.

FACILITATING PATIENT–DOCTOR COMMUNICATION

Digital solutions need to be accessible

A plethora of health apps exist and their number is likely to increase. Good quality control for apps so that they can be trusted, provide reliable information and are easy to access for patients and doctors is vital. Healthcare apps need to be accessible to all of the healthcare professionals involved in a patient's journey. Digital tools should also be customised to ensure accessibility for the patient group they serve; for example, voice technologies, rather than touch technologies, are more suitable for people with visual impairment.

Whether digital devices or apps can be incorporated into and distributed by national healthcare systems, or accessed only by private healthcare or individual purchase, is topical when discussing accessibility of devices. Some technologies remain expensive and unaffordable for the majority of patients that could benefit from their use.

Data privacy and protection concerns still exist

Widespread take up of health apps is hampered by a lack of confidence in security and fears about data being shared with a third party. Questions were raised about sharing data with countries with different privacy laws and the difficulty in specifying the ownership of data after collection and storage.

In future, patient organisations should collaborate with digital communities and other key stakeholders, such as doctors and policymakers, to determine the risks associated with data privacy in the digital realm, potential implications for patients and to decide on risk management techniques. Patients agreeing to their personal data being accessed by doctors digitally want a safe, well-regulated, digital environment with compliance to privacy laws.

EUROPEAN
PATIENT
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SUMMIT
CREATING
CONNECTIONS

A Look Into The Future

Summit Close

What’s Next?

Keeping Connected: Call to Action!

EPIS Action Plan

SUMMIT CLOSE

As Day 2 drew to a close, summaries from each workshop were given by the workshop leads, covering the main take-home messages and action points. Common themes included: the value of continued collaboration for offline and online patient organisation activities; defining and understanding the target audience and using offline and online communication channels; having clear fundraising or campaign strategies that incorporate digital technologies, but not solely relying on them; using a combination of complementary digital and traditional approaches, such as face-to-face meetings, to unlock the true potential of digital technologies for patient organisations.

SUMMIT CLOSE

Christoph Thalheim (Director for External Affairs for the European Multiple Sclerosis Platform [EMSP]), Stanimir Hasurdjiev (Chairperson of the Bulgarian National Patients' Organization and Board Member of the European Patients Forum) and Sanja Njegic (Head of Region Europe Patient Advocacy and Relations, Novartis Pharmaceuticals) closed the meeting on behalf of the Steering Committee by opening the floor to attendees to discuss take-home messages:

> "For those of us that live with severe migraine and headache disorders, I think it is the very first time we have ever felt really listened to and respected, and the array of speakers has been quite impressive. I must congratulate everyone who put this programme together"
> *Migraine Association of Ireland, European Headache Alliance*

> "I was amazed to see how we can collaborate in today's event, and it was a great pleasure to meet a lot of people that are from other areas but with very common things to do together. I'm taking a lot of learnings and a lot of new friends that I made here"
> *Israeli Association for Young Rheumatoid Arthritis Patients*

From a Novartis perspective, the Summit provided evidence that the co-creation process works to develop this kind of initiative and represents the right way forward, stimulating the creation of a large networking platform across disease areas with common themes among the communities.

WHAT'S NEXT?

Looking to the future, there are several ways to build connections and continue the conversation from the EPIS 2016 meeting. Using the hashtag #innovate4patients on Twitter, it is possible to follow, continue and join the conversations that arose after the meeting. Linking up with attendees using social media may encourage future initiatives independent of this meeting.

We promise to remain committed to continuation of the EPIS initiative in 2017, which may again be a face-to-face meeting, or use some of the novel technologies discussed during EPIS 2016 to bring together attendees in a digital meeting, which is beneficial for those unable to travel.

The website (EPIS2016.com) is available to attendees with presentations from the plenary sessions, workshops and disease forums which are available for download. Patient organisations can therefore gain free access to presentations that may inspire the planning of future initiatives. Posters presented at the Summit covering many of the successful patient organisation initiatives are also available to download on the website.

www.EPIS2016.com

The Steering Committee once again thanks all attendees for their positive energy, active contribution and ongoing feedback via surveys and emails at the Summit. Please keep us informed of future initiatives you have engaged in or have carried out based on discussions at the Summit, as well as any success stories or fruitful collaborations initiated after the Summit! We hope you found the meeting to be informative and interactive and look forward to seeing you again at EPIS 2017.

ACTION PLAN – KEEPING CONNECTED: CALL TO ACTION!

EUROPEAN
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Novartis Region Europe	We promise to remain committed to the EPIS initiative, to keep conversing and working with patient organisations towards a shared goal of improving our services for the patients we serve.
Patient organisations	Utilise social media to keep in touch with patient organisation members.
	Visit the hashtag: #innovate4patients to see and interact with social media savvy attendees.
	Access the website: www.EPIS2016.com for inspiration on activities, initiative and solutions to common problems.
	Get in touch with Novartis to share your experiences and feedback following the meeting.
	Fill in the below action plan. In 6 months we will be sending an email to receive feedback on whether your action plan was carried out following the meeting, and if not, what problems did you face that prevented you from doing so.

Please fill in the below action plan. We would love to see these action plans, so please feel free to send us a copy at: EUPAGSummit@ashfieldhealthcare.com

ACTION PLAN – EPIS ACTION PLAN

What were your key learnings from the Summit?	Which of these key learnings do you intend to implement in your patient organisation's future activities, and how do you intend to implement these?
Timelines: when do you plan to have implemented these learnings into your activities?	How will you measure the success of implementing these key learnings in your activities?

Please fill in the above action plan. We would love to see these action plans, so please feel free to send us a copy at: EUPAGSummit@ashfieldhealthcare.com

Disease Forums

Ankylosing Spondylitis Disease Forum Summary
Asthma Disease Forum Summary
Heart Failure Disease Forum Summary
Migraine Disease Forum Summary
Multiple Sclerosis Disease Forum Summary
Psoriasis and Psoriatic Arthritis Disease Forum Summary
Rare Auto-inflammatory Conditions Disease Forum Summary
Retina Disease Forum Summary

Disease Forums

On Day 2, there were eight different disease forums, comprising of a mixture of presentations, many of which described best practices of different patient organisations with an emphasis on digital technologies; there were also interactive discussions with attendees regarding their experiences and challenges as patient organisations. Please see below for specific disease forum summaries. A number of photographs and illustrations taken throughout the disease forums have also been included, highlighting their interactive and productive nature!

ANKYLOSING SPONDYLITIS DISEASE FORUM SUMMARY

This forum brought together patient organisations with research and pharmaceutical communities to share best practices in managing the needs of ankylosing spondylitis (AS) patients. It started with a review of the community experience, highlighting quality of life as a critical consideration, as well as discussing ways to raise awareness of the daily burden of AS, educate patients and the public, and how to foster better doctor–patient communication to improve clinical and patient satisfaction outcomes.

A delay of up to 10 years between the onset of first symptoms and diagnosis of AS is common. This delay in diagnosis contributes to disease severity and progression. A patient organisation from Denmark created an initiative to highlight the importance of patient experiences and liaising with the patient community to improve diagnosis. The initiative used data from a patient health survey to build a large educational campaign which included press releases, magazine and TV adverts, as well as social media platforms to share survey information directly with patients. The campaign hit its stride and grabbed plenty of attention on social media – a video posted on the organisation's Facebook page sharing one patient's experience of getting a diagnosis was widely viewed and shared. The campaign has led to patients getting an earlier diagnosis through increased awareness of AS; they are now armed with more information and are asking their primary care doctors for quicker referrals to specialists.

Another initiative in Russia showed the importance of digital technology and social media to educate patients and reduce patient isolation. The AS Patient Association uses their website to provide tools for AS patients, including YouTube videos on helpful exercises, as well as a further information search function and the ability for patient advocates to connect patients seeking help with doctors. Despite Russia being a large country, it only has 1700 rheumatologists – many patients do not have quick access to a specialist. The website can provide a resource for patients to reach out to a doctor for help. It also has a programme called E-cabinet which allows the patient to track their quality of life by reporting their symptoms online; the flagging of symptoms or patterns received by the treating doctor indicates when they should make a doctor's appointment.

All participants agreed that communication between doctors and patients needs to improve. Education and preparation of patients was identified as a key goal. If patients are better prepared for their appointments, they can make the most of the limited time they have with their doctors. Digital tools are available now that help patients get ready for their appointments, enable them to track their symptoms so they can show the doctor a snapshot of their condition and define useful terms. As patients frequently don't know what questions to ask and are intimidated or embarrassed about the emotional impact of their condition, they often find talking to their doctor difficult. This can contribute to the slow pace of diagnosis. The lack of communication between various doctors treating the same patient is also problematic – doctors need to come to an agreement about appropriate courses of treatment across specialties. Digital tools that enable patients to quickly communicate changes in their daily quality of life were highlighted as useful for enhancing patient-doctor interactions within the short time frame that is available during an appointment.

The forum reviewed preliminary results investigating the burden of AS in Spain. These data are initial results from AS ATLAS, a project that investigates AS prevalence, treatment and patient quality of life in 12 countries. This undertaking will require development of a detailed questionnaire to gather information on legislation around AS, diagnosis trends, healthcare resources, treatment availability, employment and disability. The large dataset generated will be used to determine long-term plans and goals, to ensure a high quality of life for patients and the best clinical outcomes. Beyond ATLAS, additional approaches for understanding the burden of AS were proposed, including assessing the economic impact of AS (not solely on individuals, but on society as a whole). Forum attendees were excited about the prospect of using the data from ATLAS to foster relationships between patient organisations, healthcare professionals and politicians, to bring about changes in government policy. The forum concluded with a discussion of general challenges and next steps. The importance of understanding regional variability and expanding the available databases to include a large number of countries was highlighted as key to having a powerful dataset which could be used to drive policy change. ATLAS is a good case in point; the project involved data collection from all over Europe and will serve as a milestone moving forward. Many attendees agreed that proactive action is required, driven by accurate epidemiological data, reflecting the burden of AS. By knowing the actual number of AS patients and focusing on building relationships, policy change can be achieved.

ASTHMA DISEASE FORUM SUMMARY

This forum brought together researchers and members of patient organisations to share best practices in meeting the needs of patients with asthma. After initial presentations from three patient organisations on their initiatives, the discussion explored ways to improve the quality of life for severe asthma patients, including the use of patient-reported outcomes (PROs) to inform future educational strategies.

Speakers shared their initiatives, aimed at improving early diagnosis, providing digital tools to help patients with disease management and increasing investment in asthma research. It is also important for family members to be involved in discussions about disease management, particularly related to disease burden (for example, missed school days and sport training sessions). Asthma UK created a partnership with Experian and the NHS; using their healthcare and demographic data, they developed a profile of the characteristics of UK adult asthma patients. Social media was then used to target high-risk patients, some of whom were unaware that they may suffer from asthma or allergies, and educate them about the disease.

Another patient organisation used a simple initiative to improve early diagnosis by enlisting pharmacists in Austria to identify people at risk of developing asthma. The pharmacists completed a questionnaire every time they answered questions from the general public who were seeking treatment for allergy or asthma relief. This initiative ran during the high allergy months of April and May. Almost half of the patients who were identified as potentially ‘at risk’ in this programme were referred to doctors and received early intervention that may have prevented the development of asthma.

The value of early outreach was highlighted by another initiative in Finland which targeted young teens with asthma to find out how well patients follow through with their treatment plan. An initial survey was used to develop targeted digital tools for these patients to improve how they adhere to their prescribed treatment. Results showed that when teens are well, they may not take their asthma medication regularly, despite having confidence in the initial advice from their doctor. The initiative placed a spotlight on areas that need more research investment and will help the patient organisation lobby for lung diseases to become a political priority.

ASTHMA DISEASE FORUM SUMMARY

A recent survey of severe asthma patients was presented, emphasising that little has changed in patient quality of life in the last 10 years, regardless of high investment in research and treatment. It revealed that 9 out of 10 patients had poor or no control of their asthma – according to their doctors – even though they were happy with their treatment plan. Doctors measure asthma control by results from tests; however, patients measure control by how well they feel and the impact of their asthma on everyday life (for example, the ability to get out of bed in the morning, going to work and feeling productive). This disconnect in treatment expectations and goals for patients and doctors needs review; a thorough understanding of the patient perspective will enable good treatment outcomes.

Poor quality of life can predict the asthma patient's frequency of hospitalisation. PROs provide a report on the status of a patient's health directly from the patient without interpretation by a doctor/scientist. PROs can be very beneficial in determining the impact of treatment and patient well-being. For PROs to usher in a new era of improved clinical decision-making, they must be easy to access and record, with data being accurate, valid and reusable to support patient care.

Establishing a new approach to managing asthma, with appropriate partnerships with the patient community, is important in the future. Digital technologies represent a huge opportunity to connect with and educate asthma patients. Digital platforms provide a useful tool for doctors to assess the quality of patient control of asthma and its impact on their quality of life.

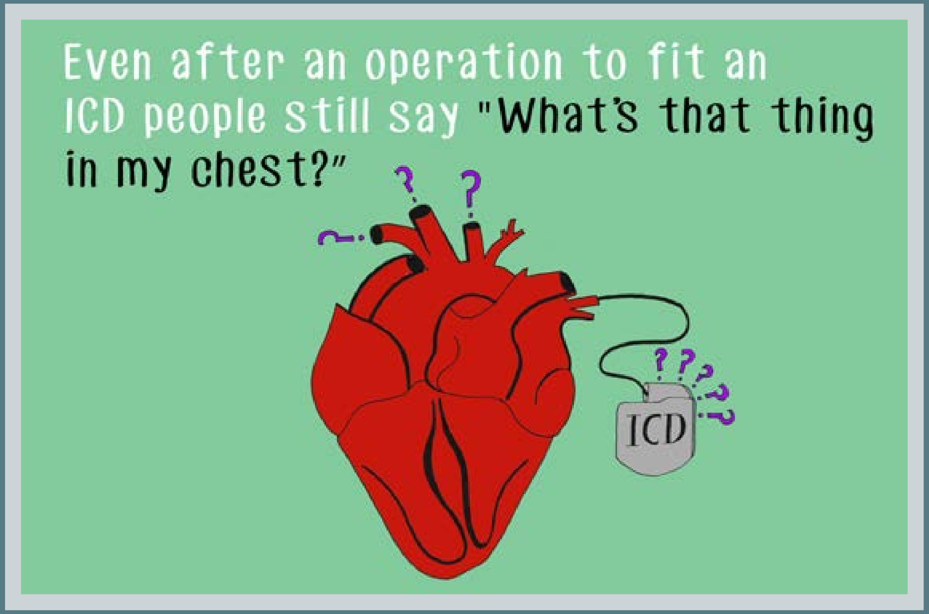
HEART FAILURE DISEASE FORUM SUMMARY

The World Health Organization (WHO) recognises heart disease as the leading cause of death worldwide. The importance of raising awareness and identifying methods to increase the number of people diagnosed at an early stage of heart failure was the focus of this forum.

Patients are often not diagnosed or misdiagnosed due to the lack of specific heart failure symptoms. The most common symptoms of heart failure are breathlessness, fatigue and swelling of the hands and feet. These symptoms can also occur in chronic obstructive pulmonary disease (COPD) and heart failure patients can be wrongly diagnosed with this condition.

General practitioners (GPs) may also associate symptoms such as breathlessness and fatigue as being age related in elderly patients; however, heart failure is ageless and can be fatal if not diagnosed. Using programmes to raise public and clinical awareness of heart failure is essential so that patients get the right help at the right time – before it's too late!

Could I have heart failure? This is a question that patients need to raise with their GPs. Once patient knowledge is increased about the seriousness of heart failure, they may be more likely to challenge their diagnosis or dismissal of initial symptoms, and this may lead to the desired referral to a cardiologist.



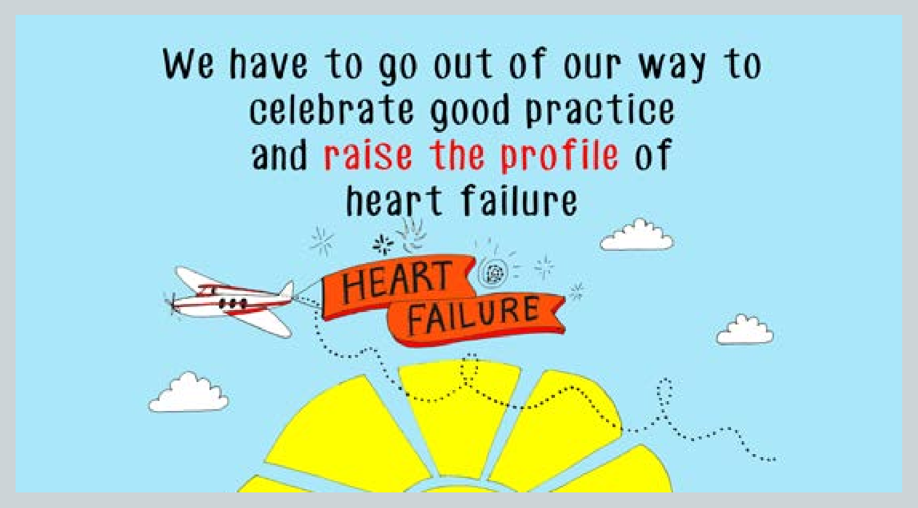
HEART FAILURE DISEASE FORUM SUMMARY

When heart failure is diagnosed, it is common for patients to have a defibrillator implanted. Patients need to be particularly educated about the relative benefits of device options when reaching the palliative stage as it is often debated whether a defibrillator should be switched off once the palliative care stage has been reached.

A visually engaging booklet, designed to educate people on heart disease, is under development by Croí; it aims to aid heart failure detection and provide information on the available diagnostic tests and treatments. Croí will work with disease associations across Europe to translate the booklet into other languages for their patients.

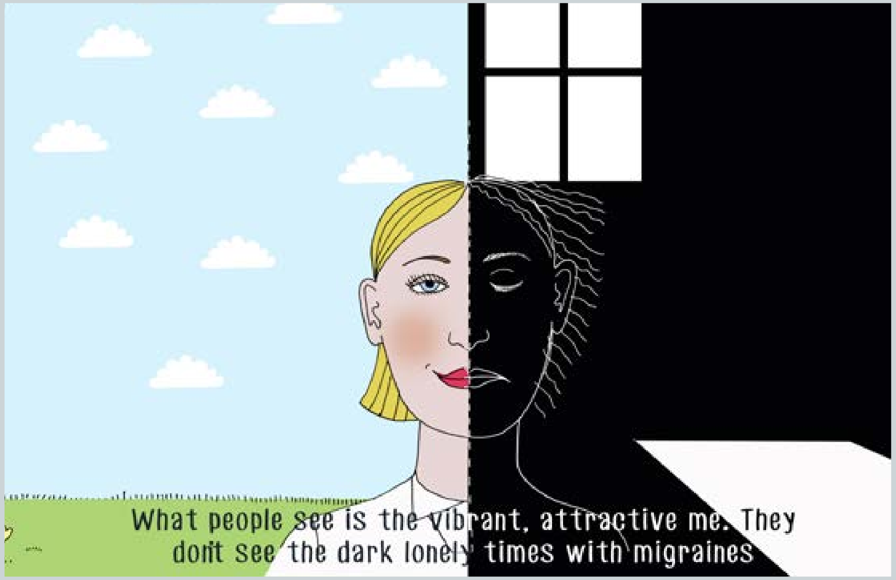
The Heart Failure Policy Network has a call to action for governments across Europe to move heart failure up the government agenda. This creates an opportunity for heart failure associations to collaborate with the Heart Failure Policy Network to raise awareness of this disease.

Medication alone may not stabilise disease or improve health; self-help groups and heart failure associations are dedicated to helping patients deal with the emotional aspect of being diagnosed with a long-term illness. When workshops and activities are organised for patients on a regular basis, they can focus on having fun and forget about their illness for a while. The support provided by patient organisations is valuable to improve well-being and to achieve better health outcomes for patients.



MIGRAINE DISEASE FORUM SUMMARY

This forum aimed to gain insight into the migraine patient journey and to identify gaps in meeting patients' needs. The forum opened with patient advocates sharing best practices in raising awareness of the real-life consequences of migraine in patients, healthcare professionals and the general public. The discussions recognised the key challenges and unmet needs of the migraine patient community and proposed an integrated approach to migraine care.

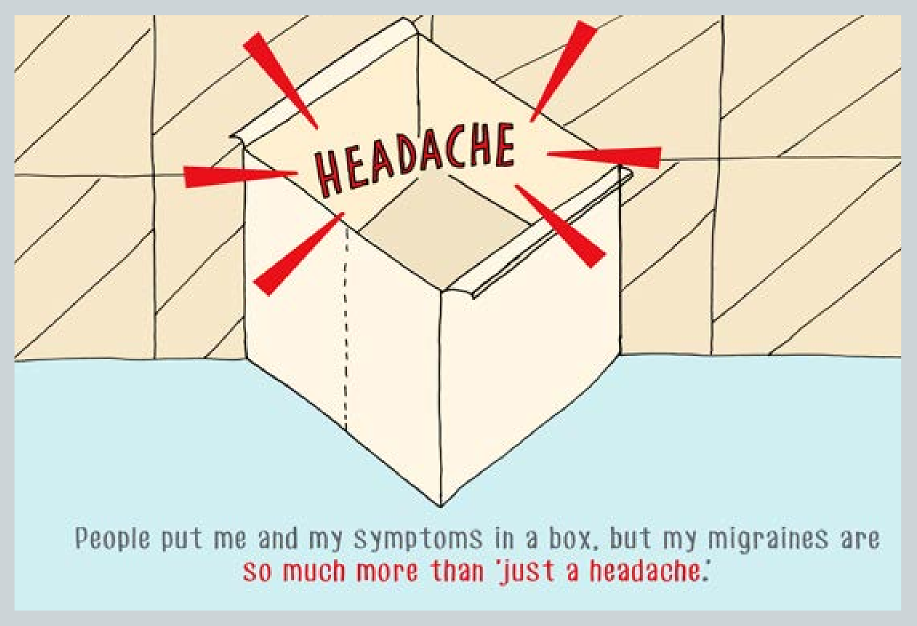


Migraine is invisible: when patients are suffering, they aren't seen, and when they are seen, they aren't suffering. Considerable progress is needed to change attitudes of the general public to the burden of migraine and to reduce the social stigma that leads to patient invisibility and shame. Patient advocacy groups are putting the patient firmly at the centre of care decisions by promoting wider interactions with patients through a variety of channels, including social media, lobbying and education.

MIGRAINE DISEASE FORUM SUMMARY

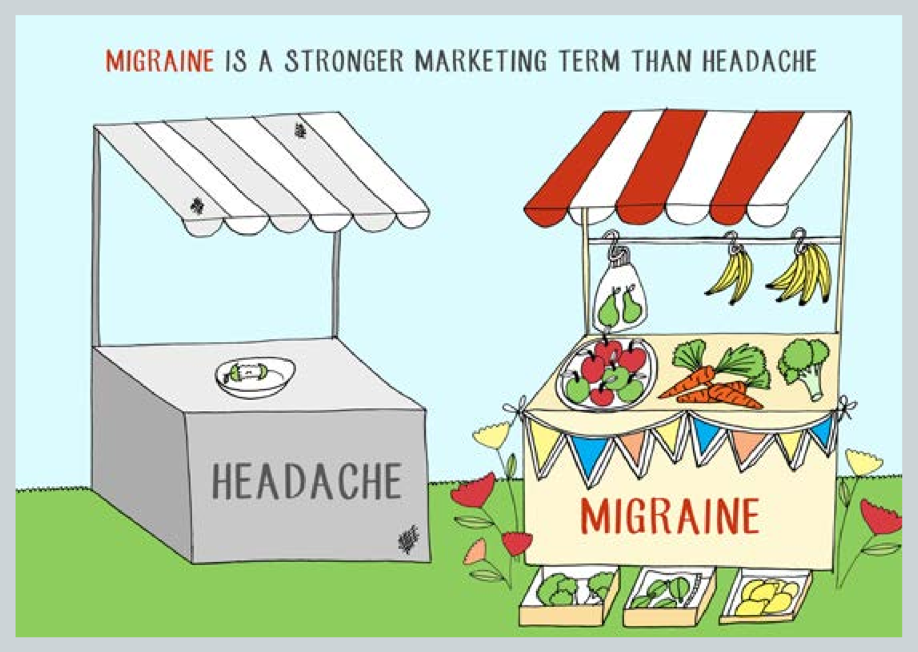
One example of a patient initiative that successfully used storytelling as a way to connect patients is the ‘Under the Hat’ campaign, which encouraged patients to share their stories on social media. The goal was to spread awareness, compassion and understanding among the general public. The campaign used an online platform to share tools for migraine patients and social media hashtags to spread the word. Another group in Russia provides digital tools to improve patient education around ways to manage headache and migraine; they’ve noticed that use of the digital tools resulted in improved self-management of migraine and better quality of life. Several projects used research obtained directly from patient experiences to address political priorities identified by the migraine community. These initiatives were targeted at influencing policy through shared decision-making to change treatment access and care pathways. Two programmes in Ireland and Wales were highlighted, revealing the importance of patient voices in influencing policy. For the project in Wales, patient reports on the quality of available care – which confirmed inferior treatment options when compared to other parts of the UK – were used by the patient organisation to action an overnight change in Welsh healthcare policy regarding migraine.

Three key challenges were identified: 1) public perception of migraine (stigma); 2) awareness of the effects of migraine on everyday life; and 3) management of migraine. The discussion focused on ways to teach patients how they can take control of their disease and on developing coordinated teams of healthcare providers, including specialists, general practitioners, pharmacists, nurses, nutritionists and physiotherapists, to provide effective care plans.



The main unmet needs outlined were: 1) lack of public understanding of migraine; 2) need for early diagnosis; 3) lack of patient knowledge about treatment options; and 4) lack of multidisciplinary approaches to treatment. This last point was determined to be the most important. Since many front-line healthcare professionals do not know the best migraine treatments, patients are left to self-medicate. A multidisciplinary approach would include teaching patients how to control their disease through lifestyle choices and would coordinate input from many healthcare professionals.

MIGRAINE DISEASE FORUM SUMMARY



Changing the perception of migraine needs champions; however, many famous sufferers aren't willing to be known as migraine patients because of the stigma associated with the disease. Future programmes should use patient stories to engage the public and digital platforms to attract younger patients. The final recommendation from the discussion was for a three-pronged approach to future migraine programmes, targeting public understanding, educating healthcare professionals and increasing patient awareness.

MULTIPLE SCLEROSIS DISEASE FORUM SUMMARY

This forum discussed the digitally-powered future, where technology improves human interaction for patients with multiple sclerosis (MS), using the collective desire of patients and patient organisations for better healthcare and self-management opportunities. It began with a review of community experiences, providing individuals with the opportunity to share best practices in MS for digital health management; it concluded with highlighting the demand and potential for digital technology to empower and engage patients in enhancing their care and self-management.

Digital technologies are frequently adopted by MS patient organisations to raise awareness of the disease, educate and support patients and advertise fundraising events (for example, using social media and webpages). The emphasis of events is to focus not on patients' *disabilities*, but their *abilities*, celebrating their physical and cognitive skills in a range of activities, including skiing, swimming, tournaments and sports days.

Social media is an increasingly important channel used by patient organisations to create disease awareness and to encourage people who engage with organisations to take further action for the cause (for example, donating, volunteering, attending an event or signing a petition). Amongst some of the success stories was a video made available online that told the backstory of a Spanish, newly diagnosed MS patient, covering the emotional and psychological impact of an MS diagnosis and living with the illness. The video raised the organisation's social media profile and aided their finances through viewings being connected to the patient organisation's donation page. An MS buddy system used in the Czech Republic has also proved popular, where patients have access to other MS patients by phone or online for support and advice.

Smartphone apps have been developed for MS patients in order to promote physical activity; one example is the 'Geocaching' app, a modern-day treasure hunting game similar to the popular 'Pokémon GO' app. Players use a global positioning system (GPS) to find a hidden cache of treasure in different locations, encouraging them to stay active without forcing them to exercise. Another game app used by MS patients has delivered improvements in cognitive function with a personalised approach to address mental decline.

Digital technologies are not used for optimal benefit in the clinical setting. Plenty of health apps exist which enable patients to track their own health and record data; for MS patients, this would require the daily recording of flares or other symptoms to discuss with their doctor. The clinical use of apps by doctors to assist with assessment and decision-making is yet to be realised; this is because there is limited time to review patient data on an app before or during the patient–doctor consultation to influence patient care. Multiple log-in details, which are required to access data recorded in apps, are another barrier to taking full advantage of the content uploaded by patients. Doctors have expressed that a portal of patient diaries from different apps with a single log-in to access data, as well as the use of questionnaires before doctor's appointments, may go some way to reap the full potential of digital technologies in healthcare.

MULTIPLE SCLEROSIS DISEASE FORUM SUMMARY

The European Medicines Agency (EMA) identified that there is limited access to real-world data to optimise medicinal development and decision-making across Europe. Collating real-world data can benefit researchers, EMA and healthcare professionals, as well as lowering the cost of medicinal development and enabling innovations. The EMA delivered an initiative on patient registries to improve the use of existing registries.

The European Multiple Sclerosis Platform (EMSP) has developed a network of European patient registers through EUReMS, which several countries now use to work together on four studies, communicating and sharing ideas with each other and feeding data into this central analysis centre. It has also developed data-handling routines to harmonise data from different registers into comparable study datasets. The EMSP has initiated a patient-reported outcomes, work-focused analysis, integrating data from UK, German and Polish registries. Their vision is to develop a pooling and central analysis hub for all relevant MS data at a European level, coordinated by a European network of patient registries, cohorts and databases in collaboration with academia and patient advocates.

The USA is well ahead of Europe and has already established a national infrastructure for patient-centred clinical research – PCORnet. It has 13 clinical data and 20 patient-powered research networks and holds data from approximately 145 million Americans.

PSORIASIS AND PSORIATIC ARTHRITIS DISEASE FORUM SUMMARY

The WHO psoriasis resolution, which recognises psoriasis as a serious, non-communicable disease (NCD), has been vital in drawing attention to the public health impact of psoriasis. This forum brought together various patient organisations representing patients with psoriasis and/or psoriatic arthritis to firstly gain insight into current community experience of using the resolution as an advocacy tool.

Adoption of the resolution is not mandatory; therefore, the International Federation of Psoriasis Associations (IFPA) and national patient organisations will play an active role in holding governments and policymakers to account on this global commitment, checking that member states enforce the implementation of national action plans based on the resolution. The German Psoriasis Association had previously struggled to engage with politicians, but this all changed when they worked with several associations of dermatologists to host a press conference in Berlin, which triggered a new kind of political discussion. These kinds of partnerships are crucial to establish a dialogue with policymakers. Finding politicians that can act as champions for psoriasis can help to ensure that the patient organisation voice is heard in the political sphere.

Questionnaires or surveys are useful tools for collecting reliable scientific data that attract the attention and support of politicians and healthcare decision makers – a technique used by Spanish and Portuguese patient organisations. Acción Psoriasis set out to achieve uptake of the resolution by using a survey to help identify the ideal treatment approach for psoriasis, alongside its economic evaluation, to demonstrate the social return on investment – these kinds of initiatives play a major role in influencing healthcare decision makers. In Denmark, National Clinical Guidelines exist

which contribute to ensuring uniform treatment services of a high quality across the country. The resolution was implemented as a National Clinical Guideline, demonstrating that existing guideline formats can help with the adoption of the resolution. Key lessons from Denmark regarding the adoption of the resolution as a guideline were to ensure that the guideline itself is easy to implement, compulsory, has a focus on referral and screening for comorbidities and incorporates all treatment options.

How patients with psoriasis/psoriatic arthritis can overcome the immense social and psychological challenges they face was an important discussion point in the forum. Limited guidance is available for patients and clinicians to manage the psychological impact of the conditions; therefore, it was observed that there is a need for specific training to address this issue. One campaign in England produced training modules for general practitioners and dermatologists for this purpose. There should also be involvement of all different branches of healthcare, including psychologists, to improve all aspects of disease management. Coping techniques can be employed to help improve an individual's well-being, such as setting goals and action planning, or forming habits and routines to alleviate the stress of keeping to, sometimes, demanding treatment regimens. Although the forum agreed that these techniques may be beneficial, it was felt that the focus of helping to reduce the social and psychological burden of psoriasis and psoriatic arthritis should remain on finding novel treatments, as limited or inadequate treatment options underlie poor quality of life. Therefore, it will be the role of the patient organisation to put pressure on the research community to investigate new therapeutic options that improve quality of life.

Public awareness and patient activation campaigns, such as World Psoriasis Day, have made great inroads in reducing the social stigma that adversely affects patients' quality of life. 'Ask Your Derm' is a patient activation campaign supported by Novartis which is being rolled out across Austria; it was established after a survey determined the impact of psoriasis on patients and their quality of life. Patients contributed to the development of the campaign concept and provided insights into the best media channel to target before the campaign was launched. Campaign activities included various print displays across the city, a short film for viewing in dermatologists' waiting rooms, radio commercials, a website and online adverts. Other innovative social media campaigns were discussed in the forum, including the application of temporary tattoos resembling a psoriasis plaque for the general public on beaches in Spain. Photographs were uploaded to social media to raise awareness of patient experiences with psoriasis. Successful campaigns like these can be adapted for different countries and can be very useful to appeal to hard-to-reach patients. The rise of social media has allowed unconventional, patient-centric campaign approaches to resonate with the public and it is hoped that they lead to an attitude shift in managing conditions like psoriasis/psoriatic arthritis.

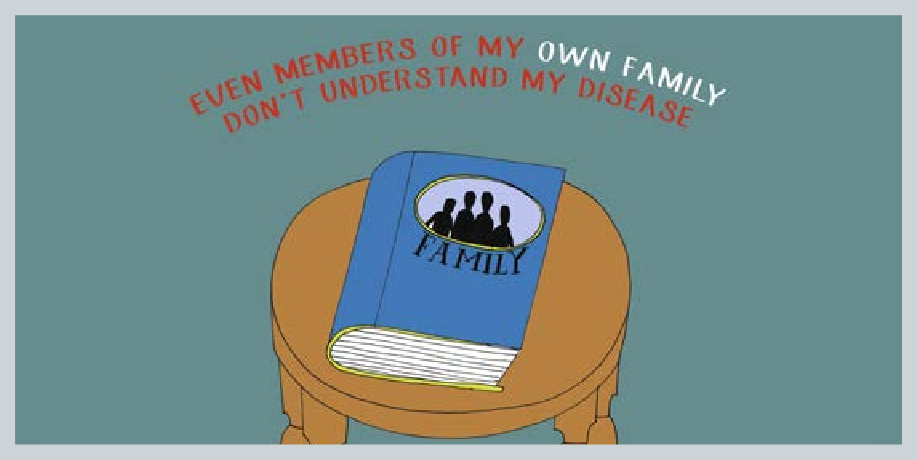
Improvements are also needed in the diagnosis of psoriatic arthritis and the patient-clinician consultation. Novartis have this in their sights and have worked in collaboration with a steering committee of patient organisation representatives and healthcare professionals to design and develop two ‘symptom checker’ questionnaires, as well as a consultation guide (to help guide a patient’s conversation with a clinician) and a consultation diary (aiding patients to track their symptoms and provide information to their clinician). An additional tool being developed is a dictionary of terms that will promote a common language between patients and clinicians. A challenge with implementing these initiatives may be their time-consuming nature; to overcome this issue, it will be important to listen to patient organisations’ experience of engaging patients with questionnaires. Digital tools like these hope to drive a positive change in the way limited consultation time can be utilised and reward patients with a more tailored and productive experience. Initiatives that provide free-to-access, co-created resources were welcomed and deemed extremely useful across the patient groups represented at the forum.

RARE AUTO-INFLAMMATORY CONDITIONS DISEASE FORUM SUMMARY

This forum discussed ways in which the European rare auto-inflammatory conditions patient community can connect with each other and share experiences with other rare disease communities. Participants were given the opportunity to share best practices and initiatives.

Auto-inflammatory diseases are rare conditions predominantly affecting children and their families. Sufferers and affected families often feel isolated. Dynamo Camp was established in Italy to provide free holidays for children with severe and chronic illnesses between the ages of 6 to 7 years. The camp offers a range of programmes for patients to join, with and without their families. Through the dedication of its members and fundraising activities, Dynamo Camp is now able to reach patients in Dubai, Morocco, Iraq and many other countries. Patient organisations expressed great interest in the opportunities offered by Dynamo Camp.

In Scotland, the Scottish Network for Arthritis in Children (SNAC) organises activities dedicated to the parents of children with auto-inflammatory conditions. Events have been organised so that parents can seek support and encouragement from other parents in a similar situation. Family weekends and annual conferences are often organised by various patient organisations, with the support of rheumatology staff, to provide affected families with information, education and support. During these conferences, patient organisations are given the opportunity to network and discuss future collaborations.



In some countries, particularly Italy, patients have to travel far to receive treatment. This often means that affected families have to relocate or stay in hotels surrounding the hospital, and this carries a high financial burden. The Association for Infantile Rheumatic Diseases (AMRI) supported families with a hospitality programme during the treatment period. It has rented five fully furnished flats, equipped with domestic appliances and close to the hospital, which can house up to 11 families at a time. By absorbing the rental cost, the association lowered the financial burden on affected families.

Rare diseases can have an early onset (for example, juvenile idiopathic arthritis). Between the ages of 16 to 22 years, patient care is transferred from paediatric to adult rheumatology. During this phase, healthcare management shifts from the parent to the individual. Studies have shown that 1 in 3 patients will stop therapy at this stage, leading to poor clinical outcomes. Efforts are being made by Die Deutsche Rheuma Liga, Germany, in collaboration with the German Arthritis Research Centre and the German Federal Ministry of Health, to run transitioning programmes to support individuals in taking responsibility for their own healthcare. Die Deutsche Rheuma Liga is also encouraging young adults to contribute to developing the guidelines for this transition.

Networks and forums exist to bring patient communities together (for example, the European Network for Children with Arthritis). This network consists of 98% of adults who have children with juvenile idiopathic arthritis. It is proactive in arranging annual conferences which provide parents and patients with the opportunity to exchange experiences and discuss potential solutions to common issues surrounding patient care.

Networking at a regional level is also important. The Russian Patients' Union and Association of Rare Diseases initiated the collaboration with legislative power bodies to change regulations for rare diseases in Russia. As a result, many new standards of care and regional programmes for rare diseases were introduced. Similarly, the Israeli association, Mifrakim Tzeirim, has successfully joined forces with government institutions to become part of the policymaking discussions on biosimilars with other patient organisations.

Another successful example of networking and collaboration was presented by the French association, Kourir, who found a way to recognise and communicate the efforts of researchers to patients and their families. It established a Kourir award which grants money for the worthiest research project for the treatment of juvenile idiopathic arthritis; the award ceremony takes place during the European Paediatric Rheumatology conference.

EURORDIS has introduced RareConnect.org, which is a social network developed for people living with rare diseases. It offers a platform for those affected by rare diseases to interact, share experiences and gain insight to new information. The platform enables the rare disease community to overcome language barriers, as information is available in several languages. Periodicfevers.com is another website supported by Novartis that is designed to empower and support those suffering with rare diseases at a regional/European level.

Social media has become a part of daily life and is recognised as an effective platform for people to stay connected in the healthcare community. Digital technologies provide patients with an opportunity to monitor their disease and become more engaged with their disease community and healthcare. For patient organisations to optimise their online presence and benefit patients through their social outputs, many are training their members on how to effectively use social media to deliver social content and campaigns. Novartis has also developed an online social media masterclass that have been launched in 2016 and will continue to be launched through 2017 in different countries.

Patient associations have expressed a growing interest in acquiring skills related to management issues, as a high percentage of these associations are not professionalised. The FEDER online training programme has been developed to enhance strategic communication, team management and motivational and social responsibility within organisations.

RETINA DISEASE FORUM SUMMARY

This forum brought together groups from a number of retina patient organisations to share best practices in meeting the needs of patients with retinal diseases, discuss advances in the management of retinal diseases and explore the impact of these advances on patient care.

Visually impaired people can often face isolation. In France, a recent initiative by Retina France matched low vision people with a trained guide who can transport them to their ophthalmology appointments because family members are not always available and taxis can be expensive. Since the start of the initiative 5 years ago, more than 1000 matches have helped to empower this patient group to make contact with ophthalmologists and influence their care.

People with low vision can feel vulnerable when they walk into a room and do not know who is there. Novartis is currently upgrading the ViaOpta app in partnership with Microsoft so that it discreetly informs the user who is in the room; they take a photo and it provides a voice description of the people there. ViaOpta can also communicate the names of people in the room if their details have previously been stored within the app and synchronised with Facebook contacts. It is hoped that this will help people with low vision gain confidence and feel secure in their environment. There is a lack of awareness about low vision and limited knowledge about visual disabilities. In Spain, a programme was initiated by Accion Vision Espana in schools to change this, as children are tomorrow's society. The project included short talks, video testimonials and games, successfully showing that visually impaired people are able to perform many tasks but may have different requirements (for example, mobile phone access) which need to be accounted for.

In Spain (Macula Retina), a parliamentary commitment was obtained to ensure adequate training for optometrists, with the aim of improving early detection of retinal diseases. This commitment included improvements to ophthalmologist-patient communication, as ophthalmologists are judged to have a lack of empathy and often fail to provide adequate information to patients and family members.

With our ageing population, there are an increasing number of people being affected by retinal diseases, such as age-related macular degeneration (AMD). Early detection and intervention are very important to slow disease progression. The AMD Awareness Week was introduced in Ireland (Fighting Blindness) in 2005 to increase awareness of AMD and to offer free testing for people at-risk. In 2015, 626 people were tested in mobile testing units, with 18% of them (who believed they were symptom-free) requiring an ophthalmologist referral.

In Poland, there is an unmet medical need for people with AMD – most patients have limited access to treatment within the public healthcare system. An audit of patient care was carried out by Retina AMD Poland, involving interviews with patients, payers and physicians; the report that followed revealed the cost of treatment and, more importantly, non-treatment of AMD.

RETINA DISEASE FORUM SUMMARY

The report also confirmed the importance of close collaboration between key stakeholders, helped to increase disease awareness and change the mindset of physicians.

Clinical diagnosis may not be precise because of the similarity of retinal diseases and lack of access to a genetic diagnosis. More than 250 genes are known to be responsible for inherited retinal degenerations; however, 40% of genes are still unknown. In Ireland, the Gateway 5000 initiative by Fighting Blindness is providing genetic testing for 5000 people with genetic retinal diseases, in order to help discover new genes responsible for inherited retinal degenerations. So far, 1100 affected individuals with inherited retinal degenerations have been sequenced and results will lead to a more accurate diagnosis for many patients.

PROs measure the efficacy of an intervention such as a new therapy, device or community programme. These measures are important because they come directly from the patient, with no interference by a clinician. Measuring improvements is difficult for retinal conditions as patients' definition of improvement can vary a lot, depending on the individual and the condition. Many visually impaired people want increased independence, but this can range from being able to drive again or reading a few words on a page. For some patients, an improvement in sight is feasible; for others, the best outcome is slowing disease progression.

There is an explosion in gene therapy research, making gene therapy closer to reality for patients with retinal diseases. Patient organisations need to work together to identify patients for clinical trials, as the earlier these diseases are treated, the better the outcome. Gene therapy cost is a concern; however, ultimately, it could offer patients access to therapy that could make a real and ongoing difference to their vision.

Patients need to be kept well-informed about the latest treatment advances and patient organisations have a vital role in making this happen. It is important to note that visually impaired people may struggle to read printed documents and websites; therefore, font style and size, as well as the colour and layout of materials, will require careful consideration.

A European Reference Network for rare eye diseases has been applied for and a decision is awaited in early 2017. This is good news for patients and an important step forward for retinal disease care, giving equal access to diagnosis and treatments, including newly evolving therapies, to patients with rare retinal degenerative diseases throughout Europe.

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