4th Annual

PATIENTS AS PARTNERS EUROPE

Millennium Gloucester Hotel London Kensington, London, UK

January 27-28, 2020

Bringing Value Back to Patients

PATIENTSEUROPE










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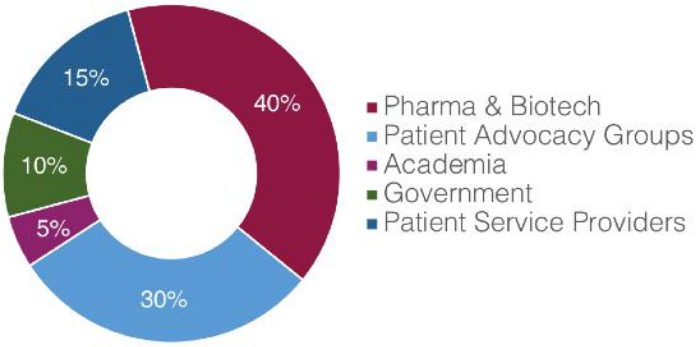
WHO SHOULD ATTEND

Patients as Partners EU is where pharma and patient advocacy leadership share best practices on the implementation of patient partnering in medicines development. Each session demonstrates the what, where, when and how to co-create solutions with patients and measure the impact of those initiatives. Together we are advancing patient participation for better clinical outcomes.

Patients as Partners EU Attendees Get Access to the Following Benefits:

- **30+** Multi-stakeholder speakers
- **18+** Hours of discussion
- **17+** Sessions covering strategies to involve patients in medicines development
- **10+** Networking activities
- **5+** Patient-led sessions
- **14+** Pharmaceutical company presentations on a specific example of collaborating with patients
- **7** Essential program chapters:
  - Patient Voice Fundamentals
  - Patient Journey Mapping
  - Upskilling Communications in Patient Engagement
  - Patient Involvement in Regulatory Decisions
  - Diversity & Representation in Medicines Development and Patient Access
  - Patient Advisory Boards: Shared Learnings from Industry Leaders
  - Metrics that Matter in Patient Engagement

TARGET AUDIENCE



Join 100+ Leaders from:

Industry Segments:

- Mid-to-large pharma
- Biotech (all sizes)
- Patient Advocacy Organizations
- Government
- CROs
- Clinical technology, mobile, digital and service companies
- Academia

Titles/ Functions:

- Heads of Patient Engagement/ Involvement/ Recruitment
- VPs/ Directors of Clinical Operations & Outsourcing
- Heads of Patient Advocacy
- Clinical Development Innovation Directors
- VPs of Clinical Affairs
- Research Involvement Managers
- Clinical External Alliance Directors

ADDITIONAL FEATURES:

Exhibit Hall Benefits Include:

- Breakfast and lunch
- Evening reception
- Meet the exhibitors
- Ask the Patients
- Meet the keynote
- B-to-B tables
- Technology demos
- Coffee/ tea
- Patient-centric teachers with therapy dogs

Attendee Post-Conference Benefits:

- Post conference summary report
- Access to slides from on-site presentations
- Photos from the event

DAY ONE - MONDAY, JANUARY 27, 2020

8:30 am
Registration and Tea/Coffee

9:00 am
Co-Chair's Welcome & Opening Remarks
Andrew Garvey
Global Patient Advocacy Lead, **GSK**

Claire Nolan
Patient Involvement Facilitator, **Charity Research Involvement Group**

Rosamund Round
Director, Patient Innovation Center, Medical and Scientific Services, **PAREXEL International**

PATIENT VOICE FUNDAMENTALS

9:15 am
Patient Keynote Guest: Insights and Lessons from a Patient Advocate who Experienced the GDNF Trial
Our Patient Keynote guest, Lesley Gosden is living with Parkinson's and is an outstanding patient advocate, who experienced the GDNF clinical trial. In this session, Lesley will give us an insight into living with Parkinson's, about the GDNF clinical trial, lessons for all stakeholders and in particular how the success rate of clinical trials could be improved from the patient's point of view.
Lesley Gosden
Parkinson's Patient and Advocate

9:45 am
Ask the Patient Panel: My Ideal Trial Design
Patient advocates take the lead in this panel, where they work with the audience on how they would design the ideal trial. More specifically:
- What would it include and why?
- Preferences around decentralized trials vs. otherwise?
- What would make a huge difference for patients?
- Giving and getting feedback preferences
- Who in the audience would be willing to implement something as a result of hearing these points?

Panelists:
Matt Eagles
Parkinson's Patient and Advocate

Lesley Gosden
Parkinson's Patient and Advocate

Andrew Warrington
Type I Diabetes and Digital Therapeutics Patient Advocate

DEVELOPING A PATIENT-INCLUSIVE CULTURE

10:15 am
How Janssen is Creating and Scaling a Patient-Centric Culture
Janssen has consistently demonstrated a commitment to creating and scaling a culture where the patient is at the center of the trial. In this session, Patient Engagement & Advocacy Lead Daniel De Schryver provides shared learnings on:
- Breaking down organizational silos to integrate the patient voice into other functions [i.e., market access, commercial]
- Leveraging diverse communication methods to establish permanent dialogue between patient and company early on
- Developing and engaging with a patient expert panel to gather qualitative and quantitative insights
- Co-creating a patient centricity charter with patients themselves to establish and elevate said principles

Daniel De Schryver
Patient Engagement & Advocacy Lead, EMEA, **Janssen**

10:45 am
Morning Networking Break

PATIENT JOURNEY MAPPING

11:25 am
How Takeda is Using Digital Journey Mapping to Design Patient-Led Trials
Through a design-thinking approach, Takeda created and implemented a digital journey map to ensure a continuum of care throughout the medicine development life cycle for patients. Takeda
will share how they developed this approach and why, the impact on patients and research and bring attendees through the process:
- Identify and collect endpoints; define what's beneficial for patients and communities to maximize standard of care
- Go beyond the patient in journey mapping; involve caregiver and doctor voices throughout the continuum, from R&D to commercialization
- Align digital journey maps with patient-centered outcomes
- Scale patient journey toolkits across various therapeutic areas

Ilaria Piubelli
Global Patient Engagement, **Takeda**

Lu Zheng, PhD, MBA
Senior Director, Head of Global Strategic Patient Services, **Takeda**

11:55 am

Santhera on Building and Co-Creating a Systematic Patient Journey Framework

Santhera co-created a patient journey framework to develop a respiratory medicine and transform access to care and management for the DMD community. They will be sharing the following:

- How Santhera developed the patient journey map, including a visual representation of DMD patient groups and advisory boards
- The various methods applied in listening and applying patient feedback
- The patient's perspective on the added value of bringing in the respective community into a study
- How this framework has transformed the internal cross-functional work at Santhera

Vanessa dos reis Ferreira, PhD MBA
Head of Patient Advocacy Europe, **Santhera**

12:25 pm

The CRO Perspective in Designing a Trial to Fit a Patient's Lifestyle?

This is an opportunity to hear from CROs on what they are doing to pave the road forward for patient-centric medicine development.

12:55 pm

Lunch

2:10 pm

Joint Patient Perspectives on How to Best Collaborate with Industry for Patient Benefit

- How are patient organizations encouraging and motivating their respective communities to be involved in shaping research?
- What tips do patient organizations have on assisting industry to collaborate in maximizing patient benefit?
- What needs to be put in place in patient advocacy groups to ensure smooth, efficient, compliant (and auditable!) data gathering?
- What does good collaboration look like?

Panelists:

Alain Cornet
General Secretary, **Lupus Europe**

Claire Nolan
Patient Involvement Facilitator, **Charity Research Involvement Group**

Natasha Ratcliffe, PhD
Research Involvement Manager, **Parkinson's UK**

Jon Spiers
CEO, **Autistica**

UPSKILLING COMMUNICATIONS IN PATIENT ENGAGEMENT

Afternoon Breakouts Begin – Choose from One of the Following:

BREAKOUT A

2:45 - 3:15 pm

The Progress of GSK's Training Program on Building Patient Engagement, Communication Skills & Competencies

It is not consistent across industry, the level of communication skills needed to work with patients. In response, GSK ran a pilot program in January 2019 across Europe, training site staff on communication skills and facilitating group discussions. The scope of training involved developing communication skills via active listening to patients. It also entailed facilitating 1-1 discussions and focus groups. This talk will share some of the outcomes from the program, along with specific ways to scale this in your own organization.

Considerations:

- How did GSK make the experience more friendly for patients?
- What key skills did they enforce in training to enhance patient experience?
- How did GSK measure the value and impact?
- How can industry up-skill its employees for more effective communication and patient engagement?

Kay Warner
Patient Engagement Lead, **GSK**

BREAKOUT B

2:45 - 3:15 pm

JnJ on HealthCaring Conversations for Clinical Research™: An Evidence-based Approach to Patient-Centered Conversations

Enhancing the patient experience in clinical trials is nothing new. However, unless it's a scalable concept, it's just not going to be effective. To combat communication challenges in clinical trials, Janssen developed a soft-skills training platform to help sites adequately communicate with study participants. This mini training is virtually based on three pillars around behavioral science, where communication style of site staff will help patients:

1. Understand interest and motivation
2. Foster a deeper connection
3. Feel empowered

This session will explore how the organization got to deploying this framework, along with successes and challenges shared. It will also bring to light how they measured its efficacy and impact, along with scalable, take-home methods on rolling out a similar program.

Sue Gowland
Senior Site Manager and HealthCaring Conversations Ambassador Western Europe, **Johnson & Johnson**

BREAKOUT A

3:15 - 3:45 pm

Norgine on the Role of Social Media and The Rise of the Expert Patient

Social media has risen as a viable channel for patients in increasing awareness of rights and their collective voice throughout medicines development. From an industry vantage point, social media is a solid tool for 'listening' to the patient voice, providing insights into their experience and expectations. Nonetheless, industry is generally wary of navigating the compliance-driven atmosphere and stipulations regarding data security and privacy. Integrating multi-stakeholder perspectives, this session will delve into following questions and considerations:

- How is social media pushing the boundaries of who the expert is — expert patient vs. physician?
- What are some of the ways in which organizations are utilizing social media to capture patient voice?
- What would we like to see pharma doing with social media in patient engagement?
- How do we deal with confidential information properly and ensure that there's more that patients want to hear about trial?
- How are we challenging compliance standards in relation to social media use in medicines development?

Liz Clark, MB BS, MSc, FFPM
VP of Medical Affairs, **Norgine**

BREAKOUT B

3:15 - 3:45 pm

Ipsen on Using Patients as Authors to Strengthen the Patient Voice in Plain Language Summaries

In response to the growing need for health literacy and transparency, the EU's newly-launched clinical trial regulation requires all sponsors conducting clinical trials to distribute plain language summaries. This session will look at ways to enhance the patient role in scientific publications, taking a look at:

- The educational need for patient advocacy groups to get studies published
- Use cases of supporting the transition toward patient co-produced research
- Methods encouraging patients to get more involved in broader publications
- Specific metrics indicating how the patient voice adds value to clinical research outcomes

Lucie Keeber, PhD
Global Medical Affairs Director – Rare Diseases, **Ipsen**

3:45 pm
Afternoon Networking Break

PATIENT INVOLVEMENT IN REGULATORY DECISIONS

4:15 pm

How Regulations are Incorporating the Patient Voice

International regulatory bodies like the FDA and EMA recognize the value of patient inclusion, and in recent years have adopted guidances for industry to involve patients meaningfully. This session discussion will update the audience on the latest on how regulations are incorporating the patient voice. Discussion points include but are not limited to:

- How are evolving regulations making it easier for patient and caregiver voices to be heard?
- What's the overview of the regulatory landscape regarding patient involvement?
- What level of influence do patients need to address regulatory decisions?
- How are changing regulations impacting industry expectations and ambitions?
- How is industry currently guiding patients to navigate evolving regulatory environment?

Domenico Merante, MD
VP, Clinical Development, **Sosei Heptares**

Sol Yates
Associate Director Regulatory Affairs Development, **Grünenthal**

4:45 pm

The Impact of Patient Public Involvement (PPI) on Health Technology Assessment (HTA) Decisions?

- What we are looking at and expecting from strategic patient involvement?
- What role do patients currently play in HTA and regulatory discussions?
- What criteria would the clinical trials need for patient involvement to be set up for reimbursement?
- What does good PPI look like?

Moderator:
Vanessa Pott
Director, Patient Advocacy and Strategic Partnerships, **Merck KGaA**

Panelists:
Claire Davis, PhD
Patient Involvement Facilitator, **Health Technology Wales**

Jennifer Dickson
Public Involvement Coordinator, **Scottish Medicines Consortium**

Šarūnas Narbutas
President, **Lithuanian Cancer Patients' Coalition (POLA)**

Donna Walsh
Executive Director, **European Federation of Neurological Associations (EFNA)**

5:15 pm - Networking Reception

DAY TWO - TUESDAY, JANUARY 28, 2020

8:30 am
Tea/Coffee

9:00 am
Co-Chair's Day One Recap & Opening Remarks
Andrew Garvey
Global Patient Advocacy Lead, **GSK**

Claire Nolan
Patient Involvement Facilitator, **Charity Research Involvement Group**

Rosamund Round
Director, Patient Innovation Center, Medical and Scientific Services, **PAREXEL International**

DIVERSITY & REPRESENTATION IN MEDICINES DEVELOPMENT AND PATIENT ACCESS

9:15 am
How Biogen is Enhancing Diversity and Representation and the Impact on Clinical Research
Diversity and representation are not just 'nice to haves' metrics in your trials — they're absolutely essential. Here is what Biogen is doing about it.

- What are today's industry practices around enhancing diversity and representation in patient recruitment?
- How are we distinguishing between ideal versus real patients in study design?
- What are some examples aligning a diverse trial landscape to a stronger end-result?
- What is the cost of being invisible and underrepresented?
- How can we tailor our communication strategies to reach more diverse groups?

Sharon Allin
Senior Manager Patient Recruitment, **Biogen**

Narinder Chopra
Director of Patient Feasibility and Enrolment, **Biogen**

9:45 am
Access to Treatment and Medication in Eastern European EU Member States
We are honored to have two patient perspectives representing Eastern Europe who will address:

- The healthcare needs of Central and Eastern European countries, citing specific examples from Myeloma Euronet Romania
- A look at enhancing better cooperation among industry, patient groups and regulatory bodies
- Identified clinical trial gaps run in Eastern Europe and considerations for overcoming barriers to growth
- Call to action and opportunities

Viorica Cursaru
Founder and President, **Myeloma Euronet Romania**

Theodora Varkonyi-Weisz
Patient Advocacy Director Europe, **Akcea Therapeutics**

10:15 am
Demonstrating Patient Value in Working with Industry: Nothing About You, Without You
When measuring patient engagement value, the KPIs tend to be more geared toward the organization, not the patients themselves. Incorporating the perspectives of a Chief Patient Officer and a disease experience expert — aka the patient– this talk will seek to answer the following questions:

- Why are patients working with us?
- How are we ensuring disease experience experts are an integral part of all key decision-making in our R&D efforts?
- What's in it for the patient community to engage with pharma
- How can we continue to relay the patient value in the work that we do?

Christine Janus
CEO, **International Alliance of Dermatology Patient Organizations (IADPO)**

Camilla Krogh Lauritzen, MSc, MCC, MMBA
Chief Patient Officer, **LEO Pharma**

10:45 am
Networking Break

11:25 am
Roche on Merging Engagement & Advocacy for an End-to-End Patient Partnership Function
By successfully bringing engagement and advocacy functions under one roof, Roche will share how they changed their internal infrastructure to set a strategic framework for patient partnerships.
Specifically:

- How has merging this function changed trial procedures?
- What were some of the KPIs and results?
- What is the impact on patients?
- How can we ensure that this function is standardized and systematic?
- How are you bringing value back to the patient?

Sanja Njegic
Global Head of Patient Partnership, **Roche**

PATIENT ADVISORY BOARDS: SHARED LEARNINGS FROM NOVO NORDISK AND ULTRAGENYX

11:55 am

How Novo Nordisk is Capturing the Patient Voice with Advisory Boards to Build a Sustainable Patient Engagement Model

Novo Nordisk walks the walk in building a sustainable patient engagement model. They understand that industry leaders are increasingly looking for effective ways to capture the patient voice in medicines development. This session will highlight how they improved their methods on collaborating with patients, through creating long term partnerships to discover unmet needs.

Key Takeaways:

- The organization's tangible benefits of developing long term partnerships with patients
- Methods on how they structured this function internally to involve patients early in pipeline development
- Tools and techniques for co-creating solutions with patients

Charline Coquerel Couniot
Head of Global Patient Engagement and Advocacy, **Novo Nordisk**

Sherina Kuruvilla
Associate Director Global Patient Relations, **Novo Nordisk**

12:20 pm

Digital Health Management: Exploring the Benefits of Virtual Patient Advisory Boards

Ultragenyx will provide perspectives on how they are employing virtual advisory boards and why. This talk will also focus on Ultragenyx's rare disease monitoring program, and how it is enhancing the patient value.

- Identify the role of virtual advisory boards, and how they are used to reduce common barriers in travel, time and recruitment.
- Enabling patients to respond to questions surrounding trials in their own time, providing broader and better insights at a global level.
- Overcoming any potential language barriers in patient communication, especially in casting a wide net.

Tom Pulles, MD
VP of Medical Affairs and Patient Advocacy, **Ultragenyx**

12:50 pm - Lunch

PILOTS, PROGRESS & TOOLS

1:50 pm

A Multi-Stakeholder Take on Defining a Sustainable Framework for Patient Engagement

Pfizer, EFPIA and EPF convene to share insights on how to define the criteria for systematic, meaningful, ethical, and sustainable patient engagement. Discussion will encompass the following:

- Current examples of how initiatives like PARADIGM & PREFER are building scalable frameworks, involving stakeholders spanning the patient engagement continuum
- The different ways patient preferences are gathered in research
- An overview of different elements of sustainability for patient engagement: process, HR, resources, and money, and fair-market value

Moderator:
Berkeley Phillips
Medical Director, **Pfizer**

Panelists:
Zsófia Bakonyi
Senior Manager Partnerships, **European Federation of Pharmaceutical Industries and Associations (EFPIA)**

Mathieu Boudes
Public/Private Partnership Coordinator, **European Patients Forum (EPF)**

2:10 pm

Pfizer and NIHR Share Data from Pilot Study on a New Network Approach to Connecting Patients with Pharma to Contribute at the Protocol Design Stage

This joint presentation will describe how the NIHR Clinical Research Network collaborated with Pfizer to design, develop and pilot a network approach to connecting companies and patients who are willing and able to contribute at the protocol design stage. Having overcome countless compliance and legal challenges in the pilot, the speakers will reveal new case study material from a small group of early adopter life science companies that are helping to test the model ahead of the official service launch (Winter 2019).

- Discover how a network approach has enabled the development of a national framework for meaningful patient and public involvement in clinical research
- Identify where patient involvement can be most impactful for improved patient recruitment and retention
- Diagnose potential challenges and issues with current approaches in patient involvement
- Propose new ways of working that will avoid common pitfalls when asking patients to help shape clinical research
- Learn how to apply elements of the UK's best practice model for patient involvement locally
- Learn about best practice – challenges, successes and solutions in patient engagement in clinical research design
- See the benefit of having an independent facilitator or 'go-between'

Furthermore, attendees from Patients as Partners Europe 2019 will see how this Service has developed over the last year; the challenges, success and lessons learned from implementing a National Service to facilitate patient involvement at the clinical design stage.

Sophie Evett
Feasibility Lead, Study Optimization, Global Product Development, **Pfizer**

Gareth Powell
Patient Engagement in Clinical Development Service Delivery Lead, NIHR Clinical Research Network, **National Institute for Health Research (NIHR)**

2:40 pm
Afternoon Networking Break

2:55 pm
TransCelerate Patient Experience Tools
The participants will gain an understanding of TransCelerate's Patient Experience Initiative and the toolkits:

- Understand how the Patient Protocol Engagement Toolkit helps you design clinical studies with patient inputs
- Learn how the Study Participant Feedback Questionnaire is intended to improve patient centricity in clinical studies
- Hear what some of our toolkit early adopters have to say about their experience utilizing the toolkits

Sherina Kuruvilla
Associate Director Global Patient Relations, Novo Nordisk

4:00 pm
Conference Concludes