ISMPP University

Patients in Focus: Redefining Scientific Conference Dynamics

December 13, 2023

Webinar will
begin promptly at:
11 AM ET / 4 PM GMT

ISMPP International Society for Medical Publication Professionals™

ISMPP Would Like to Thank…

. . . the following Titanium and Platinum Corporate Sponsors for their ongoing support of the Society:

INIZIO MEDICAL
AstraZeneca
Daiichi-Sankyo
parexel
Bristol Myers Squibb™
Ashfield MedComms An Inizio Company
Nucleus Global An Inizio Company
apothecom An Inizio Company
AMGEN
BAYER
Lumanity
IPG HEALTH MEDICAL COMMUNICATIONS
gsk GlaxoSmithKline
MedThink SciCom
A fingerpaint Company
GILEAD Creating Possible
HCG Healthcare Consultancy Group TO MAKE YOU FIRST, WE LEAD
Pfizer
Roche
sanofi
Takeda
VERTEX
ISMPP International Society for Medical Publication Professionals

ISMPP Announcements

- The next CMPP exam is March 1, 2024
  - Application deadline of February 1

CERTIFIED MEDICAL PUBLICATION PROFESSIONAL™
CMPP
ISMPP

ISMPP International Society for Medical Publication Professionals™

ISMPP Announcements

2024 European Meeting of ISMPP

Innovation: The New Tradition

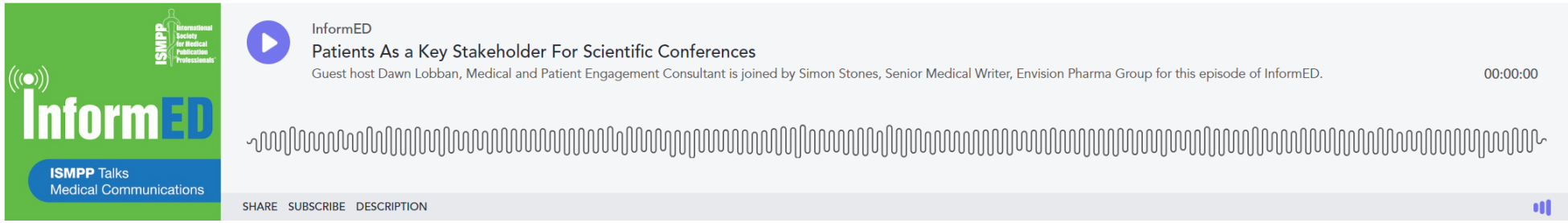
23-24 January 2024

Novotel London West

Registration is open!

ISMPP International Society for Medical Publication Professionals

ISMPP Announcements



Related InformED Podcast released November 14

How To Ask Questions

Feel free to ask a question at any time, however all questions will be held until the end the of the presentation.

To ask a question, open the Q&A window, type your question into the Q&A box. Click Send

Note: Check Send Anonymously if you do not want your name attached to your question in the Q&A

We will make every effort to respond to all questions live (out loud)

ISMPP International Society for Medical Publication Professionals™

Disclaimer

- Information presented reflects the personal knowledge and opinions of the faculty and does not necessarily represent the position of their current or past employers

Patients in Focus: Redefining Scientific Conference Dynamics

Simon Stones
Senior Medical Writer, Envision Pharma Group; Patient/Caregiver Advocate

Brittany Wolf Gianares
Director, Patient Centricity Lead, Global Scientific Communications, Pfizer Oncology

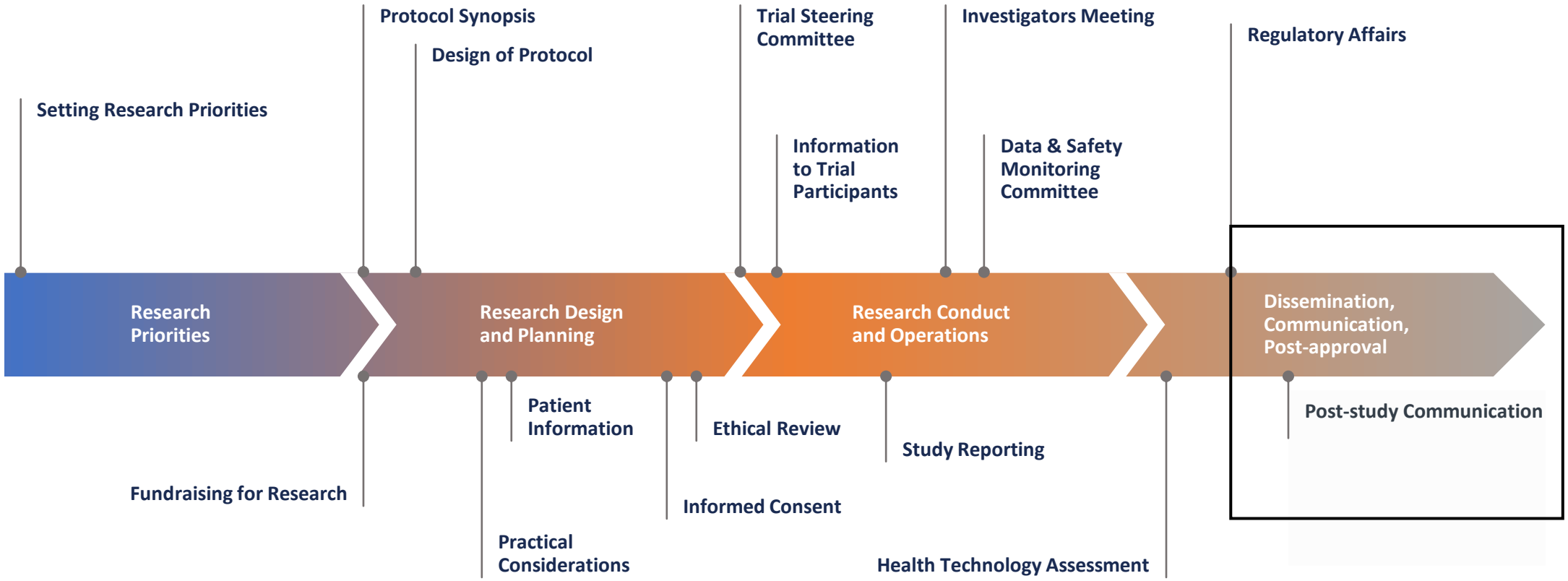
Eamonn Rogers
Chairman of Patient Office at European Association of Urology

Moderator: Dawn Lobban
Co-chair of the ISMPP Patient Engagement Taskforce

The Faculty

ISMPP International Society for Medical Publication Professionals™

Patients should be involved throughout the medicine development life cycle – including data communication[1]



1. Geissler J, et al. *Ther Innov Regul Sci*. 2017;51(5):612–619. https://doi.org/10.1177/2168479017706405 and at www.eupati.eu

Patient involvement in publications has exploded in recent years and is now well established

CURRENT MEDICAL RESEARCH AND OPINION
2022, VOL. 38, NO. 2, 189–200
https://doi.org/10.1080/03007995.2021.1997221
Article ST-0562.R1/1997221

ORIGINAL ARTICLE

OPEN ACCESS

Plain language summaries of publications of company-sponsored medical research: what key questions do we need to address?

Dawn Lobban[a]*, Jason Gardner[b]* and Robert Matheis[c]; on behalf of the ISMPP PLS Perspectives Working Group

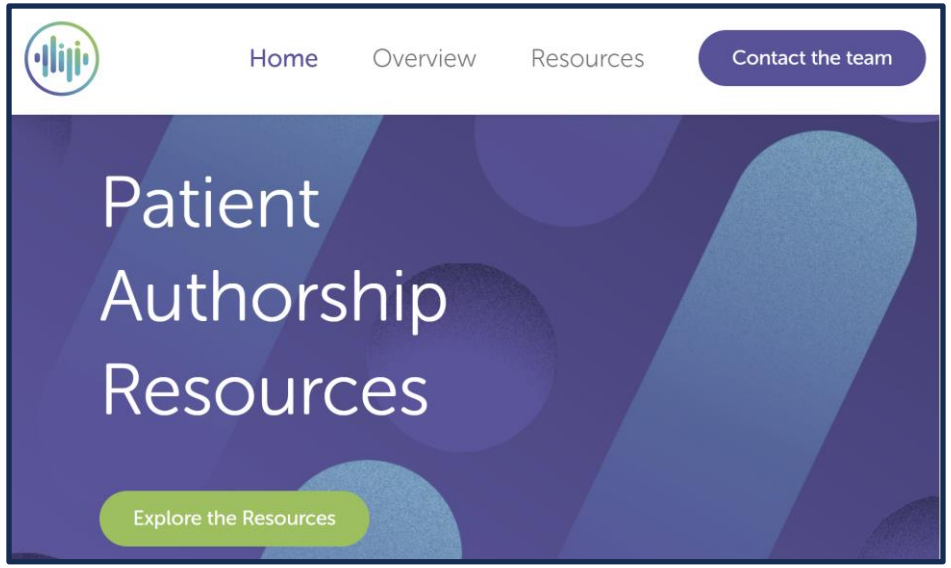
Richards *et al. Research Involvement and Engagement* (2020) 6:38
https://doi.org/10.1186/s40900-020-00213-6

Research Involvement and Engagement

COMMENTARY Open Access

Guidance on authorship with and acknowledgement of patient partners in patient-oriented research

Dawn P. Richards[1,2*†], Kathryn A. Birnie[1,3†], Kathleen Eubanks[1], Therese Lane[1], Delane Linkiewich[1], Lesley Singer[1], Jennifer N. Stinson[1,4] and Kimberly N. Begley[1]



Annals of Internal Medicine RESEARCH AND REPORTING METHODS

Good Publication Practice (GPP) Guidelines for Company-Sponsored Biomedical Research: 2022 Update

Lisa M. DeTora, PhD, MS; Dikran Toroser, PhD; Angela Sykes, MA, MPhil; Christine Vanderlinden, PhD; Fiona J. Plunkett, PhD; Trevor Lane, MA, DPhil; Eline Hanekamp, PhD; Laura Dormer, BSc; Faith DiBiasi, BSc, MBA; Dan Bridges, PhD; Lise Baltzer, MBA; and Leslie Citrome, MD, MPH

.....but what about patient involvement in scientific conferences?

Is it happening?

- To what extent?

What are the opportunities to be involved?

- What roles could they play?

What is the value?

- Why is this of interest?

Do patients want to be involved?

- Who are they?

What are the barriers to involvement?

- Practical? Regulatory?

What initiatives exist to encourage further involvement?

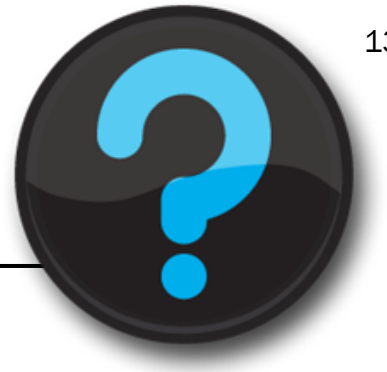
- What can we do as publication professionals?

ISMPP International Society for Medical Publication Professionals™

Patients in Focus: Redefining Scientific Conference Dynamics

- Objectives
  - Understand the value of involving patients in scientific conferences to ensure that insights from all key stakeholders in medicine development are included
  - Be aware of the opportunities and challenges faced by patient partners wishing to participate in scientific conferences
  - Be able to identify and support opportunities to include patient partners in all aspects of scientific conferences including as attendees, presenters, and organizers

Do you have experience of working as/with patient partners at a scientific conference



- Yes
- Not yet – but it is on the plan
- No – but I would like to
- No – I am not sure of the value

From Spectator to Influencer: The Role of Patients at Scientific Congresses

Simon Stones, PhD, ISMPP CMPP™

Senior Medical Writer, Envision Pharma Group; Award-Winning Patient/Caregiver Advocate and Member of the EULAR PARE Committee

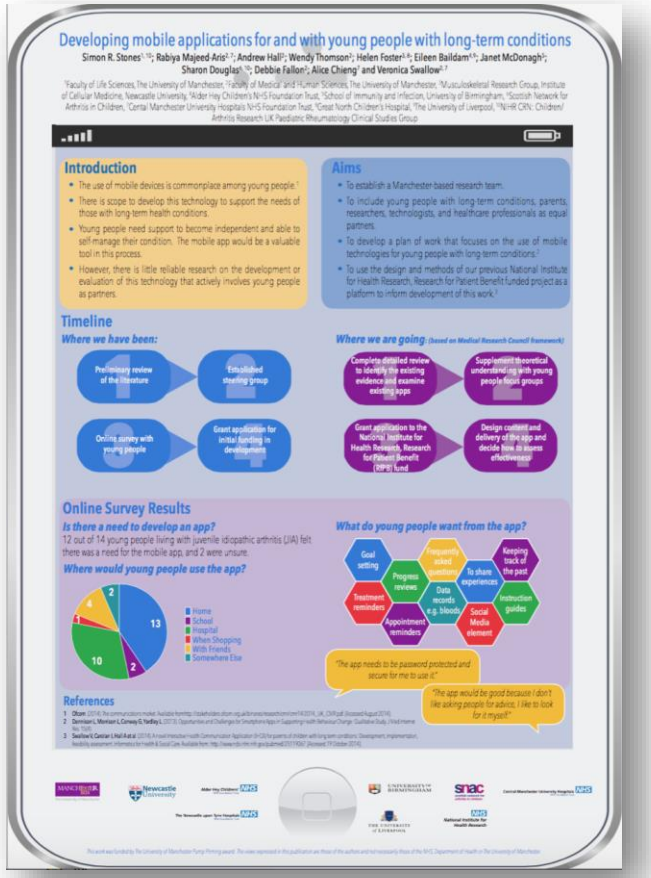
ISMPP International Society for Medical Publication Professionals™

Patient Advocacy Maze

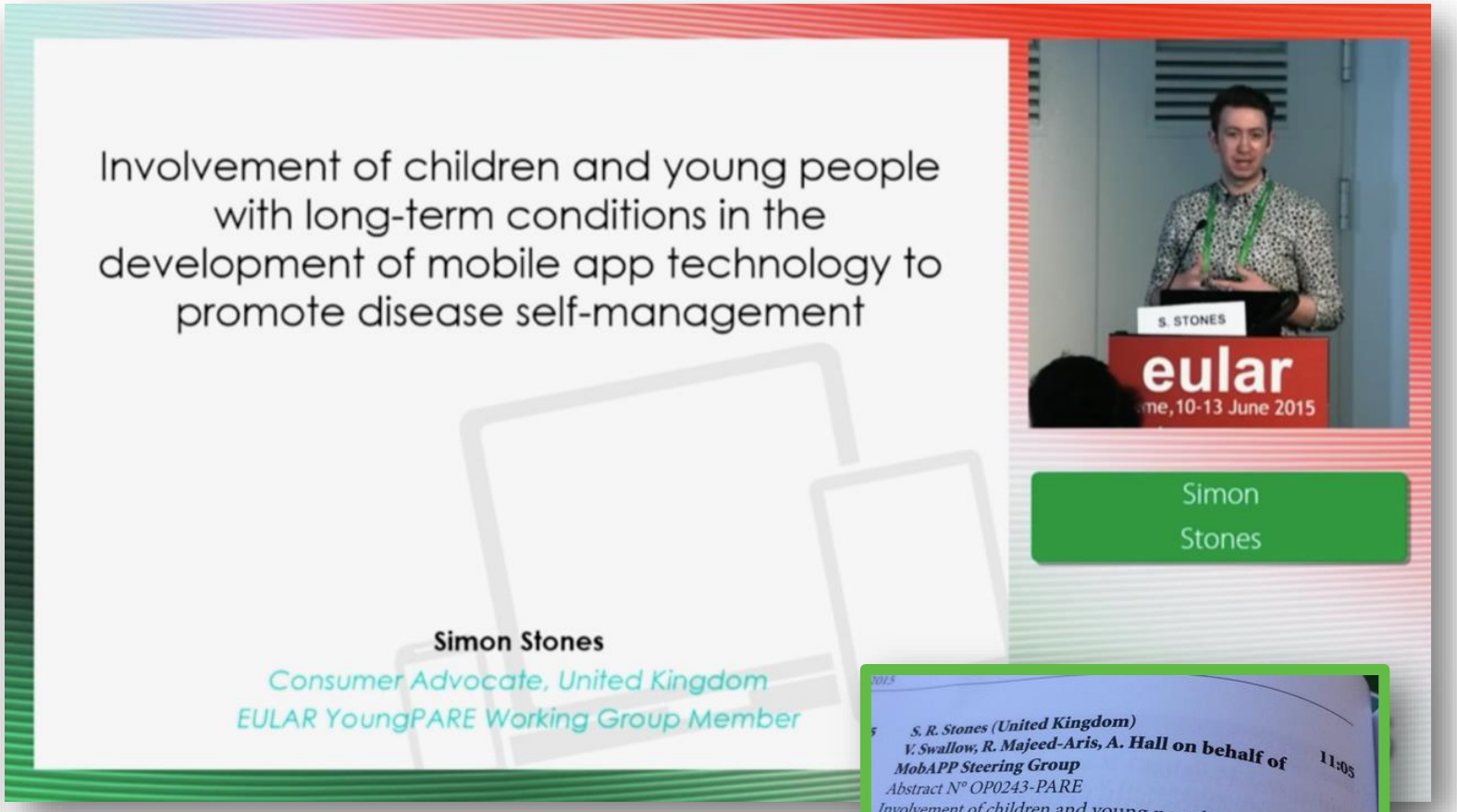
- Long-term conditions since childhood
- Informal carer for parents
- Introduction to advocacy aged 18 years
- First pediatric rheumatology clinical study group patient partner in the UK
- Founding member of EULAR Young PARE (European network of advocates aged 18–35 years)
- Board Member of two patient organizations – Fibromyalgia Action UK (2016–2020) and RAiISE (2018–present)
- Former President of the European Network of Fibromyalgia Associations
- Healthcare PhD, conducted as an expert patient in rheumatology
- Patient engagement and involvement consultant for academia, the pharmaceutical industry, and patient organizations
- Medical communication and publication professional

EULAR = European Alliance of Associations for Rheumatology; PARE = People with Arthritis/Rheumatism in Europe

First Congress Experiences



National Institute for Health and Care Research (NIHR) INVOLVE Conference, November 2014



European Alliance of Associations for Rheumatology (EULAR) Annual European Congress of Rheumatology, June 2015

ISMPP International Society for Medical Publication Professionals

The Value of Patients at Congresses

Independent patient advocates

Patient organization representatives

Opportunities

- Integrated congress track
- Separate sessions
- Collaborative sessions
- Opening session
- Plenary sessions

*Patients should **never** be on the sideline…*

Absorb information and assess the landscape

Disseminate information with communities

Present abstract research

Facilitate and/or moderate sessions

Strategic input to the congress agenda

Platform for education and networking

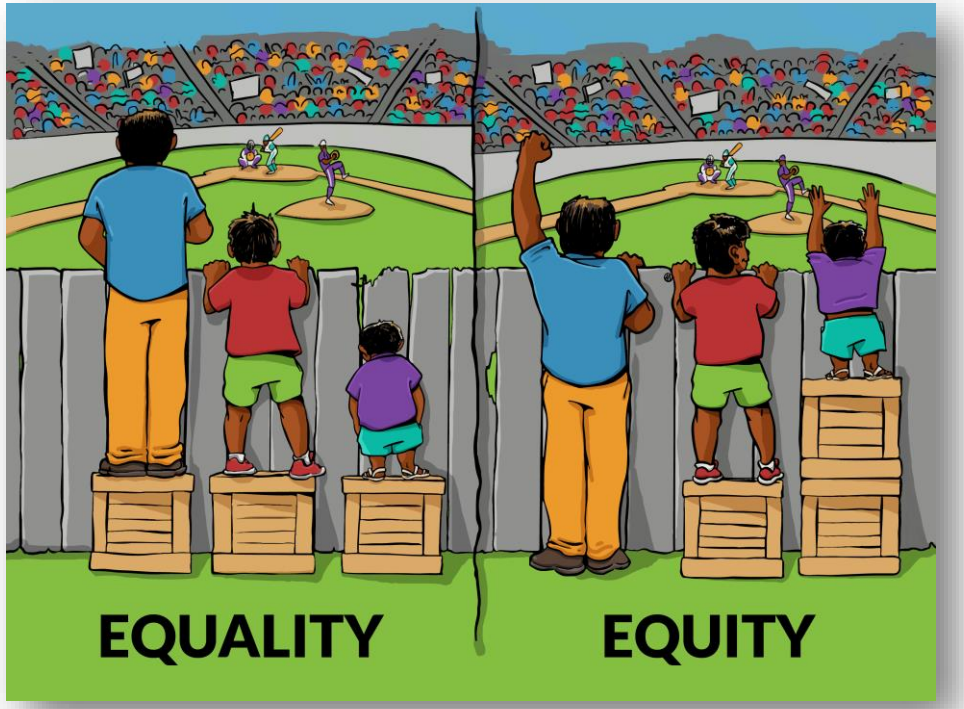
ISMPP International Society for Medical Publication Professionals™

Challenges and Frustrations

Trying to fit patients into a health care professional model

- Patients can be made to feel inferior
- Reality vs equality vs equity vs justice vs inclusion

"When you invest in patients, it benefits everybody"



Interaction Institute for Social Change | Artist: Angus Maguire

Registration fees and expenses

Emotional, technical, and functional accessibility

Regulatory restrictions

Case Study: Annual European Congress of Rheumatology

"[EULAR] is a renowned forum for interaction between medical doctors, scientists, people with arthritis/ rheumatism, health professionals and representatives of the pharmaceutical industry worldwide"

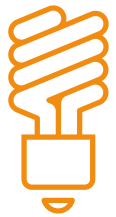
Patient perspective / PARE research track → Abstracts scored by a panel of PARE representatives and recommendations made to the EULAR Scientific Committee

PARE Abstract Session

PARE Themed Session

PARE/HPR/Scientific Joint Theme Session

PARE Poster Tour



Highlights Session

PARE Abstract Award

12 sessions

EULAR = European Alliance of Associations for Rheumatology; HPR = Health Professionals in Rheumatology; PARE = People with Arthritis/Rheumatism in Europe

ISMPP International Society for Medical Publication Professionals

Case Study: Annual European Congress of Rheumatology

At the EULAR Congress 2023, 12,000+ delegates from around 125 countries attended; 200–300 patients

Abstract bursaries

- Complimentary registration, including on-demand access
- Three nights' accommodation
- € 350 for travel and living expenses

Registration fees

Categories	Early bird fee
PARE delegates	€ 181
Patients and family	€ 24

- EULAR awards bursaries to presenting authors* of abstracts selected as oral presentation, poster tour and poster view to facilitate attendance
- Registration, accommodation, and travel are covered for invited speakers
- Additional bursaries are also made available for EULAR Patient Research Partners to apply for

EULAR = European Alliance of Associations for Rheumatology; PARE = People with Arthritis/Rheumatism in Europe

Opportunities for More Inclusive and Collaborative Congresses

Quick and easy (easier) wins

- Plain language summaries
- Plain language podcasts
- Integrated patient tracks
- Guidance and tailored support
- Hybrid congresses

Long-term vision

- **International guidance** that facilitates open, transparent, and inclusive exchange of scientific information amongst all stakeholders
- **Strong commitment** from organizational leadership, including representation of patient leaders at the highest level of governance

ISMPP International Society for Medical Publication Professionals™

Demonstrate Your Commitment with the Patients Included™ Conference Charter

- Active involvement of patients in the design and planning of the event (including themes, topics and speakers)
- Involvement of patients in delivering the congress
- Visibility of patients in the physical audience
- Travel and accommodation expenses are paid in full (and in advance) for patients involved in the congress program
- Scholarships are provided by the congress organizers to allow patients affected by the relevant issues to attend as delegates
- Accessibility requirements are accommodated
- All applicable sessions, breakouts, ancillary meetings, and other programme elements are open to patient delegates
- Access for virtual participants is facilitated, with free streaming video provided online wherever possible

patientsincluded.org

ISMPP International Society for Medical Publication Professionals

Advocating for Health Literacy and Patient Inclusion in the Scientific Dialogue

Brittany Wolf Gianares

Director, Patient Centricity Lead, Oncology
Global Scientific Communications, Pfizer

ISMPP International Society for Medical Publication Professionals™

A Wave of Patient-focused Initiatives is Changing Healthcare, But Gaps Remain

TODAY

THE EVOLUTION OF PATIENT-FOCUSED INITIATIVES

A recent shift to embrace involvement of patients and their families in all aspects related to a patient's medical journey

Goal *to educate and empower patients to be involved in research and to provide ways to voice their needs*

FUTURE STATE

THE REMAINING NEED

Opportunity for increased patient involvement in research, medical meetings, and as co-authors in publications

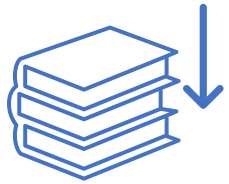
Goal *to engage with patients in* ***co-creation*** *so their perspectives can be heard in the scientific community*

ISMPP International Society for Medical Publication Professionals™

Low Health Literacy Impacts Patient Engagement

Health literacy is a person's ability to find, understand, and use information and resources to help them make healthcare decisions for themselves and others

Low health literacy levels remain a hurdle



Social, structural, and economic factors impact literacy

Challenges with Patient-Physician dialogue impacts shared decision-making

Lack of understanding and adherence to care plans

Barrier to engaging patients in clinical research

Underrepresentation of diverse populations in clinical trials

ISMPP International Society for Medical Publication Professionals™

Improving Health Literacy to Enable Patient Participation in the Scientific Dialogue

Patients need to be able to understand and access scientific information to be engaged in the congress space

How can we do this?

- Plain language summaries and scientific education resources
- Age-tailored and culturally-tailored educational resources (translations); accessibility features
- Open access publications and enhanced publication content
- Partner with advocacy groups to drive awareness of resources
- Ensure diversity among healthcare teams at community centers and institutions
- Leverage care coordinators/ sub-investigators to ensure their communities are aware of clinical trials and that their needs are reflected in trial designs
- Deploy latest technology to help improve access to trials and scientific information

ISMPP International Society for Medical Publication Professionals™

Implementing Health Literacy Best Practices for Increased Patient Engagement

Understand the patient journey and unmet needs of unique populations

Develop resources to empower them to understand medical topics and emerging scientific data

Disseminate data in plain language so patients can be a part of the shared decision-making process

Empower patients to be a part of the scientific dialogue by giving them a platform at congresses

We cannot achieve full patient inclusion in drug development and associated activities if they are not fully empowered and informed, not only about their rights and obligations, but about peculiarities of the science we co-create that are most meaningful to them.[1]

Understanding the Patient Journey

A complete assessment of patient needs in the real world is required to understand gaps, identify opportunities for education, and understand the “Moments that Matter Most.”

Qualitative Insights

A two-pronged approach

Quantitative Insights

ISMPP International Society for Medical Publication Professionals™

Improving Health Literacy in the Congress Space

Breaking Down the Complex Aspects of Cancer Care

- Through insights gathered from patients and through preference data, key education gaps were identified leading resource development to improve health literacy.
- The goal of these tools is to empower patients to participate in congresses, but are also featured on the congress floor, further evolving offerings to be inclusive of patients.
- Topics revolve around understanding and interpreting data from abstracts, utilizing PLS, navigating the clinical trial process, and understanding the basics of medical meetings and how to find scientific information.

Links to: Patient-Friendly Health Literacy Resources for Cancer Patients and Caregivers | Pfizer

Plain language summaries are conduits for patients being included in congresses

How we started
(2018–2021)

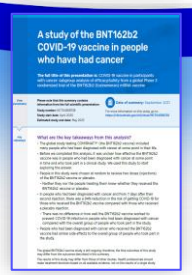
2018 ASCO ANNUAL MEETING

First industry abstract PLS (APLS) pilot at ASCO, with 12 APLS developed (June 2018)

Expansion of APLS pilot (2019-2020)

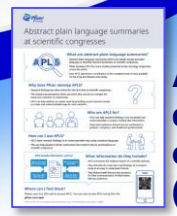
Company-wide publication policy established based on health literacy best practices (February 2020)

Company expansion of novel AI-based health literacy tool to assess readability



PLS for ESMO 2021 oral presentation on COVID-19 vaccine in participants with cancer (Sep 2021)

ESMO 2021 plain language podcast on bladder and kidney cancer highlights (Sep 2021)



APLS educational one-pager (Jan 2022)

Where we are
(2022–2023)

Routine posting of PLS content on @PfizerOncMed

APLS QR code booklet for distribution at congresses and on @PfizerOncMed (Jun 2022)

Adapting PLS templates to auditory and linguistic learners, and translating into new languages

600+ PLS developed since 2018 including PLSPs of pivotal clinical trials and real-world evidence studies

Expand PLS access to both patient and HCP audiences (2024+ goal)

Where we're going
(2024+)

International Society for Medical Publication Professionals

Reference: *Wolf Gianares, et al.* "Achieving Health Equity Through Shared Decision-Making: Evolution of Plain Language Summaries (PLS)" Presented as a Poster Tour at the 19th Annual Meeting of ISMPP, April 2023

Integrate patient-authored abstracts within the scientific program to provide a platform for patients

THE PATIENT PERSPECTIVE TRACK IS…

- A scientific meeting session that is fully integrated with the congress program
- A track with submissions that are reviewed and curated by a Scientific Committee
- An opportunity for patient advocates and patients to share perspectives on research (ex: surveys, focus groups, collaborative studies)

IT IS NOT…

- A Symposium or Expert Theater supported exclusively by Industry
- A promotional program with content developed outside of the scientific meeting sessions by Sponsors
- Session devoted to case studies or anecdotal information sharing

ISMPP International Society for Medical Publication Professionals™

Patient Attendance at Scientific Conferences: Experience of the European Association of Urology (EAU)

Eamonn Rogers, MD

Chairman of the EAU Patient Office

Board Member of the EAU

ISMPP International Society for Medical Publication Professionals™

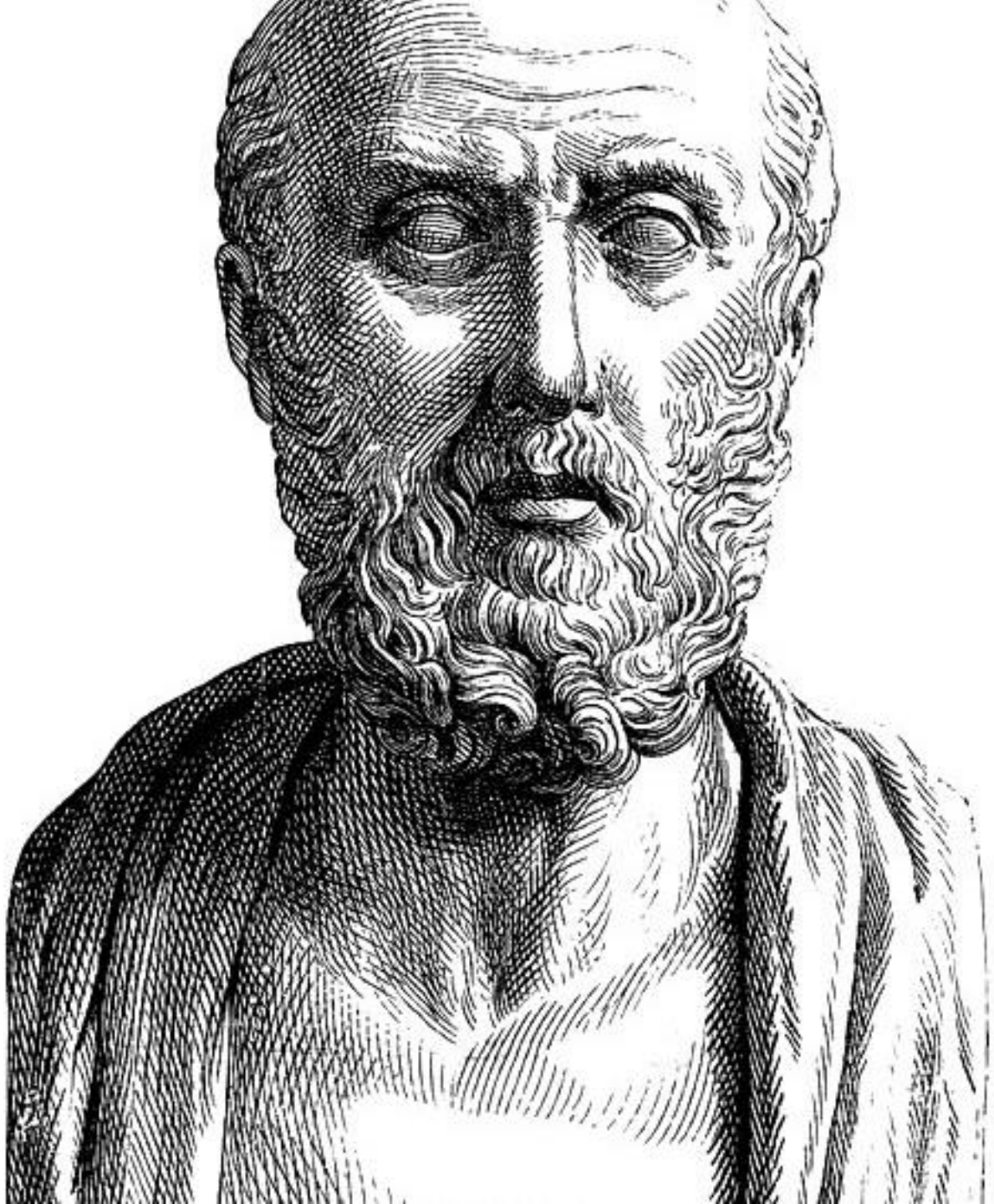
EUROPEAN ASSOCIATION OF UROLOGY

eau Patient Office

ISMPP International Society for Medical Publication Professionals

Hippocrates

'It is far more important to know what person the disease has than what disease the person has’



About EAU Patient Information

The leading urological authority in Europe for patients

Mission

Every urological patient in Europe should have access to high quality and reliable patient information.

Well-informed patients lead to better patient involvement in the shared decision-making process and adherence to the treatment plan.

COMPREHENSIBLE PATIENT INFORMATION

- The content is translated in **plain language**
- Extensive library of **educational materials**, including videos, medical illustrations and leaflets on all urological conditions, treatments etc.

MULTI LANGUAGES

- A variety of **European & non-European languages** including Turkish, Arabic & Chinese
- A **wide range of urological topics** enables urologists, nurses, patient advocates and other HCPs to educate patients easily on their conditions.

RELIABLE CONTENT = EVIDENCE-BASED

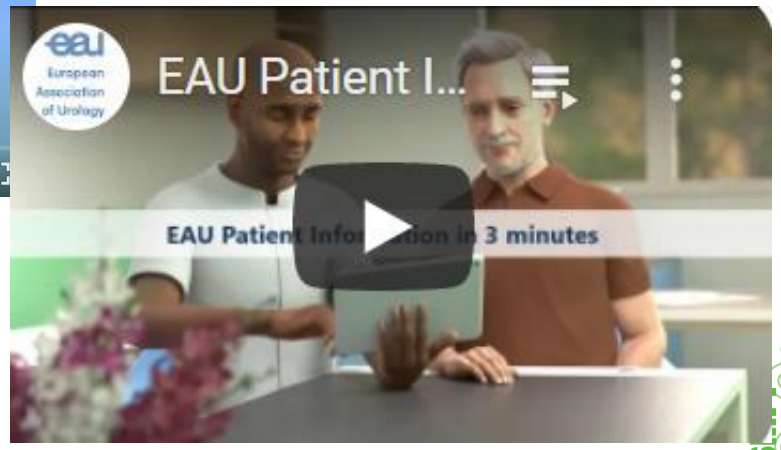
- The content is based on the scientific evidence from the EAU Guidelines that is **used by more than 8,000 urologists across Europe and beyond.**
- It is **regularly updated** with the latest scientific evidence and expert recommendations.

ISMPP for Medical Publication Professionals

Animated Videos

Latest videos:

- OAB Syndrome
- ADT-related CVD
- Patient Office in 3 Minutes



No. of views of EAU animated videos on YouTube and Facebook: Almost **11,000,000**

International Society for Medical Publication Professionals

eau Patient Office
Urology Resources

1 Choose the resource that is best for you

2 Scan the QR code with your phone camera

3 Learn about the condition and save the page for future reference

Prostate Cancer

What is prostate cancer?

Video on Radical Prostatectomy

Androgen Deprivation Therapy (ADT) Educational Programme

Video on Hormone therapy-related cardiovascular disease (HRPC)

Erectile Dysfunction

What is erectile dysfunction?

Video on Erectile Dysfunction

Urinary Incontinence

What is urinary incontinence?

Video on Urodynamic Testing

EAU Patient Information Portal

Research Outcomes Digital Natives

- Healthcare **professionals and patients** make up most visitors to the portal
- The **treatment pages** are most visited
- There is a **demand** for information relating to **softer issues** such as quality of life, living with a disease, survivorship and socio-economic issues
- **Illustrations and videos** are considered extremely helpful

ISMPP International Society for Medical Publication Professionals™

Future: Patient Office Vision

- Data-driven shared decision making, based on EAU Patient Information Website
- Empower patients to capture and report PROMS
- Empower patients to participate in research
  - Promote diversity in research participation
- Patients as educators
  - EAU webinars; EAU Talent Incubator; patient advocate accreditation in urological disease

*IDEAL FORUM: Medical Conferences

ISMPP International Society for Medical Publication Professionals™

EAU Congress Paris 24

EAU24 Patient Day Sessions & Workshops

- Urological Patient Presentations
- Roundtable #1: Nutrition – Patients with cancer and the importance of nutrition
- Roundtable #2: Penile Cancer
- Roundtable #3: Inflammatory Bladder
- Roundtable #4: Use of digital technology & data driven shared decision-making
- Roundtable #5: Health Literacy
- Workshop: Living with the Burden of OAB
- Workshop: AI for Beginners

https://eaucongress.uroweb.org/patient-day/

ISMPP International Society for Medical Publication Professionals

EAU23 PATIENT DAY HIGHLIGHTS

EAU23 Patient Advocacy Medal of Excellence
EAU23 Patient Presentation Awards

ISMPP International Society for Medical Publication Professionals

Examples of scientific submissions by Patients

- Sexual function of men undergoing invasive prostate cancer treatment vs active surveillance – results of the EUPROMS study*****
- Ten years' experience of peer support by specifically trained prostate cancer patients*****
- Accrual of African American men into prostate cancer clinical trials: Collaborations to incorporate patient perspectives

EAU encourages patients to speak directly to healthcare professionals in plenary sessions

ISMPP International Society for Medical Publication Professionals™

Samples of Take-Home Messages from Patient Day

- Healthcare professionals, healthcare providers and representative bodies such as the EAU must use patient reported data to address the **unmet needs** identified by patients
- Healthcare providers should involve patients in the co-design of clinical pathways and facilities
- There is a collaborative spirit among patients to benefit society in general e.g. participating in research
- **Patient reported outcomes reported by patients may differ from patient reported outcomes reported by clinicians**

ISMPP International Society for Medical Publication Professionals

EAU TV: Patient Office endorses Commitment to Collaboration in Continence Care (4Cs) Initiative

Education

UROwebinar: (Data-driven) Shared Decision-making (SDM) in the management of incontinence

Moderator(s)
Mrs. M.L. Van Poelgeest-Pomfret (NL)

Presenter(s)
Mrs. J. Ghith (US)
Mr. J. Phillips (GB)
Dr. M.R. Van Balken (NL)

Date & time
Tuesday, 31 October 2023, 18:30 - 19:30 CET

This webinar intends to clarify the value of (data-driven) Shared Decision-making (SDM) in the management of incontinence.

Benefits of Patients attending Medical Conferences

- Upgrades continual learning and knowledge
- Hands on skill development (soft skills)
- Building professional networks
- Diversity of patient cohorts on discussion panels broadens horizons
  - Boomers; Millennials; GenXers etc
- Patient narratives can inspire
- Improves healthcare innovation
  - Caregiver and partner perspective
  - Digital healthcare technology / Delivery

ISMPP International Society for Medical Publication Professionals™

Challenges

- Cost
  - Registration / Travel /Accommodation
- Translations
- Lay language
- Health literacy
- Cultural diversity
- Use of digital technology

ISMPP International Society for Medical Publication Professionals™

PATIENT INVOLVEMENT IN MEDICAL CONFERENCES ENHANCES PATIENT / PHYSICIAN PARTNERSHIP :

EAU SYSTEMICALLY EMBRACES A CULTURE OF PATIENT CENTREDNESS: STILL MUCH TO LEARN

Audience Q&A

To ask a question, open the Q&A window, type your question into the Q&A box. Click Send.

ISMPP International Society for Medical Publication Professionals™

2024 ISMPP U Webinars

Upcoming 2024 ISMPP U Schedule to be released February 2024

ISMPP University

Patients in Focus: Redefining Scientific Conference Dynamics

December 13, 2023

Webinar will
begin promptly at:
11 AM ET / 4 PM GMT

ISMPP International Society for Medical Publication Professionals™

Thank you for attending!

We hope you enjoyed today's presentation.

After closing out of Zoom, please click the CONTINUE button on your screen to take our short survey. Thank you!

ISMPP International Society for Medical Publication Professionals