

Virtual 16th Annual Meeting of ISMPP

The Evolving Role of the
Scientific Communications
Professional in an Open World



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June 16-18, 2020 | Presented Virtually



Patient involvement in medical communications: A live how-to guide

Release Date: June 17, 2020 | Expiration Date: June 18, 2020 (Live); August 31, 2020 (Enduring)

Estimated time to complete activity: 45 minutes

Jointly provided by Postgraduate Institute for Medicine (www.pimed.com) and ISMPP (www.ismpp.org)



Target audience and learning objectives

Target audience:

- This activity is intended for medical publication and medical communication professionals engaged in transmitting evidence-based scientific information to healthcare professionals, payors, patients and the public

After completing this activity, the participant should be better able to:

- Be aware of the scope of medical communications activities where patients can be involved
- Understand best practice considerations (and approaches to avoid) for 3 activities: patient authorship of a peer-reviewed publication, patient involvement in an advisory board, and patient presentation at a scientific symposium
- Consider perspectives from key stakeholders: patients, industry, and publications professionals
- Be equipped to apply the practical guidance to discuss, plan and implement patient involvement activities in their own organizations

Educational credit

Continuing Pharmacy Education

- In support of improving patient care, this activity has been planned and implemented by the Postgraduate Institute for Medicine and ISMPP. Postgraduate Institute for Medicine is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

- **For additional information and instructions on how to obtain credit please refer to:** <https://ismpp.memberclicks.net/continuing-pharmacy-education-participation>



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Live Q&A – Ask questions!



You can submit questions at any time during this presentation using the Q&A box at the bottom of your screen

Meet your faculty

The publications professional perspective



**Dr Lauri Arnstein,
MA MBBS**

Patient Partnership
Scientific Liaison,
Envision Pharma Group

The patient perspective



Dawn Richards, PhD

Founder, Five02 Labs
Volunteer Vice
President, Canadian
Arthritis Patient Alliance



Trishna Bharadia

Health Advocate and
Patient Engagement
Champion

The pharma perspective



Vanessa Pott

Director, Global Patient
Insights & Advocacy,
Merck KGaA,
Darmstadt, Germany



Disclaimer and disclosures

- The opinions expressed here are those of the individual panelists and do not necessarily reflect those of employer(s) past or present or ISMPP
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In relation to this educational activity:

- The faculty have nothing to disclose
- The PIM planners and managers have nothing to disclose
- The ISMPP planners and managers have nothing to disclose

Session overview

PATIENT INVOLVEMENT IN MEDICAL COMMUNICATIONS

1

Authorship of a peer-reviewed publication

2

Involvement in an advisory board

3

Involvement in a scientific symposium



Getting to know our audience (1)

Have you involved patients and carers in medical communications activities?

1. Yes – routinely
2. Yes – infrequently
3. Not yet – but we would like to start
4. No – and we have no plans to do so



Getting to know our audience (2)

What is the biggest barrier to involving patients and carers in medical communications activities?

1. Knowing where to start
2. Resource & funding
3. Compliance challenges
4. Internal company culture
5. Other

Why involve patients and carers in medical communications?

Benefits for pharma

Improve clinical trial recruitment and retention

—

Reduce time to regulatory approval

—

Reduce time to reimbursement

—

Improve treatment adherence

—

Build trust and reputation as a patient-centric company

Benefits for patients

Make communications more relevant, appropriate and suitable for the intended audience ie, 'with patients, for patients'

—

Develop a more informed patient community

—

Enable patients to build support networks

—

Help patients to understand the pharma industry

Benefits for agency

Provide expert medical writers with a greater sense of purpose and value in their work

—

Be a trusted partner to clients

—

Expand skill set

—

Build trust and reputation as a patient-centric company



Patients as authors of peer-reviewed publications

Patient authorship is here – and practical guidance is available

Patients can and are authoring peer-reviewed publications for different types of journals – they will continue to, with or without the support of medical communications professionals

Evidence suggests that the potential benefits outweigh the risks^{1,2}

Useful guidance includes:

- 21 recommendations to guide patient authorship before, during and after manuscript development^{1,2}
- The Patient Authorship Experience Tool for patient and non-patient authors^{1,3}
- Practical tips from *The MAP*^{4,5}

1. Amstein L et al. *Research Involvement and Engagement*. 2020. In Press.

2. Amstein L et al. *Current Medical Research and Opinion*. 2019. <https://www.tandfonline.com/doi/full/10.1080/03007995.2019.1587943>.

3. Woolley KL et al. *Current Medical Research and Opinion*. 2019. <https://www.tandfonline.com/doi/full/10.1080/03007995.2019.1587943>.

4. <https://ismpp-newsletter.com/2020/05/13/patient-authorship-three-key-questions-answers-for-medical-communication-professionals-part-a/>

5. <https://ismpp-newsletter.com/2020/05/26/patient-authorship-three-key-questions-answers-for-medical-communication-professionals-part-b/>

Patient authorship: Scenario



You have a study focusing on patient-reported outcomes, and patients have been involved from its development stages



Now you are planning to publish the data, and your team are keen to co-author the publication with patients



Ask the audience

- Do you expect to see an increase in the opportunities for patient authorship in the future?





Patient involvement in advisory boards

Patient advisory boards are one of the most commonly implemented patient-centric initiatives¹

They are a key approach to gathering insights, for example:

Feedback on clinical trial elements¹

Therapy area–specific insights

Co-creation of patient experiences

Identified by a comparison of 30 patient-centric initiatives as:²

Relatively inexpensive and straightforward to conduct

Highly impactful

Guidance is in development

Legal agreements between patients and pharma companies³

Fair market value calculator⁴

1. Anderson A, Getz KA. *Ther Innov Reg Sci*. 2018; 52:469–473.

2. Stergiopoulos S et al. *Ther Innov Reg Sci*. 2020;54:103–116.

3. <https://synapse.pfmd.org/resources/70ebde2c-c00e-4289-b358b4d24e5e977/advisory-board-agreement-between-a-patient-advocate-and-a-pharmaceutical-company>

4. <https://nationalhealthcouncil.org/blog/blog-what-patient-engagement-fair-market-value-calculator/>

Patient advisory board: Scenario



You are planning to work collaboratively with patients and carers to capture their experience with a certain condition, and the impact on their lives



You want to gain direct insights on the patient experience, rather than basing these on the HCP experience



Ask the audience

- Guidance¹ recommends holding patient advisory boards face-to-face: can virtual advisory boards still provide relevant insights?



1. Anderson A, Getz KA. *The Innov Reg Sci.* 2018; 52:469–473.



Patient involvement in scientific symposia

The patient voice is increasingly being heard at scientific congresses

Conferences are increasingly:

- Offering a dedicated patient track
- Providing plain language content for broader audiences¹
- Involving patients in congress planning
- Involving patients as symposium co-hosts and presenters

Scenario



You want to incorporate the patient voice into a scientific symposium you are planning for an upcoming conference



Ask the audience

- Have you ever attended a symposium which had a patient involved?



Key takeaways



Involvement of patients and carers is feasible and adds value across the spectrum of medical communications activities



Practical resources are available to guide you – wherever you are on your patient involvement journey

Live Q&A – Ask questions!



Watching this presentation **on-demand** and have a question for the panel?
Please email ismpp@ismpp.org with the subject line:
“Patient Involvement question”

Dr Lauri Arnstein, MA MBBS

Current affiliation

- Patient Partnership Scientific Liaison, Envision Pharma Group

Relevant experience

- 2 years in a dedicated patient involvement role
- 4 years of medical writing experience
- 7 years of medical training & clinical experience (University of Cambridge, University College London, Chelsea & Westminster Hospital)
- Presented and published on patient involvement in scientific communications, focusing on plain language summaries and patient authorship



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Dawn Richards, PhD

Current affiliation

- Founder, Five02 Labs, Inc. – a firm that provides scientific and patient-related consulting services
- Volunteer Vice President, Canadian Arthritis Patient Alliance



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Relevant experience

- PhD in Analytical Chemistry (University of Alberta, 2000)
- Diagnosed with rheumatoid arthritis in 2006
- Works with clients from all sectors on science-related projects (project management, community outreach, manuscript and grant application preparation) and on projects to incorporate the patient voice and perspective
- Published and presented on patient research partner compensation in research and health; patients as people; engagement of patients in medicines development
- Current clients include: Clinical Trials Ontario, Network of Networks, Chronic Pain Network, Canadian Institutes of Health Research Institute of Musculoskeletal Health and Arthritis, Solutions for Kids in Pain, York University, Canadian Early Arthritis Cohort, Ovarian Cancer Canada

Trishna Bharadia

Current affiliation

- Independent health advocate and patient engagement consultant
- Patient Expert Partner, Envision Pharma Group



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Trishna Bharadia

Relevant experience

- Multi award-winning patient advocate with over 10 years experience in patient engagement
- Work with multiple stakeholders including industry, charities/non-profits, healthcare systems and patients
- Presented and published on patient involvement in medical communications, with a focus on plain language summaries and writing for lay audiences
- Participation in, and co-development of, medical communications events including forums, scientific symposia, focus groups, advisory boards and roundtables
- Advises and presents on patient engagement



Vanessa Pott

Current affiliation

- Director, Global Patient Insights & Advocacy, Merck KGaA, Darmstadt, Germany

Relevant experience

- I oversee collaborations with a number of patient and carer communities
- I enjoy creating one-of-a-kind partnerships that will help us achieve our vision of becoming the most patient-directed healthcare company – where patient and carer insights have a direct impact on the decisions we take throughout the research, development and commercialization of our products
- I have previously worked in Communications Stakeholder Engagement and Policy roles

Up Next!

PROGRAM TYPE	TIME (eastern)
BREAK: Poster Hour - Visit the Virtual Poster module to view member posters	12:45pm – 1:45pm
ROUNDTABLES	2:00pm – 2:45pm
How to nurture new clients into long-term relationships	
The ten most important things to know when planning an advisory board	
What matters most if you want your paper read	
Debate: Publication plain language summaries - scientific exchange or product promotion?	
Digital and enhanced media options	
ON-DEMAND (released today!)	3:00pm
Advancing Health Literacy in Clinical Research: Clear Communications for Every Participant	
Oral Presentations	
Thinking beyond the ordinary: Optimizing medical communications for rare diseases	
Putting the 'drive' in patient-driven publications	

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