Patient Engagement from the Researcher’s Perspective

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Conflict of Interest and Disclosures

Monique A.M. Gignac, PhD has none.

Patient Engagement in Research from the Researchers Perspective

...is the term “patient” appropriate?

Patient?
Consumers?
Citizens?
Citizen Engagement?
Research Ambassadors?
Presentation Objectives

1. Highlight the importance of researchers and people living with arthritis negotiating their roles early in the research process and regularly.

2. Illustrate the diverse ways that people with arthritis and researchers can work together.

3. Discuss the importance of:
   a. A common agenda
   b. Learning one another’s language
   c. Understanding research timelines

Networks & Research Teams

- Funding for large networks is becoming increasingly common
- May be national/international, multi-disciplinary and multi-sectoral
- Funders expect a high degree of knowledge translation and relevance to stakeholders

Canadian Arthritis Network (CAN)

- Research and Training program
- Active from 1998 to 2012
- 2 years of legacy funding (2012-2014)
Canadian Arthritis Network (CAN)

Research aimed at:

1. Better understanding the causes of arthritis
2. Developing and evaluating new treatments, therapeutics and interventions
3. Population and community health research

...involved nearly 200 researchers and ~ 1,000 collaborators and partners

Can Consumer Model

1. Governance of the Network (e.g., Consumer Advisory Council (CAC); Research Management Committee; Board of Directors)
2. Strategic planning
3. Training with researchers
4. Creation of information and tools
5. Members of grant projects, grant review committees and trainees/student review panels
6. Training the next generation of researchers
7. CAN Annual Conference
8. Outreach (e.g., “CAN Cares” public forums)

Lessons Learned

A successful relationship takes effort and resources
Lessons Learned

• It's critical to articulate a common agenda and vision
• Other stakeholders listen to patients (e.g., research funders, industry, government, clinicians)
• Research and advocacy agendas don't always mix well

Lessons Learned

Take time to develop a shared language and messages

• The “tentative” language of research can create frustration among researchers and consumers in moving forward

Lessons Learned

Time: Why does it take sooooooo long to do research?

Lessons Learned: Time

• The grant process is becoming increasingly long and arduous
• It can be difficult for researchers and consumers to sustain their interest in a research project over time
• The “honeymoon” period cools rapidly with the work and time needed for data collection and analysis
• Publication needs can delay getting the messages out
• There’s always another study....
And yet…

The researcher-citizen relationship often works extremely well

• Finding the right consumers isn’t always easy
• Need to make an effort to hear from diverse groups of people with arthritis
• Need to include other types of stakeholders

Bringing people together is not the same as keeping people together

Expect changes in your relationships

Thank you!

Next Speaker – Amye L. Leong, MBA
Nothing About Us Without Us: Engaging Patients in Rheumatology Research

Amye L. Leong, MBA
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Amye Leong, MBA, has nothing to disclose.

Key References and Resources
4. Outcome Measures in Rheumatology. www.omeract.org

The Early Days: What Did Patient Engagement Look Like?
Rheumatology Patient Engagement 2002
Patient Engagement Today 2002 - 2016

International
- Cochrane Systematic Reviews
- OMERACT Patient Research Partners since 2002

Regional
- EULAR Guidelines & EULAR Network of PRPs

National
- INVOLVE: UK’s National Health Service
- Canadian Foundation for Healthcare Improvement
- USA: PCORI, NIH, AHRO, FDA & C-PATH: PROMIS

Commercial
- Industry

... And growing ...

OMERACT PRPs in Malaysia 2010

Common language = EXPERIENCE with Rheumatic Disease
Concordance – Discordance with HCPs EXPERTISE

The Experience of Patient Engagement

- Leadership Support

The Experience of Patient Engagement

- Leadership Support
- Goals, Expectations
The Experience of Patient Engagement

- Leadership Support
- Goals, Expectations
  - Selection (geographical, diversity, disease duration, severity, skills, etc.)
  - Mutual training & preparation: Glossary for HPs and patients

- Logistics support: patient-to-patient, HP-patient

- Organizational support (recruitment, strategy, fundraising)
The Experience of Patient Engagement

- Leadership Support
- Goals, Expectations
- Selection (geographical, diversity, disease duration, severity, skills, etc.)
- Mutual training & preparation: HPs and patients
- Logistics support: patient-to-patient, HP-patient
- Organizational support (recruitment, strategy, fundraising, etc.)
- Dissemination: authorship, presentations

Feedback, continuous improvement

Patient Engagement: What It Looks Like
Thank you!!!

Nothing About Us Without Us: Engaging Patients in Rheumatology Research

Amye L. Leong, MBA
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RESOURCES


3. de Wit, Maartin et al. Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences. BMJ Open 2015;5:e009241. doi:10.1136/bmjopen-2015-009241


Next Speaker – M. Suzanne Schrandt, JD
Our Mission

PCORI helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community.

Our Review Criteria

During a rigorous merit review process, proposals are evaluated to assess:

- Impact of the condition on health of individuals and populations
- Potential for improving care and outcomes
- Technical merit
- Patient-centeredness
- Patient and stakeholder engagement

Conflict of Interest and Disclosures

M. Suzanne Schrandt, JD
Discloses activities with other organizations such as: Arthritis Foundation, Rheumatoid Arthritis CME and Patient Partners in Arthritis, 6
We Engage Patients and Other Stakeholders at Every Step

The Engagement Rubric

The rubric is intended to provide guidance to applicants, merit reviewers, awardees, and engagement/program officers (for creating milestones and monitoring projects) regarding patient and stakeholder engagement in the conduct of research. It is divided into four segments:

- **Planning the Study**
- **Conducting the Study**
- **Disseminating the Study Results**
- **PCOR Engagement Principles**

**Planning the Study**

- Diabetes study: Clinicians who reviewed the initial study design indicated that clinical practice is quite variable and suggested that a three-arm approach would be more appropriate for the study. The study design was revised accordingly.

- Cancer study: Patient partners determine eligibility requirements for study inclusion.

**Conducting the Study**

- Chronic pain study: The informed consent document is developed with patient partners to make it understandable to study participants.

- Chronic pain study: Patients and clinicians revise and shorten survey tool.

- Preeclampsia study: Study team will recruit via a national network of local health departments and community health centers, as well as a preeclampsia advocacy group’s website, and Facebook page.
Disseminating the Study Results

- **Chronic Trauma study**: The research team will convene a policy summit with relevant professional societies during the third year of the study to focus on identifying ways to speed the implementation of findings into practice.
- **Neurology Study**: Patient partners will co-present at large patient advocacy organization summit.
- **Chronic Sain Study**: Patient partners co-author manuscripts, present at scientific and lay conferences, and share study findings through their networks.

Engagement Principles

- Compensation for patient partners is included in the budget at an appropriate level.
- Meetings are held at a time and in a location that accommodates patient and stakeholder partners. Compensation is provided for transportation and related expenses.
- Training and educational opportunities are provided, for patient, stakeholder, and researcher partners such as training in human subjects protection.

Putting the Rubric to Work

- Greater understanding of engagement
- Stronger engagement in proposals
- Strong engagement during research

Engagement Officers: Role and Responsibilities

- Position that parallels the Program Officer role
- Partners with Program Officers and research teams to oversee and cultivate engagement throughout the life of the project
  - Ensures robust engagement is integrated into projects from time of contract formation
  - Participates in ongoing project management activities
  - Available for assistance and discussion
- Gleans promising practices from projects to share and replicate
Additional Resources

- Compensation Framework,
- Sample Engagement Plans,
- WE-Enact tool and data,

Find Us Online

www.pcori.org

Association of Rheumatology Health Professionals

Thank you for participating!

Questions: arhp@rheumatology.org