

From Patient to Researcher

Becoming an ePatient

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@anetto

#RSIResearchDay

Disclosures

I have the following relevant financial relationships to disclose:

- I receive compensation from research projects with academic institutions. Through the Canadian Arthritis Patient Alliance I work on projects funded by unrestricted grants from pharmaceutical companies.
- I will receive an honorarium for speaking today.

Burden of Disease and Treatment



My Team

Rheumatologist
Physiotherapist
Occupational Therapist
GP doctor
Orthotist
Speech Language Pathologist
Hand Surgeon
Foot Surgeon
Oral and Maxillofacial Surgeon
Pharmacist
Dentist
ME
My husband DON



TEAMWORK:
Interdisciplinary collaboration

15 years later - Just one exercise



Clinical Trial



Real life support groups



IPE Health Mentor Program/CACHE



Computer Age and online support

Support Groups



Information



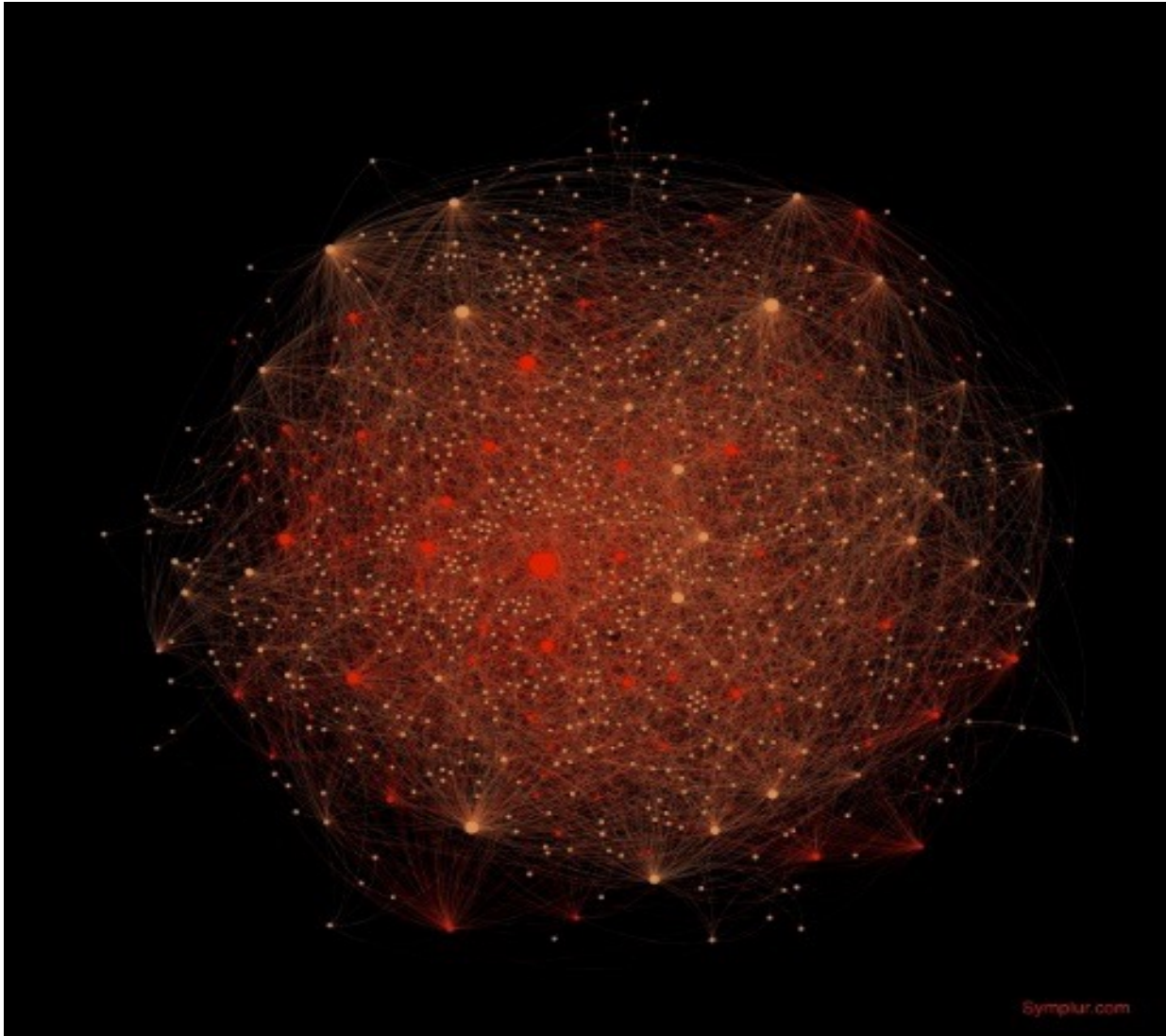
Disruptive ideas

“
PATIENT ENGAGEMENT
is the **BLOCKBUSTER**
DRUG of the century **”**

 **eye for pharma**

LEONARD KISH
QUOTED IN FORBES MAGAZINE 9.2.2012

Social Media Changes Everything



IDEO Design Challenge



Evolving Patient-Researcher Collaboration: An Illustrative Case Study of a Patient-Led Knowledge Translation Event

By

Jenny Leese,

Sheila Kerr,

Annette McKinnon,

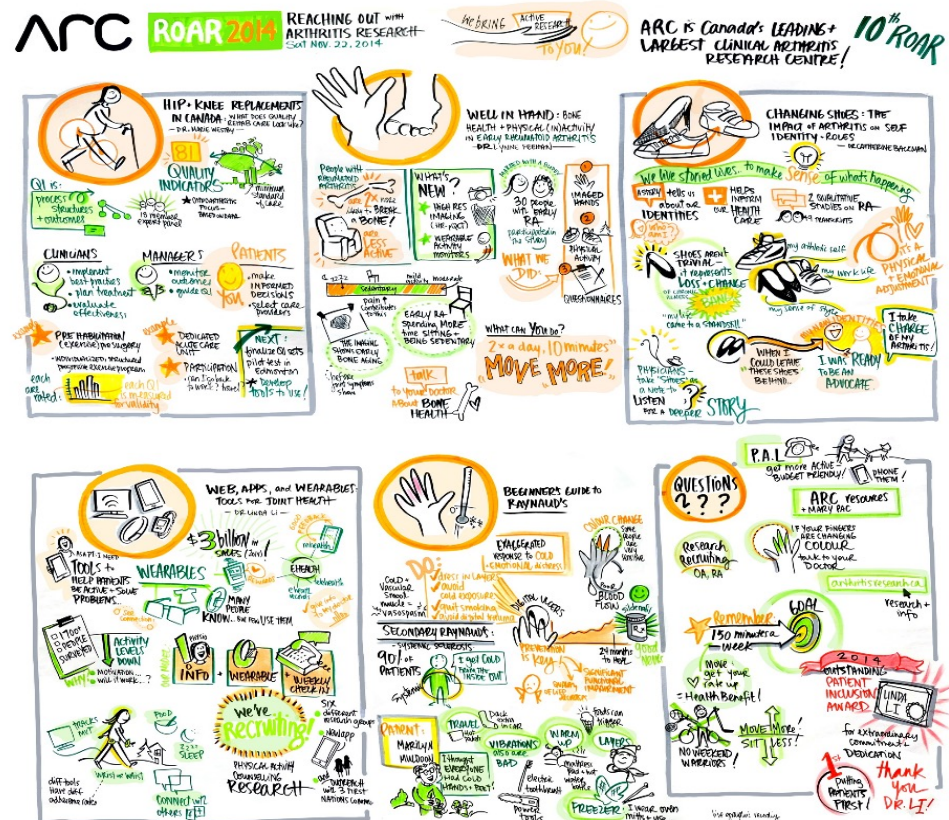
Erin Carruthers,

Catherine Backman,

Linda Li

and Anne Townsend

August 4, 2017



Presenting our PaCER poster at BC Patient Safety and Quality Forum



How did Patient Oriented Research come about?

National 10-year strategy introduced in 2011 to improve healthcare systems and practices

- “At CIHR, we want to help transform the role of patient ... to a **proactive partner** who helps shape health research and, as a result, health care.”
 - *Canadian Institutes of Health Research*
- "Patients need to be involved in all aspects of research to ensure questions and results are relevant"
 - *Support for Patient-Oriented Research (SPOR) Program*



SPOR Demonstration Project

Patients as Partners in Research Planning Guidelines

Authors and Patient Advisors:

Alies Maybee SPOR Team Lead

Brian Clark

Annette McKinnon

Emily Nicholas Angl



<https://ossu.ca/for-researchers/patient-engagement-resources/>

Funding is provided by Ontario SPOR SUPPORT Unit, which is supported by the Canadian Institutes of Health Research and the Province of Ontario.

Challenges and solutions in POR

Potential barriers - patients

Unfamiliar with topic and language

Unfamiliar with research methods

Alone on the team – the ‘stranger’

Unsure of the team’s expectations and the value of my contributions

⋮

Potential Solutions

Provide accessible resources

Supportive team

Team pictures and bios circulated

Pair experienced/naïve patients

Proactive inclusion

Patients as partners vs patients as subjects

Working together as
partners in research



Studying the patients as
subjects/participants
in research



Patient Advisors Network

**Patient Advisors
Network**



Independent
Informed
Connected



PAN and Learning Together



Example of Clickable pdf pop-up

Original research: Understanding... | The "Handling" of power in the... | Learning Together: Evaluation fr... | CEPPP Infographic V7 Nov 23 20... | +

indd.adobe.com/view/8af4cb10-a621-4c0e-9ccd-21810c88ec1f

Hashtag Finder | McDoor | Symplur Signals | Image | "Measuring the Imp..." | Conference organiz... | The importance of... | Slack | YOUR READABILITY... | Your disability activi... | fibe1_on_en.pdf | Decentring white fe... | Outcomes of Hand... | Other bookmarks

LEARNING Together An Evaluation Framework for Patient and Public Engagement in Research

STAGES: APPRECIATION, PROJECT CO-DESIGN, READINESS, PARTNERSHIP GUIDELINES, ROLES, DIVERSE PERSPECTIVES, IMPROVING SYSTEMS, TRANSFORMING CARE, CHANGING CULTURE, REFINING RESEARCH, TRANSFORMING PRACTICES, TRANSFORMATION.

WELCOMING

- ★ Ensuring respect, trust and transparency within the project team
- ★ Empowering patient partners in their contributions to the project
- ★ Ensuring safety for all partners
- ★ Providing a safe space to share values and preferences
- ★ Adapting protocols and processes to improve research partnership
- ★ Respecting policies, protocols, and processes related to cultural, psychological, physical, gender and emotional safety
- ✚ Having policies, protocols, and processes related to cultural, psychological, physical, gender and emotional safety
- ✚ Adopting a trauma-informed approach for all partners

GUIDING PRINCIPLES

- ★ RELATIONSHIP BUILDING
- ★ CO-BUILDING
- ★ EQUITY, DIVERSITY & INCLUSION
- ★ SUPPORT & BARRIER REMOVAL
- ★ TRANSPARENCY
- ★ SUSTAINABILITY
- ★ TRANSFORMATION

CLICK HEADINGS FOR MORE INFO

★ = MUST HAVE
✚ = NICE TO HAVE

Graphic by Heather Collett of freewright.com

Windows taskbar: Mozilla Firefox, CEPPP I..., S, Desktop, annette, This PC, Network, 11:07 AM 5/24/2023

Impact of our efforts to have patients included

‘Patients Included’ is standard for conferences

It’s common to see patient partners on research teams

New ways to evaluate patient impact – if it’s not measured...

Compensation regularly offered

Courses for patients/researchers learning together

Patients in governance in health care eg PCHO Boards

Patient led research projects

CIHR/EA funding for 20 patient research queries through
Evidence Alliance ie PATIENTS as Co-Leads

Teaching award – Carolyn Canfield Canadian Association for
Medical Education (CAME) 2023 Certificate of Merit Awards

Patients in rehab sciences research and education

- “Model” patient
- Health Mentor
- Public Member of COTO (regulatory college – 3 year term)
- CACHE Curriculum Development Panel
- Advisory team and chapter co-author of textbook, Promoting Occupational Participation
- Priority Setting Partnership – Gaps in OT Research



Patients in Education and Research

Carolyn Canfield, patient and adjunct professor in UBC's Department of Family Practice funded the **Canfield Distinguished Scholar in Patient Partnerships at UBC**. She intends advance the field of patient and community partnership in health care.

Patient partner Maureen Smith starts June 1 as an Adjunct Professor at U of T and serving on a PhD Technical Advisory Committee

CAPA (Canadian Arthritis Patient Alliance) has 50% of an OT student placement. We're excited. A first for us and for OT.

First patient partner on the InterFaculty Curriculum Committee (IFCC) of the IPE Curriculum for the U of T.)

Student Leadership

Health Mentor – first steps/levels of responsibility

Verbatim Theatre

Student led clinics

Organizing RSI conference

Chapter author/ critical readers of Enabling Occupation

Joining patient or social justice groups as Advisors or as Board Members eg Sjogren's Society

Allied Health Leadership

Martha Piper, PT, first female **President** of UBC

Heather McPherson, OT who is currently **President and CEO** of Toronto's Women's College Hospital

Brenda Merritt OT, **Dean, Faculty of Health** Dalhousie University

Giovanna Boniface OT **Chief Implementation Officer** Royal Architectural Institute of Canada

Mary Forhan OT – **Scientific Director** – Obesity Canada

Catherine Backman OT – **Senior Scientist** – Arthritis Research Canada

Karen Goldenberg, OT, **Co-founder**, private practice community occupational therapy service (unheard of in the 1970s)

How can Rehab Sciences promote patient partnership and collaboration in research?

Include us in research papers, thesis, student research – PAN as a possible resource for patients

Make the research you produce more accessible

Encourage your clients to get involved if they show interest.
People love to help.

Develop a philosophy of co-delivery and co-production

Grow relationships and collaborations and find out we're not so different.

Recent research projects

- Just Accepted! Analysis of Plain Language Summaries for BMJ EBM (co-author)
- BMJ Rapid Review – AI in Colonoscopy
- Scoping review – Approaches to anti-racism in patient/public partnership in research (Patient Partner co-leads) Evidence Alliance
- Grant Reviewer - BMJ, CIHR, AMS, The Arthritis Society
- Research teams – Falls, Medication Management in older adults, PEIRS Scale, Medication Decision Making, Appropriating and asserting power on inflammatory arthritis teams

Links and resources

SPOR Strategy for Patient-Oriented Research <https://cihr-irsc.gc.ca/e/41204.html>

Patient Advisors Network (PAN) <https://www.patientadvisors.ca/>

CEPPP - Centre of Excellence on Partnership with Patients and the Public
<https://ceppp.ca/en/>

Learning Together - <https://ceppp.ca/en/uncategorized/learning-together-evaluation-framework-for-patient-and-public-engagement-ppe-in-research/>

Canadian Patient Partner Study (CPPS)
<https://bmjopen.bmj.com/content/12/9/e061465>

PEIRS Patient Engagement in Research Scale
<https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0206588&type=printable>

IMHA Institute of Musculoskeletal Health and Arthritis <https://cihr-irsc.gc.ca/e/13217.html>

IDEO <https://cantwait.ideo.com/>

Health Strategy



Blockbuster Drug

REHABILITATION
— 2030 —
a call for action



**World Health
Organization**



PATIENT ENGAGEMENT

is
the

**BLOCKBUSTER
DRUG**

of the
century



LEONARD KISH
QUOTED IN FORBES MAGAZINE 9.2.2012

Thank you

QUESTIONS?

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