

# Launch of the Patient-centred Research (PACER) Network

2:00 – 3:00 pm Tuesday 12<sup>th</sup> June 2018

Kids Research, The Children's Hospital at Westmead, NSW 2145

 @pacernetwork #pacerlaunch

# Welcome!

- Patient-centred research to improve care and outcomes - Prof Jeremy Chapman, Clinical Director of Medicine and Cancer, Westmead Hospital
- What can we learn from the patient and family journey? – Ms Chandana Guha
- Overview of the PACER Network
- Questions and networking



*“Some doctors treat us like we are just sitting in bed waiting to be told, ‘OK, you can have this now, you can have that now.’ They think, ‘well, you’re just a patient, what would you know?’”*

Lancet 2014; 383: 156–65

## Research: increasing value, reducing waste 1

### How to increase value and reduce waste when research priorities are set

Iain Chalmers, Michael B Bracken, Ben Djulbegovic, Silvio Garattini, Jonathan Grant, A Metin Gülmezoglu, David W Howells, John P A Ioannidis, Sandy Oliver

**US \$240 billion → 85% wasted**

**High priority questions now addressed  
Patient-important outcomes not assessed**

**Research decisions are not based on questions relevant to users of research.**

Inappropriate research design, methods, and analysis

Inefficient research regulation and management

Inaccessible or incomplete research information

Biased and unusable research reports

Research waste

**JAMA**<sup>®</sup>  
The Journal of the American Medical Association

**Patient-Important Outcomes in Registered Diabetes Trials**

Gunjan Y. Gandhi, MD, MSc

JAMA. 2008;299(21):2543-2549



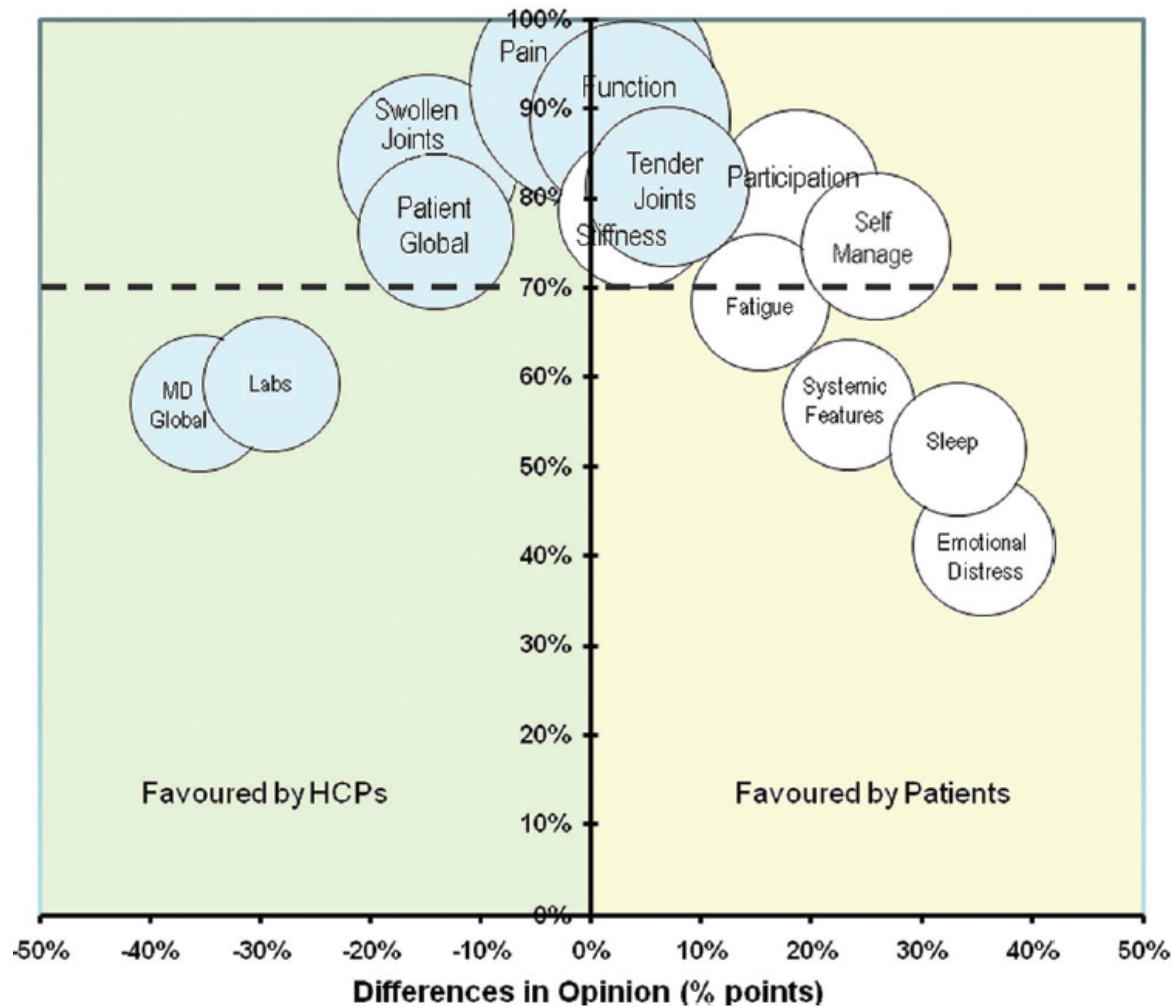
**The idolatry of the surrogate**

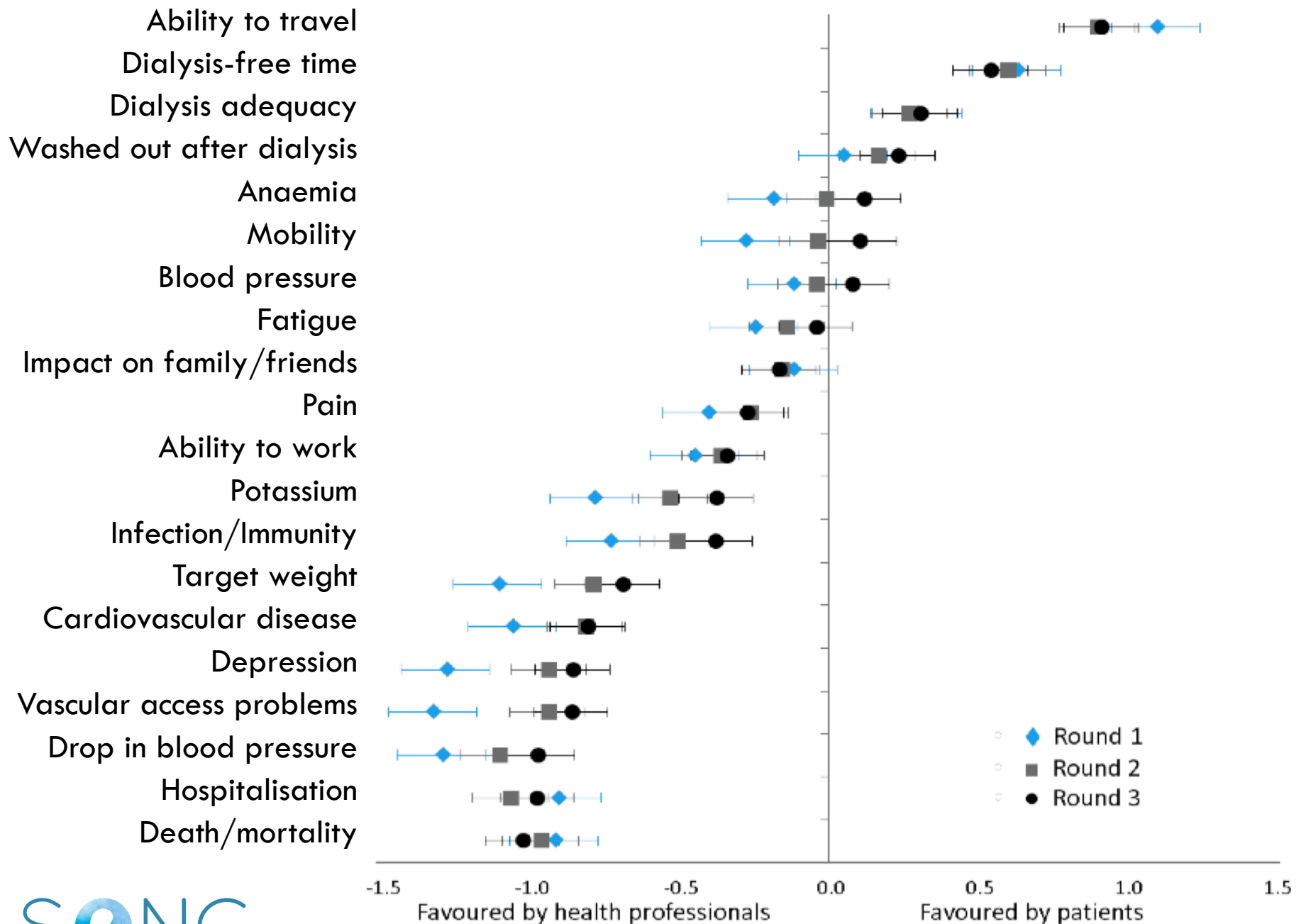
John S Yudkin

BMJ 2011;343:d7995

# Identifying core domains to assess flare in rheumatoid arthritis: an OMERACT international patient and provider combined Delphi consensus

Susan J Bartlett,<sup>1,2</sup> Sarah Hewlett,<sup>3</sup> Clifton O Bingham III,<sup>2</sup> Thasia G Woodworth,<sup>4</sup> Rieke Alten,<sup>5</sup> Christoph Pohl,<sup>5</sup> Ernest H Choy,<sup>6</sup> Tessa Sanderson,<sup>3</sup> Annelies Boonen,<sup>7</sup> Vivian Bykerk,<sup>8</sup> Amye L Leong,<sup>9</sup> Vibeke Strand,<sup>10</sup> Daniel E Furst,<sup>11</sup> Robin Christensen<sup>12</sup> and The OMERACT RA Flare Working Group







“Providers and patients must share responsibility for understanding individual patients’ **goals** and **preferences** and for **making decisions** about treatments.”



“That there should be so much talk about what patients need and want without them being present prompted me to take action.” – Lucien Engelen





**Australian Government**

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**National Health and Medical Research Council**

“Research informs healthcare decisions. Research institutions, researchers, consumers and community members should work collaboratively to support, facilitate and value the contribution that consumers and community members make to research, and its development, conduct and communication.”

# Patient-centred care – a strategic priority



“develop partnerships that enable our research to make a difference, locally and globally.” Patient-centred care identified as a core academic area.



We will ensure the voice of the people of western Sydney is heard in all aspects of care - health care policy, planning, design, delivery and evaluation.”



“committed to broader engagement with health care consumers and the wider general public to facilitate research that answers questions that matter most to them. This is the right thing to do: if we seek to support a health system that is patient-centred, our research activities should be too.”

# Why PACER?

To facilitate knowledge exchange, cross-disciplinary collaboration, and innovation in conducting and implementing patient-centred research and patient involvement in research.

- **Patient-centred research** generates evidence that helps patients and their caregivers communicate and make informed decisions about their health. Understanding their values, goals, and priorities are needed to inform patient-centred care. → evidence
- **Patient involvement** refers to patients being active partners in research who contribute their experiences and perspectives across the stages of the research process – setting the research priorities, designing, conducting, reporting, and disseminating research. → partnership





## Advisory Group

Allison Tong, Patrina Caldwell, Jeremy Chapman, Stephen Leeder, Don Nutbeam, Tania Sorrell

## Coordinating Committee



Talia Gutman

RESEARCH OFFICER, PHD CANDIDATE



Charlotte Logeman

RESEARCH OFFICER



Danielle Muscat

RESEARCH FELLOW



Simon Carter

PAEDIATRIC NEPHROLOGIST, PHD  
CANDIDATE



Karine Manera

RESEARCH OFFICER, PHD CANDIDATE



Angela Ju

RESEARCH OFFICER, PHD CANDIDATE



Camilla Hanson

POST-DOCTORAL RESEARCHER



Sharon Lee

CLINICAL TRIALS MANAGER

# Core activities

Webinars

Workshops

Other events e.g. forums

Resources

Listserve

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### Webinars

### Workshops

### Other events e.g. forums

### Resources

### Listserve

Every second Tuesday 2 pm – 3 pm

<b>Jul</b>	Patient involvement in research <i>Talia Gutman</i>
<b>Aug</b>	Health literacy <i>Danielle Muscat</i>
<b>Sept</b>	Nominal group technique <i>Simon Carter</i>
<b>Oct</b>	Co-production in Aboriginal health research <i>Simone Sherriff, Hilary Miller</i>
<b>Nov:</b>	Patient-reported outcome measures <i>Angela Ju</i>

<http://pacernetwork.org.au/webinars/>

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## Qualitative Research 8<sup>th</sup> June 2018



**Eliciting patient preferences and values using choice experiments** (details tbc)

<http://pacernetwork.org.au/pacer-workshops/>

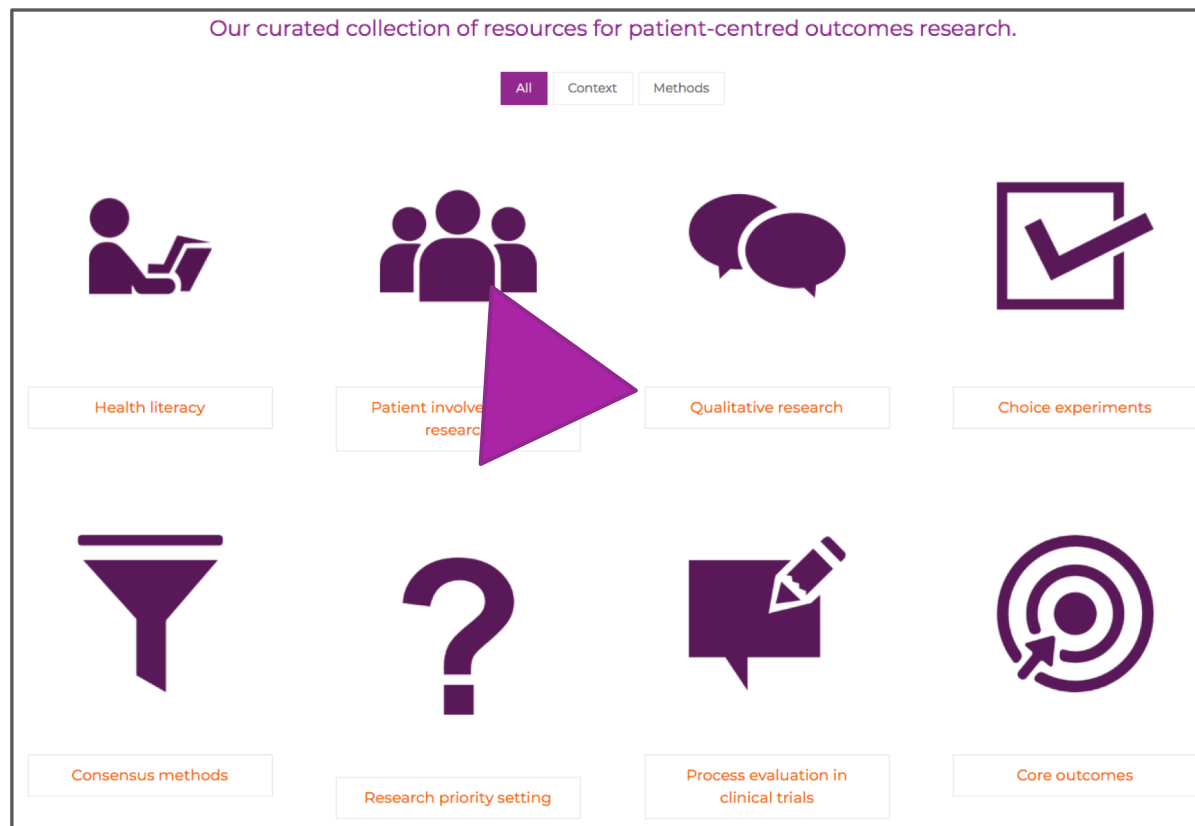
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## Patient involvement in research

Patient and caregiver involvement in research can help to improve the relevance, quality, and value of research. Patients/caregivers are involved as active partners in research, and contribute their experiences and perspectives across the stages of the research process – setting the research priorities, designing, conducting, reporting, and disseminating research.

### Key references and resources

#### General

[Clarifying the role of patients in research](#) – Liabo K et al BMJ 2018; 361:k1463  
[INVOLVE \(UK\)](#) provides resources on how to involve patients and the public in research  
[NIHR \(UK\)](#) National Standards for Public Involvement  
[Cochrane Consumers and Communication](#)  
[Involving People in Research](#)

#### Reporting guidelines

[GRIPP2 reporting checklists: tools to improve reporting of patients and public involvement in research](#) – Staniszewska S et al BMJ 2017;358:j3453

#### Examples

[Impact of patient involvement on clinical practice guideline development: a parallel group study](#) – Armstrong MJ et al Implementation Science 2018;13:55

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Listserv

**Post a message to PACER members**

**Post your message to the PACER  
listserv!**

You can send a message about events,  
research opportunities, resources,  
papers, or relevant questions to all  
members of the PACER Network by  
sending an email to:

**[pacер@mailman.sydney.edu.au](mailto:pacер@mailman.sydney.edu.au)**

(This listserv is moderated)

229 members





- Forums, symposiums
- **Connect** – researcher/member profiles
- **Showcase** – exemplars of patient-centred projects & initiatives
- Online discussion board
- Research projects
- Patient Advisory Board & Patient portal





# Questions and suggestions

PACERNETWORK.ORG.AU



THE UNIVERSITY OF  
**SYDNEY**



The Sydney  
children's  
Hospitals Network  
care, advocacy, research, education



**kids**  
**research**



The  
Westmead  
Institute  
FOR MEDICAL RESEARCH



**Health**  
Western Sydney  
Local Health District