EMPOWERMENT

KNOWLEDE IS POWER

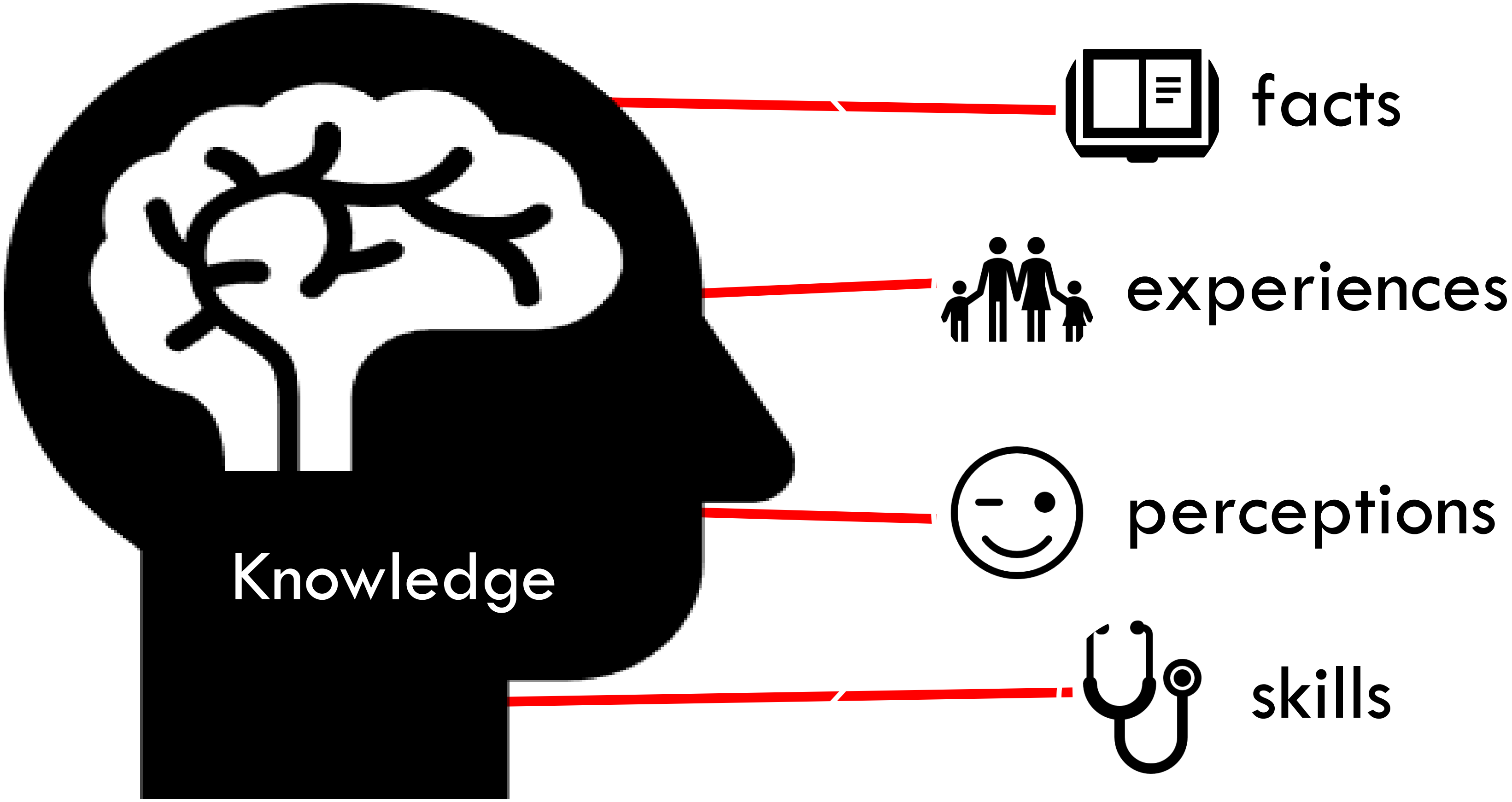
Consumers as part of the research cycle: an essential prerequisite for knowledge translation

Lisa Harvey

Professor, Sydney School of Medicine
University of Sydney
Australia

THE UNIVERSITY OF SYDNEY

What is knowledge?



Knowledge

facts

experiences

perceptions

skills

What is knowledge translation?

Knowledge Translation is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system This process takes place within a complex system of interactions between researchers anc knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user.

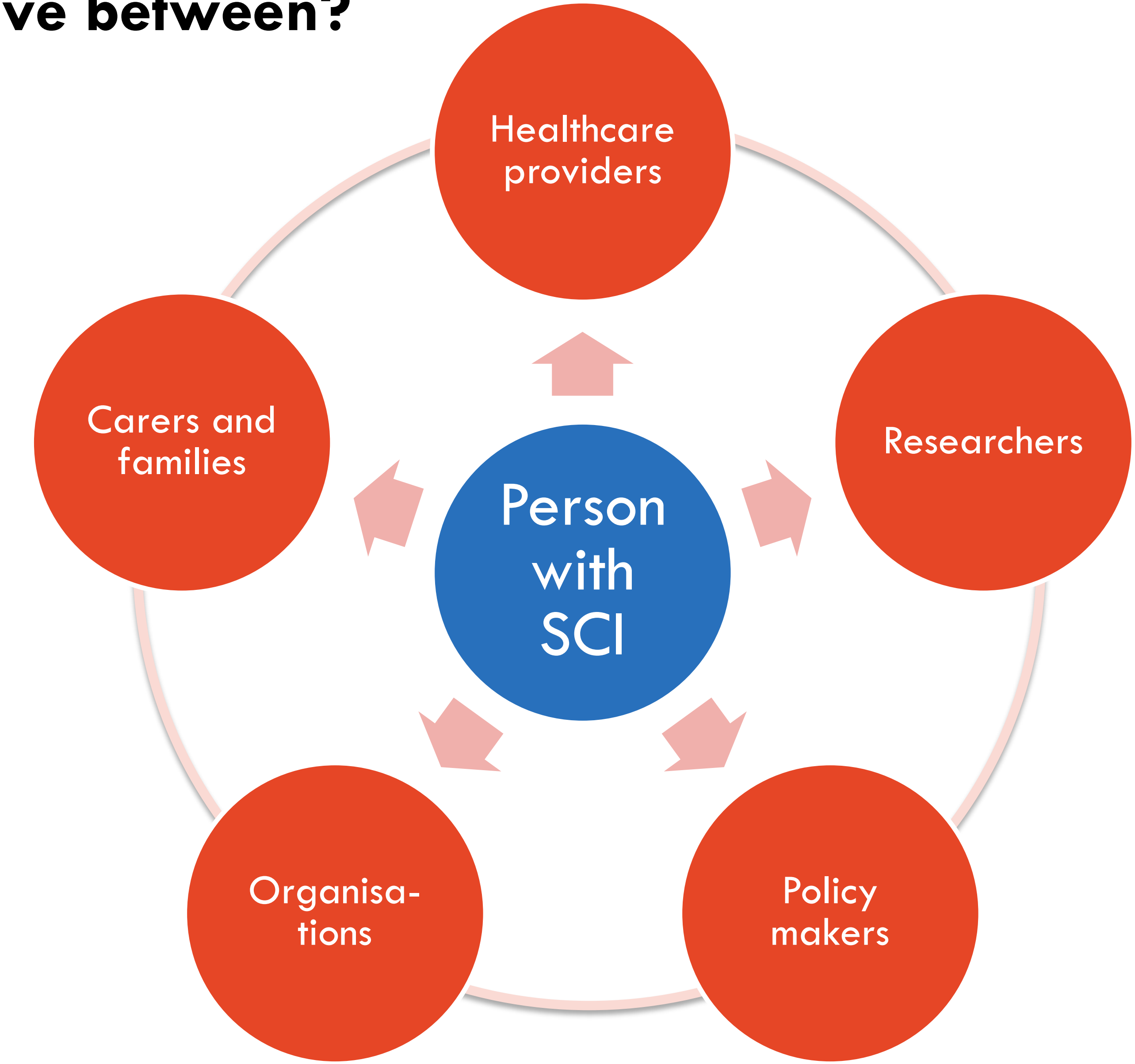
What is knowledge translation?

P
O
W
E
R

- Pulling together of knowledge = *synthesis*
- Sharing of knowledge = *exchange*
- Spread of knowledge = *dissemination*
- Use of knowledge = *application*

Getting the **right** information, to the **right** people, at the **right** time, and in a format they can use, so as to influence healthcare

Who does the knowledge need to move between?



Healthcare providers

Carers and families

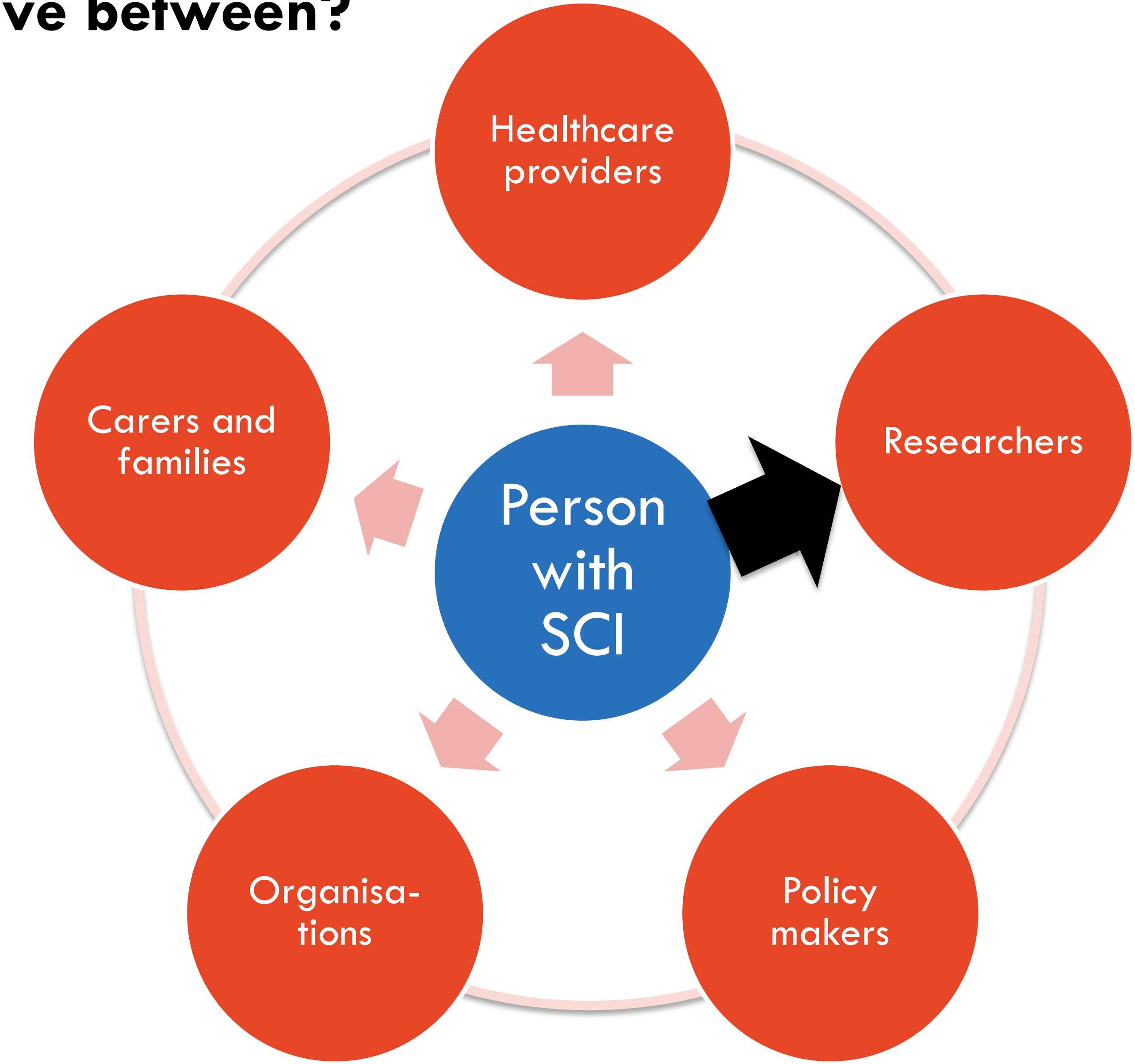
Person with SCI

Researchers

Organisa-tions

Policy makers

Who does the knowledge need to move between?



Person with SCI

Healthcare providers

Researchers

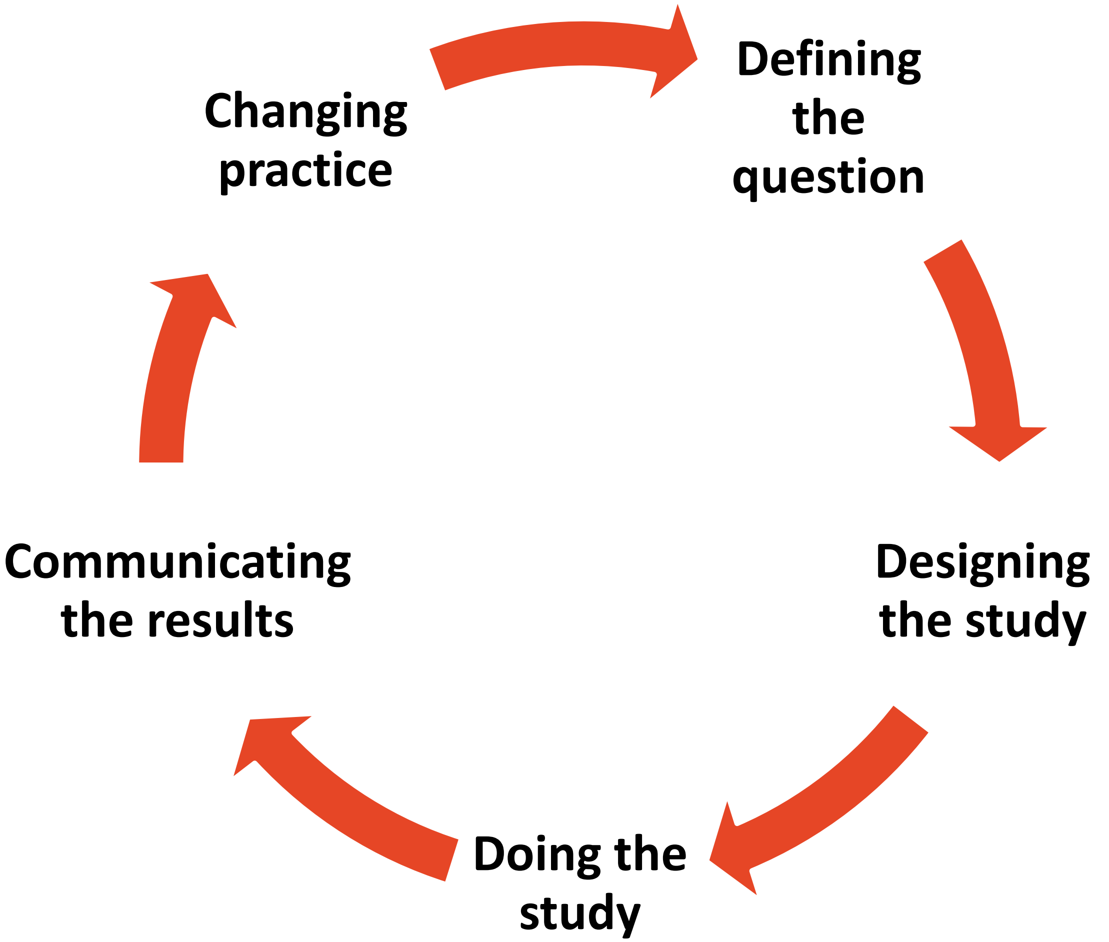
Policy makers

Organisa-tions

Carers and families

We have a knowledge translation problem

The gap occurs at all steps of the cycle



Changing practice

Defining the question

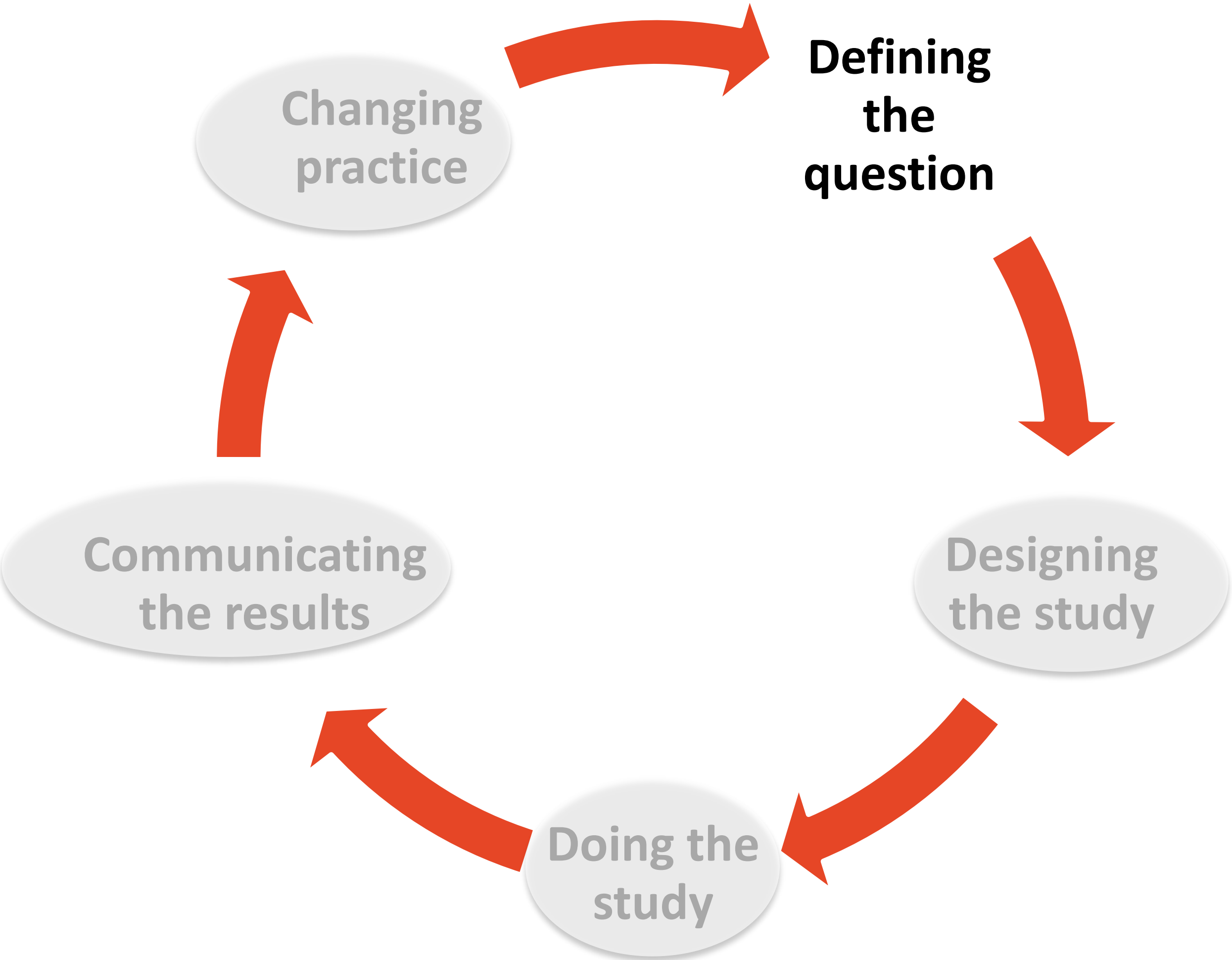
Designing the study

Doing the study

Communicating the results

Consumers need to be involved in all steps

The gap occurs at all steps of the cycle



Defining the question

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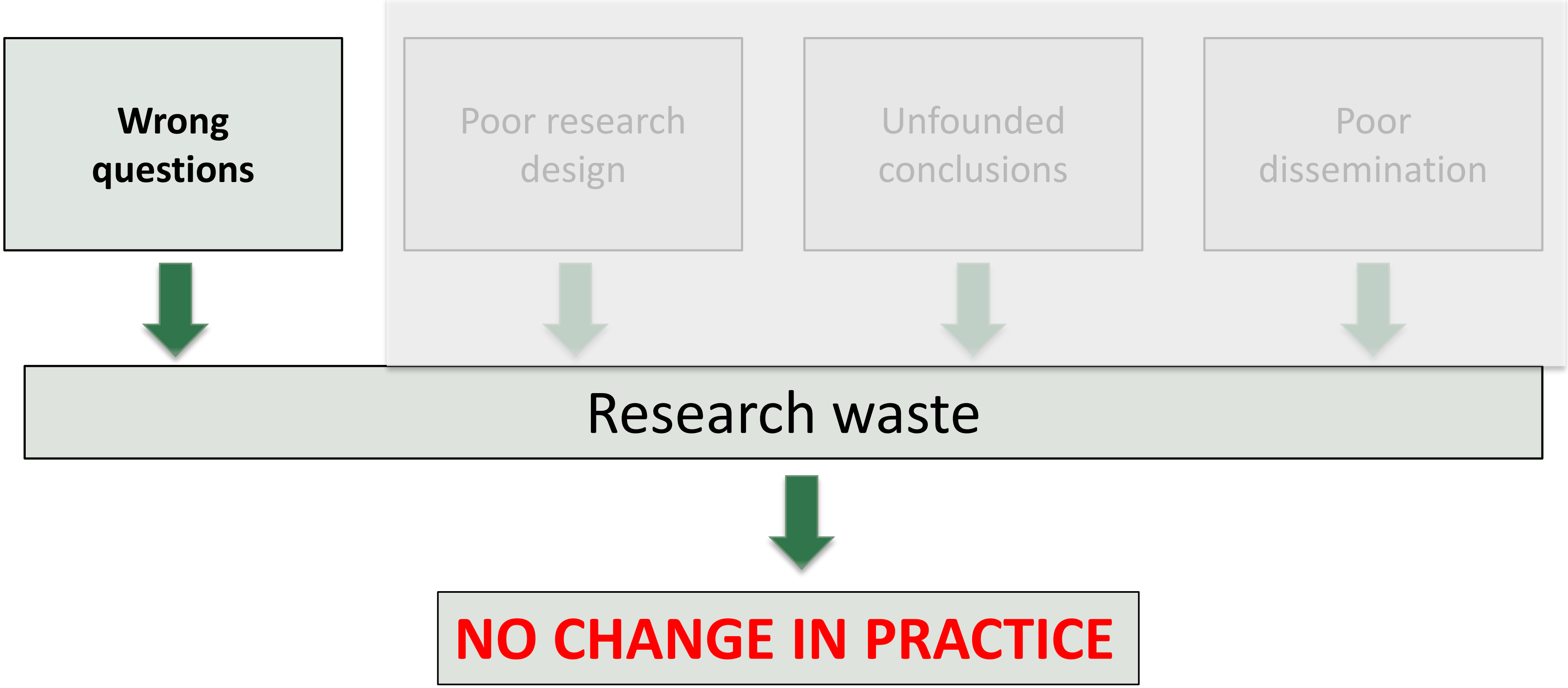
Changing practice

Chalmers & Glasziou Lancet 2009; 374: 86–89

85% of research is wasted, usually because it asks the wrong questions, …… or does not change practice.



Wrong questions

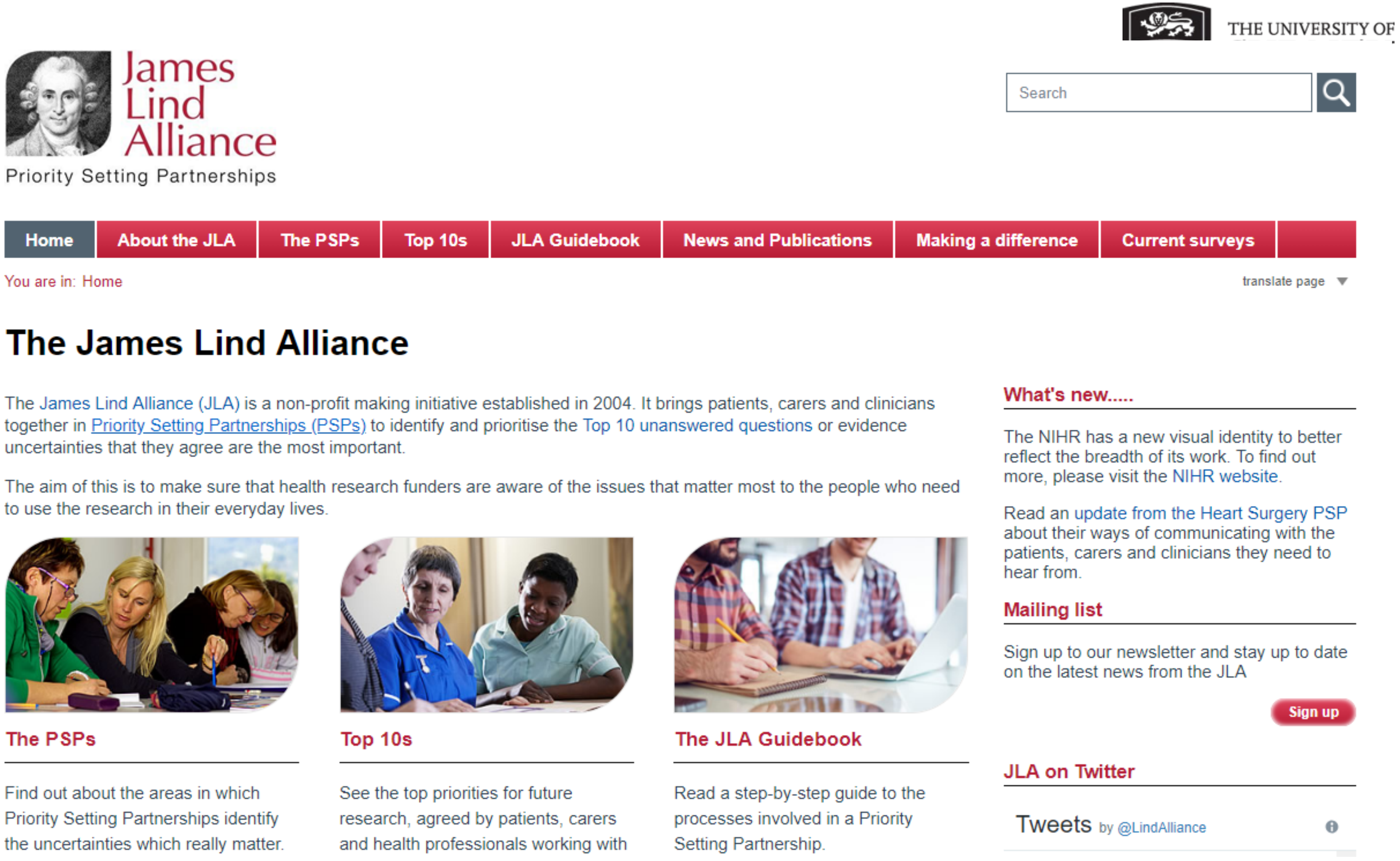
Poor research design

Unfounded conclusions

Poor dissemination

Research waste

NO CHANGE IN PRACTICE



The James Lind Alliance

The James Lind Alliance (JLA) is a non-profit making initiative established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 unanswered questions or evidence uncertainties that they agree are the most important.

The aim of this is to make sure that health research funders are aware of the issues that matter most to the people who need to use the research in their everyday lives.

The PSPs

Find out about the areas in which Priority Setting Partnerships identify the uncertainties which really matter.

Top 10s

See the top priorities for future research, agreed by patients, carers and health professionals working with

The JLA Guidebook

Read a step-by-step guide to the processes involved in a Priority Setting Partnership.

What's new.....

The NIHR has a new visual identity to better reflect the breadth of its work. To find out more, please visit the NIHR website.

Read an update from the Heart Surgery PSP about their ways of communicating with the patients, carers and clinicians they need to hear from.

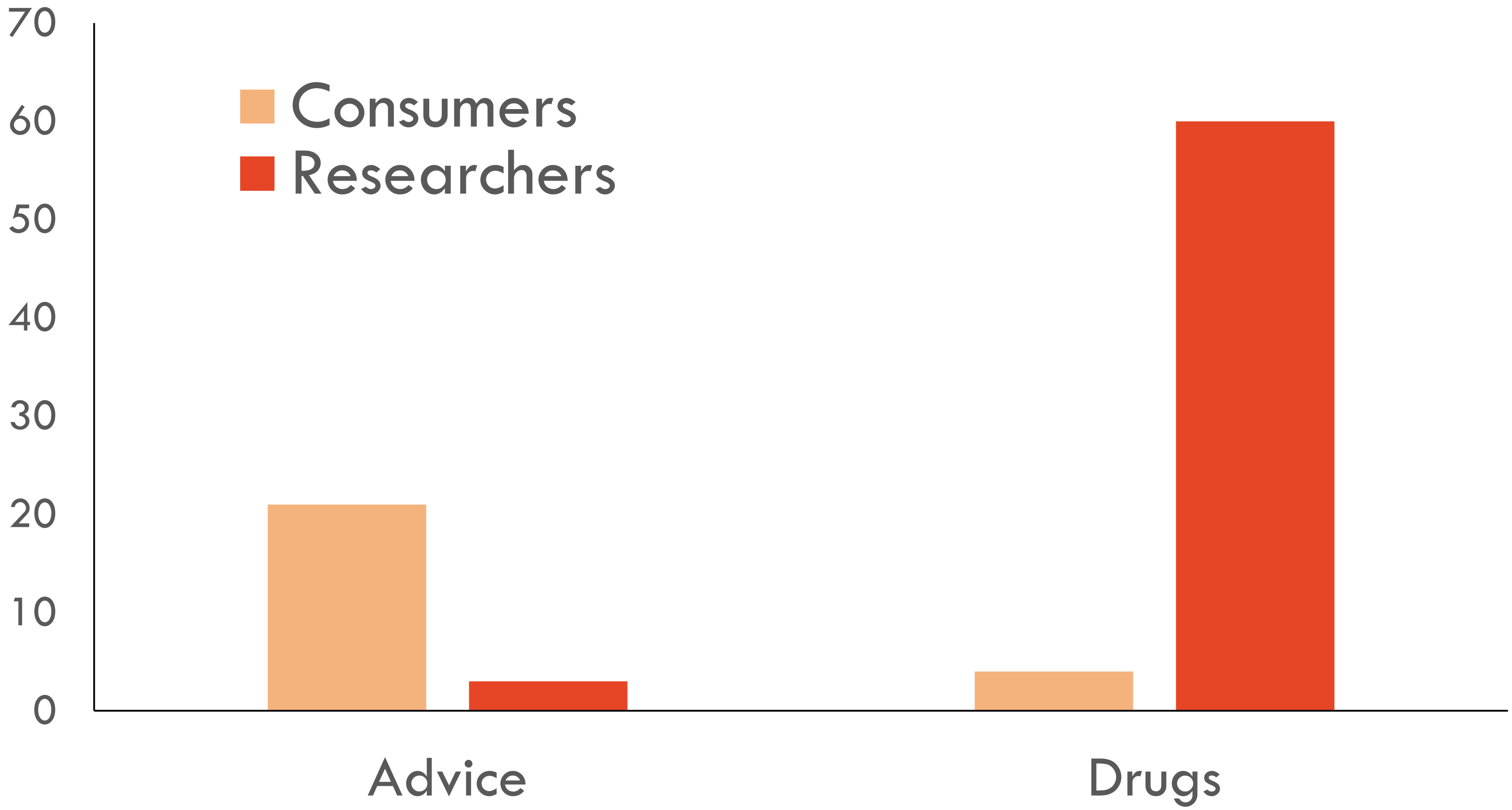
Mailing list

Sign up to our newsletter and stay up to date on the latest news from the JLA

JLA on Twitter

Research on the effects of treatments often overlooks the shared interests of patients, carers and clinicians. As a result, questions that they all consider important are not addressed and many areas of potentially important research are therefore neglected.

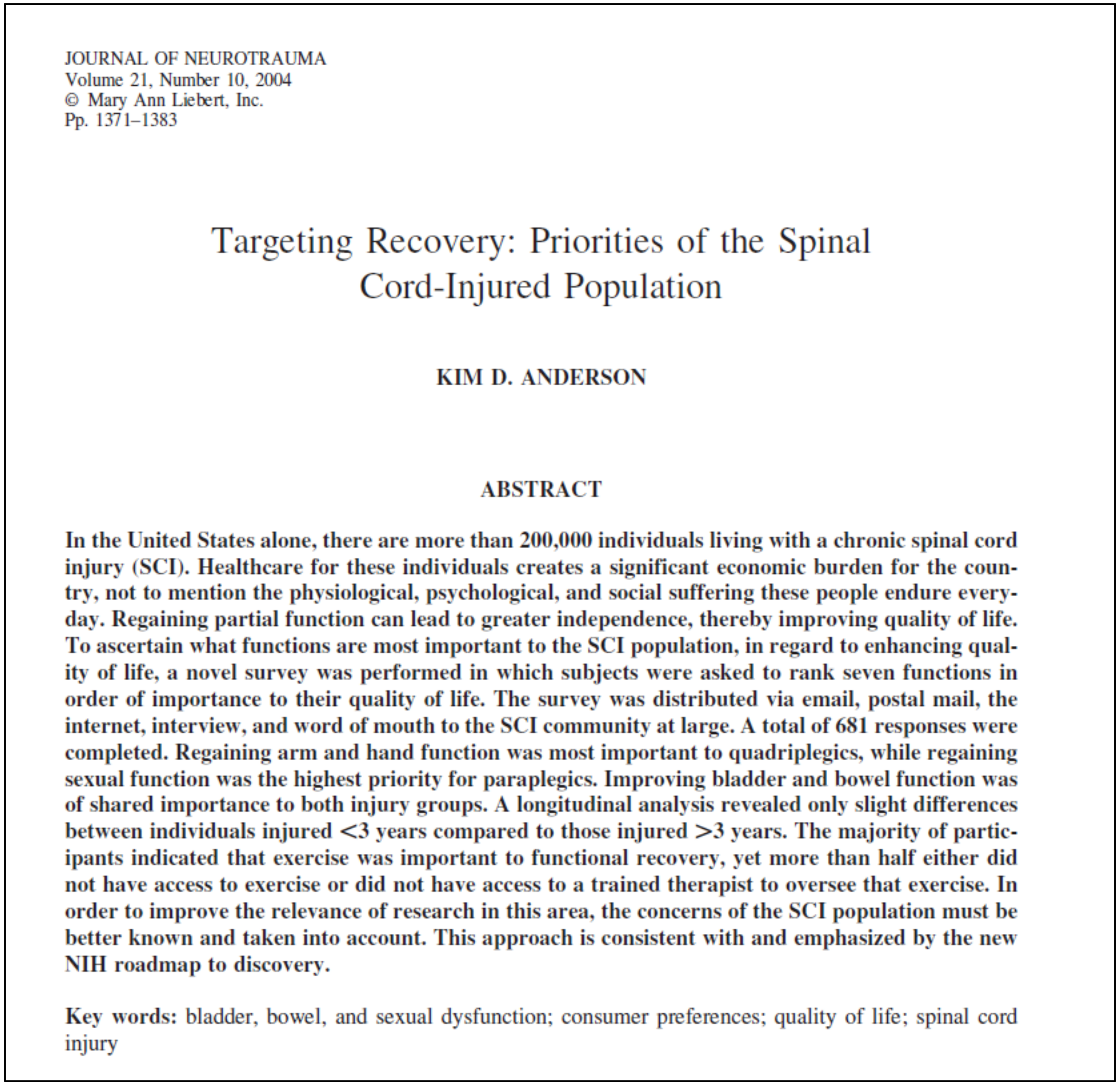
Mismatch between consumers' and researchers' priorities



Tallon D, Chard J, Dieppe P. *Lancet* 2000; 355: 2037-2040

Research – consumers' perspectives

Citations = 798



JOURNAL OF NEUROTRAUMA
Volume 21, Number 10, 2004
© Mary Ann Liebert, Inc.
Pp. 1371–1383

Targeting Recovery: Priorities of the Spinal Cord-Injured Population

KIM D. ANDERSON

ABSTRACT

In the United States alone, there are more than 200,000 individuals living with a chronic spinal cord injury (SCI). Healthcare for these individuals creates a significant economic burden for the country, not to mention the physiological, psychological, and social suffering these people endure everyday. Regaining partial function can lead to greater independence, thereby improving quality of life. To ascertain what functions are most important to the SCI population, in regard to enhancing quality of life, a novel survey was performed in which subjects were asked to rank seven functions in order of importance to their quality of life. The survey was distributed via email, postal mail, the internet, interview, and word of mouth to the SCI community at large. A total of 681 responses were completed. Regaining arm and hand function was most important to quadriplegics, while regaining sexual function was the highest priority for paraplegics. Improving bladder and bowel function was of shared importance to both injury groups. A longitudinal analysis revealed only slight differences between individuals injured <3 years compared to those injured >3 years. The majority of participants indicated that exercise was important to functional recovery, yet more than half either did not have access to exercise or did not have access to a trained therapist to oversee that exercise. In order to improve the relevance of research in this area, the concerns of the SCI population must be better known and taken into account. This approach is consistent with and emphasized by the new NIH roadmap to discovery.

Key words: bladder, bowel, and sexual dysfunction; consumer preferences; quality of life; spinal cord injury

OPEN

Spinal Cord (2016) 54, 341–346
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www.nature.com/sc

ORIGINAL ARTICLE

Top ten research priorities for spinal cord injury: the methodology and results of a British priority setting partnership

JJ van Middendorp[1,2,3], HC Allison[1,2], S Ahuja[4], D Bracher[5], C Dyson[5], J Fairbank[6], A Gall[7], A Glover[8], L Gray[9], W El Masri[10], A Uttridge[11] and K Cowan[12]

Study design: This is a mixed-method consensus development project.
Objectives: The objective of this study was to identify a top ten list of priorities for future research into spinal cord injury (SCI).
Setting: The British Spinal Cord Injury Priority Setting Partnership was established in 2013 and completed in 2014. Stakeholders included consumer organisations, healthcare professional societies and caregivers.
Methods: This partnership involved the following four key stages: (i) gathering of research questions, (ii) checking of existing research evidence, (iii) interim prioritisation and (iv) a final consensus meeting to reach agreement on the top ten research priorities. Adult

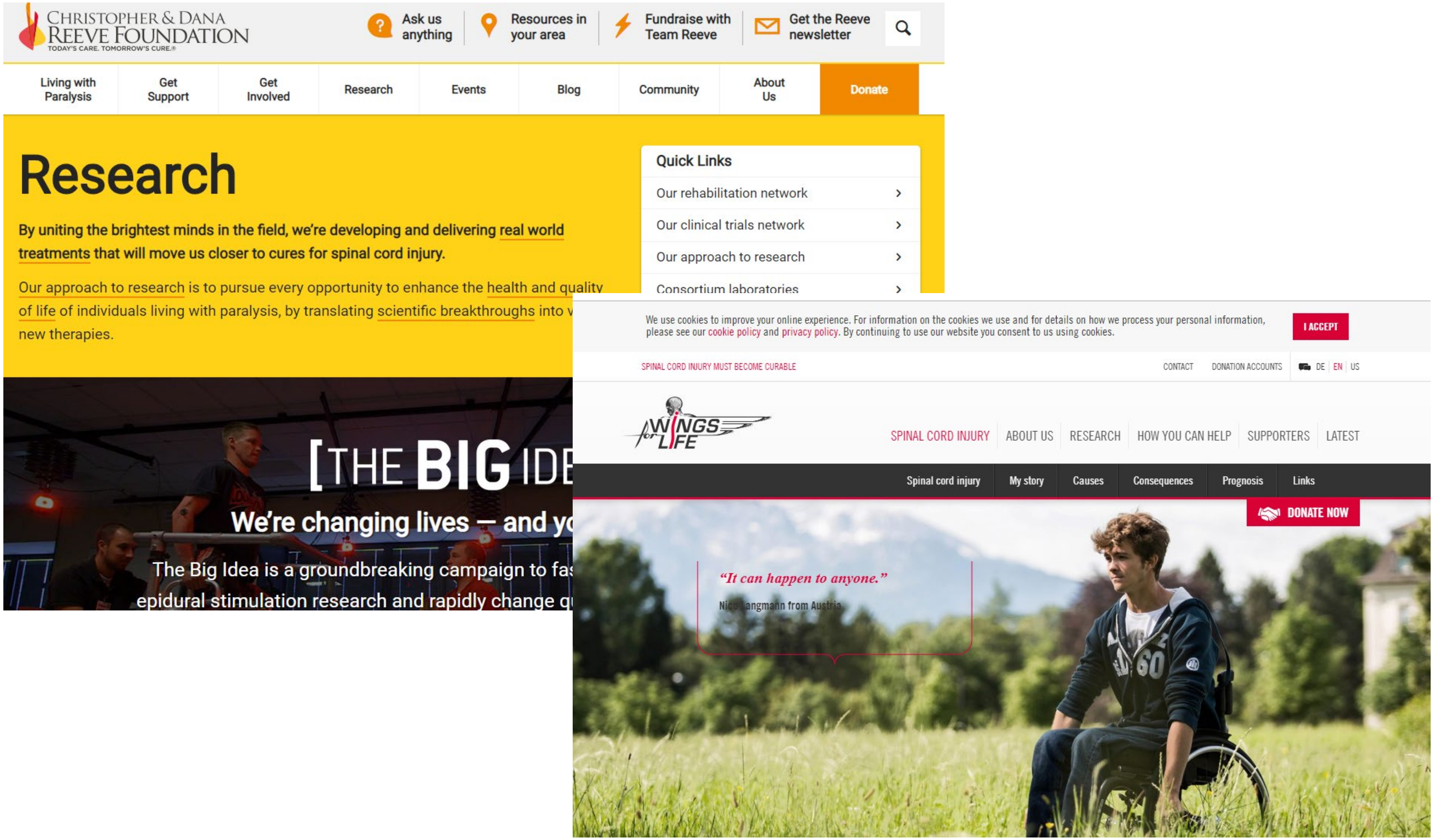
Top 5

- Physiotherapy
- Stem cell therapy
- Care packages in the community
- Bladder management
- Early mobilisation versus bedrest

31 other studies that have looked are research priorities.

(Bragge Spinal Cord 2015)

Some organisations are setting research strategies in SCI



CHRISTOPHER & DANA REEVE FOUNDATION
TODAY'S CARE. TOMORROW'S CURE.®

Research

By uniting the brightest minds in the field, we're developing and delivering real world treatments that will move us closer to cures for spinal cord injury.

Our approach to research is to pursue every opportunity to enhance the health and quality of life of individuals living with paralysis, by translating scientific breakthroughs into v
new therapies.

[THE BIG IDE

We're changing lives — and yo

The Big Idea is a groundbreaking campaign to fas
epidural stimulation research and rapidly change q

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"It can happen to anyone."

Nico Langmann from Austria

ISCOS
The International
Spinal Cord Society

+

About ESCIF

Professional and consumer societies need to work together to set research strategy

MS Society

MS Society
Research Strategy
2018-22

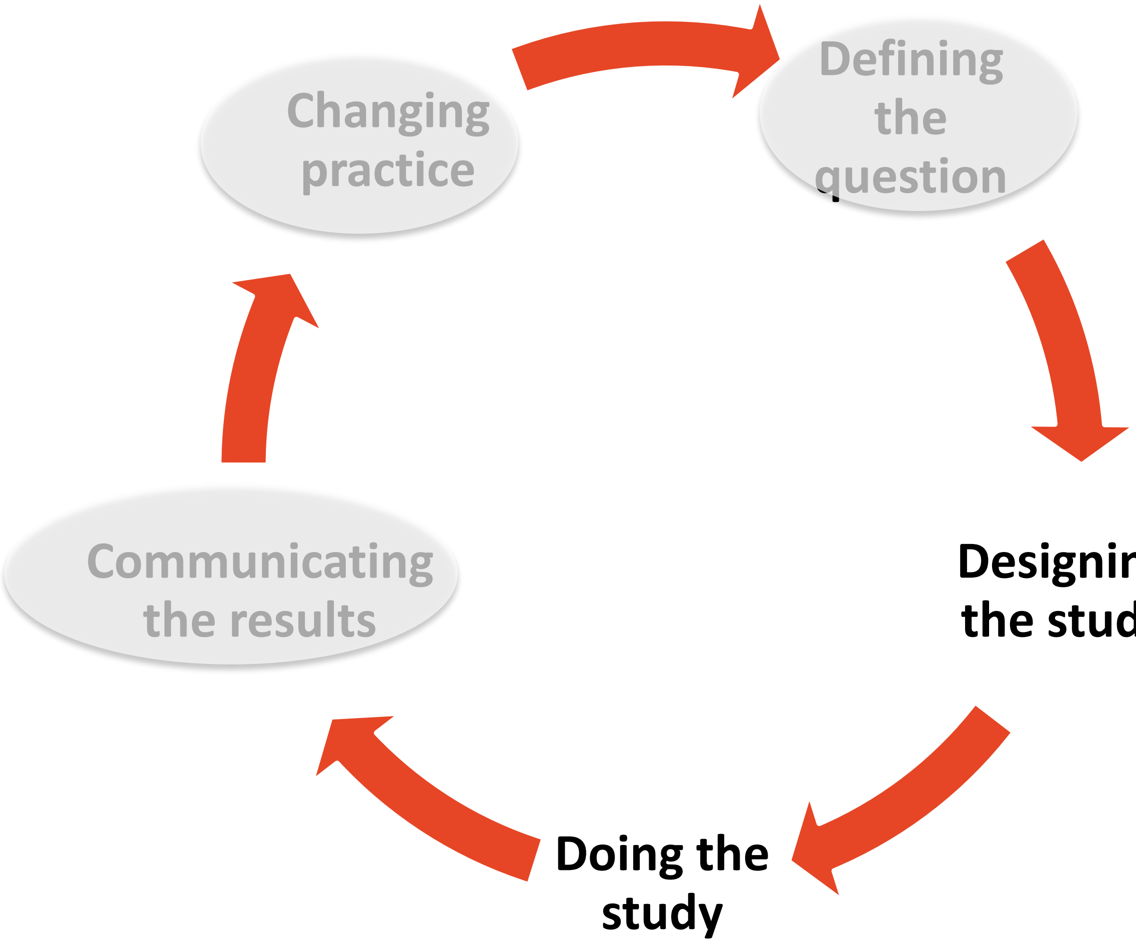
“It's a new world of cooperative research involving the patients.”

Sue Polson, Research Network member

14

www.mssociety.org.uk

The gap occurs at all steps of the cycle



Defining the question

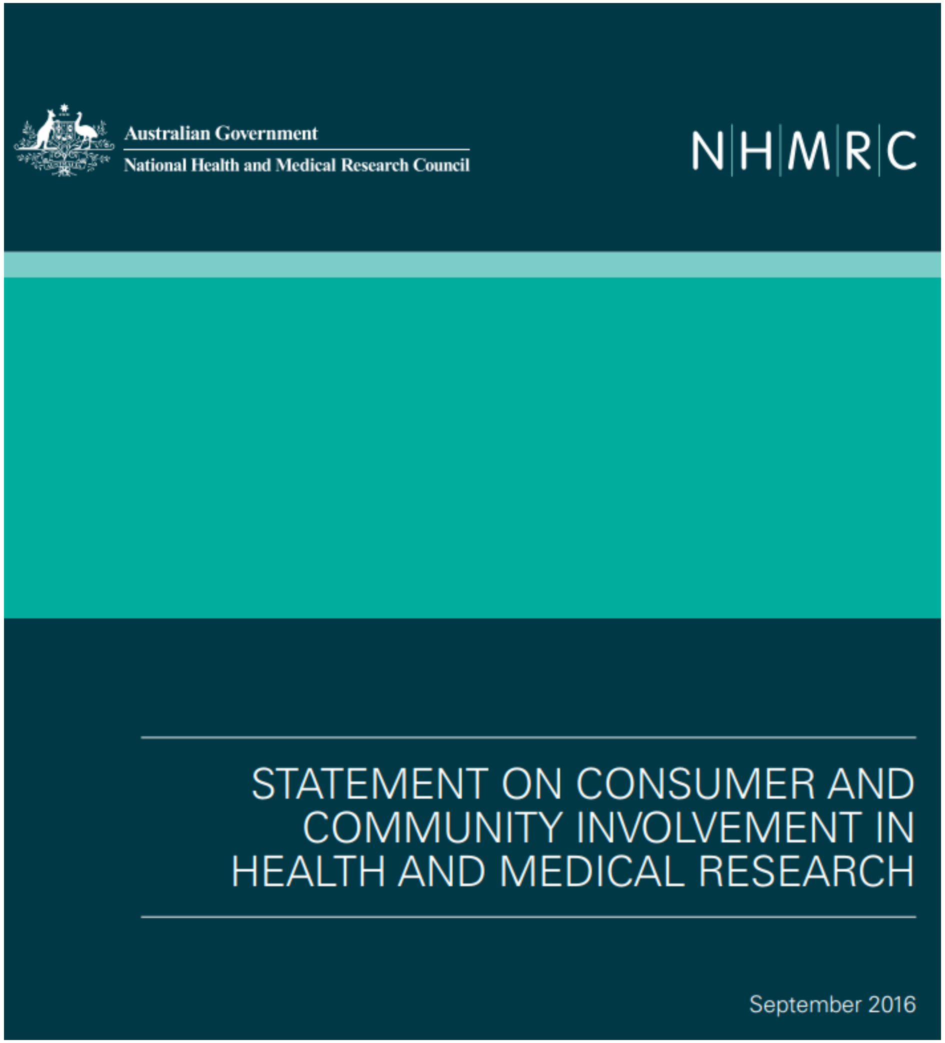
Designing the study

Doing the study

Communicating the results

Changing practice

Acknowledgement worldwide of importance of including consumers



Australian Government
National Health and Medical Research Council

NHMRC

STATEMENT ON CONSUMER AND COMMUNITY INVOLVEMENT IN HEALTH AND MEDICAL RESEARCH

September 2016

The **active** involvement of consumers ……….benefits the quality and direction of research.

Consumer involvement is about research **being carried out** with or by consumers …… rather than to, about or for them.

Tokenism – include one person with SCI in the research team

☒

Who will researchers tend to include?

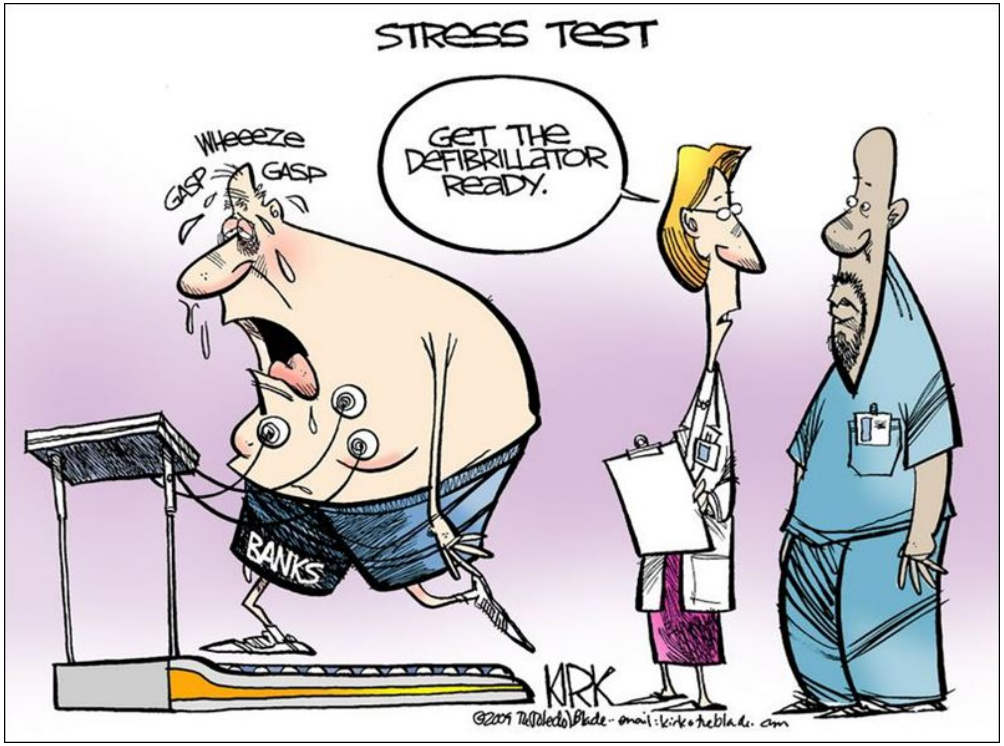
- Someone who mirrors themselves
- Someone who is very obliging
- Someone who has the same research priorities as themselves

☑

Who should researchers include?

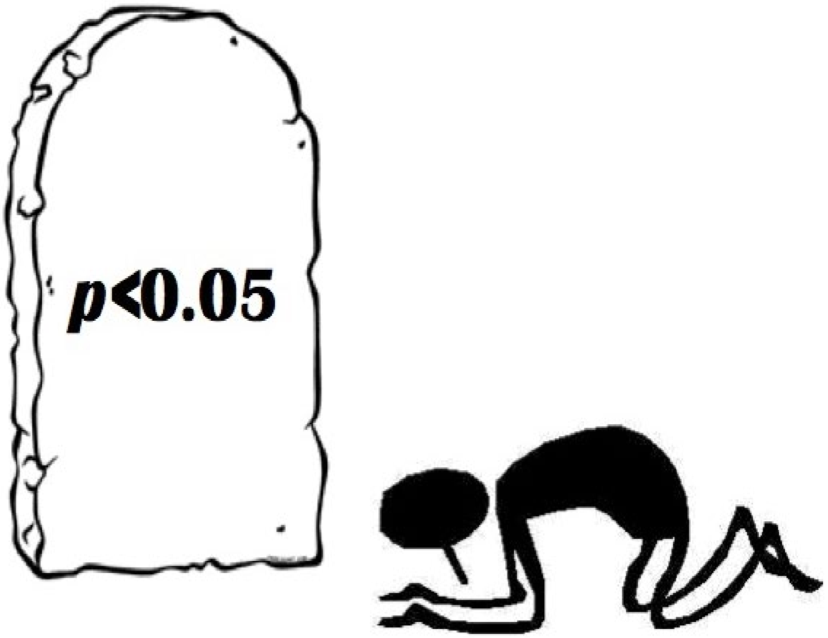
- Someone who is very different to themselves
- Someone who is willing to express contrary views
- Someone who appreciates the research priorities of all

Researchers often expect too much from participants



Researchers need the consumer perspective

Is the size of the treatment effect worth it?

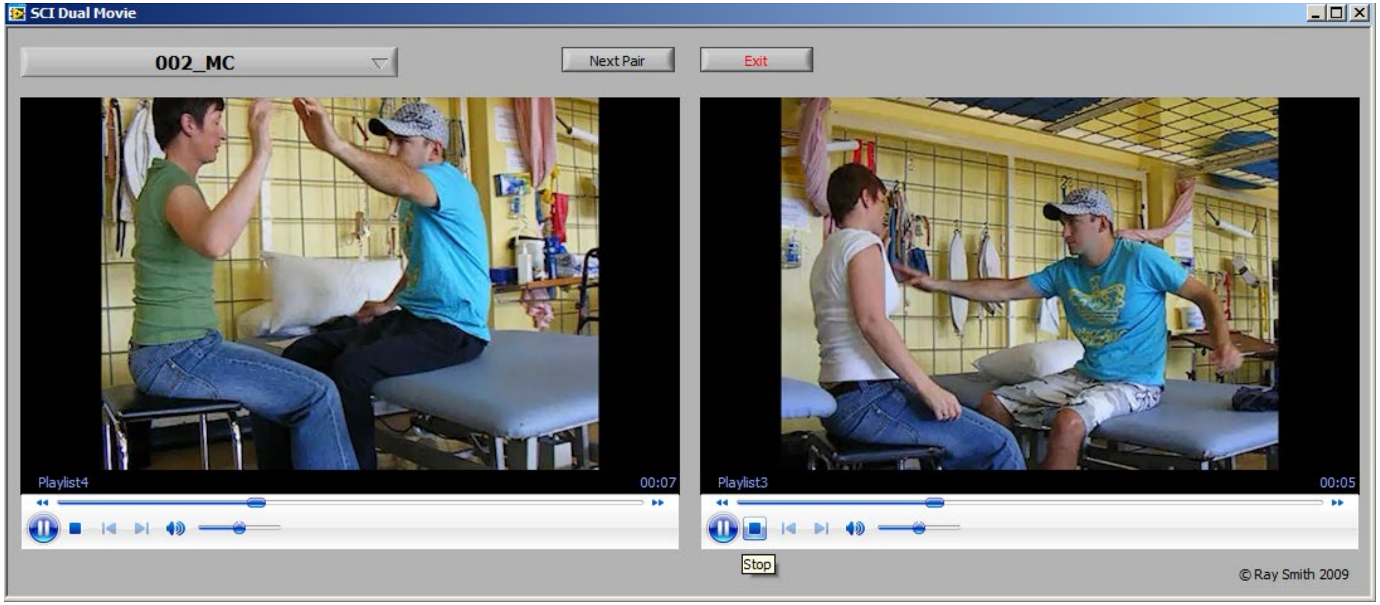


Treatments can **NOT** be recommended on the basis of p values

Treatments must be recommended on the basis of the size of the treatment effect after considering:

- Time
- Cost
- Effort
- Potential for harm

Consumers as assessors of change

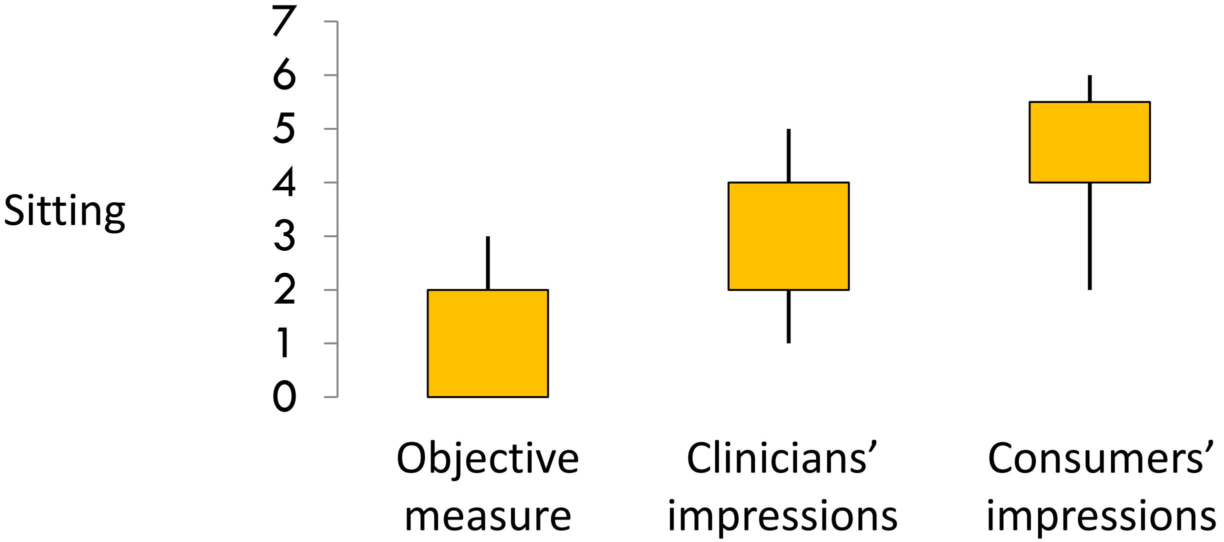


30 minutes training every day for 8 weeks.

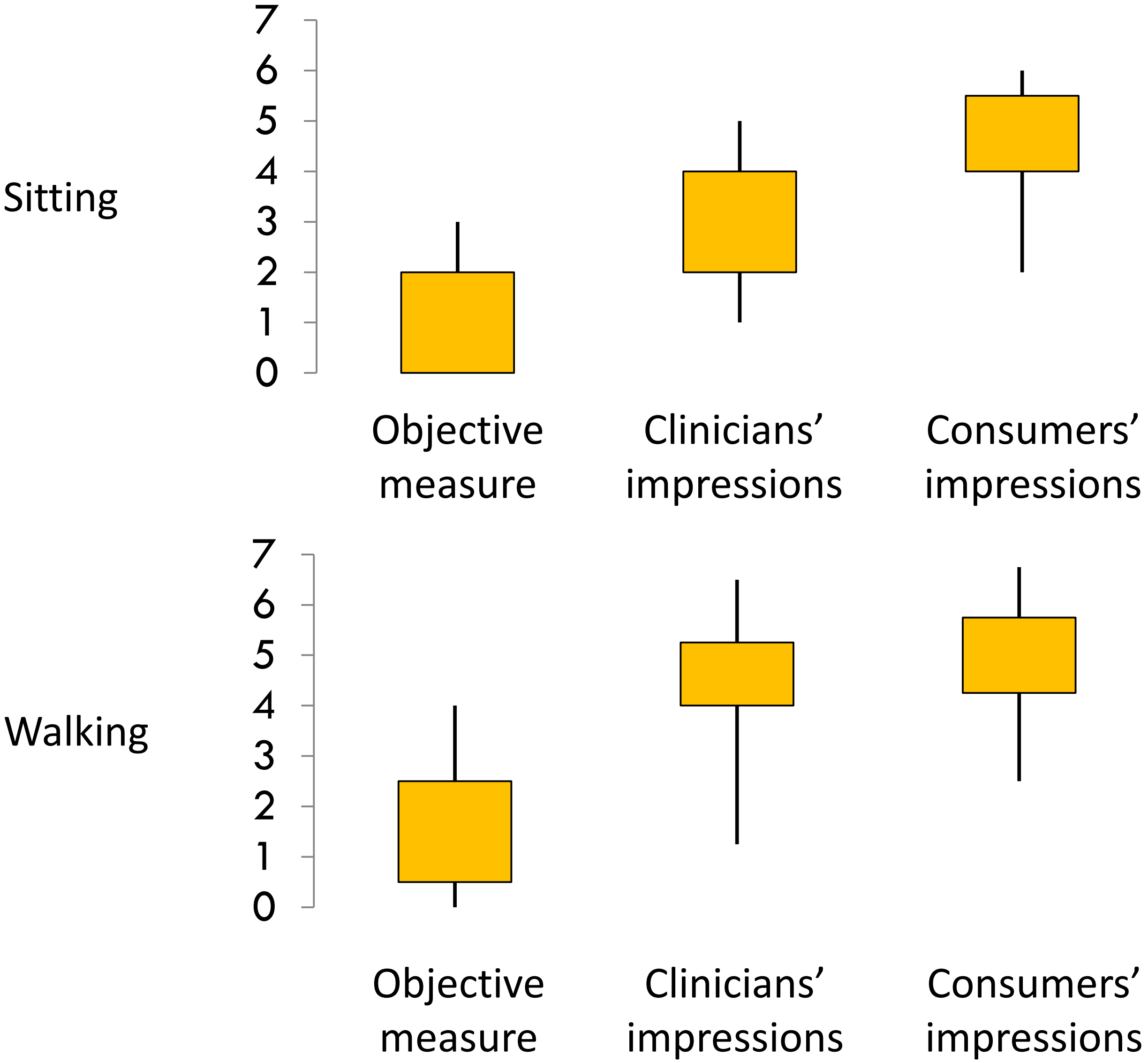
Rate any change?

-7	A very great deal worse
-6	
-5	
-4	
-3	
-2	
-1	
0	No change
1	
2	
3	
4	
5	
6	
7	A very great deal better

Consumers as assessors of change



Consumers as assessors of change



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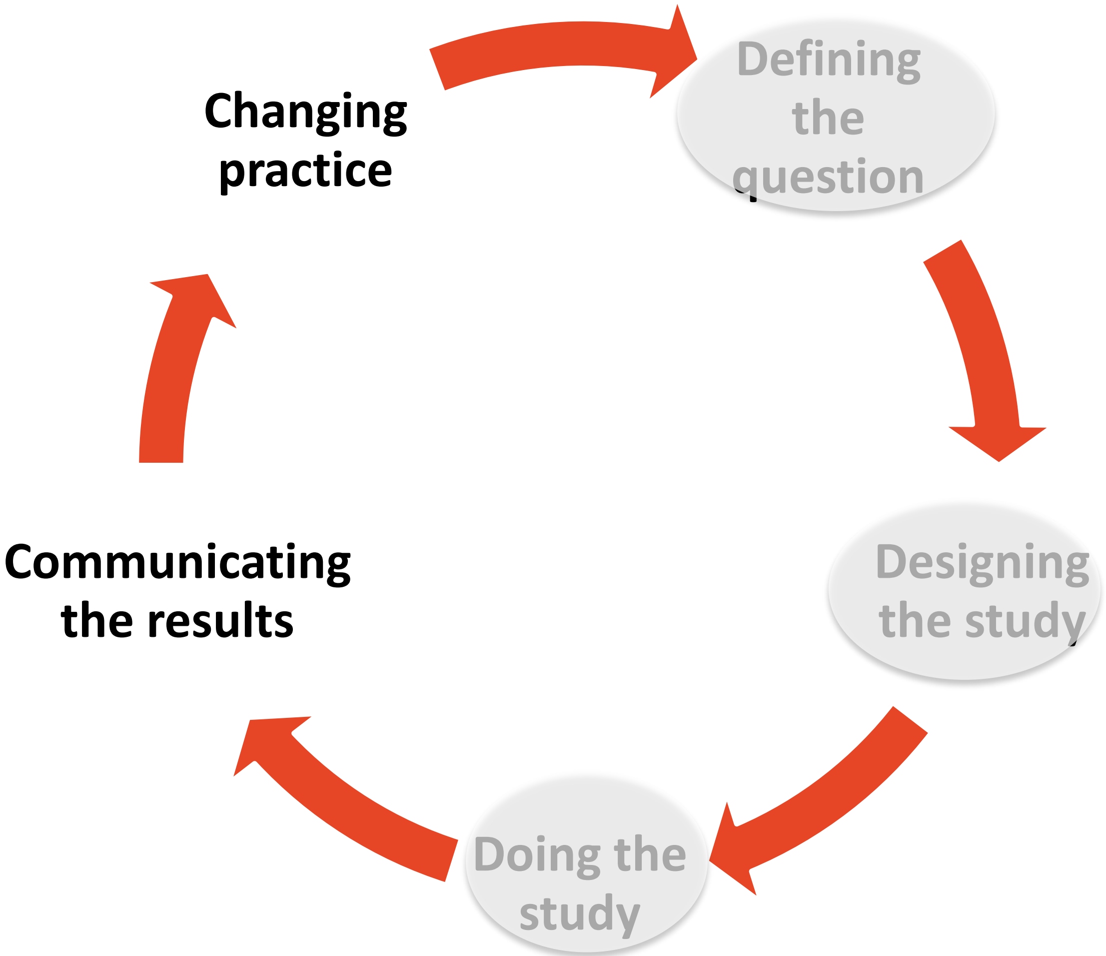

Changing practice

Defining the question

Designing the study

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The answer is 17 years, what is the question: understanding time lags in translational research

Zoë Slote Morris[1] • Steven Wooding[2] • Jonathan Grant[2]

[1]Institute of Public Health, University of Cambridge, Cambridge CB2 0SR, UK
[2]RAND Europe, Cambridge CB4 1YG, UK
Correspondence to: Jonathan Grant. Email: jgrant@rand.org

DECLARATIONS

Competing interests
None declared

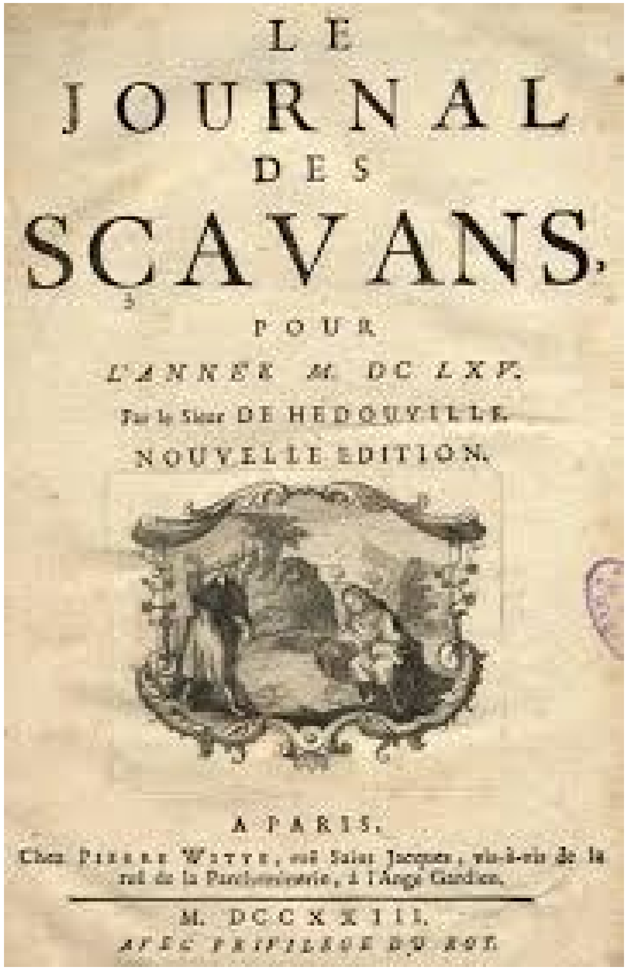
Funding
This is an independent paper funded by the Policy Research Programme in the Department of Health. The views

Summary

This study aimed to review the literature describing and quantifying time lags in the health research translation process. Papers were included in the review if they quantified time lags in the development of health interventions. The study identified 23 papers. Few were comparable as different studies use different measures, of different things, at different time points. We concluded that the current state of knowledge of time lags is of limited use to those responsible for R&D and knowledge transfer who face difficulties in knowing what they should or can do to reduce time lags. This effectively 'blindfolds' investment decisions and risks wasting effort. The study concludes that understanding lags first requires agreeing models, definitions and measures, which can be applied in practice. A

It takes on average 17 years for research findings to be implemented into practice

We are drowning in research papers



LE
JOURNAL
DES
SÇAVANS,
POUR
L'ANNEE M. DC LXV.
Par le Sieur DE HEDOUVILLE.
NOUVELLE EDITION.

A PARIS,
Chez PIERRE WITTE, rue Saint Jacques, vis-à-vis de la rue de la Parcheminerie, à l'Ange Gardien.
M. DCCXXIII.
AVEC PRIVILEGE DU ROY.

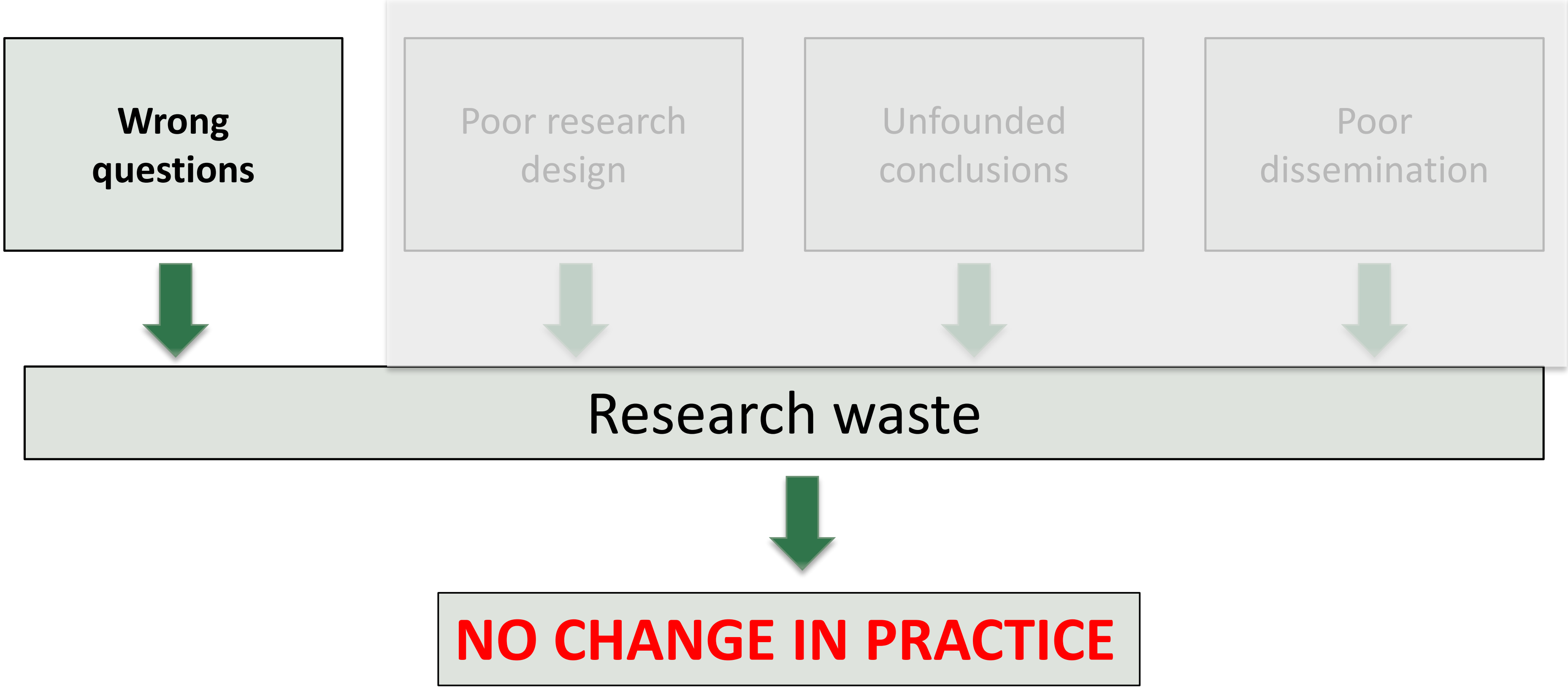
One of the first journals (1665)

Now – over 1m journals

1m journals X 12 editions X 15 papers X 60 years
= 11,000 million!!!

Chalmers & Glasziou Lancet 2009; 374: 86–89

85% of research is wasted, usually because it asks the wrong questions, …… or does not change practice.



Wrong questions

Poor research design

Unfounded conclusions

Poor dissemination

Research waste

NO CHANGE IN PRACTICE

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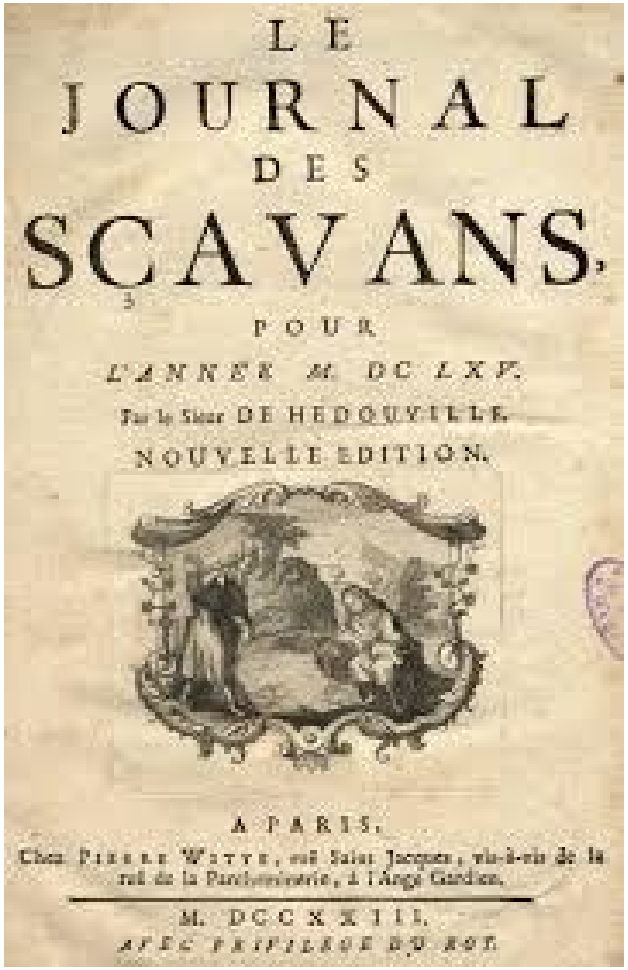

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AVEC PRIVILEGE DU ROY.

"………as dull as telephone directories and twice as obscure……."

(Smith J R Soc Med 2006 Mar; 99: 115–119).

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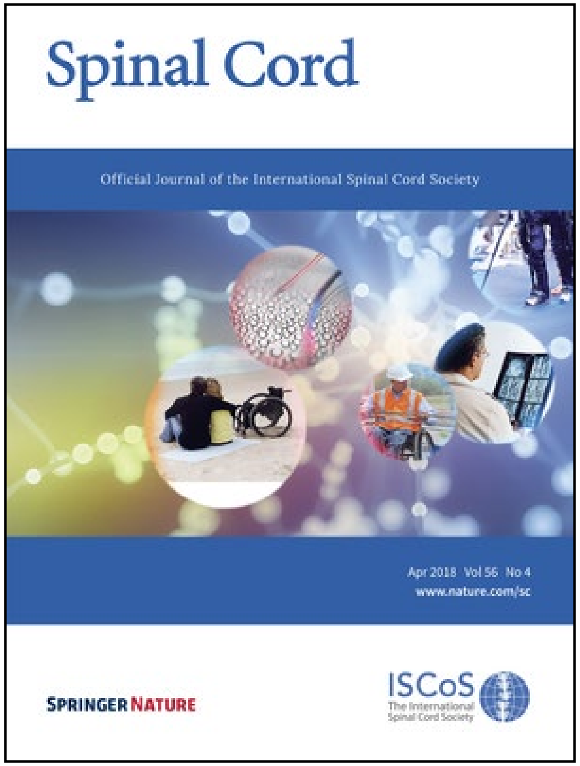
Except for one......of course


Spinal Cord

Official Journal of the International Spinal Cord Society

Apr 2018 Vol 56 No 4
www.nature.com/sc

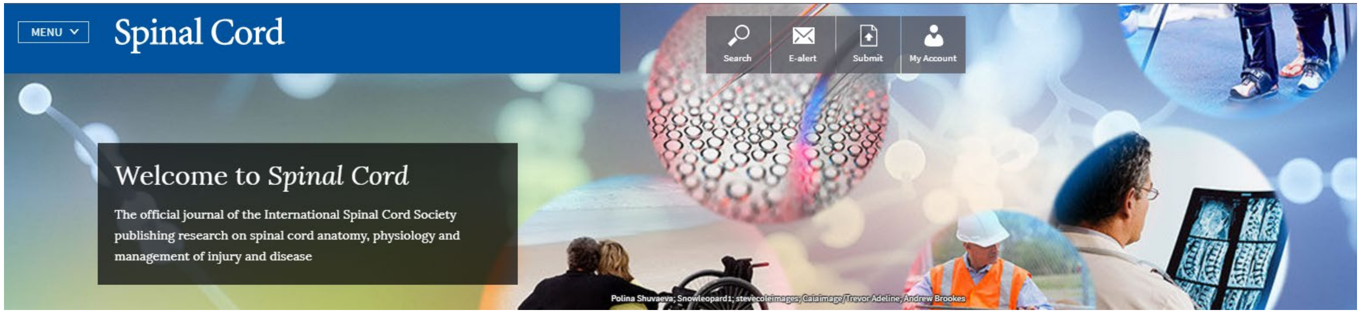
SPRINGER NATURE

ISCoS The International Spinal Cord Society

ISCOS The International Spinal Cord Society

SPRINGER NATURE

SpinalCord@JournalSCI



Welcome to *Spinal Cord*

The official journal of the International Spinal Cord Society publishing research on spinal cord anatomy, physiology and management of injury and disease

Polina Shuvaeva; Snowleopard1; stevecoleimages; Caiaimage/Trevor Adeline; Andrew Brookes

www.nature.com/SC

Researchers are “SPINNING” results


Spinal Cord (2015) 53, 417
© 2015 International Spinal Cord Society All rights reserved 1362-4393/15
www.nature.com/sc

EDITOR'S PAGE

Spin kills science

LA Harvey
Sydney, Australia
E-mail: lisa.harvey@sydney.edu.au

Have you ever wondered why so much published research in the area of spinal cord injuries (SCI) has positive conclusions? Simple probability tells us that these results are not reflective of the full truth. Researchers can’t possibly be picking winners every time they tackle a question. So what is going on here? The most likely explanation for the high proportion of positive conclusions is that many researchers are putting a positive spin on the conclusions of their negative research. Spin is rampant in all areas of medical research and SCI research is no exception.[1–4]

Spin puts negative findings in a more palatable way to editors, journals, patients, funders and readers. There are

Why?

- Passionate
- Self interest

Academic institutes are “SPINNING” results

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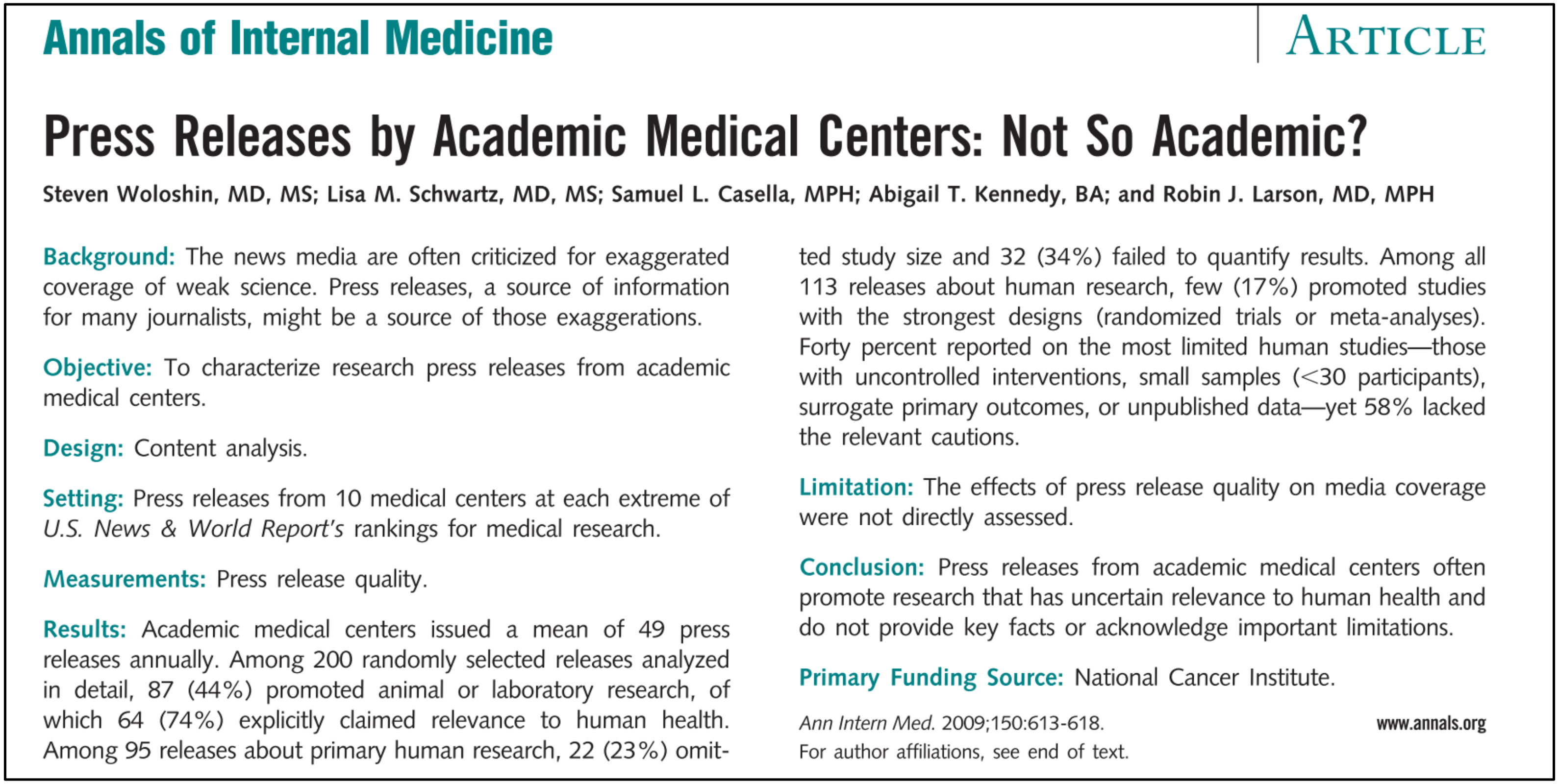


Annals of Internal Medicine | ARTICLE

Press Releases by Academic Medical Centers: Not So Academic?

Steven Woloshin, MD, MS; Lisa M. Schwartz, MD, MS; Samuel L. Casella, MPH; Abigail T. Kennedy, BA; and Robin J. Larson, MD, MPH

Background: The news media are often criticized for exaggerated coverage of weak science. Press releases, a source of information for many journalists, might be a source of those exaggerations.

Objective: To characterize research press releases from academic medical centers.

Design: Content analysis.

Setting: Press releases from 10 medical centers at each extreme of *U.S. News & World Report's* rankings for medical research.

Measurements: Press release quality.

Results: Academic medical centers issued a mean of 49 press releases annually. Among 200 randomly selected releases analyzed in detail, 87 (44%) promoted animal or laboratory research, of which 64 (74%) explicitly claimed relevance to human health. Among 95 releases about primary human research, 22 (23%) omitted study size and 32 (34%) failed to quantify results. Among all 113 releases about human research, few (17%) promoted studies with the strongest designs (randomized trials or meta-analyses). Forty percent reported on the most limited human studies—those with uncontrolled interventions, small samples (<30 participants), surrogate primary outcomes, or unpublished data—yet 58% lacked the relevant cautions.

Limitation: The effects of press release quality on media coverage were not directly assessed.

Conclusion: Press releases from academic medical centers often promote research that has uncertain relevance to human health and do not provide key facts or acknowledge important limitations.

Primary Funding Source: National Cancer Institute.

Ann Intern Med. 2009;150:613-618. www.annals.org

For author affiliations, see end of text.

Press releases from academic medical centers often promote research that has uncertain relevance to human health and do not provide key facts or acknowledge important limitations.

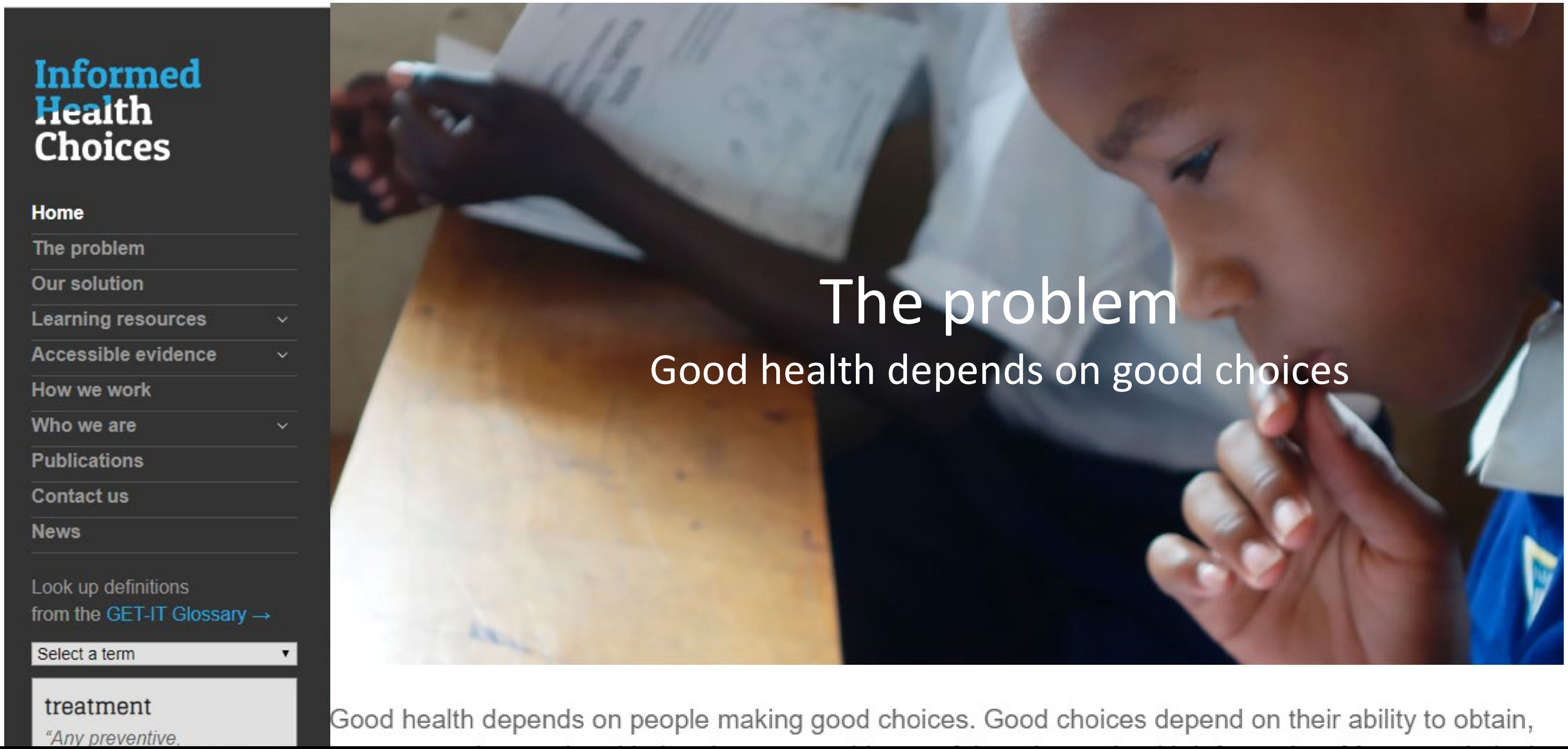
How are we getting research results?

The web

Social media and networking

The media

We need improved research literacy



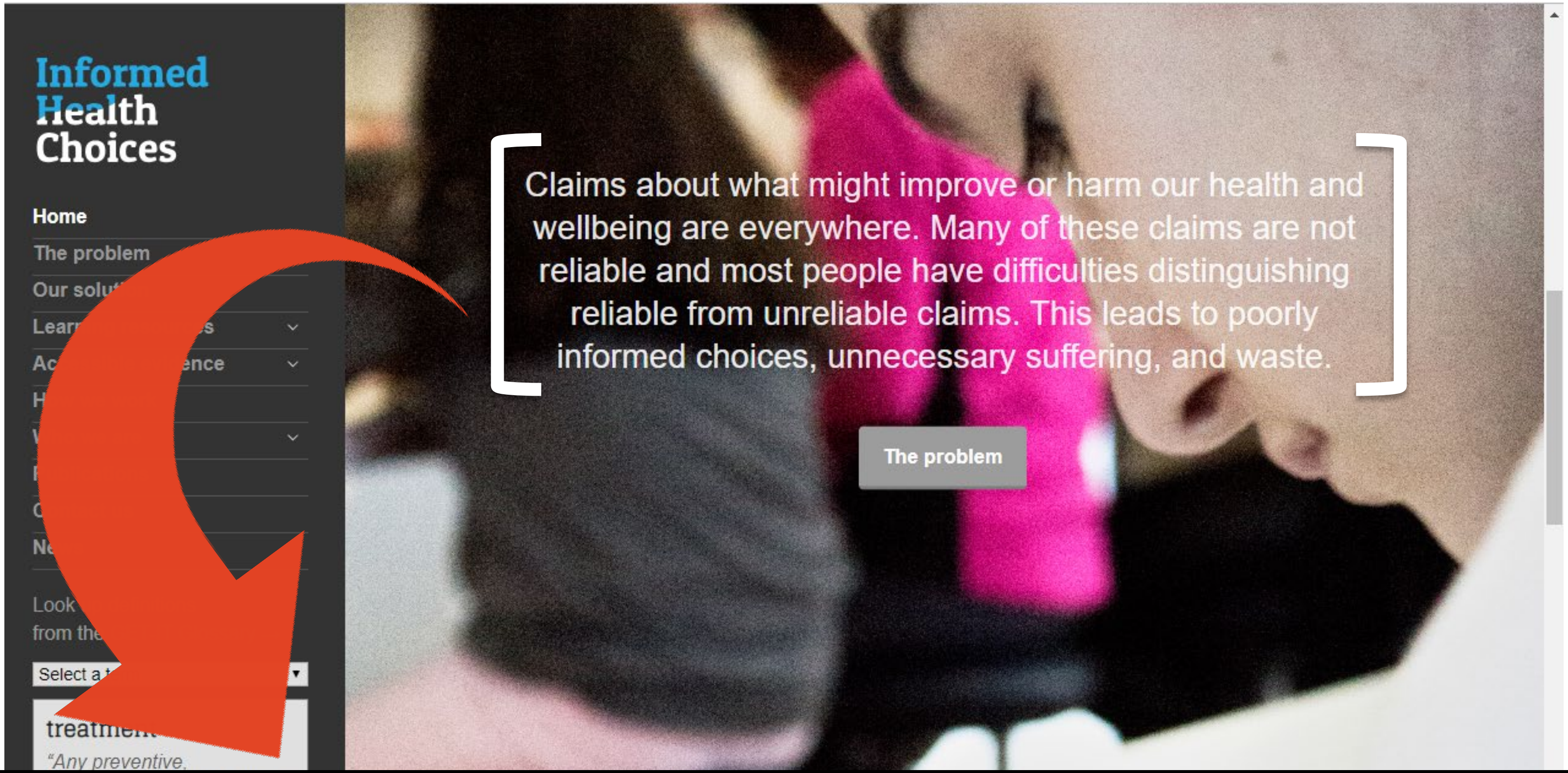
The problem

Good health depends on good choices

Good health depends on people making good choices. Good choices depend on their ability to obtain,

Good health depends on people making good choices. Good choices depend on their ability to obtain, process, understand and judge the trustworthiness of the relevant health information. Most people lack that ability and they lack access to reliable information.

We need improved research literacy



Claims about what might improve or harm our health and wellbeing are everywhere. Many of these claims are not reliable and most people have difficulties distinguishing reliable from unreliable claims. This leads to poorly informed choices, unnecessary suffering, and waste.

Claims about what might improve or harm our health and wellbeing are everywhere. Many of these claims are not reliable and most people have difficulties distinguishing reliable from unreliable claims. This leads to poorly informed choices, unnecessary suffering, and waste.

We need trustworthy summaries of evidence

CONSUMER GUIDE: UPPER LIMB FUNCTION

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Preservatio
Upper Limb
Function:
What You
Should Kno

A Guide for People
with Spinal Cord Inju

consortium for
SPINAL CORD
MEDICINE
CLINICAL PRACTICE GUIDELINES
Administrative and financial support provided by Paralyzed Veterans of America

CONSUMER GUIDE: PRESSURE ULCERS

SPINAL CORD MEDICINE

Pressure Ulce
What You Sho
Know

A Guide for People with
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consortium for
SPINAL CORD
MEDICINE
CLINICAL PRACTICE GUIDELINES
Administrative and financial support provided by Paralyzed Veterans

SCIRE
SPINAL CORD INJURY REHABILITATION EVIDENCE: Version 2.0
www.icord.org/scire

CHAPTER EIGHT
Respiratory Management
Following Spinal Cord Injury

A William Sheel, PhD
W Darlene Reid, BMR (PT), PhD
Andrea F Townson, MD FRCPC
Najib Ayas, MD FRCPC, MPH

icord
LAWSON
ST JOSEPH'S HEALTH CARE
UBC
Vancouver Coastal Health
G.F. Strong Rehab Centre
Western

We need results of research written in a way that is understandable by all

Cochrane Database of Systematic Reviews

Non-pharmacological interventions for chronic pain in people with spinal cord injury

Cochrane Systematic Review - **Intervention** | Version published: 28 November 2014

Inga Boldt | Inge Eriks-Hoogland | Martin WG Brinkhof | Rob de Bie | Daniel Joggi | Erik von Elm

Authors’ summary

For tDCS the pooled mean difference between intervention and control groups in pain scores on an 11-point visual analogue scale (VAS) (0-10) was a reduction of **-1.90 units (95% confidence interval (CI) -3.48 to -0.33; P value 0.02) ……….**

Consumers’ summary

Results from two studies ….suggested that transcranial direct current stimulation reduced pain and ……….that exercise programmes for chronic shoulder pain provided pain relief.

We need to provide knowledge in different and accessible formats

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elearnSCI.org

www.elearnSCI.org

Elearning for health professionals and consumers in SCI: a way to reach all

We need to support people to access knowledge

Courses run regularly by ISCoS and others

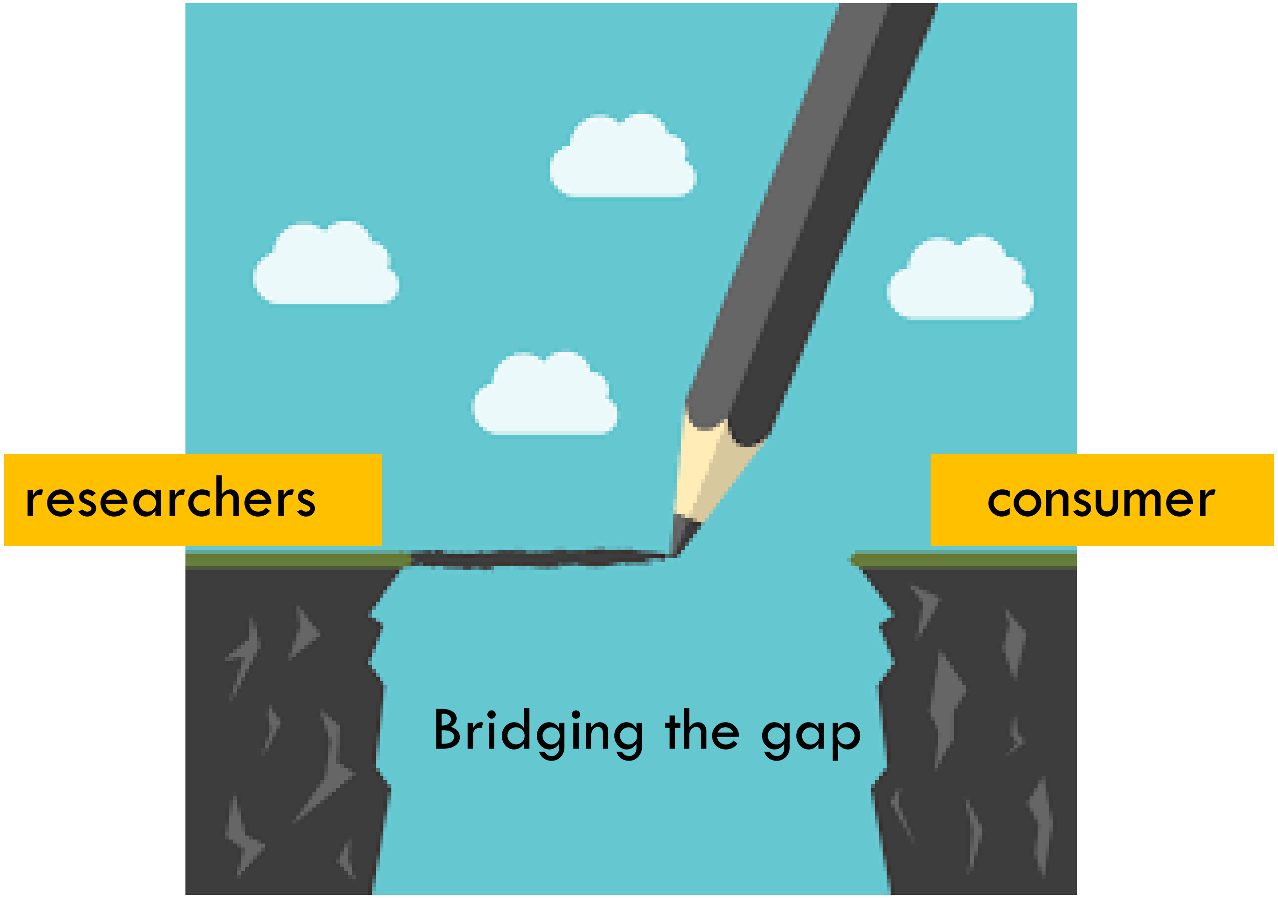
THEY ARE FREE FOR ALL!

FREE ONLINE COURSES

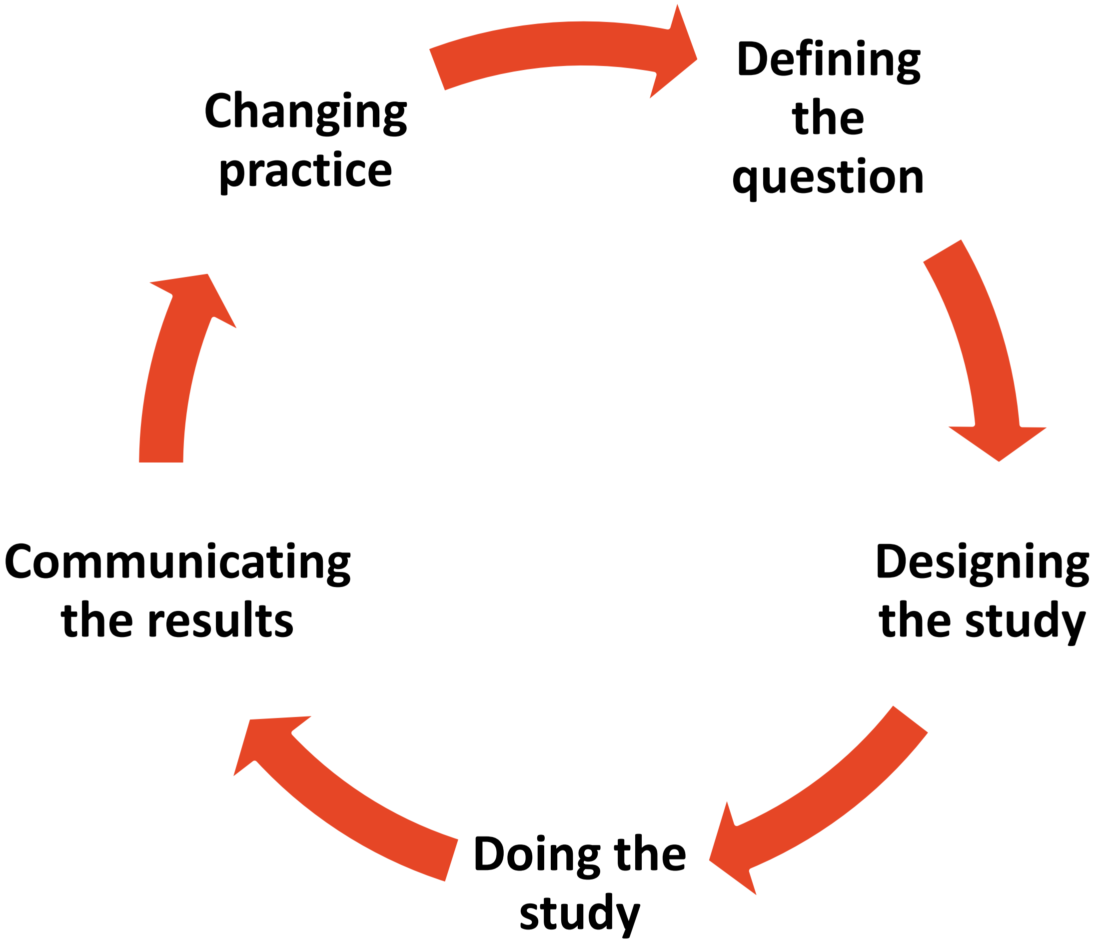
Management of Spinal Cord Injuries

In summary, we need ……………….

We need to bridge the gap between researchers and consumers



We need meaningful consumer involvement in all steps of the research cycle



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Essential and part of knowledge translation

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University of Sydney, Australia
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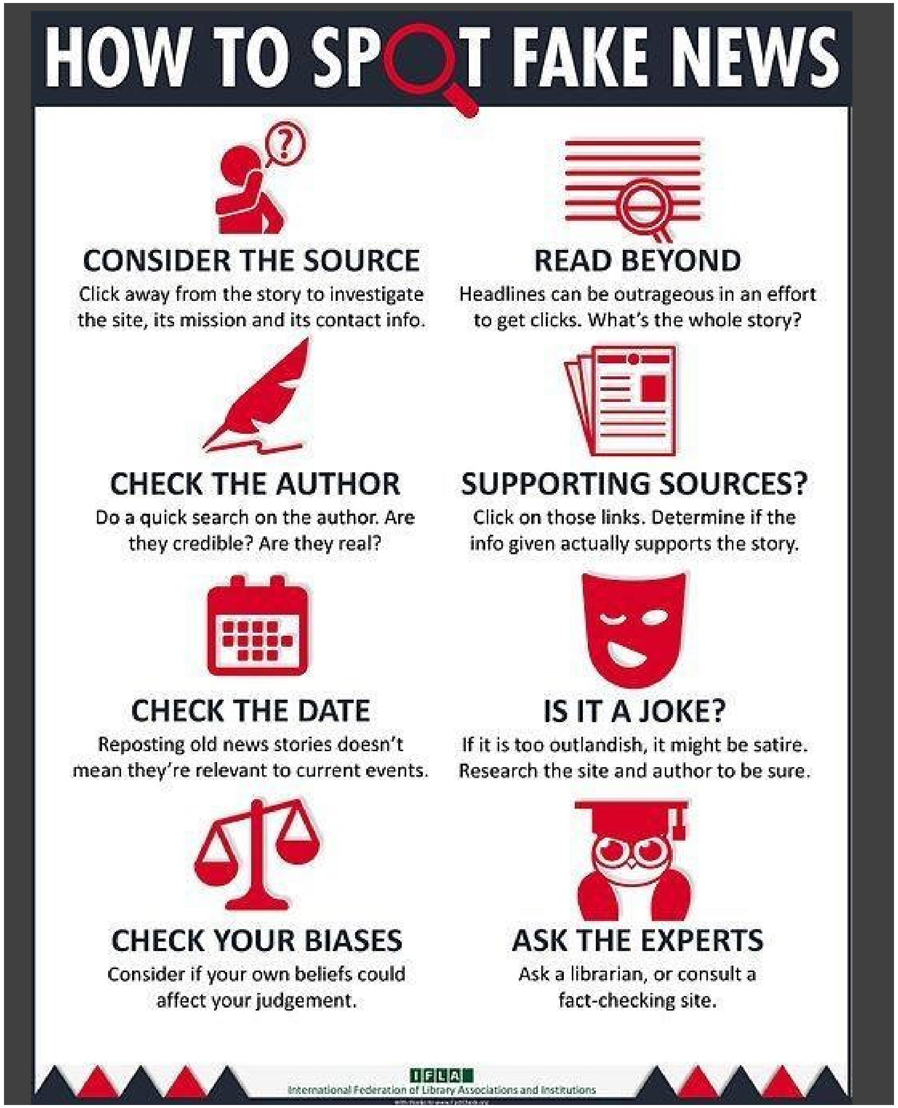
SYDNEY

The solution – science literacy



HOW TO SPOT FAKE NEWS

CONSIDER THE SOURCE
Click away from the story to investigate the site, its mission and its contact info.

READ BEYOND
Headlines can be outrageous in an effort to get clicks. What's the whole story?

CHECK THE AUTHOR
Do a quick search on the author. Are they credible? Are they real?

SUPPORTING SOURCES?
Click on those links. Determine if the info given actually supports the story.

CHECK THE DATE
Reposting old news stories doesn't mean they're relevant to current events.

IS IT A JOKE?
If it is too outlandish, it might be satire. Research the site and author to be sure.

CHECK YOUR BIASES
Consider if your own beliefs could affect your judgement.

ASK THE EXPERTS
Ask a librarian, or consult a fact-checking site.

IFLA
International Federation of Library Associations and Institutions

Develop science literacy to be able to distinguish between reliable and unreliable claims

https://mailchi.mp/6b0b1ebf1bfd/august-2017-monthly-digest?e=2a53a448f3

The solution – science literacy

JOURNAL OF EVIDENCE-BASED MEDICINE

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ARTICLE

Key concepts that people need to understand to assess claims about treatment effects

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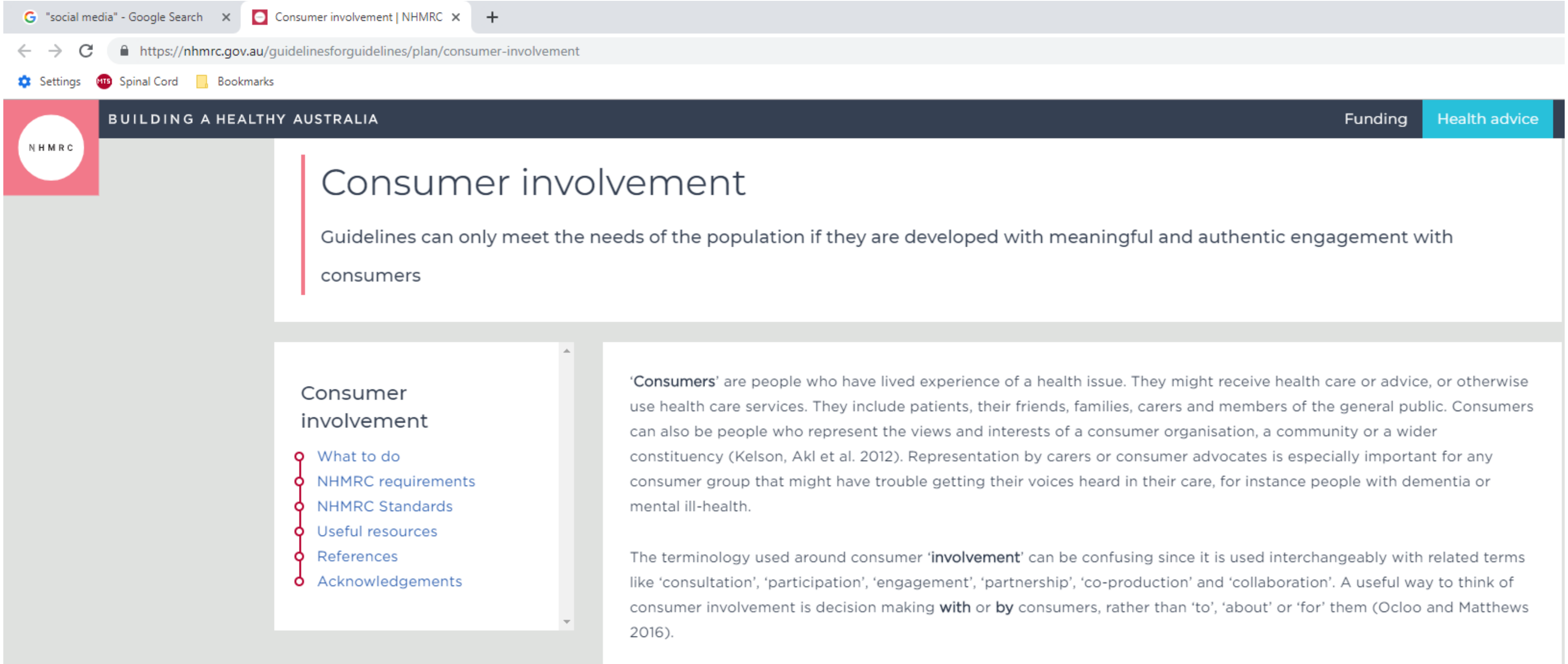
Keywords
Evidence based medicine; health literacy; user involvement.

Correspondence
Astrid Austvoll-Dahlgren, Norwegian Knowledge Centre for the Health Services,

Abstract

Objective: People are confronted with claims about the effects of treatments and health policies daily. Our objective was to develop a list of concepts that may be important for people to understand when assessing claims about treatment effects. **Methods:** An initial list of concepts was generated by the project team by identi-

We need consumers to be involved in Clinical Practice Guidelines



Consumer involvement

Guidelines can only meet the needs of the population if they are developed with meaningful and authentic engagement with consumers

Consumer involvement

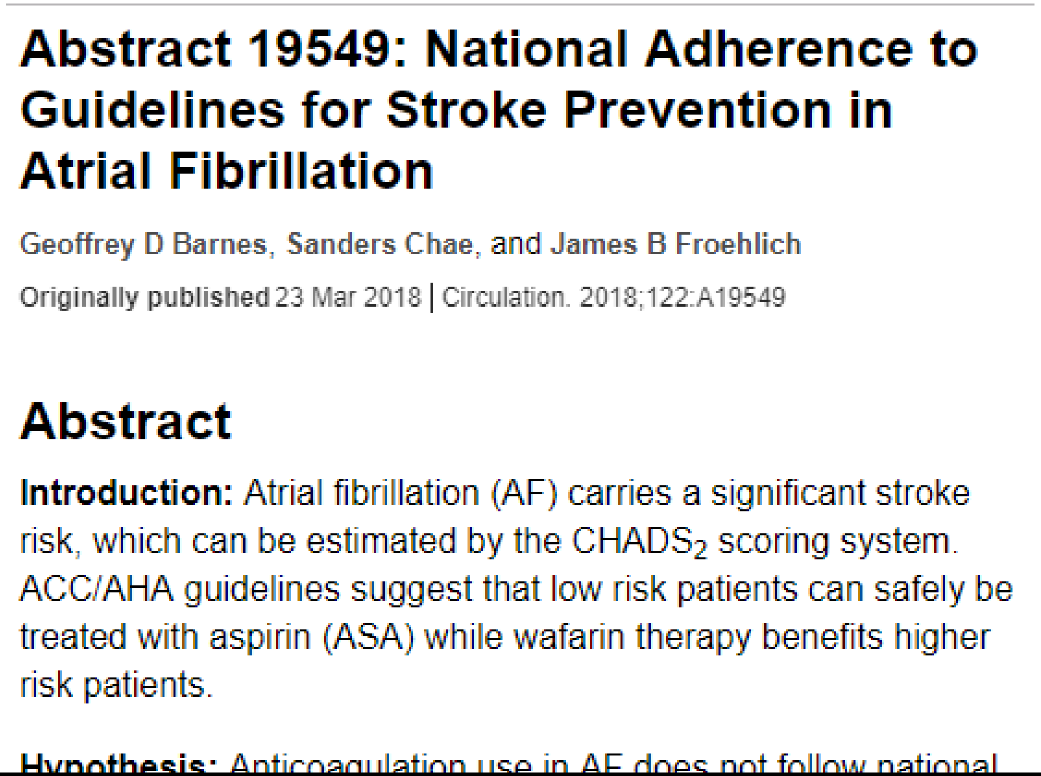
- What to do
- NHMRC requirements
- NHMRC Standards
- Useful resources
- References
- Acknowledgements

'**Consumers**' are people who have lived experience of a health issue. They might receive health care or advice, or otherwise use health care services. They include patients, their friends, families, carers and members of the general public. Consumers can also be people who represent the views and interests of a consumer organisation, a community or a wider constituency (Kelson, Akl et al. 2012). Representation by carers or consumer advocates is especially important for any consumer group that might have trouble getting their voices heard in their care, for instance people with dementia or mental ill-health.

The terminology used around consumer '**involvement**' can be confusing since it is used interchangeably with related terms like 'consultation', 'participation', 'engagement', 'partnership', 'co-production' and 'collaboration'. A useful way to think of consumer involvement is decision making **with** or **by** consumers, rather than 'to', 'about' or 'for' them (Ocloo and Matthews 2016).

Guidelines can only meet the needs of the population if they are developed with meaningful and authentic engagement with consumers.

We need to ensure care is delivered according to Clinical Practice Guidelines



Abstract 19549: National Adherence to Guidelines for Stroke Prevention in Atrial Fibrillation

Geoffrey D Barnes, Sanders Chae, and James B Froehlich

Originally published 23 Mar 2018 | Circulation. 2018;122:A19549

Abstract

Introduction: Atrial fibrillation (AF) carries a significant stroke risk, which can be estimated by the CHADS$_2$ scoring system. ACC/AHA guidelines suggest that low risk patients can safely be treated with aspirin (ASA) while wafarin therapy benefits higher risk patients.

Hypothesis: Anticoagulation use in AF does not follow national

There is inconsistent care, and
clinicians are not following clinical practice guidelines

Why do we care about research?

therapy/care

Evidence-based ~~medicine~~

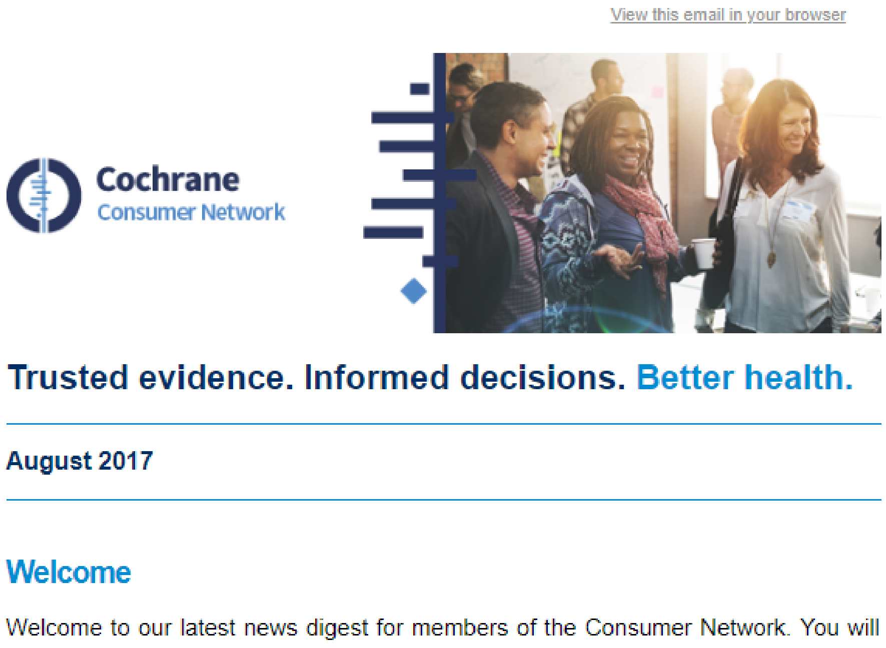
We need trustworthy summaries of evidence

Results of high quality clinical trials

High quality systematic reviews

.....that everyone understands

Trusted evidence.
Informed decisions.
Better health.



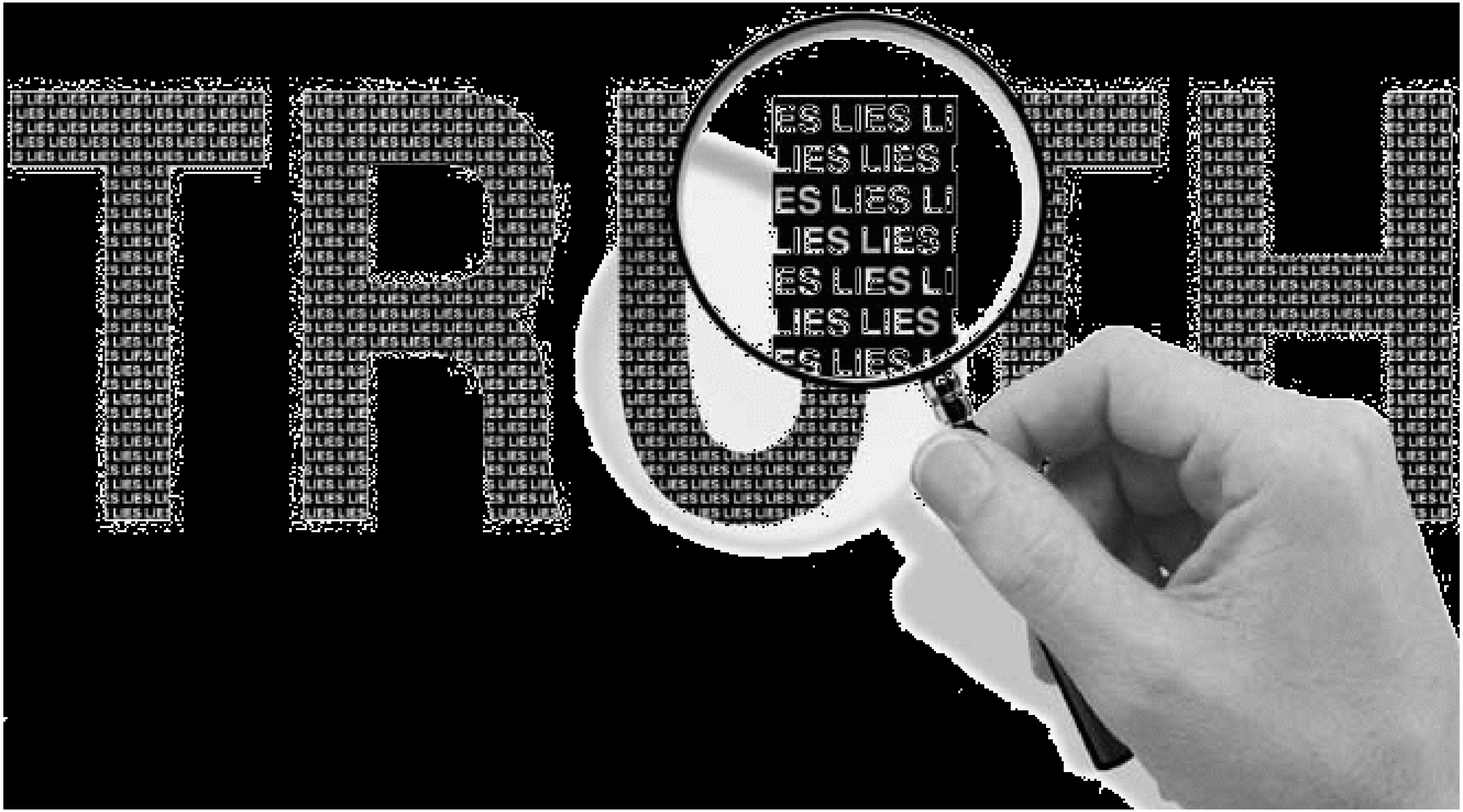
Trusted evidence. Informed decisions. Better health.

August 2017

Welcome

Welcome to our latest news digest for members of the Consumer Network. You will

www.cccrg.cochrane.org


TRUTH
LIES LIES LIES