


# The Many Meanings of Perineal Injuries



 Pexels, Pixabay

Care-seekers' and care-providers' perspectives on second-degree perineal injuries, their implications, and potential to improve care.

# The involvement of non-researchers in the prioritization of research

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SBU



# Evidence gaps – interventions and methods with evidence uncertainties

SBU collects scientific evidence gaps in the field of healthcare, dental care, social services, occupational health and safety, and functioning and disability, in order to identify areas where new primary research is needed.

## Search the database

The database contains information on where research or summarized knowledge is lacking. Note that the database only contains evidence gaps for practice-based research and does not include basic research. [Read more](#)



— Or —

[Advanced search](#)

## Evidence gaps collected in areas

[Health care](#)



[Social services](#)



[Dental care](#)



[Work environment](#)



[Functional disability](#)



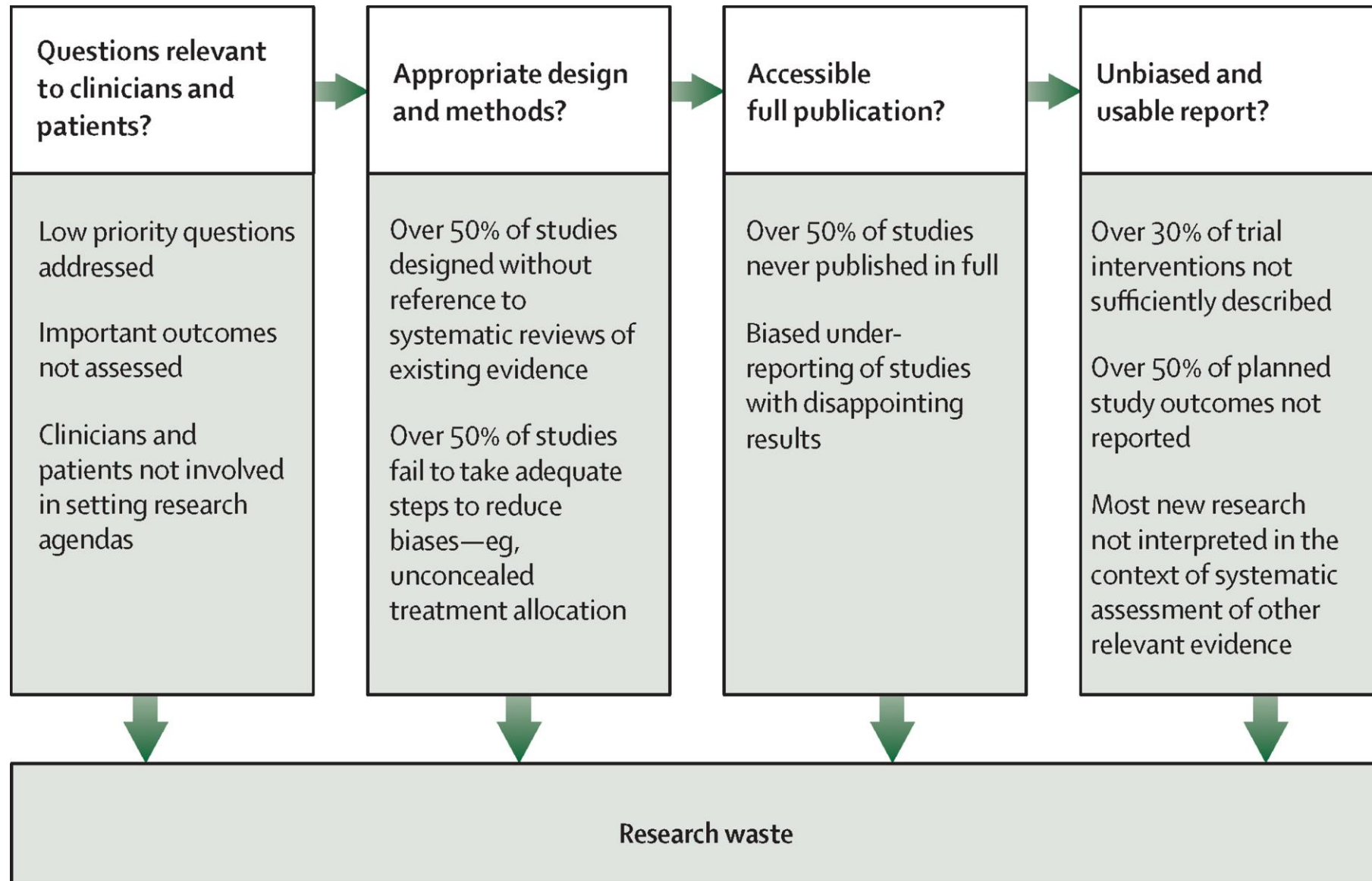
# Viewpoint

## Avoidable waste in the production and reporting of research evidence

# 85% of Health Research Funding is wasted avoidable

Sir Iain Chalmers and Paul Glasziou  
'Avoidable waste in the production and reporting of research evidence', The Lancet, Volume 374, Issue 9683, Pages 86 - 89, 4 July 2009,







The use of **core outcome sets** (COS) facilitates that more research can be combined systematic reviews

By prioritizing research questions, you can get an additional perspective on which questions are most important to answer

# Involvement of consumers in research prioritisation process of evidence gaps

By the involvement of consumers when prioritizing research questions, you can get an additional perspective on which questions are most important to answer





# What are the most important research questions?

Not likely that all questions will be researched.

- Priorities/choices of research are often made based on researchers and research funders
- More rarely based on what those who will be directly affected think is important



# James Lind Alliance (JLA)

- JLA is an independent British organization that was established in 2004
- Funded by the National Institute for Health Research (NIHR) and operated by the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
- Patients, consumers, carers and profession identify and prioritise the most important evidence gaps in their area "Prioritising setting partnerships"
- The top list of the research priorities are published



**Table 1** Areas, scientific knowledge and scientific knowledge gaps obtained from systematic reviews of high or moderate quality.

Areas	Systematic review of moderate or high quality	Scientific knowledge	Scientific knowledge gaps
First degree tear	●	■	●
Second degree tear	●	●	●
Third and/or fourth degree tear	●	■	●
Deeper vaginal tear	■	■	●
Injury caused by episiotomy	●	●	●
Injury of the levator ani muscle	■	■	●
Acute uterine prolapse	■	■	●
Injury of the pelvic bones	■	■	●
Diastasis of pubic symphysis	■	■	●
Specific injuries in genitally mutilated	■	■	●
Fistula between urinary bladder and vagina or between anus and vagina	■	■	●
Hemorrhoid	■	■	●
Perineal pain	●	●	●
Dyspareunia	●	●	●
Urine incontinence	●	■	●
Anal incontinence	●	■	●
Defecation difficulties	■	■	●
Uterus rupture	■	■	●

● = Yes ■ = No ● = Yes (some)

Scientific knowledge = A systematic review with high or moderate quality demonstrates the effectiveness of a treatment.

# Lipoedema – diagnosis, treatment, and experiences

A systematic review and assessment of medical, economic and ethical aspects



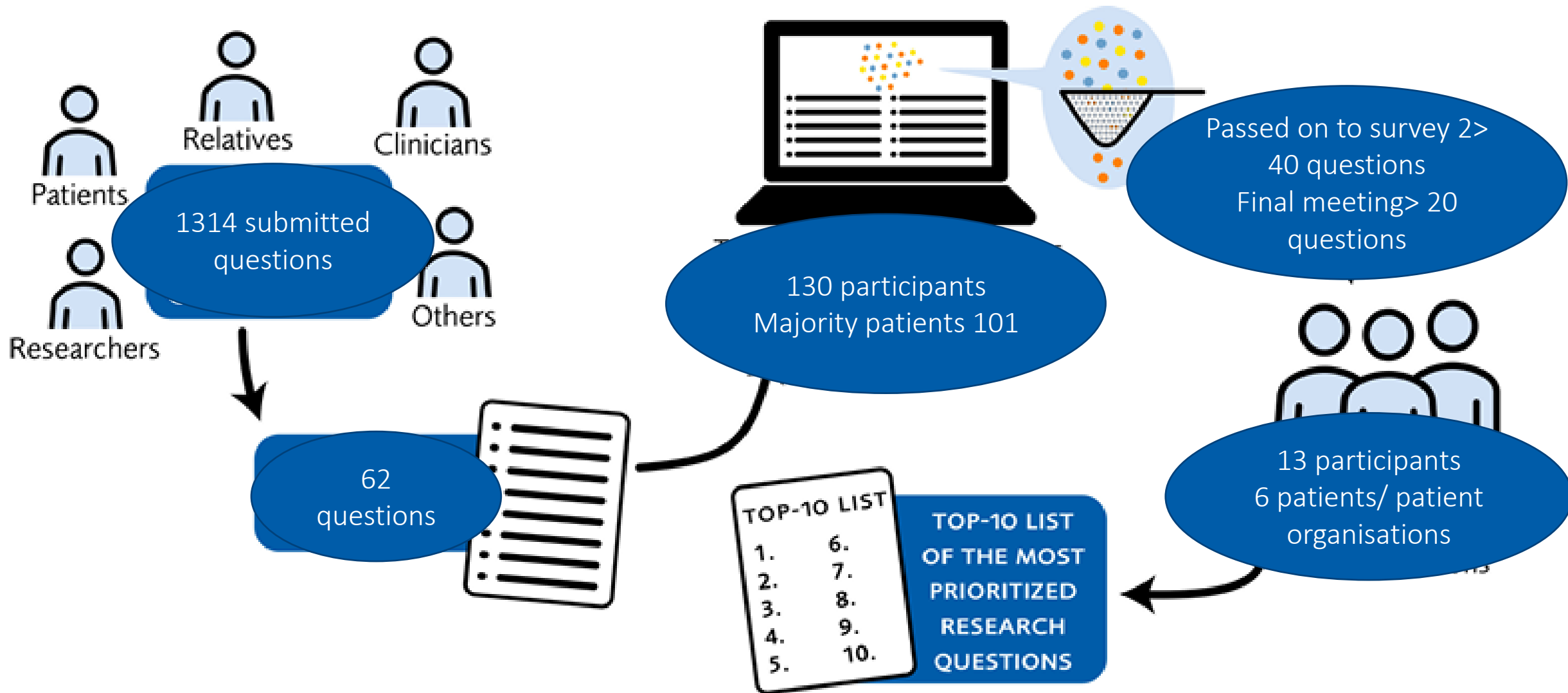
Reading time approx. 13 minutes

Published: July 1, 2021

Publication type: [SBU Assessment](#) ▾

## Conclusions

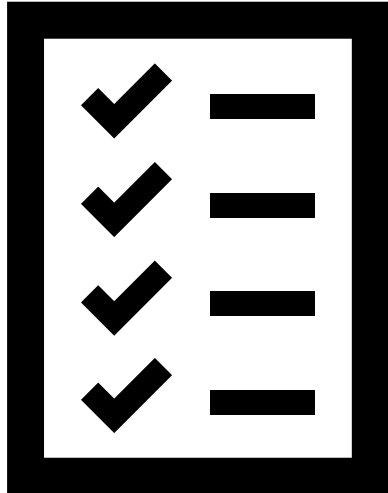
- No scientific studies assessing tests to diagnose lipoedema, or methods to distinguish between lipoedema and other conditions were identified.
- There is a lack of scientific studies, with an acceptable risk of bias, assessing methods to treat or cure lipoedema.
- No scientific studies exploring the perceptions or experiences of people living with lipoedema, nor of healthcare professionals who care for people with lipoedema were identified.



- TOP-10 LIST**
- 1.
  - 2.
  - 3.
  - 4.
  - 5.
  - 6.
  - 7.
  - 8.
  - 9.
  - 10.

**TOP-10 LIST OF THE MOST PRIORITIZED RESEARCH QUESTIONS**

# The final prioritization is a result of discussion and compromise from the participants



- The questions discussed at the meetings (approximately 20) are already prioritized
- Between 12-20 participants who are affected by the condition have jointly agreed that this is a prioritized question
- The list is sent out to everyone who participated in the prioritization surveys to try to capture dissenting opinions
- Some questions that have progressed are not included on the top list as the group believes that it's not actually more research that is needed but rather political decisions, or changes in practice
- Individual persons will have dissenting opinions

# Published prioritising projects in Research priority setting database

<https://ois-old.lbg.ac.at/priority-setting-database/>

## RESEARCH PRIORITY SETTING PROJECT DATABASE

### Explore research priority setting projects worldwide!

The priority setting project database provides a comprehensive overview of any projects in which researchers have worked together with stakeholders to define research priorities. The database serves both as a source of inspiration for future priority setting projects and as a research tool for unanswered research questions and under-researched topics.

799 projects

1 2 3 ... 80 next

Items per page

10

Sorting of items

Alphabetical

Topic

Year

**The James Lind Alliance  
Approach to Priority  
Setting for Prostate Cancer  
Research: An Integrative  
Methodology Based on  
Patient and Clinician  
Participation**

#### AUTHORS

Lophatananon et al. (2011)

#### LINK

<https://doi.org/10.1111/j.1464-410X.2011.10609.x>

#### TOPIC

health, cancer

#### RESEARCH FOCUS

prostate cancer

#### COUNTRY

Europe, UK

#### STAKEHOLDER

academics/researchers, family/friends/carers,

Project Of The Week

# Prioritize research outcomes, development of a Core Outcome Set (COS)?

The use of **core outcome sets** (COS) facilitates that more research can be combined systematic reviews



**How many different outcomes do you think are used in treatment studies in provoked vulvodynia?**

**63**

## Core outcome set

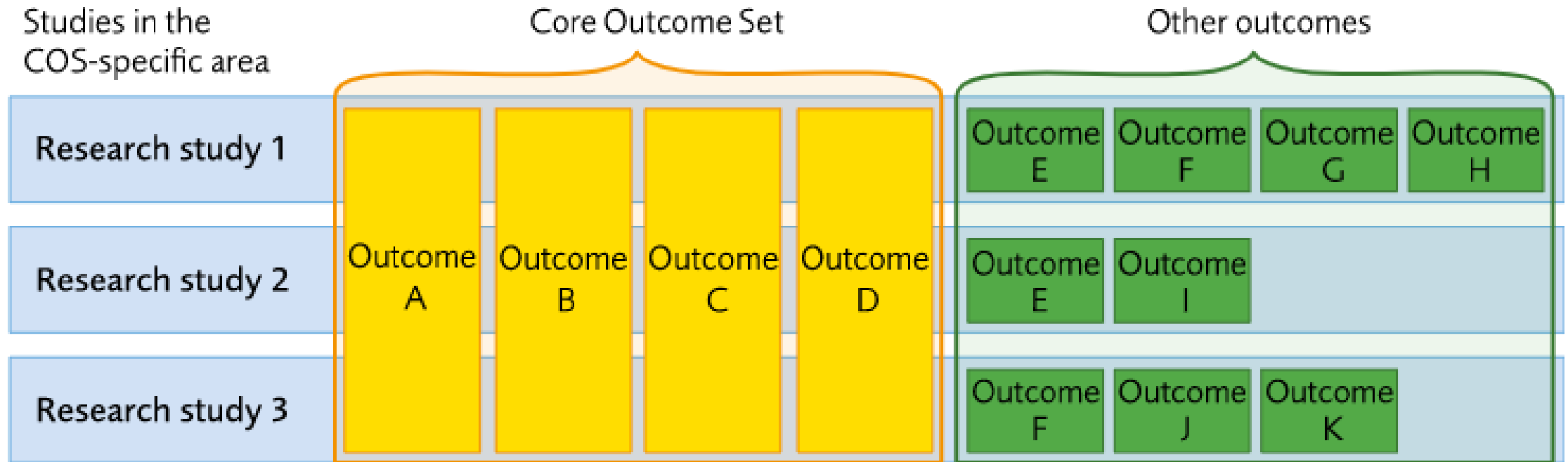
An agreed standardised set of outcomes that should be measured and reported, as a *minimum*, in all clinical trials in specific areas of health or health care.

*COMET definition*

# Core outcome set

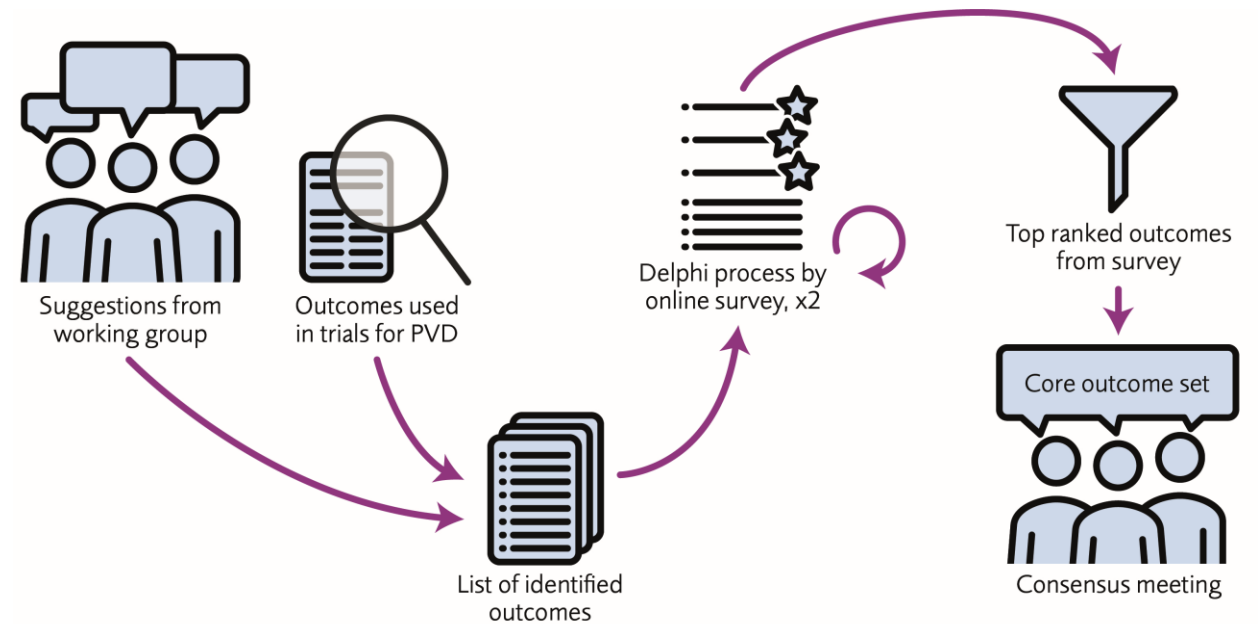
A few outcomes that should be measured in all future studies in a specific area

Video: <https://www.youtube.com/watch?v=D0Q9vypSYeE>



# Method

1. Ensure that a COS is needed
  - Check if one exists or is in the process of being developed
2. Specify
  - The population and the intervention
3. Identify outcomes
  - Which outcomes are used in the published research?
  - Which outcomes are important to patients/clients/professionals? (survey or qualitative study)
4. Prioritising
  - Delphi survey
  - Consensus meeting



# Published COS projects in The COMET database

<https://www.comet-initiative.org/>

The screenshot displays the COMET Initiative website. At the top, a navigation bar includes links for Home, Search the COMET Database, Resources, COS Endorsement, COS Uptake, Patents and the Public, Events, About us, and COMET VIII. Below this is the COMET Initiative logo and the title "Core Outcome Measures in Effectiveness Trials". A subtitle explains that a core outcome set (COS) is an agreed standardised set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or health care.

The main content area is divided into several sections:

- Search the COMET database:** A search box with a "Search Database" button and a link to "Click here for advanced search".
- Register New Study:** A green button with the text "Register New Study" and a note: "To tell us about a project or study, click the button below."
- COS Alerts:** A section stating "COMET is offering a free alerts system for newly registered or published studies in a chosen area. Click here to sign up."
- Resources:** A section featuring a PLOS Medicine article titled "Core Outcome Set-StANDards for Development: The COS-STAD recommendations".
- COMET Video:** A video player showing a woman juggling fruit, with the title "What are core outcome sets? (A COMET Initiative video)".
- Recently Added Studies:** A list of three studies:
  - Inclusion of participants from low-income and middle-income countries in core outcome sets development: a systematic review
  - Development of a core outcome set for person-centred outcomes in end-of-life care in critical care
  - Consensus development of priority outcome domains for community mental health care by multiple stakeholders: Online Delphi study in Japan
- Tweets by @COMETInitiative:** A tweet from @COMETInitiative: "Request to observe a COS consensus meeting - mailchi.mp/d640fb2a586d/r..."

# Thank you!

Website: [sbu.se/en](https://sbu.se/en)



# If you want to know more, COMET

- COMET Initiative

<https://www.comet-initiative.org/>

- COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN)

<https://www.cosmin.nl/>

- The Core Outcome Set-STAndards for Development (COS-STAD)

<https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002447>

- The Core Outcome Set-STAndardised Protocol Items (COS-STAP)

<https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-019-3230-x>

<https://www.comet-initiative.org/Downloads/COS-STAP%20Reporting%20Checklist%20template.docx>

- The Core Outcome Set-STAndards for Reporting (COS-STAR)

<https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002148>

<https://www.comet-initiative.org/Downloads/COS-STAR%20Reporting%20Checklist%20template.docx>

# If you want to know more, JLA

- The priority setting project database

<https://ois-old.lbg.ac.at/priority-setting-database/>

- The James Lind Alliance

<https://www.jla.nihr.ac.uk/>

- JLA Guidebook

<https://www.jla.nihr.ac.uk/jla-guidebook/>

- Reporting guideline for priority setting of health research (REPRISE)

<https://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/s12874-019-0889-3>

<https://www.jla.nihr.ac.uk/news/reprise-reporting-guidelines/24495>

# More

- EVBRES <https://evbres.eu/>
- EVIR- Ensuring Value in Reserch <https://evir.org/about-us/>
- TranspariMED <https://www.transparimed.org/>
- Catalogue of Bias <https://catalogofbias.org/>
- Enhancing the QUAlity and Transparency Of health Research (reporting guidelines) <https://www.equator-network.org/reporting-guidelines/>
- Testing treatments <http://www.testingtreatments.org/>
- THAT'S A CLAIM! <https://thatsaclaim.org/>
- Students 4 best evidence <https://s4be.cochrane.org/>
- ...