



National Institute for
Health Research

Improving Research Integrity: A funders' perspective

@Matt_Westmore



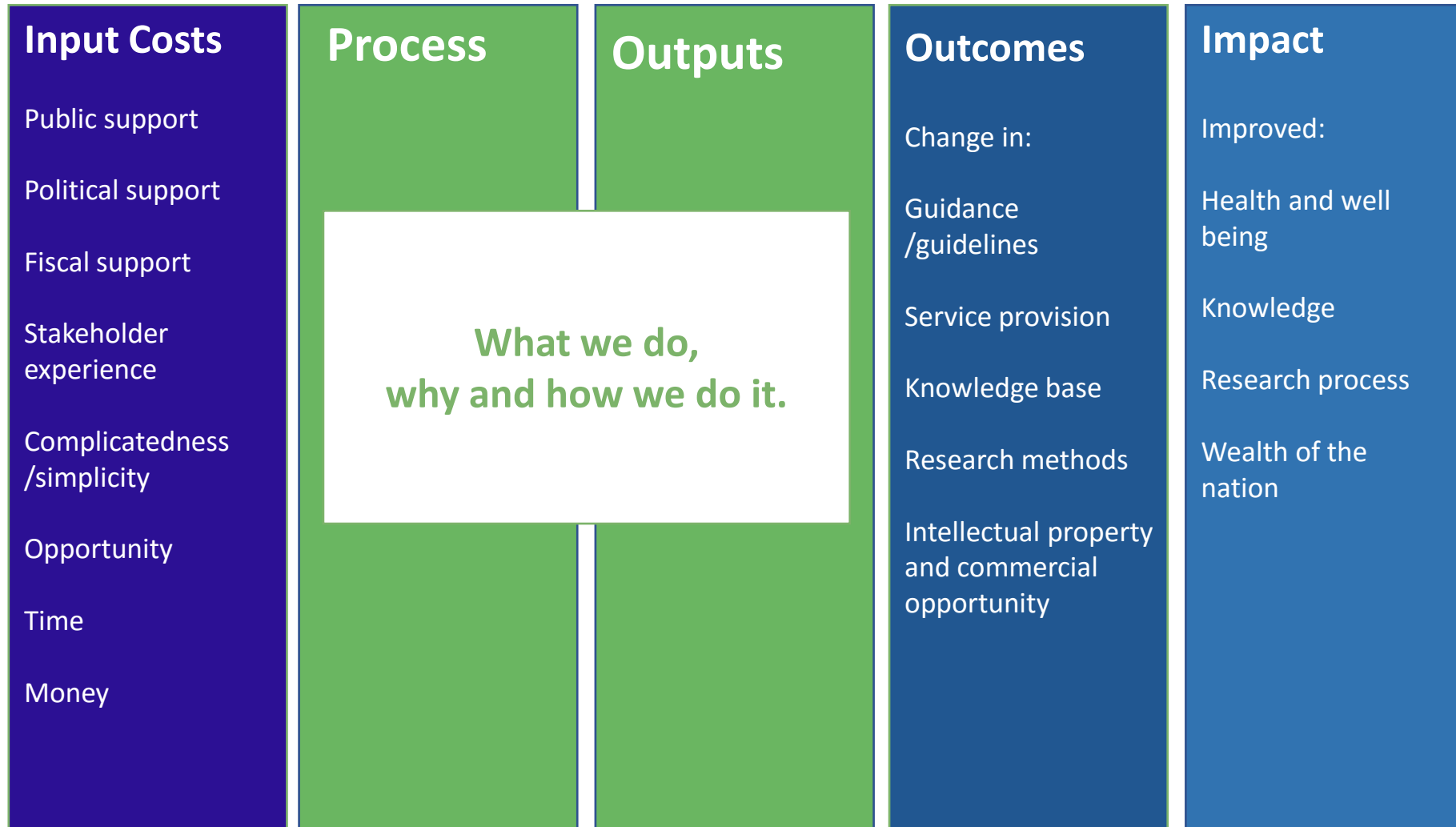
Conflicts and bias

- I work for the National Institute for Health Research
- I am the NIHR's lead for Adding Value in Research
- I am on the REWARD and EBRN Steering Committees
- I co-chair the Ensuring Value in Research Funders' Collaboration and Development Forum
- I work for the University of Southampton in a business development role

An abstract painting on a dark blue background. It features several irregular, dark, textured shapes scattered across the canvas, some of which are accented with small red dots. A large, circular, dark shape in the center-right is heavily crisscrossed with thin, light-colored lines. A small, bright yellow circle is located in the upper left quadrant. The overall texture is rough and layered, suggesting a mixed-media or heavily worked surface.

Why do funders care?

Dogan, 1959, Between 11 and 12, Galwerija Umjetnina, Split



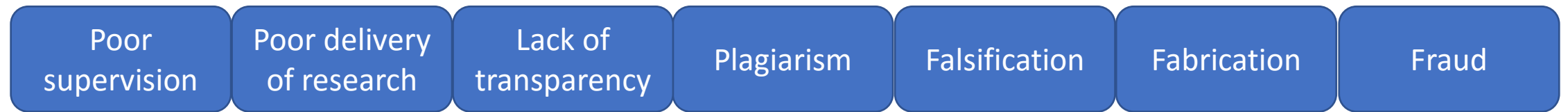
What is Research Integrity?

Sunset on approach to Split International Airport, @matt_westmore

The concordat to support research integrity

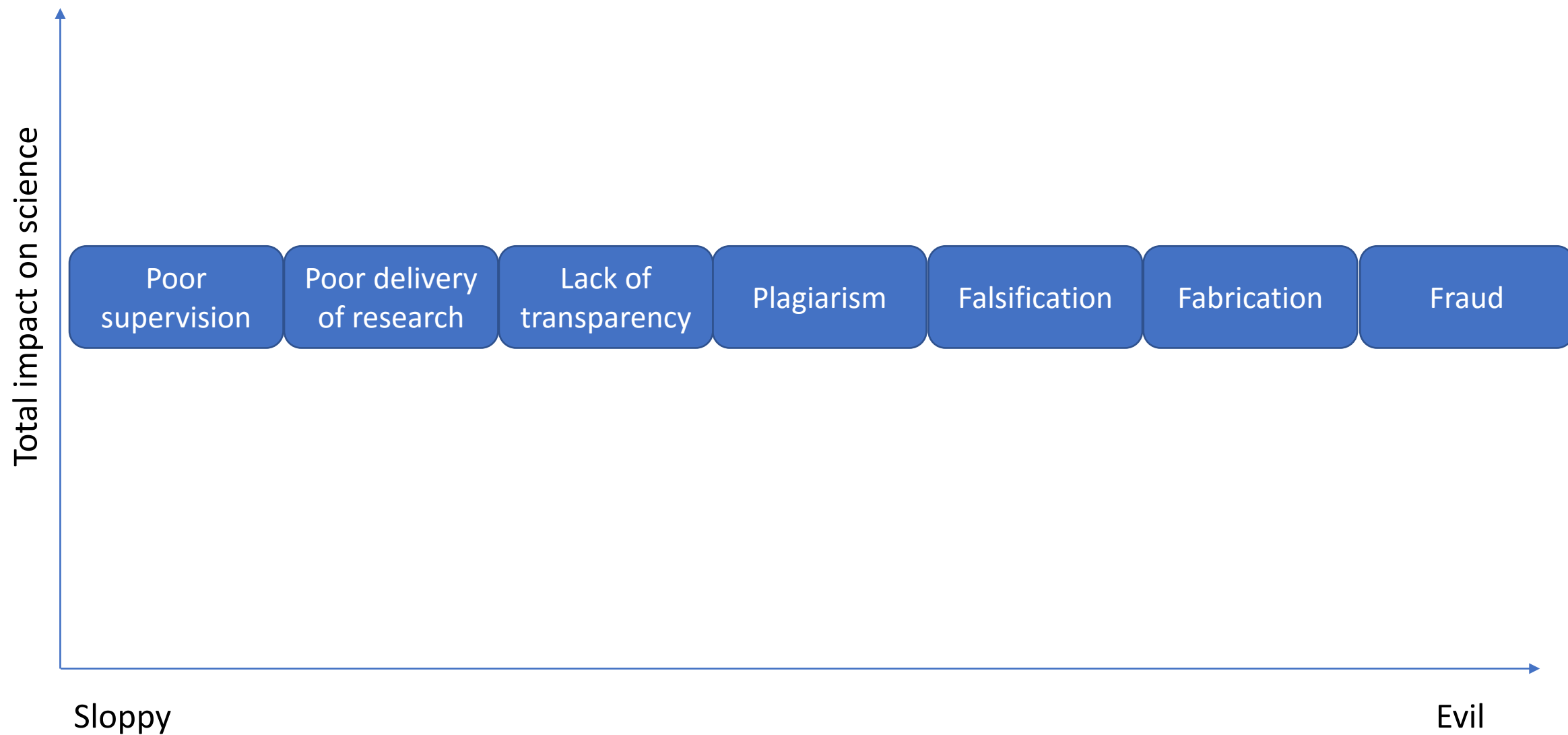


- ...highest standards of rigour and integrity in all aspects of research
- ...research is conducted according to appropriate ethical, legal and professional frameworks, obligations and standards
- supporting a research environment that is underpinned by a culture of integrity and based on good governance, best practice and support for the development of researchers
- using transparent, robust and fair processes to deal with allegations of research misconduct...
- working together to strengthen the integrity of research and to reviewing progress regularly and openly



Mis-behavior
Wasteful practice

Misconduct
Illegal practice



Research misbehaviour

Rank Product of frequency and impact on **TRUTH**

- 1 Insufficiently supervise or mentor junior coworkers
- 2 Insufficiently report study flaws and limitations
- 3 Keep inadequate notes of the research process
- 4 Turn a blind eye to putative breaches of research integrity by others
- 5 Ignore basic principles of quality assurance



What can we do to improve research integrity?

**Relevance and expressed
need**

Ensuring we set justifiable
research priorities.

Excellence

Ensuring robust research
design, analysis and
management

Openness

Ensuring methods and findings
are accessible, complete and
usable

Academic culture

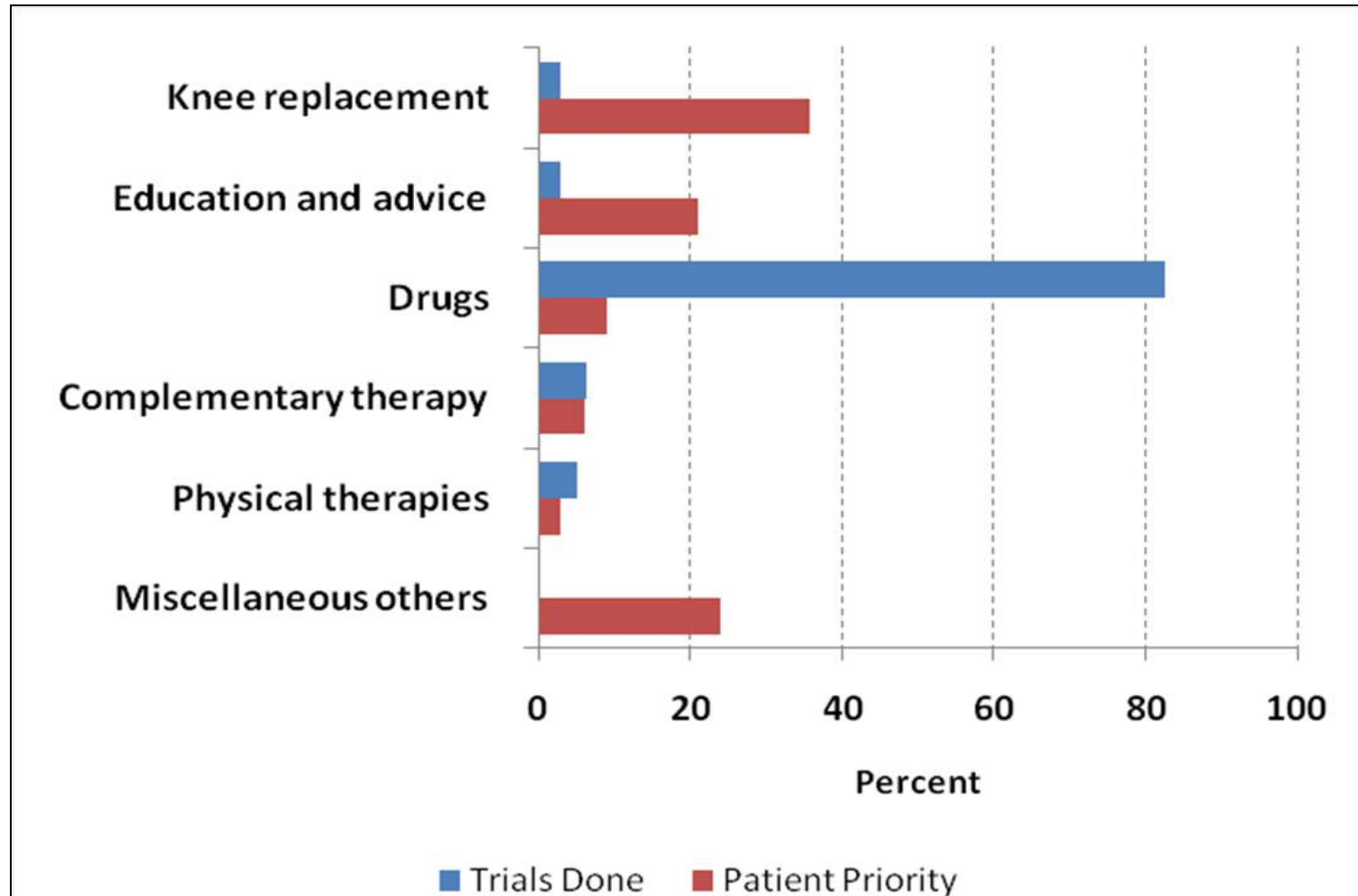
Should you involve patents and the public in every stage?





Questions relevant to users of research

1. Priorities are set involving those who use and are affected by health research
2. New research should be set in the context of a systematic review or rigorously determined evidence gap

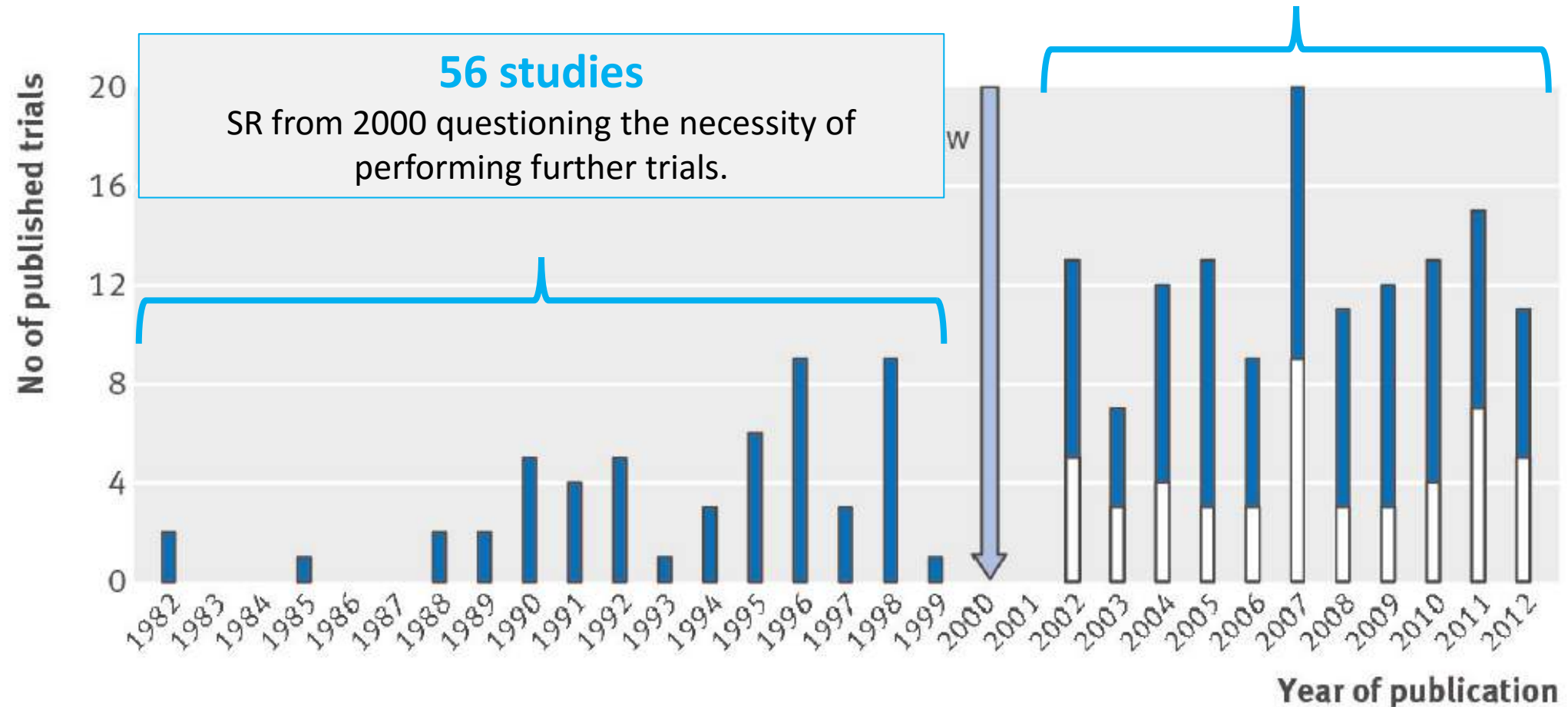


Tallon, D. et al. (2000) 'Relation between agendas of the research community and the research consumer', *The Lancet*, Vol. 355. pp. 2037-40

Habre 2014

Lidocain before propofol

136 NEW studies since 2000
49 clinically relevant
87 REDUNDANT STUDIES





Appropriate research design, conduct and analysis

3. Designed using advances in research methods and taking steps to reduce bias

5. Studies registered at inception



Efficient research regulation and delivery

- 4. Actively manage research in a risk proportionate way
- 6. Protocols, methods and materials should be made available early



**Unbiased, usable and accessible
full research reports**

- 7. Methods, interventions and findings reported in full
- 8. Support replication and reuse of data

What % of clinical trials ever publish?

Table 4 | Sponsors with highest proportion of trials reported

Sponsor	Total trials on EUCTR	Due trials	Due trials with results	% reported
Gilead Sciences	213	31	31	100.0
Chiesi Farmaceutici	94	37	37	100.0
CSL Behring	72	25	25	100.0
Alcon	71	20	20	100.0
Genentech	63	18	18	100.0
Vertex Pharmaceuticals	62	19	19	100.0
Daiichi Sankyo	62	12	12	100.0
Almirall	53	37	37	100.0
Ferring Pharmaceuticals	53	19	19	100.0
Sanofi	573	111	110	99.1

Table 5 | Sponsors with highest proportion of trials unreported

Sponsor	Total trials on EUCTR	Due trials with results	Due trials	% reported
Hospitals of Paris	194	0	7	0.0
Karolinska Institutet	189	0	21	0.0
Radboud University	178	0	3	0.0
Charité-Universitätsmedizin Berlin	177	0	63	0.0
Erasmus University	161	0	3	0.0
University of Amsterdam	153	0	4	0.0
Agostino Gemelli University Polyclinic	142	0	11	0.0
Ghent University	126	0	19	0.0
VU University Medical Centre	126	0	3	0.0
Utrecht University	122	0	6	0.0



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Health Research*

Journals Library

The National Institute for Health Research (NIHR) is the world's first health research funder to publish comprehensive accounts of its funded research within its own publicly and permanently available journals. Through the NIHR Journals Library, you can see the projects being funded as well as the final published journal reports.

Select



Please enter the search term



Advanced



Findings disseminated effectively

9. Findings should be set in the context of previous evidence and systematic reviews.

10. Disseminate knowledge to end users

FALSE HOPES —

Crowdfunding raises millions for quack cancer remedies, like coffee enemas

In the UK, \$10M went to unproven, potentially harmful treatments for desperate patients.

BETH MOLE - 9/20/2018, 1:15 PM



Is cancer fundraising fuelling quackery?, Newman, 2018, BMJ

The role of Research-on-Research



Who will fund RoR?

Funder	Eligibility	Type of funding
Chief Scientist Office	Scotland	Within standard research programmes
Cochrane	Global	Number of routes. For example through the Methods Innovation Fund, and one off projects such as Project Transform
European Union	EU	Within standard research programmes (Horizon 2020)
FORTE	Sweden	Not explicitly out of remit but not asked for either
Graham Boeckh Foundation		Specific project for International Alliance of Mental health Research Funders and RAND Europe
Health Research Board	Ireland	Specific scheme through HRB Trial Methodology Research Network
Laura and John Arnold Foundation	Global	?
Macmillan Cancer	UK	?
Medical Research Council (MRC)	UK	Through Methodology Hubs
National Institute for Health Research (NIHR)	UK	As part of a wider study. E.g. Studies Within A Trial
National Science Centre	Poland	?
NIHR-MRC	UK	Specific scheme: Methodology Research Programme
Patient Centered Outcomes Research Institute (PCORI)	USA	Specific programme. Improving Methods for Conducting Patient-Centered Outcomes Research (PCOR)
Research Council of Norway (RCN)	Norway	Specific programme. Research for research- and innovation policy (FORINNPOL)
Wellcome Trust	UK and LMICS	Specific scheme.
William T Grant Foundation	USA	Specific scheme - Improving the Use of Research Evidence
ZonMW	Netherlands	Specific schemes – Fostering Responsible Research Practices and More Knowledge with Fewer Animals

Link to this sheet: <http://bit.ly/2N9n4sR>

Key questions funders are interested in

How to change academic culture to improve research integrity

How to change incentives to improve research integrity

Impact and effectiveness of patient/public involvement

Effectiveness of different approaches to peer review

Effectiveness of different approaches to setting research priorities

When is enough enough

Effectiveness of different approaches to trial recruitment or retention

Effectiveness of different publishing models to reduce bias

Effectiveness of different approaches to dissemination

How to enable/facilitate research implementation

How to enable/facilitate replication and reuse of data

What/how is routine and/or BIG data useful

How to evaluate the impact of research projects, programmes and researchers

Do the Ensuring Value in Research guiding principles raise the probability of impact/cost?

Take home messages

- Not being evil is not enough
- Yes and Yes but in Orange
- Coffee enema anyone?

