

What do funders do to increase value and reduce waste in research?

Mona Nasser Associate Professor in Evidence Based Dentistry

Project Team: Paul Glasziou, Iain Chalmers, Mike Clarke, Hans Lund, Hanna Nykvist, Kjetil Gundro Brurberg

THE TimesHigherEducation @timeshighered

Funders 'not doing enough' to reduce medical research waste
bit.ly/2n0yLXi



Lars G. Hemkens @LGHemk... · 14h

There is an elephant in the room for improvement

Mona Nasser @monalisa1n

How do funding agencies compare to each other
#researchwaste

Medical research funders, governments and research waste – are taxpayers getting 'bang for their buck'?

By **Mona Nasser** - posted Tuesday, 14 March 2017 Sign Up for free e-mail updates!

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It's estimated that 85% of medical research is wasted.

This is not because it was a bad idea to carry it out in the first place, or that scientists and researchers are profligate with their projects. The waste comes from asking the wrong question, bad design or poor reporting – and in a study carried out with colleagues from around the world, and published online in The Lancet, we found that at the root of this issue were funding bodies not taking responsibility for the efficiency of the research they have used public money to fund, and governments not holding those funding bodies to account.

SIMON DENEGRİ'S LAY REVIEW
The public, health research and democracy


Lancet study puts NIHR top of the intl league table for health research in the public interest inc. public involvement @TheLancet



Ari Friedman @AriBFriedman · 12h

Would love to see this including PCORI, AHRQ, as well as how good they are at funding social sciences.

CERN Accelerating science



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Scientists

Accelerators Experiments Physics Computing Engineering Updates

About CERN

What is the universe made of? How did it start?
Physicists at CERN are seeking answers, using some of
the world's most powerful particle accelerators



National Human Genome
Research Institute


Search Genome.gov

Español

Research Funding Research at NHGRI Health Education Issues Newsroom Careers About

Education

All About The Human Genome Project (HGP)



The Human Genome Project (HGP) was one of the great feats of exploration in history - an inward voyage of discovery rather than an outward exploration of the planet or the cosmos; an international research effort to sequence and map all of the genes - together known as the genome - of members of our species, *Homo sapiens*. Completed in April 2003, the HGP gave us the ability, for the first time, to read nature's complete genetic blueprint for building a human being.

In this section, you will find access to a wealth of information on the history of the HGP, its progress, cast of characters and future.

Any beneficial intervention can have adverse effects

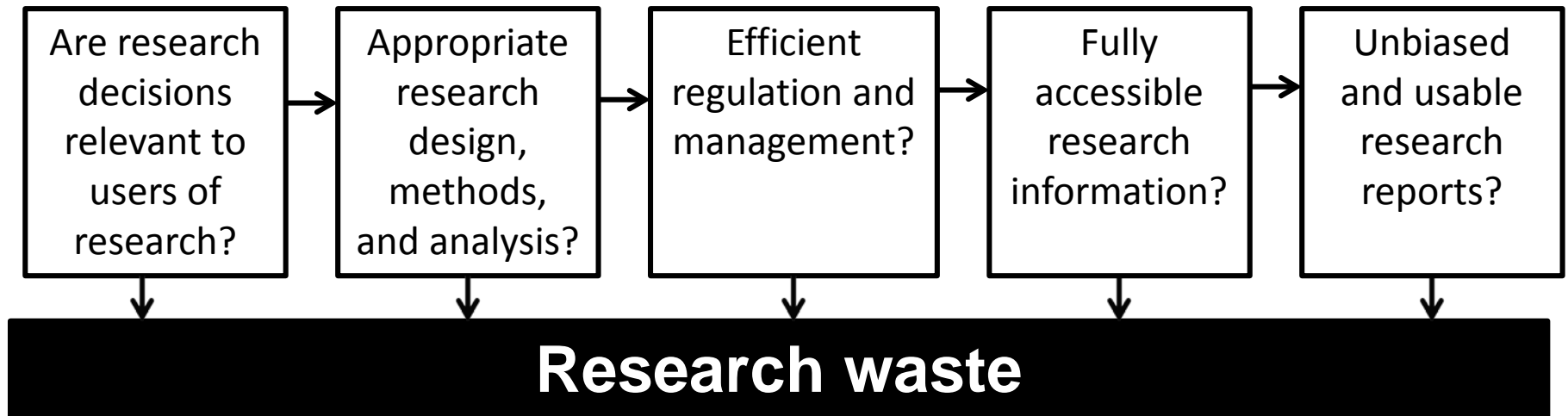
Research policies and regulations that make it easier to conduct research – can have adverse effects

e.g. Publication Bias

REWARD statement (www.researchwaste.net)

... “We believe we have a responsibility not just to seek to advance knowledge, but **also to advance the practice of research itself**. This will contribute to improvement in the health and lives of all peoples, everywhere. “

AVOIDABLE WASTE OR INEFFICIENCY IN BIOMEDICAL RESEARCH

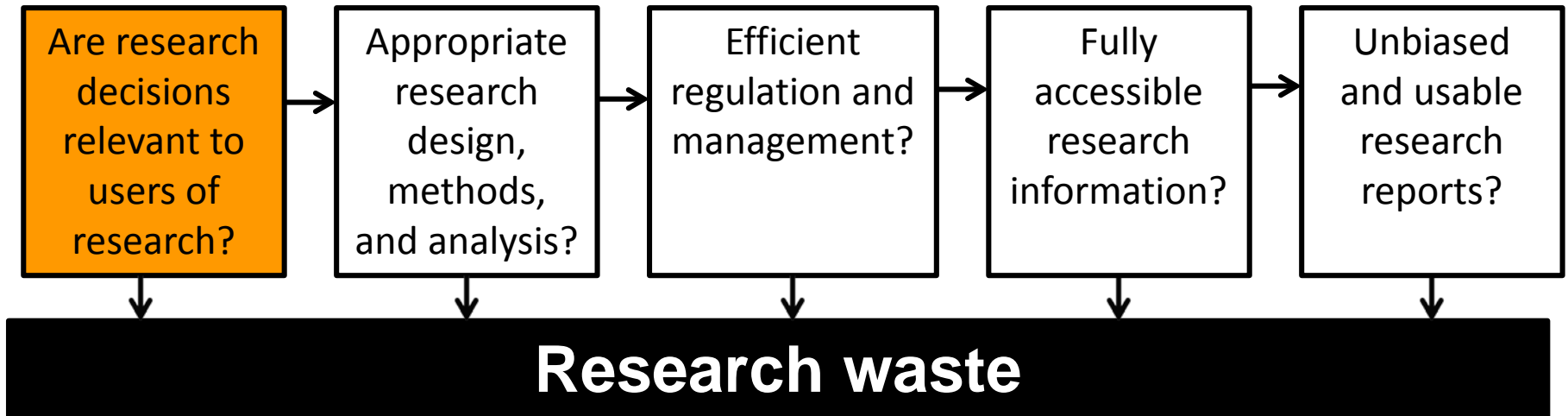


Funding agency	Country
National Institute for Health Research (NIHR)	UK
Medical Research Council	UK
Wellcome Trust	UK
French Ministry of Health	France
l'Agence Nationale de la Recherche	France
Deutsche Forschungsgemeinschaft	Germany
The Netherlands Organisation for Scientific Research	Netherlands
Danske Regionsråd	Denmark
Regional Health Research Councils (Helse)	Norway
National Health and Medical Research Council (NHMRC)	Australia
Canadian Institutes of Health Research (CIHR)	Canada
National Institutes of Health (NIH)	USA
Patient-Centered Outcomes Research Institute (PCORI)	USA

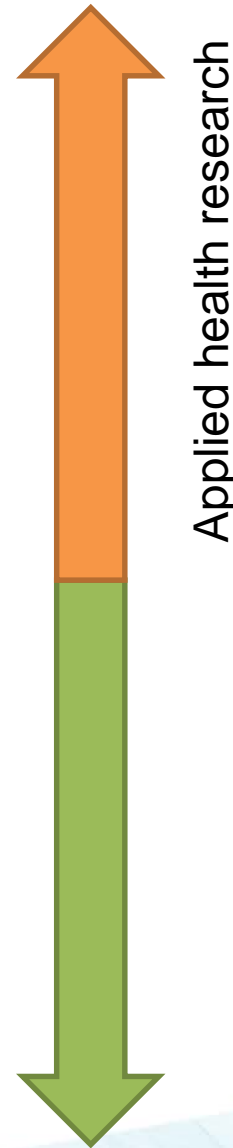
- Browsing websites
- Using Manuals and Handbooks
- Searching websites
- Make-up of committees

Note – the project focuses only on information available on the website. We will later contact funders to assessed whether we have accessed appropriate information and interpreted it appropriately

AVOIDABLE WASTE OR INEFFICIENCY IN BIOMEDICAL RESEARCH



French Ministry of Health (FMoH)
National Institute for Health Research (NIHR)
The Netherlands Organisation for Health Research and Development (ZonMw)
National Health and Medical Research Council (NHMRC)
Regional Health Authorities (RHA)
Canadian Institutes of Health Research (CIHR)
Wellcome Trust (WT)
Medical Research Council (MRC)
National Institute of Health (NIH)
Danske Regioner (DR)
l'Agence Nationale de la Recherche (ANR)
Deutsche Forschungsgemeinschaft Deutsche (DFG)



Basic and clinical research

Beyond health research

How priorities are set? Are patients and public involved?

UK	NIHR
Netherlands	ZonMw
USA	PCORI
UK	MRC
Norway	RHA
Australia	NHMRC
Canada	CIHR
USA	NIH
UK	Wellcome trust
France	FMoH
France	ANR
Germany	DFG
Denmark	DR

Prioritisation process is transparently and patients are partners in the decision making

Some information on the plan for a prioritisation process but not on implementation

Patients involvement is very limited

No patient involvement in the priority setting process

No information on how priorities are set

NHS
**National Institute for
Health Research**



**James
Lind
Alliance**

Priority Setting Partnerships



ZonMw

Participation

In selecting projects to support, ZonMw seeks to involve stakeholders, including the ultimate target group or end users, whose knowledge is based on practical, personal experience. By 'involve' we mean consulting, asking for advice, collaborating, and/or involving end users in project decisions.



**Engagement Rubric
for Applicants**

PCORI engagement principles:

- Reciprocal relationships
- Co-Learning
- Partnerships
- Transparency

It is important that patient partners are not confused with patient subjects; patient partners are members of the research team and involved in the planning, conduct, and dissemination of the research, whereas patient subjects are those individuals actually enrolled into the study as participants.



Separate 'health' and 'social care' **prioritisation panels**. The health panel:
Public members: 6
Universities (Deputy Chairs): 2
Practice/Service Providers: 5
Policy : 5

Aims and objectives

Our vision is for Wales to be internationally recognised for our excellent health and social care research that has a positive impact on the health, wellbeing and prosperity of the people in Wales.

To achieve our vision we will:

- **Ensure public involvement and engagement is central to what we do and visible in all elements of it**
- Ensure our work is aligned to Welsh Government policy and has real impact
- Fully integrate our infrastructure and programmes
- Invest in areas in which Wales excels and is unique
- Increase capacity in health and social care research in Wales
- Develop ways of working that ensure excellent delivery and maximise the use of resources

Public members (usually two) will be sought for **each funding board**. Public members will be recruited via open advert on the Health and Care Research Wales website and through the Involving People team

Involving People Network

The Involving People Network brings together members of the public from across Wales who are interested in working with researchers to improve treatments and care.

Members have a real impact on research carried out in Wales and have a wide range of interest areas from cancer, mental health and diabetes, to ageing and emergency care.

▼ Research Funding Scheme: Social Care Grant

Current Call Status

Call launch: 5 October 2017
Call finish: 20 December 2017

Scheme Remit

The Research Funding Scheme: Social Care Grant aims to support capacity building in social care research by funding high-quality research projects. These projects will provide robust evidence with clear relevance to social care service users, carers, and/or the organisation and delivery of effective social care services.

Engagement with a breadth of social care stakeholders is encouraged throughout the research process. Where appropriate, practitioners and service users should be involved to ensure maximum potential for uptake of research outputs. Close collaborative working between academic and service provider organisations is also encouraged. This can add value and increase impact, through facilitating and shaping the research and working with the project to increase knowledge exchange.

Multidisciplinary research teams and research partnerships with social care practice are strongly encouraged. All applicants should include a dissemination plan that shows clearly how the key messages from the research will be effectively communicated to relevant social care and support policymakers, organisations and/or individuals.

Applicants should also state clearly the likely impact of their findings in the short, medium, and longer term and explain how these will lead to improvements to social care and support and/or service user/carer wellbeing.

▼ Research for Patient and Public Benefit (RfPPB) Wales

Current Call Status

Call launch: 5 October 2017
Call finish: 20 December 2017

Scheme remit

This scheme is intended to support research which is related to the day-to-day practice of health service staff and will have an impact on the health of NHS users.

Funded research projects are likely to fall into the areas of health service research and public health research, although other areas are not excluded from the scheme. For more information please visit our [RfPPB webpage](#).



ELSEVIER

Journal of Clinical Epidemiology 66 (2013) 511–521

**Journal of
Clinical
Epidemiology**

An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews

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Accepted 25 November 2012; Published online 9 March 2013



Robert Kemp @RSKemp01 · 17h



I get the feeling turning all that green would = gr8er benefit 2 pts than all interventions funded currently by same institutions

Mona Nasser @monalisa1n

How do funding agencies compare to each other

#researchwaste

@iainchalmersTTi

@PaulGlasziou @tweethlund

@ebrnetwork @CAPSMG

#lancet

Health Research (CHRR)					
National Institutes of Health (NIH)	USA				
Deutsche Forschungsgemeinschaft (German Research Foundation) (DFG)	Germany				
French Ministry of Health (FoH)	France				
L'Agence Nationale de la Recherche (ANR)	France				
Nederlandse organisatie voor gezondheidsonderzoek en zonnovatie (ZonMw)	Netherlands				
Danske Regioner (DR)	Denmark				
Regional Health Authorities in Norway (RHA)	Norway				

* For details of coding of table elements see Supplementary Table 1.

Framework for Establishing Research Priorities



- Topic generation
 - engagement of multiple stakeholders, especially patients, is critical at this stage
- Systematic review and Gap analysis
- Value of information analysis
- Peer and stakeholder review

Are applicants who seek support for new research required to refer to systematic reviews of existing evidence?

UK	NIHR
USA	PCORI
UK	MRC
UK	WT
Germany	DFG
Netherlands	ZonMw
Canada	CIHR
France	FMoH
France	ANR
Denmark	DR
Norway	RHA
Australia	NHMRC
USA	NIH

Primary research is not funded without a systematic review

Only Clinical trials are not funded without a systematic review

Systematic reviews are encouraged before new research but are not mandatory

Primary research is funded without a systematic review

NIHR definition of a systematic review

- Is completed according to a predetermined methodology
- Methodology is adequately described to allow, in principle, replication by others
- Has well defined and justified inclusion and exclusion criteria
- Minimises bias and random error in a way **proportionate to the risk of an inappropriate funding decision**
- Maximises completeness in a way **proportionate to the risk of an inappropriate funding decision**
- References ongoing studies
- Critically appraises for quality and relevance
- Synthesises [in a credible way and without introduce new bias]

PCORI definition of a systematic review

11: Standards for Systematic Reviews

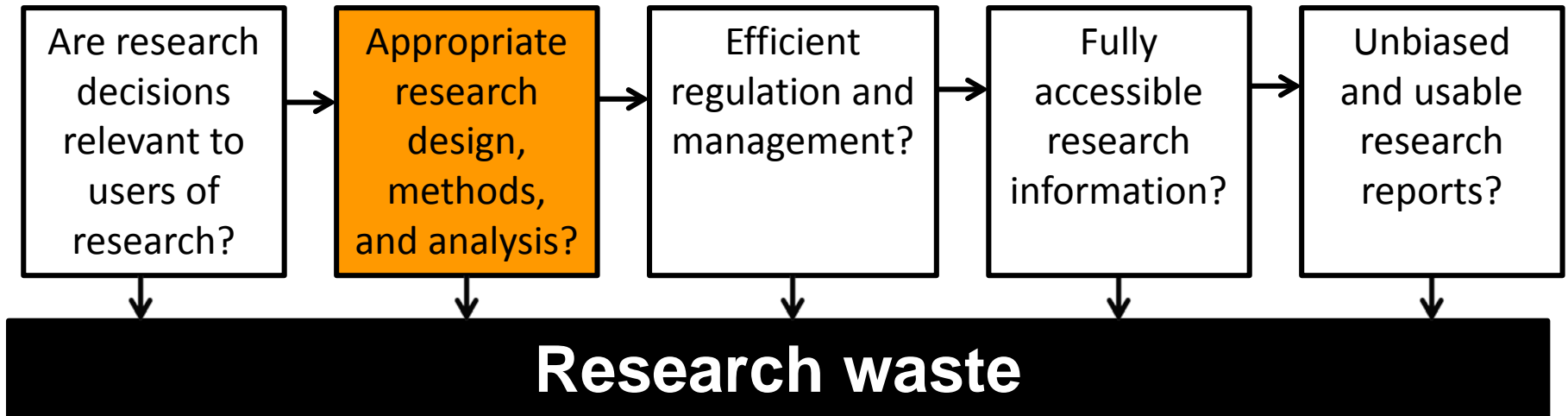
SR-1: Adhere to National Academy of Medicine (NAM) standards for systematic reviews of comparative effectiveness research, as appropriate.

Systematic reviews, which critique and synthesize the existing literature, can also identify evidence gaps and inform decisions of how to address these gaps. Existing standards for systematic reviews developed by credible authorities, such as the Cochrane Collaboration and the Agency for Healthcare Research and Quality, vary somewhat in their recommended standards. The PCORI Methodology Committee endorses the standards issued by the NAM in 2011 but recognizes both the importance of conducting systematic reviews consistent with updates to methodological best practices and that there can be flexibility in the application of some standards without compromising the validity of the review, including the following:

- Searches for studies reported in languages other than English are not routinely recommended but may be appropriate to some topics.
- Dual screening and data abstraction are desirable, but fact-checking may be sufficient. Quality control procedures are more important than dual review per se.
- Independent librarian peer review of the search strategy is not required; internal review by experienced researchers is sufficient.

Researchers should describe and justify any departures from the 2011 NAM standards (e.g., why a particular requirement does not apply to the systematic review).

AVOIDABLE WASTE OR INEFFICIENCY IN BIOMEDICAL RESEARCH



Examples of research support infrastructure

NIHR	UK	NIHR has research design services throughout the country to support researchers
MRC	UK	The MRC support research infrastructure e.g. Hubs for Trials Methodology Research (HTMR) Network.
FMoH	France	The French Ministry of Health supports hospital-based research structures (DRCI) and regional networks (REGSI) to support and train researchers.

Examples of research support infrastructure

CIHR	Canada	CIHR, as part of its strategy for Patient-Oriented Research (SPOR) , supports patient-oriented research and trials (SUPPORT) units .
NHMRC	Australia	NHMRC funds pre-defined networks such as the Population Health Research Network.
NIH	USA	NIH has extensive research infrastructure that supports registries and biomedical information systems.

Research Design and Conduct Service

The aim of the service is to support staff working in social care and NHS in developing research projects for public benefit as well as improving the health and wellbeing of the people of Wales, and is funded by the Welsh Government.

The All Wales Research Design and Conduct Service provides guidance and advice to enable researchers to both assess the potential of an idea and to develop a study or trial idea effectively up to the point of application for funding.

NHS Research & Development offices

Research and development (R&D) is a core function of NHS Wales. There are seven Health Boards and three all-Wales Trusts and all organisations have a R&D team lead by a R&D Director to provide a range of services including:

- Developing and delivering a research strategy for the organisation, in collaboration with university colleagues
- Providing support to researchers through the research pathway, from grant application to dissemination of results
- Ensuring information about research is available to patients and clinicians
- Ensuring staff and other resources are in place so that studies can be delivered
- Ensuring the organisation fulfils its legal, regulatory and financial responsibilities relating to research it hosts or sponsors, and managing risks relating to these responsibilities

NHS R&D offices draw on central services provided by the Health and Social Care Research Wales [Support Centre](#) and [Research Delivery Staff](#). A key aim is to increase the number of studies NHS Wales can offer people in Wales.

[R&D Offices - Contact details](#)



Nicola Low
@nicolamlow



@trished @TheLancet
@monalisa1n @iainchalmersTTi
@PaulGlasziou Are funders funding
research to see if the practices
reduce waste in output?

25/03/2017, 07:08



Sarah Knowles @dr_know · 11h



Very glad "research on research" is
being recognised. Gets dismissed
(avoided?) as 'naval gazing', I think
it's getting our house in order

Mona Nasser @monalisa1n

How do funding agencies
compare to each other

#researchwaste

@iainchalmersTTi

@PaulGlasziou @tweethlund

@ebrnetwork @CAPSMG

#lancet

Does the funder provide targeted funding to undertake “research on research”?

UK	NIHR/MRC
Netherlands	ZonMw
USA	PCORI
France	FMoH
France	ANR
Canada	CIHR
USA	NIH
UK	WT
Germany	DFG
Norway	RHA
Australia	NHMRC
Denmark	DR

Dedicated funding programme for methodological research

Methodological research can be funded but there is no dedicated programme for it

Only support internal staff working on methodological research.

Not funding methodological research

MRC/NIHR	ZonMW	PCORI
Methodology research programme	Responsible Research Practices (FRRP)	Patient-Centered Outcomes Research and Methodological Research
Study of how best to design, conduct, analyse and evaluate medical and health research...	..to encourage quality, integrity, efficiency and positive social impact in scientific and academic research....	Improving methods for the design and conduct of clinical studies...

Does the funder require registration of research?

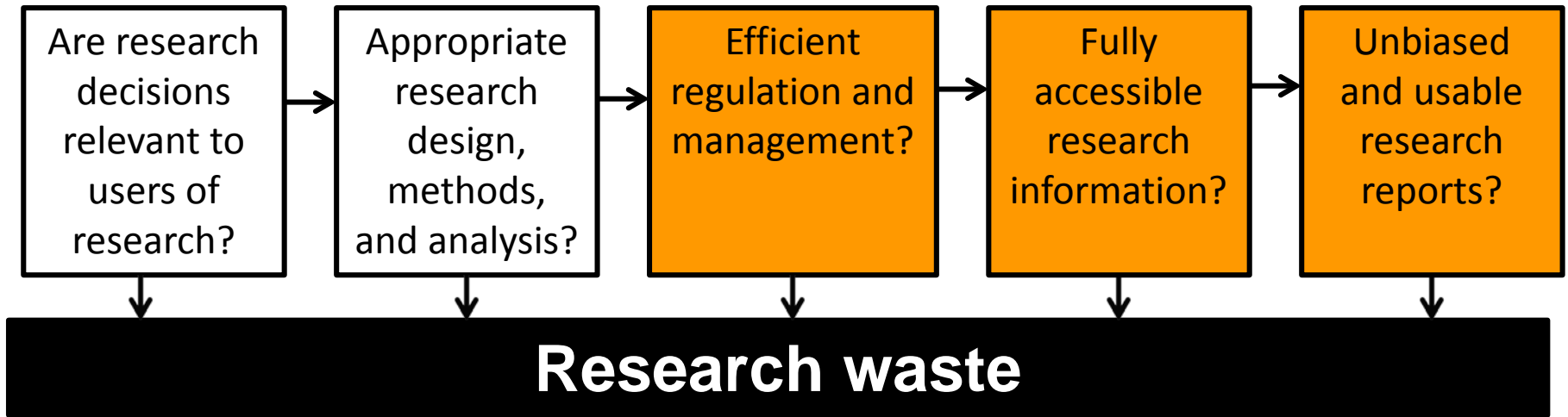
UK	NIHR
Netherlands	ZonMw
USA	PCORI
UK	WT
UK	MRC
France	FMoH
France	ANR
Germany	DFG
Norway	RHA
Australia	NHMRC
Canada	CIHR
USA	NIH
Denmark	DR

All studies have to be registered in an existing registry before they start

Only clinical trials need to be registered in an existing registry before they start

No requirement to register studies before conducting them.

AVOIDABLE WASTE OR INEFFICIENCY IN BIOMEDICAL RESEARCH



We know...

- There are some helpful **practices and policies** that are adding value and reducing research waste in research funding organisations.
- **Limited knowledge** on what policies and practices are leading to the **outcomes** we hope for.

We need to learn more

- Discussion on **constructing and implementing better practices and policies** that add value and reduce research waste in research funding organisations.
- **Need data** to evaluate the performance of these practices and policies in achieving our goals to add value to research and reduce research waste.
- We will **repeat** the survey to monitor progress.

Ensuring Value in Research (EViR) Funders' Collaboration and Development Forum

- Discussions during a meeting at the NIHR's 10-year anniversary in London in **May 2016** led to the proposal of a forum for funders.
- The Forum had its first meeting on **27 January 2017** in London and it was chaired by individuals from three major research funders: NIHR (UK), ZonMW (Netherlands) and Patient-Centered Outcomes Research Institute (PCORI – USA).
- The second meeting was organised in Amsterdam on **1 June 2017** hosted by ZonMW in Hague (Netherlands).
- The third meeting will be in **Nov 2017** in Washington (USA) hosted by PCORI in Washington, USA.
- Health and Care Research Wales is a member of EViR.

