Setting the scene: waarom is onderzoek zo belangrijk?

Saskia N. de Wildt

Pediatric Intensivist

Professor of Clinical Pharmacology

Radboudumc



Usually I am reacting to changing symptoms, but by signing up for a clinical trial I am taking back some control. On the trial I'm on, I don't know if I am getting the placebo or the active drug, but what I am receiving is a lot of monitoring. I'm in much closer contact with the study doctor than I am with my current consultant. That alone is a benefit. There is of course a chance that I am getting the active medicine; the chance that it will slow or halt my disease — a chance I would not have had without signing up for the trial. Ultimately the findings of the trial will help find a treatment in the long run, even if it doesn't help me, and that matters.'

Gareth Weeks

- Patient with primary sclerosing cholangitis

Benefits of research

For patients	For trusts	For staff
> Improved survival rates	> Improved recruitment and retention of staff	Reduced level of burnout / emotional exhaustion
> Improved sense of value through taking part in research	> Meeting CQC inspections	> Better morale and job satisfaction
> Better overall care, as represented in higher CQC ratings	> Cost-effective innovations and savings, and translation of research into practice	> Building transferable skills and developing new networks

From: Benefiting from research, UK Royal College of Physicians,

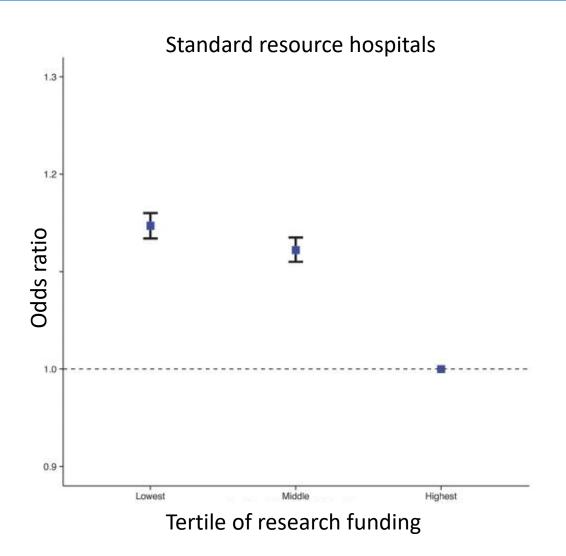
> PLoS One. 2015 Feb 26;10(2):e0118253. doi: 10.1371/journal.pone.0118253. eCollection 2015.

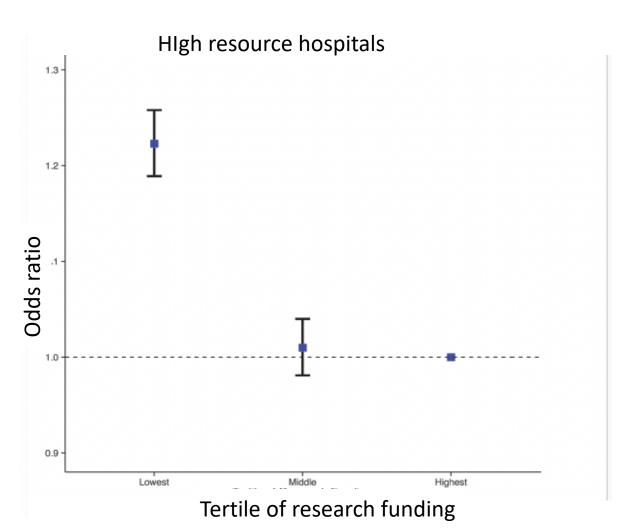
Research activity and the association with mortality

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Baris A Ozdemir <sup>1</sup>, Alan Karthikesalingam <sup>1</sup>, Sidhartha Sinha <sup>1</sup>, Jan D Poloniecki <sup>1</sup>, Robert J Hinchliffe <sup>1</sup>, Matt M Thompson <sup>1</sup>, Jonathan D Gower <sup>2</sup>, Annette Boaz <sup>3</sup>, Peter J E Holt <sup>1</sup>
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- More research funding, more recruited patients associated with reduced risk of mortality
- UK study

More research, lower mortality





Why is outcome better?

- Specific processes of care related to conduct of clinical trials
- Equipment for research available for patient care
- Accumulated knowledge from research
- Development of infrastructure
- More resources for use in clinical care
- Faster implementation and uptake of research results
- Greater collaborations between individuals, teams and organizations

Financial incentives – UK data

Drug costs covered by trials

£4,143–£7,483 per patient

£6,658 per patient in revenue from commercial studies

Additional median value per patient £ 33,089

£2.4 billion of gross value added

- £778 million non-commercial activity
- £1.6 billion commercial activity
- 39,500 jobs in UK



Source: 2019 NIHR Clinical Research Network: Impact and Value Assessment

Research infrastructure of NIHR

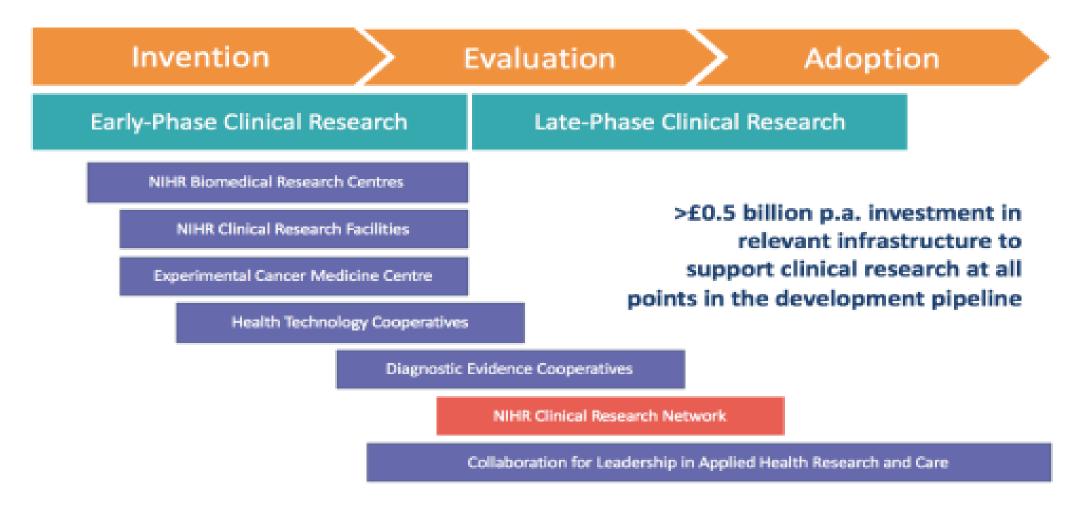
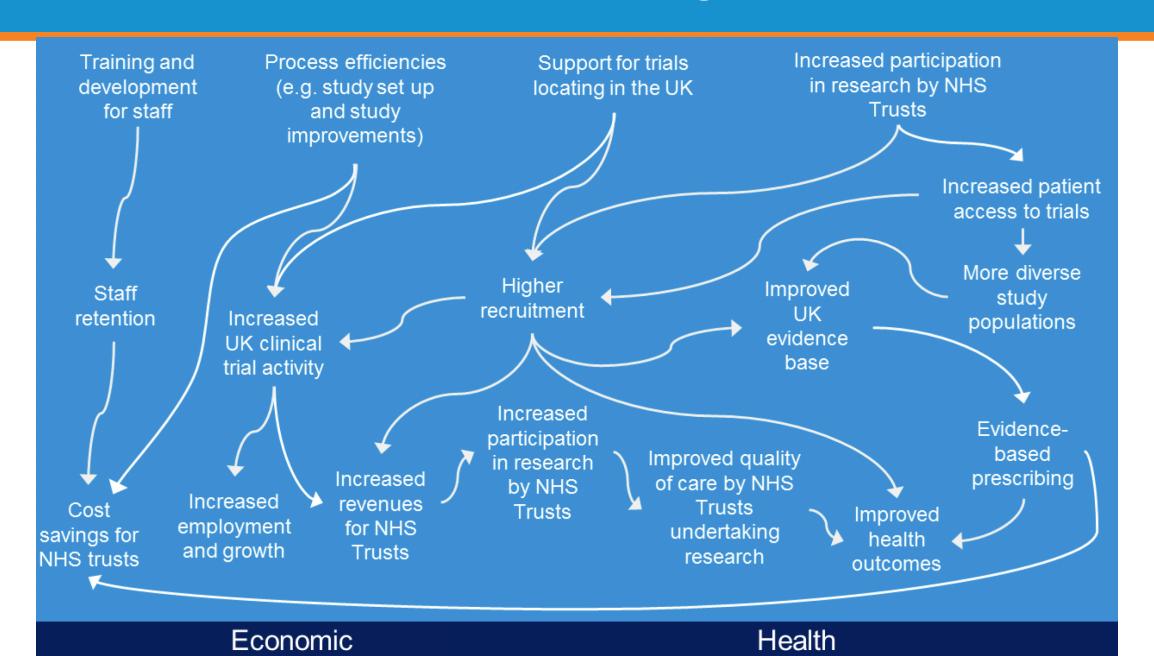


Figure 3: NIHR Funding Stream

eprinted from Evans, P. The NIHR CRN in England and Primary Care Research. June 14, 2019: Montreal,

Added value of CRN according to stakeholders



CRN study support

STUDY FEASIBILITY

STUDY SET-UP

PERFORMANCE MANAGEMENT

COMMERCIAL

- Early feedback on protocol & study design
- Site intelligence and assistance with site identification
- Facilitate expression of interest

- Commercial costing template
- Model agreement for NHS Trusts / sponsor companies & CROs
- Additional site identification support
- Training and support for clinician staff

- Study performance management (ODP database)
- CRN supported infrastructure for local capacity and capability (i.e. staff to assist with research delivery)
- Training and support for clinician staff

• Support with protocol & study design

- Site intelligence and assistance with site identification
- AcoRD

- Additional site identification support
- Training and support for clinician staff

- Study performance management (ODP database)
- CRN supported infrastructure for local capacity and capability (i.e. staff to assist with research delivery)
- Training and support for clinician staff

NON-COMMERCIAL

Platform Onderzoeksnetwerken NL





Obstetrics



Oncology



Pediatrics



Platform Onderzoeksnetwerken 2023

Onderzoeker geïnitieerde studies											
	Site identificatie	Ethische Commissie indiening	Budget support	Contractmanagement	Projectmanagement	Monitoring	Datamanagement	Statistiek	Trial Master File management	Investigator Site File management	Medical writing
WCN	X	X		X	X	X	/	/	X	X	/
Pedmed-NL	X	X	Χ	X	X				/	/	
Zorgevaluatie Nederland	X		X	X	X	X	X	X			
DUTCH ONCOLOGY ESEARCH PLATFORM		X	X		X		X	X	X	X	

Platform Onderzoeksnetwerken 2025

Onderzoeker geïnitieerde studies											
	Site identificatie	Ethische Commissie indiening	Budget support	Contractmanagement	Projectmanagement	Monitoring	Datamanagement	Statistiek	Trial Master File management	Investigator Site File management	Medical writing
WCN	X	X		Χ	X	X	/	/	X	X	/
Pedmed-NL	X	X	X	X					/		

Benefit clear, but we can do better!

- Clinical research benefits:
 - o patients, hospitals, physicians
 - the economy
 - AND thus society
- To increase clinical research activity, research networks provide value
- UK, France and Switzerland: government funded infrastructure
- EU: crucial research infrastructure, ECRIN
- In the Netherlands?

Thank you!

Cardiology



Obstetrics



Trial office

Barbara van Veen

Oncology



Pediatrics



Tessa van der Geest