

Collaboration for  
Leadership in Applied  
Health Research and  
Care South London  
(CLAHRC South  
London)

  
**National Institute for  
Health Research**

# Improving the effectiveness, efficiency and fairness of health care systems through public involvement

Professor Peter Littlejohns

*Academic lead for Education, School of Population Health and Environmental Sciences, King's College London and Deputy Director of the NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) South London.*

Katharina Kieslich – King's College London, Georgina Richardson, Robin Gauld, Barry Smith, Tim Stokes, Emma Tumilty - University of Otago New Zealand; Paul Scuffham –Griffith University Australia; Albert Weale – University College London

# Overview of Presentation

Background to our approach

Research activities and progress so far

What next ?

# Health Service Context in England

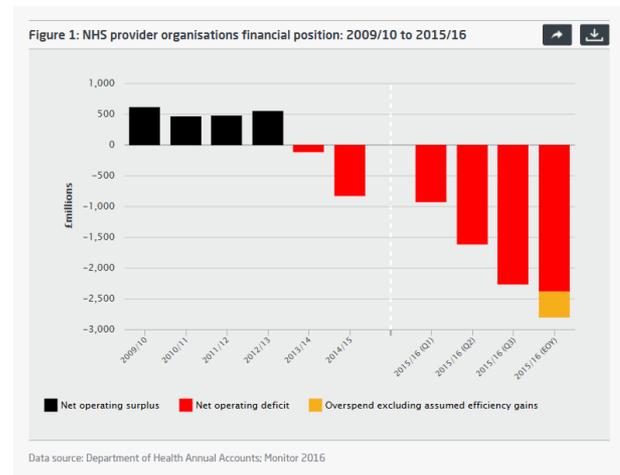
The NHS is facing its greatest financial challenge

Clinical Commissioning Groups, Health and Wellbeing Board, Sustainability and Transformation programmes and Integrated Care Systems will inevitably find themselves having to make difficult decisions on the setting of priorities.

Priority setting requires technical judgements of clinical effectiveness (what works) and cost effectiveness (is it value for money)

But these judgements are embedded in a wider set of social value judgements that underlie justifiable reasoning about priorities, including transparency, participation and justice.

Policy makers will need to explain these difficult decisions to patients, professionals, the public and politicians



The NHS response to a £1.6b boost in Budget

*"The extra money would go only some way towards filling the accepted funding gap ..... but the country could no longer avoid the difficult debate about what the health service could deliver for patients".*

NHS England chairman Sir Malcolm Grant 2017



*"tough choices and trade offs would now need to be made.....It is difficult to see how the NHS can deliver everything,"*

Chris Hopson, chief executive of NHS Providers, which represents health service managers 2017



# Some of the responses to NICE's "no" decisions

## I won't let Daddy die

Girl of six raises £4,000 for life-saving drugs the NHS won't provide

### Hero helps others fight for cancer drug

By Graham Satchell  
BBC Breakfast Reporter

Kate Spall has become an unlikely hero. A 36-year old housewife from Chester, she's become a life-saver to cancer patients around the country.



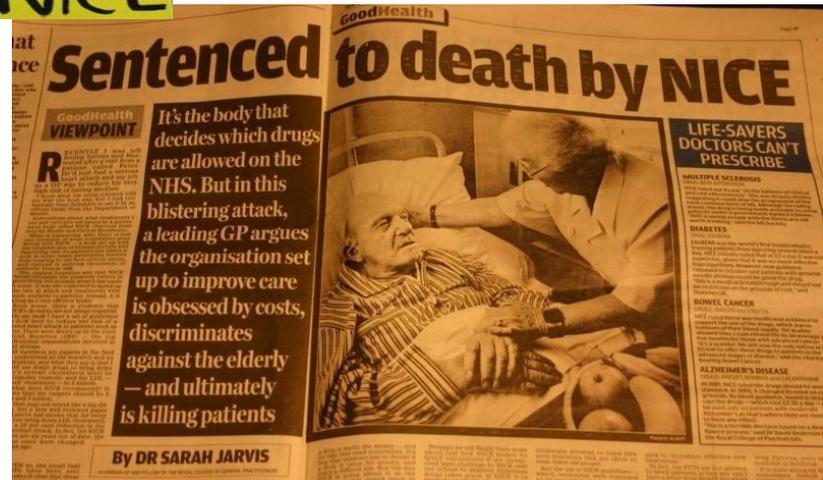
Not a doctor, she has no medical training at all, but she has become successful at convincing NHS decision-makers to fund new cancer drugs for patients who have run out of options on the NHS.



“An American asked why NICE kills people”



Main photograph: Martin Argles



# Tension between individual and public health ethics

## Liver cancer drug 'too expensive'



A drug that can prolong the lives of patients with advanced liver cancer has been rejected for use in the NHS in England, Wales and Northern Ireland.

The National Institute for Health and Clinical Excellence (NICE) said the cost of Nexavar - about £3,000 a month - was "simply too high".

Professor Peter Littlejohns, clinical and public health director at NICE, said they have to assess the cost-effectiveness of care.

Page last updated at 10:00 GMT, Thursday, 19 November 2009

## Concern at liver cancer drug decision



A drug that can prolong the lives of patients with advanced liver cancer has been rejected for use in the NHS in England, Wales and Northern Ireland.

The National Institute for Health and Clinical Excellence (NICE) said the cost of Nexavar - about £3,000 a month - was "simply too high".

But Professor Jonathan Waxman, a cancer specialist at the Hammersmith Hospital in London, disagreed with NICE's decision.

# Procedural Justice

*Provides for 'accountability for reasonableness'. For decision-makers to be 'accountable for their reasonableness,' the processes they use to make their decisions must have four characteristics*

## **Publicity**

Both the decisions made about limits on the allocation of resources, and the grounds for reaching them, must be made public.

## **Relevance**

The grounds for reaching decisions must be ones that fair-minded people would agree are relevant in the particular context.

## **Challenge and revision**

There must be opportunities for challenging decisions that are unreasonable, that are reached through improper procedures, or that exceed the proper powers of the decision-maker. There must be mechanisms for resolving disputes; and transparent systems should be available for revising decisions if more evidence becomes available.

## **Regulation**

There should be either voluntary or public regulation of the decision-making process to ensure that it possesses all three of the above characteristics.



Norman Daniels

*Mary B. Saltonstall Professor of Population Ethics*



# Social as well Scientific Values

## NICE Citizens Council



### Report of the first meeting of the NICE Citizens Council

### Determining “Clinical Need”

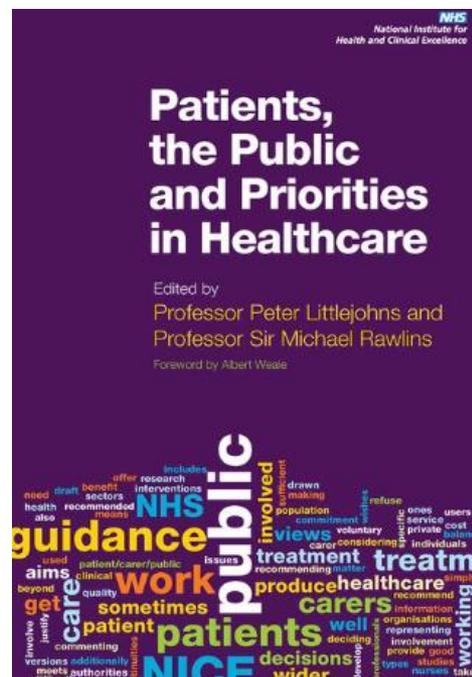
21st-23rd November 2002  
Salford

[Health Econ Policy Law](#). 2013 Apr;8(2):145-65. doi: 10.1017/S1744133112000096. Epub 2012 May 1.

### NICE's social value judgements about equity in health and health care.

Shah KK<sup>1</sup>, Cookson R, Culyer AJ, Littlejohns P.

[+ Author information](#)



# The Gresham College International Workshop 2012

At an international workshop in 2012 a social values framework emerged.

## The process of decision making

*Institutional setting (legal and collaborative)*

*Transparency (clear how decisions are made)*

*Accountability ( who is responsible and to whom)*

*Participation (all who want to be can be involved)*

## The *content* of decision making

*Effectiveness (does it work)*

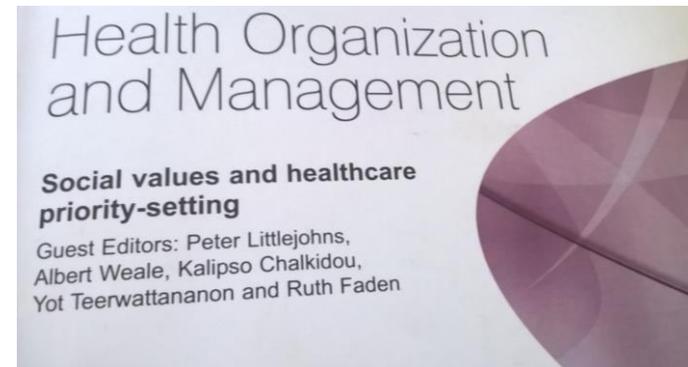
*Cost effectiveness ( value for money)*

*Fairness (to all patients)*

*Quality of care*



Thailand, China, Germany, Switzerland  
France, South Korea, UK, Norway,  
USA, South America



# Brocher Foundation International Workshop 2015

30 delegates from South Korea, UK, NICE International, USA, Norway, Thailand, New Zealand, China, Sri Lanka, Australia, Brazil, China, South Africa, Germany, Switzerland and the World Bank to specifically look at patient and public involvement



**FONDATION  
BROCHER**

# Special Edition

## [Introduction: priority setting, equitable access and public involvement in health care.](#)

Weale A, Kieslich K, **Littlejohns P**, Tugendhaft A, Tumilty E, Weerasuriya K, Whitty JA.  
J Health Organ Manag. 2016 Aug 15;30(5):736-50. doi: 10.1108/JHOM-03-2016-0036.

## [Public participation in decision-making on the coverage of new antivirals for hepatitis C.](#)

Kieslich K, Ahn J, Badano G, Chalkidou K, Cubillos L, Haeugen RC, Henshall C, Krubiner CB, **Littlejohns P**, Lu L, Pearson SD, Rid A, Whitty JA, Wilson J.  
J Health Organ Manag. 2016 Aug 15;30(5):769-85. doi: 10.1108/JHOM-03-2016-0035.

## [Public involvement in health priority setting: future challenges for policy, research and society.](#)

Hunter DJ, Kieslich K, **Littlejohns P**, Staniszewska S, Tumilty E, Weale A, Williams I.  
J Health Organ Manag. 2016 Aug 15;30(5):796-808. doi: 10.1108/JHOM-04-2016-0057.

## [Engaging the public in healthcare decision-making: results from a Citizens' Jury on emergency care services.](#)

Scuffham PA, Moretto N, Krinks R, Burton P, Whitty JA, Wilson A, Fitzgerald G, **Littlejohns P**, Kendall E. Emerg Med J. 2016 Jun 20. pii: emermed-2015-205663. doi: 10.1136/emered-2015-205663.  
[Epub ahead of print]

# Priority Setting for Universal Health Coverage 2016

*The Prince Mahidol Award Foundation (Thailand) the World Health Organization, the World Bank, the Global Fund to Fight AIDS, the China Medical Board, the Rockefeller Foundation, the Bill & Melinda Gates Foundation, Conference 2016 in Bangkok in January*

This 2016 conference focused on priority setting in the context of Universal Health Coverage (UHC) by discussing important issues, such as exploring how to organize priority setting, linking research and UHC policy, and sharing experiences of priority setting mechanisms between countries.

I organized a session on  
“Accountability, fairness and good governance in priority-setting for UHC”

## Research Article

### Accounting for Technical, Ethical, and Political Factors in Priority Setting

Katharina Kieslich<sup>1,\*</sup>, Jesse B. Bump<sup>2</sup>, Ole Frithjof Norheim<sup>3</sup>, Sripen Tantiv and Peter Littlejohns<sup>1</sup>

<sup>1</sup>Faculty of Life Sciences & Medicine, Division of Health and Social Care Research, King's College London, L

<sup>2</sup>Department of Global Health and Population, Harvard T. H. Chan School of Public Health, Boston, MA, USA

<sup>3</sup>Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway

<sup>4</sup>Health Intervention and Technology Assessment Program (HITAP), Department of Health, Ministry of Public Health, Thailand

#### CONTENTS

##### Introduction

##### Technical Approaches to Priority Setting in Health

##### The Ethics of Priority Setting

##### The Politics of Priority Setting

##### Methods

##### Case Study: Screening for HLA-B\*1502 as a Biomarker for

##### Severe Hypersensitivity Induced by Carbamazepine in Thailand

##### Case Study: The Cancer Drugs Fund

##### Concluding Observations

##### References

**Abstract**—This article investigates two cases of explore how, in addition to technical considerations, e factors shape the allocation of health resources. Fir Thai authorities adjudicated a coverage decision screening, which meets the national cost-effective only some of the conditions it can detect. See England's Cancer Drugs Fund to investigate the into decision making and political reality. Our findi concluding observations for policy makers and t priority-setting processes. First, we observe that diff produce conflicting recommendations, which mak very complex. Second, we suggest that robust proce and weighing political, ethical, and technical evid because there is no absolute standard by which r

# How can this framework approach be made useful on a day to day basis ?

The question was how to make a framework accessible to policy makers and others including patients.

As part of an UK National Institute for Health Research (NIHR) funded programme and in collaboration with University College London we have now converted the framework in to a decision support tool

Collaboration for Leadership in Applied Health Research and Care South London (CLAHRC South London)

NHS National Institute for Health Research

Investigating the best way to make tried and tested treatments and services routinely available

About us	Other organisations working to improve health services in south London	Centre for Implementation Science	Involving patients, service users and their families
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Palliative and end of life care	Psychosis	Public health	Stroke
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# Aims and objectives of NIHR Project in UK

(Collaboration for Leadership in Health Research and Care – CLAHRC South London)

Test and refine the DMAT with all stakeholders

Assess the role that values play in decision making in a national sample of NHS health institutions – Clinical Commissioning Groups.

Use the DMAT to assess whether “accountability for reasonableness” leads to more acceptable decisions

Downloaded from <http://bmjopen.bmj.com/> on September 28, 2015 - Published by group.bmj.com

Open Access

Protocol

## BMJ Open Does accountability for reasonableness work? A protocol for a mixed methods study using an audit tool to evaluate the decision-making of clinical commissioning groups in England

Katharina Kieslich, Peter Littlejohns

**To cite:** Kieslich K, Littlejohns P. Does accountability for reasonableness work? A protocol for a mixed methods study using an audit tool to evaluate the decision-making of clinical commissioning groups in England. *BMJ Open* 2015;5:e007908. doi:10.1136/bmjopen-2015-007908

► Prepublication history for this paper is available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2015-007908>).

Received 9 February 2015  
Revised 28 April 2015  
Accepted 20 May 2015

### ABSTRACT

**Introduction:** Clinical commissioning groups (CCGs) in England are tasked with making difficult decisions on which healthcare services to provide against the background of limited budgets. The question is how to ensure that these decisions are fair and legitimate. Accounts of what constitutes fair and legitimate priority setting in healthcare include Daniels' and Sabin's accountability for reasonableness (A4R) and Clark's and Weale's framework for the identification of social values. This study combines these accounts and asks whether the decisions of those CCGs that adhere to elements of such accounts are perceived as fairer and more legitimate by key stakeholders. The study addresses the empirical gap arising from a lack of research on whether frameworks such as A4R hold what they promise. It aims to understand the criteria that feature in CCG decision-making. Finally, it examines the usefulness of a decision-making audit tool (DMAT) in identifying the process and content criteria that CCGs apply when making decisions.

### Strengths and limitations of this study

- Study designed to test the effectiveness of dominant frameworks for healthcare priority setting.
- Study designed to examine healthcare priority setting processes at a local (clinical commissioning group, CCG) level.
- Study designed to test the usefulness of a decision-making audit tool (DMAT) in evaluating decision-making processes.
- Study designed to identify current strengths and weaknesses of commissioning processes at a local level.
- Results will make an empirical contribution to the literatures on accountability for reasonableness (A4R), healthcare priority setting and organisational theory.

### INTRODUCTION

Background and objectives of the study

# The Decision making Audit Tool (DMAT)

The new online version of the DMAT [priorities4health.com](http://priorities4health.com) developed in conjunction with “Uscreates”

It was launched at the London CLAHRC Research information meeting at the House of Lords in July 2017.

The DMAT has been tested in England (see other talk) New Zealand and Chile – plans for further testing in Australia, Sierre Leone, Thailand and Brazil



<https://www.uscreates.com/>



Some of the members of the three London CLAHRCs who attended

More than 100 policymakers, clinicians, researchers, representatives from charities, and patients and service users gathered on Tuesday morning this week at the House of Lords to celebrate the important applied health research being undertaken across London.

# Decision Making Audit Tool

## Welcome to this prototype Decision-Making Audit Tool (DMAT) for priorities in health.

The aim of DMAT is to help patients and interested members of the public work alongside decision-makers who make decisions about what health care services to fund (or stop funding) in their respective health systems. It is also designed to demonstrate to the wider public how these decisions have been made. This is particularly important when budgets are tight, and so funders have to prioritise funding some services or treatments over others. The current version of DMAT has been designed for the UK context, but further work is being undertaken to adapt it to other country contexts. We welcome [feedback](#) on your experience of using DMAT.

How to use

Background

Get started

[priorities4health.com](http://priorities4health.com)

# 8 domains

To complete the tool and generate a report, you must provide a response to the questions in all eight domains. However, if you are unable to answer a question, you can click the 'Don't know' option.

**1**

**Institutional setting**

**2**

**Transparency**

**3**

**Accountability**

**4**

**Participation and consultation**

**5**

**Clinical effectiveness**

**6**

**Cost effectiveness**

**7**

**Quality of care**

**8**

**Fairness**

# An example of a content domain

1

## 6. Cost effectiveness

2

3

Cost effectiveness examines the costs of a service or treatment in relation to its benefits in order to assess whether the costs of funding a service can be justified in light of the expected benefits. Cost effective judgements centred on 'value for money' can be controversial. For some, it means that there is a risk that financial considerations could be put before patients' needs. For others, it means that the needs of all patients, rather than a few, are considered and the best possible care for the largest number of patients is secured. Even when sound health economics methods are used to assess cost effectiveness, a decision has to be made on how much benefit is 'enough' benefit to justify costs. Ask the following three questions to help make your decision or judge how well the organisation is doing. There are links between the questions: read them all before answering each one.

4

5

6

7

8



6.1 Does the organisation have a system in place to collect and evaluate evidence in order to ensure that what is commissioned is cost effective?



Never



Sometimes

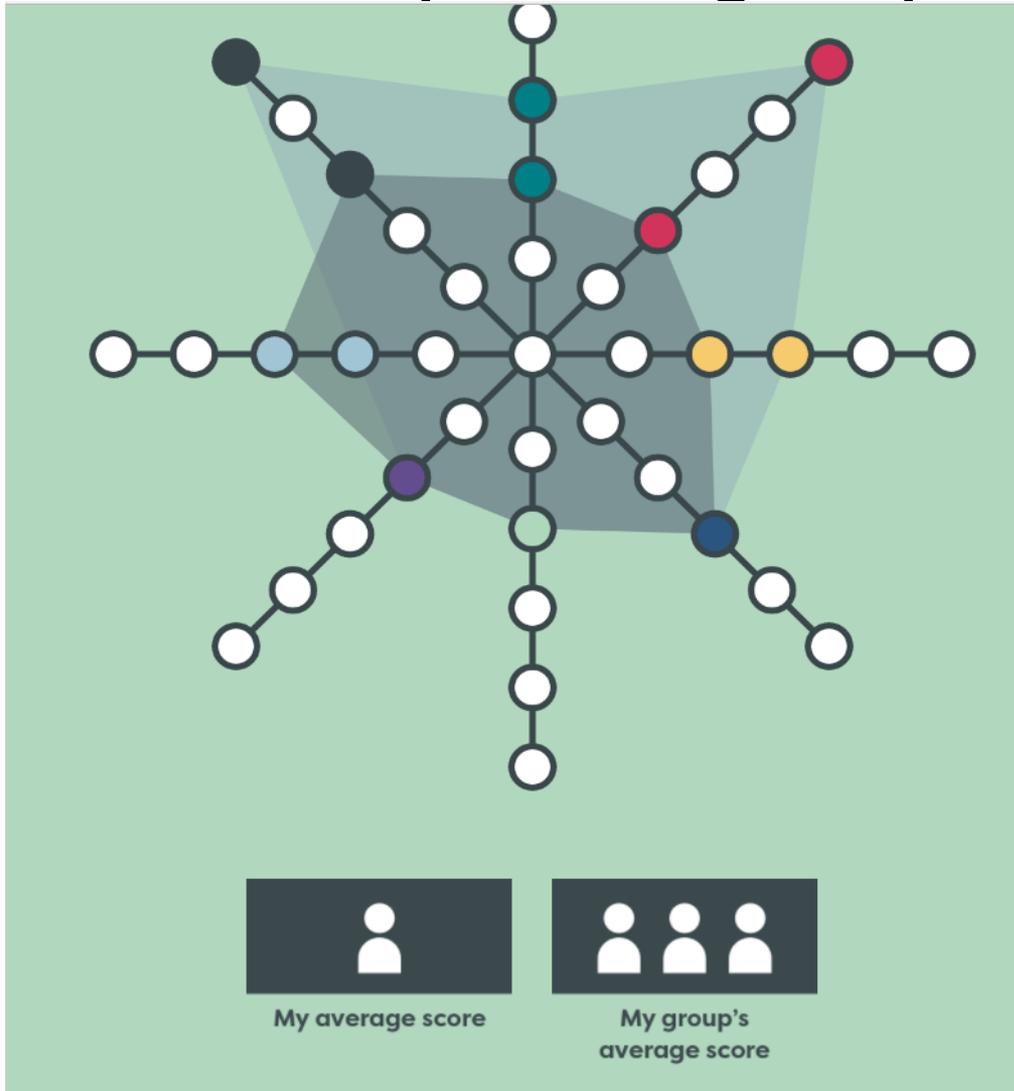


Always



Don't know

# An example of group work



# THE NEW ZEALAND PROJECT

The aim was to conduct a research project examining how health agencies in Aotearoa New Zealand make important decisions about resource-allocation and priority setting.

- To assess the fairness of decision-making in a selection of health agencies in Aotearoa New Zealand against an internationally developed assessment/audit tool
- To examine health agencies' perceptions of the tool and the fairness of their decision making, including how well they incorporate patient/public involvement
- To consult with various community groups and advocacy groups to find out what they think about evaluating the fairness of health agency decision-making, whether knowing decision making was conducted fairly influences the acceptance of decisions, and in what ways they would like to be included in decision-making where relevant to their social group.



# THE NEW ZEALAND PROJECT

## preliminary results

DMAT tool is useful and would only require minor adaptation to be used in NZ regarding Treaty, but it would be our recommendation that it operates as an internal rather than external tool.

PHARMAC scored by far the best on the tool sharing their technical reports, clear on accountability, clear on processes when evidence was unclear, etc. What let them down is no explanation as to how the factors of consideration are actually weighted, and at the time, their consultation methods were pretty passive, but these have been ramping up in the last year. Their consumer advisory committee felt that it was a uK-centric tool and needed adaptation.

MoH and DHBs, public information available did not provide enough clarity or detail to score these organizations well using the DMAT and information provided would indicate that practices for resource allocation decision-making are varied across DHBs, with them feeling the MoH makes these decision in the budget (not recognizing their remits).

Interviewees did not feel that more public engagement would help public perceptions as they felt these were driven by media stories about individuals missing out and that was hard to argue against.



**New Zealand Lotto Results**

Welcome to the all-new Lotto Results site. The new Lotto Results site gives you quick and easy access to the results of the New Zealand Lotto, Keno, Bullseye and Play 3 lottery games.

**New Zealand LOTTO**

Lotto Results For Wednesday 05/09/2018

4 12 13 30 33 35 | 37

New Zealand POWERBALL 6 New Zealand STRIKE! 35 4 12 30

[Draw Details](#) [More Results](#)

# The Lottery of Devolved Cancer Care

To contextualise the need for such a tool the film “**The lottery of Devolved Cancer Care**” was launched at the same time <https://youtu.be/gHNYAc6njTA> it uses variation in access to expensive cancer drugs in the home countries as a relevant case study for a UK setting. It is based on the circumstances that led Irfon Williams moving from Wales to England to get his treatment.

40 minutes version with more patient experience <https://youtu.be/dHv22BLFDSk>

The Lottery of Devolved Cancer Care

KING'S College LONDON

Presented by  
Peter Littlejohns  
For King's College London

Supported by  
NIHR  
National Institute for  
Health Research

Collaboration for  
Leadership in Applied  
Health Research and  
Care South London  
(CLAHRC South London)

Subjects

- Irfon Williams
- Professor Peter Clark
- Sir Andrew Dillon
- Dr. Annette Rid
- Vaughan Gething
- Andrew Blakeman
- Ali Carter
- Keith Cass MBE  
Keith Cass MBE
- Dr. Catherine Calderwood
- Dr. Katharina Kieslich

Peter Littlejohns is supported by the National Institute for Health Research.

LONDON

The image shows a title card for the film 'The Lottery of Devolved Cancer Care'. It features the King's College London logo in the top right. The title is centered at the top. Below the title, it says 'Presented by Peter Littlejohns For King's College London'. There are two logos for funding: 'Supported by NIHR National Institute for Health Research' and 'Collaboration for Leadership in Applied Health Research and Care South London (CLAHRC South London)'. A list of subjects is on the right, including Irfon Williams, Professor Peter Clark, Sir Andrew Dillon, Dr. Annette Rid, Vaughan Gething, Andrew Blakeman, Ali Carter, Keith Cass MBE (listed twice), Dr. Catherine Calderwood, and Dr. Katharina Kieslich. On the left, there are two small video thumbnails: one of a woman speaking and one of a man (Irfon Williams) speaking. At the bottom left, there is a small text credit: 'Peter Littlejohns is supported by the National Institute for Health Research.' and the word 'LONDON' is visible in the bottom right corner of the thumbnails area.

# Rockefeller Academic Residency 2018



<https://www.people4health.com/>

**Description of the Research Programme**

**How the Decision making Audit tool (DMAT) was developed**

**Worldwide Case Studies**

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Health Prioritisation Films



The role of the CLAHRC and the UK Study



How can you as a member of the public get involved

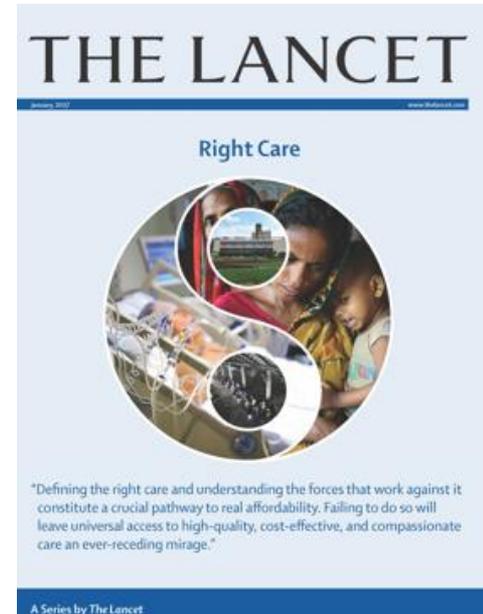
# What Next ?

More research into -

The role of the public in prioritisation with  
in Universal Health Coverage  
programmes

Accepting difficult decisions

Understanding “appropriate care”



VIEWPOINT | VOLUME 390, ISSUE 10095, P712-714, AUGUST 12, 2017

Universal health coverage, priority setting, and the human right to health

[Dr Benedict Rumbold, PhD](#)   • [Prof Rachel Baker, PhD](#) • [Octavio Ferraz, PhD](#) • [Prof Sarah Hawkes, PhD](#) •

[Carleigh Krubiner, PhD](#) • [Prof Peter Littlejohns, MD](#) • [Prof Ole F Norheim, PhD](#) • [Thomas Pegram, PhD](#) • [Annette Rid, MD](#) •

[Sridhar Venkatapuram, PhD](#) • [Alex Voorhoeve, PhD](#) • [Daniel Wang, PhD](#) • [Prof Albert Weale, PhD](#) • [James Wilson, PhD](#) •

[Alicia Ely Yamin, MPH](#) • [Prof Paul Hunt, MJUR](#)

Thank you for listening

**Professor Peter Littlejohns**

Faculty of Life Sciences and Medicine, King's College London

# THANK YOU TO OUR FUNDER

**Collaboration for  
Leadership in Applied  
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*National Institute for  
Health Research*

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<http://www.clahrc-southlondon.nihr.ac.uk/>

<http://www.priorities4health.com/>