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

NHS 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

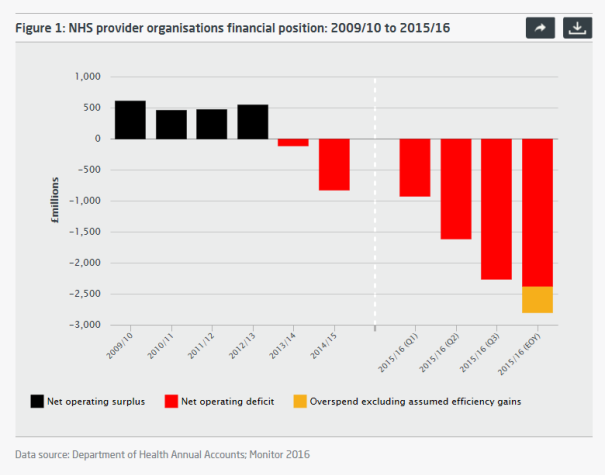
The NHS is facing its greatest financial challenge

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.

Life-extending cancer drugs wait for NHS approval

s not a doctor, she has dical training at all, but become successful at ing new cancer drugs for its th e on the NHS.

"An American asked why NICE kills people"

Main photograph: Martin Argles

GoodHealth

Sentenced to death by NICE

GoodHealth VIEWPOINT

It's the body that decides which drugs are allowed on the NHS. But in this blistering attack, a leading GP argues the organisation set up to improve care is obsessed by costs, discriminates against the elderly — and ultimately is killing patients

By DR SARAH JARVIS

LIFE-SAVERS DOCTORS CAN'T PRESCRIBE

MULTIPLE SCLEROSIS

DIABETES

CHLAMYDIA

BOWEL CANCER

ALZHEIMER'S DISEASE

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

HARVARD
School of Public Health

Social as well Scientific Values

NICE Citizens Council

Report of the first meeting of the NICE Citizens Council

Determining "Clinical Need"

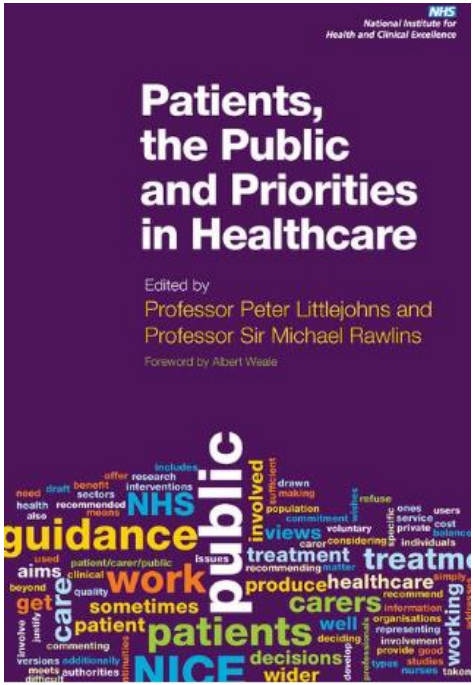
21st-23rd November 2002
Salford

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[1], 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.

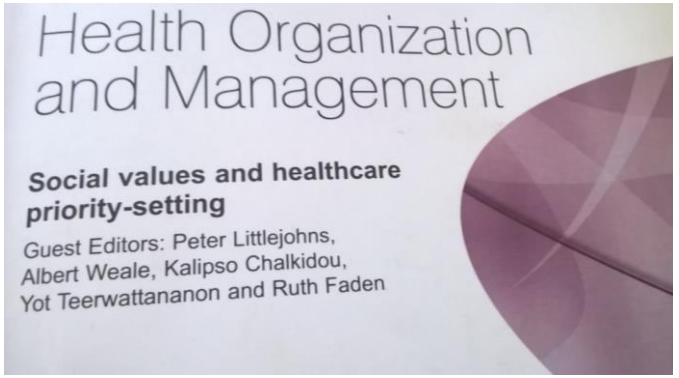
The process of decision making

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, Hauegen 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.

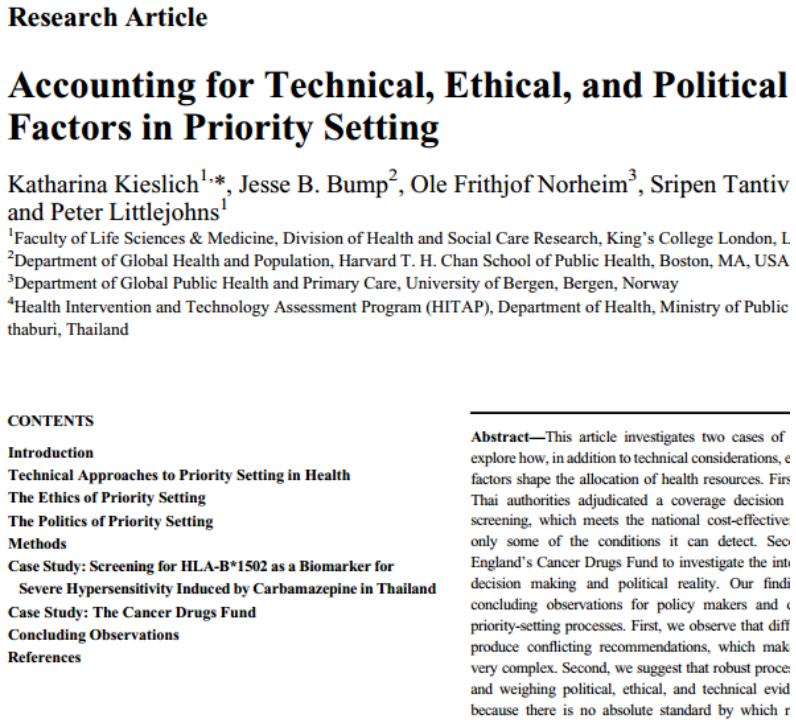
Scuffham PA, Moretto N, Krinks R, Burton P, Whitty JA, Wilson A, Fitzgerald G, **Littlejohns P**, Kendall E. Emerg Med J. 2016 Jun 20. pii: emermed-2015-205663. doi: 10.1136/emermed-2015-205663. [Epub ahead of print]

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 n 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[1,*], Jesse B. Bump[2], Ole Frithjof Norheim[3], Sripen Tantiv and Peter Littlejohns[1]

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[2]Department of Global Health and Population, Harvard T. H. Chan School of Public Health, Boston, MA, USA
[3]Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway
[4]Health Intervention and Technology Assessment Program (HITAP), Department of Health, Ministry of Public thaburi, Thailand

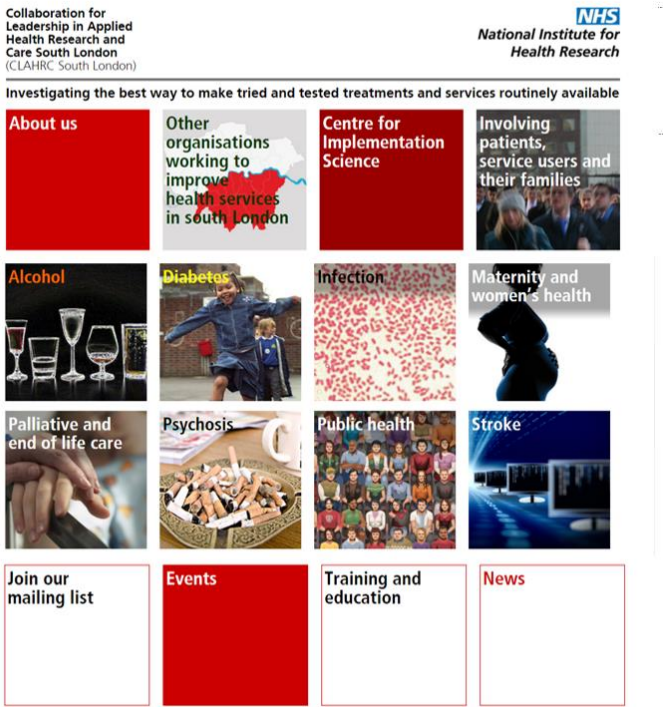
CONTENTS

Abstract—This article investigates two cases of explore how, in addition to technical considerations, e factors shape the allocation of health resources. Firs Thai authorities adjudicated a coverage decision screening, which meets the national cost-effective only some of the conditions it can detect. Sec England’s Cancer Drugs Fund to investigate the int decision making and political reality. Our findi concluding observations for policy makers and 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



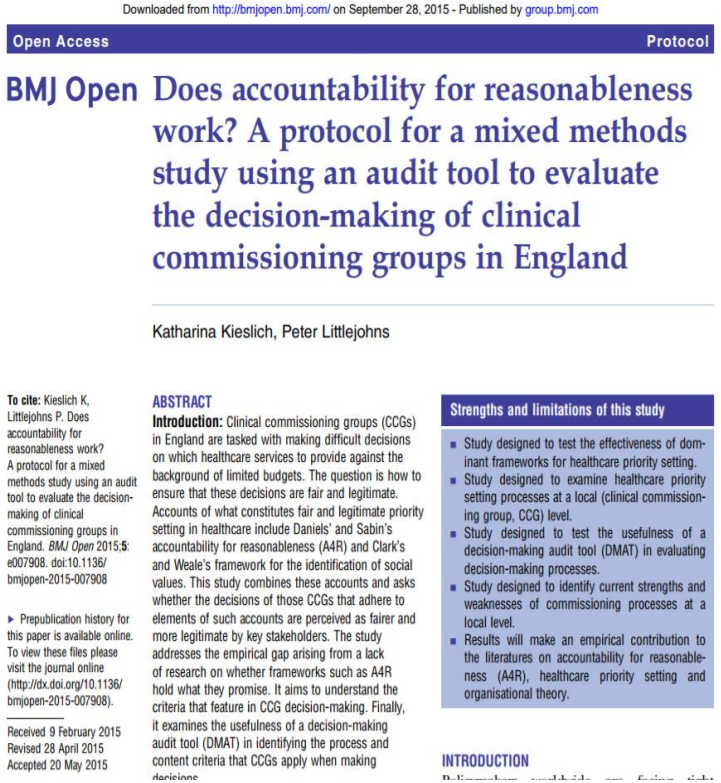
Aims and objectives of NIHR Project in UK

(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



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).

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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

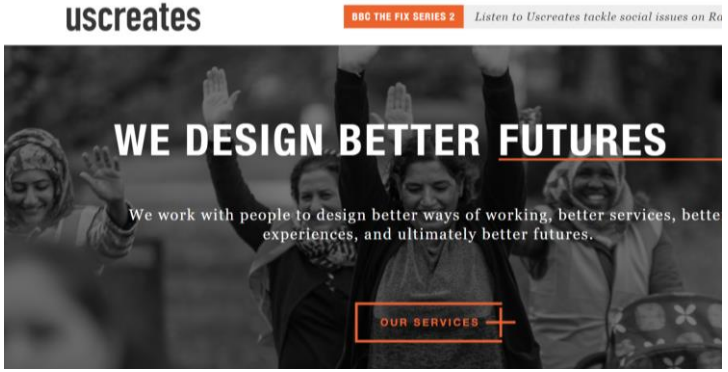
Strengths and limitations of this study

- 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

The Decision making Audit Tool (DMAT)

The new online version of the DMAT priorities4health.com developed in conjunction with "Uscreates"



https://www.uscreates.com/

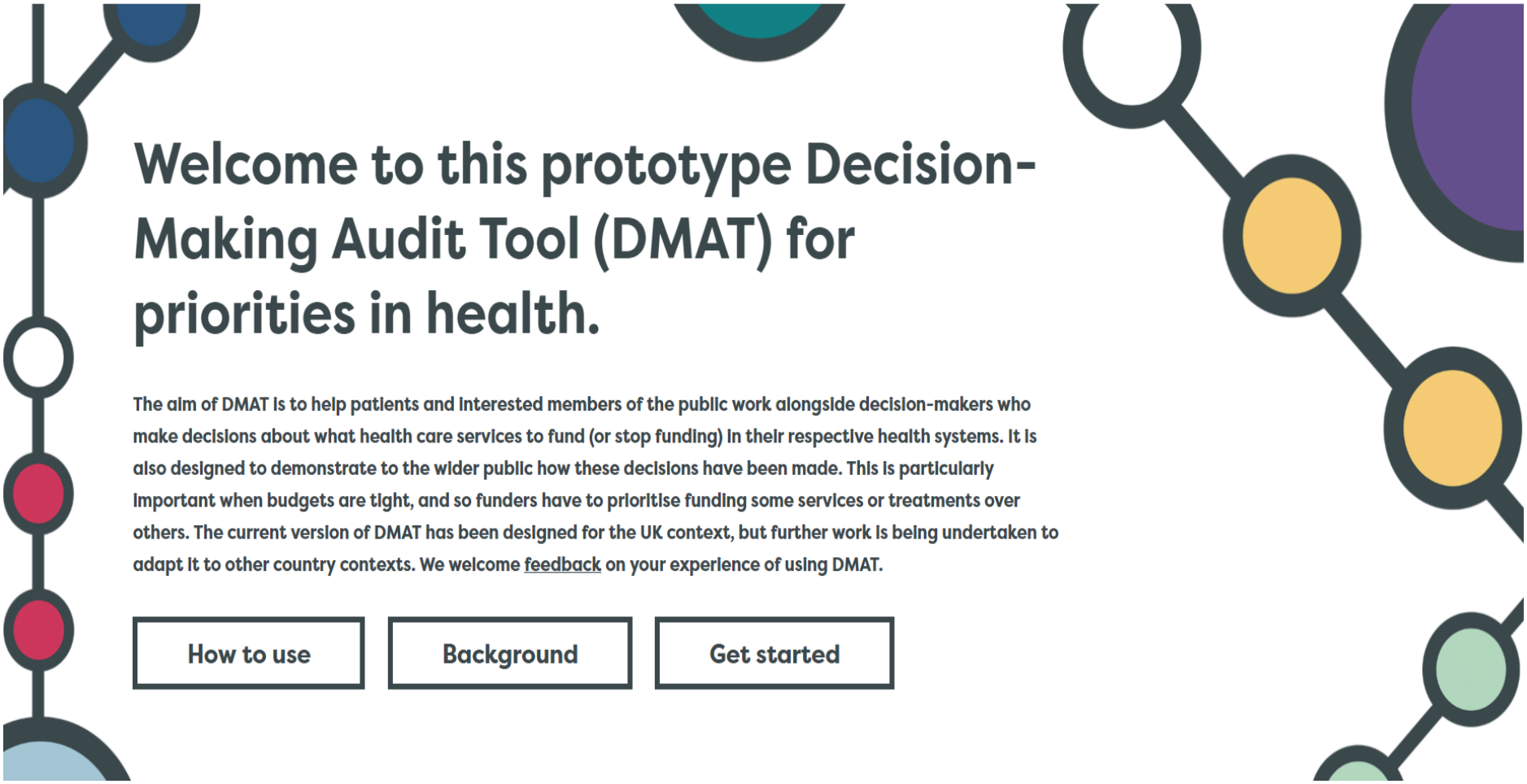
It was launched at the London CLAHRC Research information meeting at the House of Lords in July 2017.

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

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



priorities4health.com

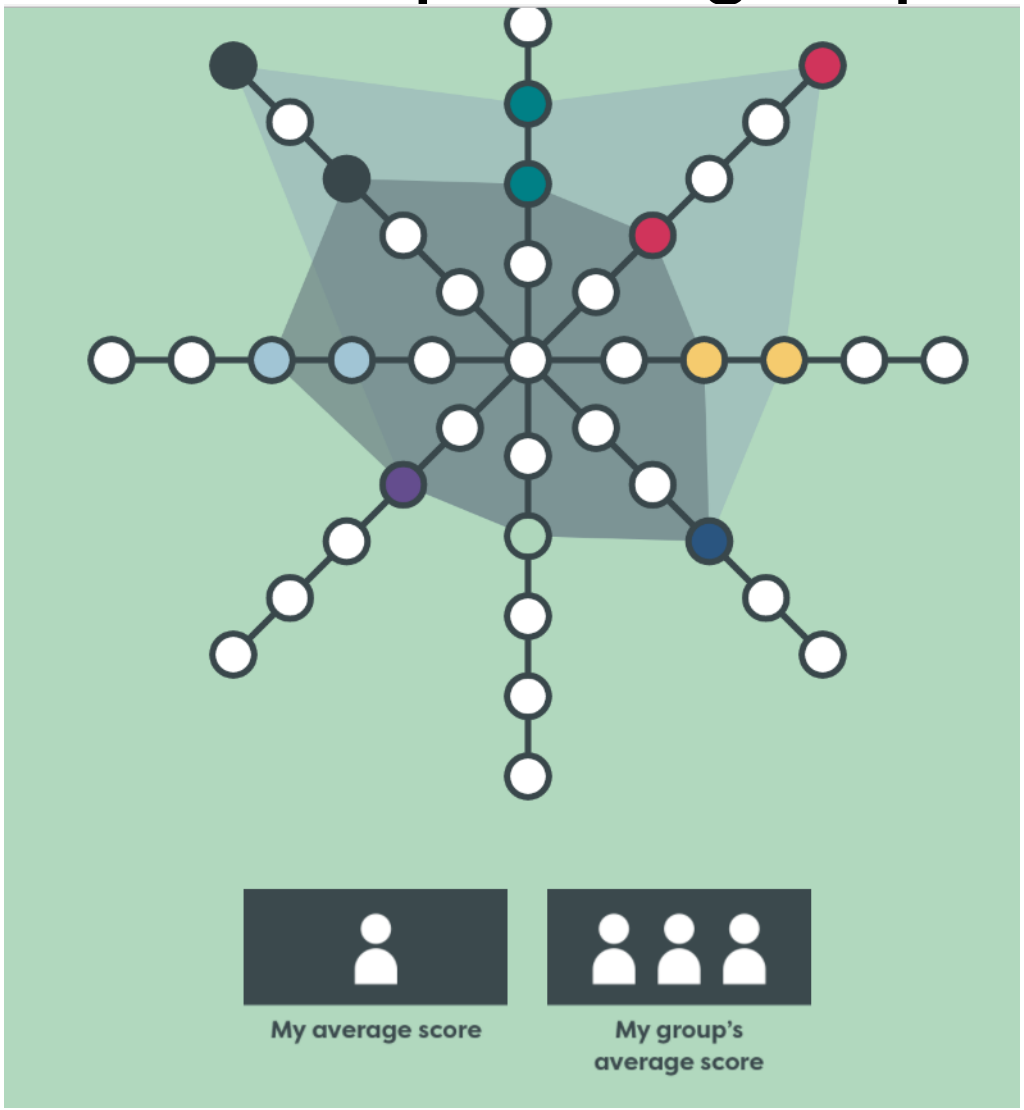
8 domains

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

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 proceses 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.

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 Ifron Williams moving from Wales to England to get his treatment.

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

Rockefeller Academic Residency 2018

https://www.people4health.com/

What Next ?

More research into -

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

Accepting difficult decisions

Understanding “appropriate care”

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 Health Research and Care South London
(CLAHRC South London)

NHS
National Institute for Health Research

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http://www.clahrc-southlondon.nihr.ac.uk/
http://www.priorities4health.com/