

# SOCIAL VALUES IN HEALTH PRIORITY SETTING



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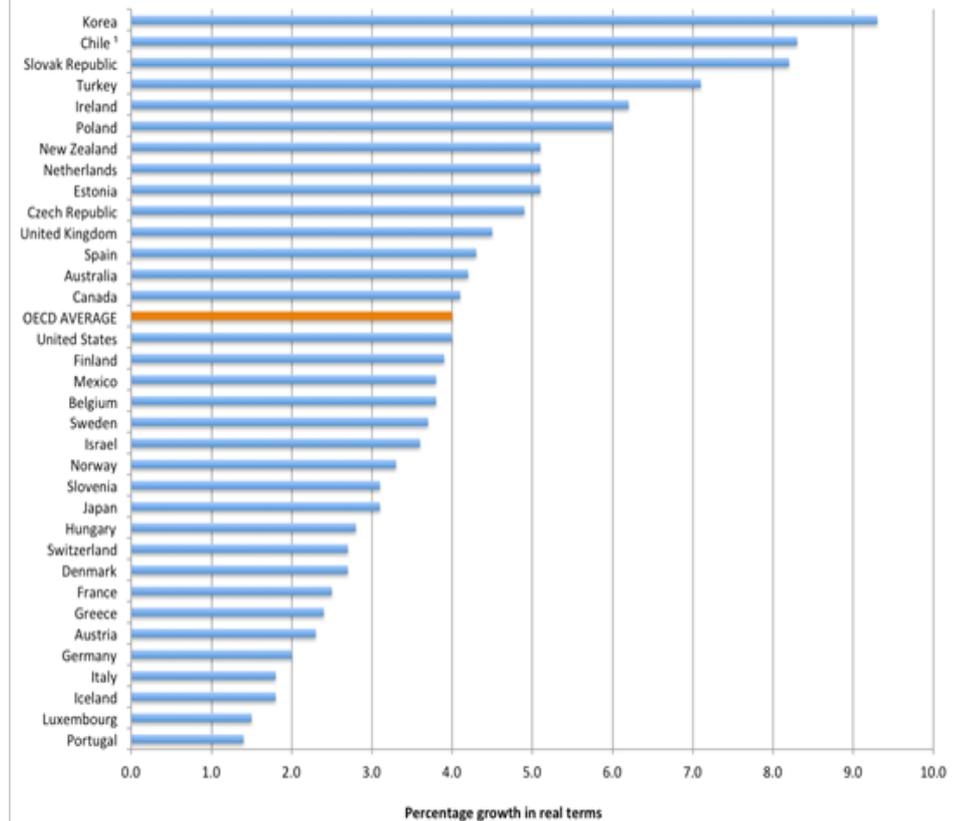
# Outline

1. Challenges to health care systems
2. Quality and value in health care
3. The challenges of making evidence-based decisions
4. Prioritisation and rationing: Common answers to common problems?
5. A social values approach
6. Conclusion

# Challenges to health care systems

- Health care expenditure continues to rise regardless of structure of health care system
- UK spends ~£110bn (figure from 2012) annually on health care, 9.2% of GDP
- Several causes for increased expenditure including demographic and technological developments as well as better informed patients
- The question is: ***How can we provide a high-quality, sustainable health care service that recognises true value and minimises inefficiencies?***

Figure 2: Annual growth rate of total expenditure on health in real terms in the years 2000-2011



Source: OECD Health Statistics 2013 (stats.oecd.org 2014)

# Why talk about quality and value?

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- Quality in health care often linked to health outcomes, performance measures etc.
- Different health actors might define quality differently – So what is ‘best quality’?
- In recent years the link between quality and value has been emphasised in the NHS and other health systems. The underlying idea is that a high-quality service will also provide the best value for the money we put in
- We achieve ‘best quality’ by looking at evidence on what works, where, how, at what costs and to what effect – and by making sure evidence is put into practice.

# The challenges of making evidence-based decisions

- Using evidence to make the best possible decision in times of tight budgets is a key feature in the NHS and other health care systems

“We seek to justify policy decisions on the basis of “known knowns”. The real problem is what to make of the “known unknowns” and the even more troubling “unknown unknowns” (Pawson, Wong and Owen, 2011)

# The challenges of making evidence-based decisions (continued)

Challenges arising when employing an evidence-based approach:

- Evidence is unavailable
- Evidence is available but the results are uncertain or difficult to interpret
- Evidence is available but one does not have the financial or human resources to process it
- Evidence is contextual
- Evidence depends on the questions one asks

# **The challenges of making evidence-based decisions (continued)**

- One has to evaluate the evidence and make it relevant to local/national/clinical/institutional context
- The process of 'making evidence relevant' requires value judgements

# Prioritisation and rationing: Common answers to common problems?

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- In light of the challenges we need to find ways to examine what we are doing in health care in order to determine what provides value for money – but *how* do we do this?
- Prioritisation and rationing – the same thing? Not quite...
- Rationing can occur ‘alone’, e.g. through cutting services without an evidence base to show that this is recommendable, or as a result of prioritisation
- Prioritisation, or priority setting, in health care usually requires principles, criteria, methods, evidence, values etc. as the basis for decision-making
- Rationing on the basis of evidence-based and acceptable principles for prioritisation more acceptable than rationing at random

# Prioritisation and rationing (continued)

*What are the principles, criteria and values that we can base health care decisions on?*

Principle	What does it say?	Benefits	Challenges
Clinical need	All that is clinically necessary and medically possible should be financed	<ul style="list-style-type: none"> <li>Individual patient is at the heart of decision-making</li> <li>Strong emphasis on clinical autonomy and patient-doctor relationship</li> </ul>	<ul style="list-style-type: none"> <li>Hard to define: Not everything that is medically possible is also necessary</li> <li>Difficult to control expenditures based on this principle</li> </ul>
Capacity to benefit	Patients who stand to gain the most from a treatment should be prioritised	Ensures a cost effective use of health care resources because of emphasis on clinical effectiveness in patient groups	Might raise questions of fairness, for example when certain age groups stand to gain more from treatment than others
Clinical effectiveness	Only interventions that achieve what they are set out to achieve should be financed	Evidence-based approach	Determining thresholds for clinical effectiveness can be challenging
Cost effectiveness	Costs of a new intervention must be justified in relation to the expected clinical benefits	<ul style="list-style-type: none"> <li>Evidence-based, value-for-money approach that allows comparisons across disease categories and interventions</li> <li>Present and future societal needs are recognised</li> </ul>	<ul style="list-style-type: none"> <li>Determining thresholds for cost effectiveness can be challenging</li> <li>Individual patients may loose out</li> </ul>
Patient characteristics	When making decisions characteristics such as age, disease severity and life-style choices should be considered	Allows consideration of societal preferences, i.e. end-of-life treatments should be values differently	<ul style="list-style-type: none"> <li>Risk of discriminating against certain patient groups</li> <li>Link between life-style choices and occurrence of disease cannot be conclusively proven</li> </ul>

# Prioritisation and rationing in the UK

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What has the approach to prioritisation been in the UK?

- Emphasis on value for money and cost effectiveness methods using incremental cost effectiveness ratios (ICERs)
- National Institute for Health and Care Excellence (NICE) established in 1999 to address 'postcode lottery' by recommending which drugs should be available on the NHS
- Prioritisation and decision-making at the local, i.e. CCG-level, much less clear
- Finding acceptable ways to prioritise and allocate resources remains a challenge. Trade-offs have to be made and the principles don't tell you how to strike a balance between them



## 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.

## NICE to approve new cancer drugs



The National Institute for Clinical Excellence is expected to approve new kidney cancer drugs for NHS use in England and Wales. Graham Satchell reports.



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.

## Cancer drugs fund 'to be extended' until 2016

A £200m-a-year fund for life-enhancing cancer drugs is to continue until 2016, the prime minister has announced.

The Cancer Drugs Fund (CDF) was set up in 2011 to help patients in England access certain drugs before they get approval for widespread NHS use.

The scheme was due to end next year, but David Cameron has pledged £400m to keep it running.



Health Secretary Jeremy Hunt said cancer sufferers in Wales were renting homes in England to access drugs

# What is value in health care?

- Need to be precise in how we talk about 'value' because, just like with quality, the term has different meaning and connotations
- Something can have a monetary value or a medical value (sometimes used interchangeably with clinical benefit) or a personal value or a societal value or a professional value...the list goes on
- There is an academic and policy trend to acknowledge the need to take into consideration not just monetary or clinical values, but also societal values. But *how* to do this and *how* to make difficult trade-offs remains a challenge.

# The role of social values

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Evidence-based guidance can be viewed as a practical manifestation of social contracts in deliberative democracies. They are a means of achieving the most efficient and ethical allocation of finite health care resources based on social values. To achieve this goal, social values will need to reflect the social/political milieu in which organisations exist and in which individuals make decisions.

## Values:

- Can be defined as broad preferences concerning appropriate courses of action or outcomes
- Reflect a person's sense of right or wrong or what 'ought' to be, e.g. "equal rights for all"
- Tend to influence attitudes and behaviour
- Can apply at an individual or societal level

# 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*



# Does accountability for reasonableness work?

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

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### ABSTRACT

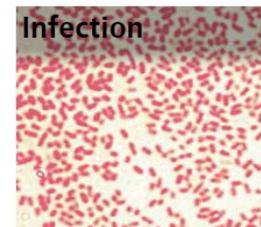
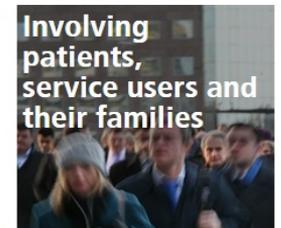
**Introduction:** Clinical commissioning groups (CCGs) in England are tasked with making difficult decisions on which healthcare services to provide against the background of limited budgets. The question is how to ensure that these decisions are fair and legitimate. Accounts of what constitutes fair 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

### 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.

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

<http://www.clahrc-southlondon.nihr.ac.uk/public-health/ccg-checklist>



# Research

- We want to test if accountability for reasonableness (A4R) works in practice
- Do clinical commissioning groups (CCGs) that adhere to A4R criteria make more legitimate and fair decisions in the eyes of the public?
- Purpose of the study:
  - a. To investigate whether those CCGs that meet A4R conditions produce more legitimate outcomes in the eyes of the public and,
  - b. To test the usefulness of a decision-making audit tool (DMAT) in research and in practice.

# The decision-making audit tool (DMAT)

- Background: International research agenda on social values in health priority setting
- Developed the DMAT based on Clark's & Weale's framework of social values in health prioritisation → includes process and content values
- DMAT used as a data collection tool and to guide our analysis of CCG documents but we also want to test whether the tool might be helpful for decision-makers and members of the public who are involved in local commissioning

# The DMAT: Asks questions on 8 domains

## Process values:

1. Institutional Setting (legal and collaborative)
2. Transparency (clear how decisions are made)
3. Accountability (who is responsible vis à vis whom)
4. Participation and Consultation (All who want to be, can be involved)

## Content values:

5. Clinical Effectiveness (does it work?)
6. Cost Effectiveness (value for money)
7. Quality of Care (High clinical standards, safety, patient experience)
8. Fairness (to all patients)

# Example: Domain 3 - Accountability

## Domain 3: Accountability

Description:

Commissioners of health services are accountable to a great number of people and organisations. Sometimes accountability is formal - legal or financial accountability, for example. Sometimes it is less formal – accountability to colleagues or to the local media. In all cases, accountability requires an ability to give reasons for and justify one's decisions.

**Item 8. The organisation has clearly states to whom it is accountable.**

1 Strongly Disagree	2	3	4	5 Strongly Agree
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*Further explanation and examples:*

Due to the different forms accountability it is important that an organisation is open whom it is accountable to. In thinking about this item, you may, for example, consider whether accountability is discussed as a stand-alone subject in an organisations' documents.

**Item 9. The organisation demonstrates that it fulfils its duty to be accountable.**

1 Strongly Disagree	2	3	4	5 Strongly Agree
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# Example: Domain 4 – Participation and Consultation

## Domain 4: Participation and Consultation

### Description:

The views of patients, health professionals, community organisations, elected representatives and the public are important because they add to the perspectives that are considered when making decisions on which health services to fund. In some countries, for example in England, commissioners have a statutory duty to consult stakeholders when making decisions. Enabling different groups contribute to decision making ensures that different views are heard and that special needs are understood.

**Item 11. The organisation consults all groups whom it is required to consult by law.**

1 Strongly Disagree	2	3	4	5 Strongly Agree
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### *Further explanation and examples:*

This item refers to the statutory duty to consult a wide range of stakeholders. Most public organisations are under a statutory duty to consult stakeholders, but the way this duty is implemented differs from one organisation to another. It is important that an organisation is transparent about any statutory obligation it may have in this regard.

# Example: Domain 4 – Participation and Consultation

**Item 12. Information on the ways in which patients, members of the public, health professionals and others stakeholders can get involved is publicly available and explained.**

1 Strongly Disagree	2	3	4	5 Strongly Agree
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*Further explanation and examples:*

This item refers to whether information about how to get involved is easily available and well explained. It is important that people who want to get involved can find the information on how to do so without much complication.

**Item 13. The organisation uses a wide range of techniques in consulting and engaging with stakeholders and the public.**

1 Strongly Disagree	2	3	4	5 Strongly Agree
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*Further explanation and examples:*

There is no right or wrong way to consult stakeholders. Techniques to consult stakeholders include surveys, public consultations and hearings, regular stakeholder forums, written consultations, public meetings with question and answer sessions, deliberative forums – to mention but a few. Depending on the purpose that participation is meant to serve, these techniques offers advantages and disadvantages. Therefore, in thinking about this item you may want to consider whether the organisation offers a range of techniques to hear people's views on decision proposals.

# Example: Domain 8: Fairness

## Domain 8: Fairness

### Description:

Fairness goes by different names. Some people talk about 'equity', others about 'justice' or 'rights'. In healthcare prioritisation, fairness relates to the question: Are all those for whom health services are commissioned treated with equal concern and respect? It is also connected to right not to be discriminated against on the basis of age, gender, ethnicity, religious background, sexual orientation or other characteristics.

**Item 26. The organisation demonstrates that it has policies in place to identify equality and diversity concerns that may arise from its decisions and strategies.**

1 Strongly Disagree	2	3	4	5 Strongly Agree
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**Item 27. The organisation can demonstrate that it commissions services on the basis of clinical need and not on the basis of other characteristics such as age, gender, ethnicity or sexual orientation.**

1 Strongly Disagree	2	3	4	5 Strongly Agree
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**Item 28. When services are prioritised for special patient or population groups (children or older people, for example), the organisation explains the reasons for this.**

# The DMAT

- Health care decision-makers and members of the public and patient advocacy groups can use the DMAT to identify strengths and weaknesses
- Using the DMAT will prompt discussions and lead to improvements in decision-making
- Might help in balancing between different values and decision-making criteria
- Can be adapted to different national contexts

# Conclusion

- The definitions of quality and value in health care are expanding. Both are no longer seen in purely monetary terms.
- Recognition that process and content (i.e. social) values are important when making decisions → But how to do this?
- Recognition that the public should be involved in determining social values that should inform priority setting, for example through deliberative processes such as mini-publics or citizens' juries. However, there are conceptual and methodological challenges in these approaches.
- Can the DMAT be used by health care decision-makers and the public to identify strengths and weaknesses in decision-making?
- Is the tool useful for the public because it provides an overview of areas to which they may want to pay attention? Can it be used to challenge decisions?

# Thank you for your attention!

If you are interested in the decision-making audit tool and our research, please contact us:

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