Health care rationing, uncertainty and complexity

Dr Tiago Moriera, Reader in Sociology, School of Applied Social Sciences, Durham University

Thursday 30th January, 2014

These are summary notes to accompany the presentation made by the above named speaker as one of the knowledge exchange seminar series organised, by the Fuse knowledge exchange group and is to be read in conjunction with the slide set, available on the Fuse website.

After the title slide (Slide 1), Slide 2, headed "Summary" lists underlying factors leading to uncertainty in health care rationing, and the different regimes of justification explored later in the presentation, from Slide 10 onwards. It includes a definition of complexity from the work of Wallerstein (1996). Slide 3 depicts a model of health care rationing, a 2x2 matrix from Ubel and Goold (1998) which illustrates different potential scenarios, depending on the scarcity of the resource being rationed, and the level of transparency with which rationing is put into effect. Rationing involves restriction of supply, potentially by any means, within two broad categories, either implicit (based on professional clinical judgement) or explicitly (based on some form of corporate process embedded in a health care system).

Different perspectives to study health care rationing (philosophy, economics, health policy, sociology) were referred to, in Slide 4. One of the basic questions that arises, particularly if an economic approach is taken, is whether health care is a commodity that can be put on the market.

Slide 5 depicts different types of models of health care rationing developed in the 1990s. These are in three main strands:
Public Education Model – this is a one way process. A Norwegian example was given which worked on the basis of explaining the prioritisation decisions to the public.
Public Dialogue Model – this is the most common model. This uses some type of forum to support the process, involving a dialogue about the science with the public as a way of strengthening the outcomes. NICE is one example of this type.
Co-production Model – this envisages a linkage between society and public health. In this option open, public controversies are seen as a healthy sign of democracy. The example was given of public disputes about advice given by NICE.
The question was posed through Slide 6 about what makes a health care rationing issue a public controversy. It was suggested that three conditions need to be in play:

- The topic gets out of control, because, for example, documents are leaked
- Membership or ownership of the dispute becomes open to all – like a supermarket
- Discussions focus on explorations of links between the technical and the political within knowledge claims, for example, is the decision in line with the NHS ethos?

In summary controversies make uncertainties within the knowledge base visible.

Slide 7 depicts the Mackenzie trough diagram, where the X axis is position of people and their opinions in relation to their access or use of expert knowledge, and the Y axis which illustrates the level of uncertainty experienced by the different groupings. The group who are alienated from institutions or feel committed to a different technology expose the level of uncertainty about the evidence. In the midst of active controversies the Mackenzie trough becomes flatter.

A distribution of uncertainty in healthcare rationing processes is illustrated in Table 1, Slide 8. This is expanded on in Slide 9 showing four categories:

1. Experts disagree – but 'no one else cares', for example, homeopathy
2. Uncertainties are visible and some form of institutional rationing is accepted
3. A very common situation – a case by case judgement approach taken, setting aside the rules
4. The primacy of common good comes to the fore in the debate and the level of uncertainty guides the process.

Slides 10 and 11 discuss regimes of justification. Slide 10 expands on point 4 (above). The quotations on the slide (Thevenot 2007, and Moriera 2012) attempt to address the question: How do people justify a course of action when the uncertainty is unknown? Slide 11 describes three main approaches which each provide a different framework for a regime of justification. These are, the market (market forces determining the distribution and availability of healthcare) based on efficiency, the laboratory, using science to establish the effectiveness of treatments, and the forum, applying consultation and discussion to arrive at rationing decisions.

Slide 12 provides an illustration, in particular, of the scientific approach (personified in the role of NICE) and the impact of the forum (shown in public and political controversy). The case study in Slide 12 relates to dementia drugs, and started in 2005 with the publication of a NICE recommendation. It led to a major debate and at one point in the controversy the Secretary of State asked for a re-consideration of the NICE analysis. Slide 12 sets out in detail a chronology of the debate and the key decisions along the way up to 2008. The end result of this case study example is that it increased the complexity and duration of appraisals.

Slide 13 shows different market measures on left of the slide. The quote on the right hand side of the slide from Rawlins and Culyer (2004) shows the dilemma that NICE are placed in where there is a conflict between clinical effectiveness and cost. Slide 14 illustrates the laboratory option in the context of the controversy over dementia drugs in the case study above, with three quotations. The quotations raise spin-off issues around the implications for caring with people with dementia, the place of using consistent approaches and a questioning of the QALY (Quality Adjusted Life Years) model that was applied by NICE. Slide 15 illustrates the role of the forum in contributing to the controversy over the dementia drug case study. In this case the popular response from the voluntary sector and in the press was that sufferers and carers were not involved, so remained unheard and consequently the process was denounced. Individual people directly affected by dementia felt betrayed by the decision making process.

Slide 16 poses the question: So what? The conclusions are:

- The "model supports an understanding of health care priority setting as underpinned by the framing and distribution of uncertainty" – education can be a corrective to being obsessed with the evidence and the reduction of uncertainty as a source of direction in rationing decisions.
- Moriera recommends that decision makers should take the uncertainty on board – and pre-emptively take their reasoning to a non-expert audience as a way of positively engaging before a major public reaction and/or public campaign arises. (This is not to say that a major public reaction might not ensue, but at least it should not be on the basis that people have not been included in the decision making process)
- The established view misses the point of the differences and the importance of exploring the different elements – effectiveness (the laboratory or science), efficiency, (the market) and the public view (the forum) – which may/may not align. There is no point in hiding the differences.

Two publications by Dr Moriera were referred to on Slide 17 which closed the presentation and are reproduced below. It was announced that they were available on kindle now.

Moriera, T (2011) 'Health care rationing in an age of uncertainty: a conceptual model' Social Science and Medicine, 72(8): 1333-1341
Moriera, T (2012) The Transformation of Contemporary Healthcare: the Market, the Laboratory and the Forum, New York, Routledge/Taylor Francis.

Discussion

Discussion took place on the following topics:

Q – It was suggested that rationing decisions are usually only contested in one direction, for example, to support the vested interests of a charity or a pharmaceutical company. Consequently the argument is flawed due to the bias this introduces.

A – Controversies enable us to see what's hidden. The case study example of the dementia drugs was that they were not good, but had some effect, some of the time. This scenario led to the debate being an open contested one.

Q – NICE say that they operate with more of a forum than a laboratory. Dr Moriera was asked his response to this.

A – Dr Moriera stated that the aim of his work was <u>not</u> to criticise NICE, although sometimes it is understood in this way. In fact he believed that NICE do try to marry the market, the laboratory and the forum and can't on all occasions, but sometimes they can. A more open pre-emptive approach (as recommended in Slide 16 and described above under conclusions) would expose controversies.

Q – The typology of regimes of justification is only applicable to health technology, but what about the rough-and-ready decisions driven by cost- cutting that are often not in the public domain?

A – Dr Moriera acknowledged the limitations of the regimes of justification, and that on occasion that they will be in contradiction to the prevailing factors that influence cost cutting measures

AR/draft as at 13th February 2014 amended on March 12th 2014

Health care rationing: uncertainty, difference and complexity

Tiago Moreira

Durham University
School of Applied Social Sciences

Summary

- **Health care rationing: sociology of knowledge perspective**

- **Uncertainty in health care rationing**
  - **an increasing reliance of public policy on networks of expertise**
  - **growing uncertainties relating to the effects of science and technology**
  - **erosion of the lay-expert boundary in decision making processes**

- **Difference: Regimes of justification**
  - **Efficiency ≠ Effectiveness ≠ Involvement**
  - **Dementia drugs controversy (2005-08)**

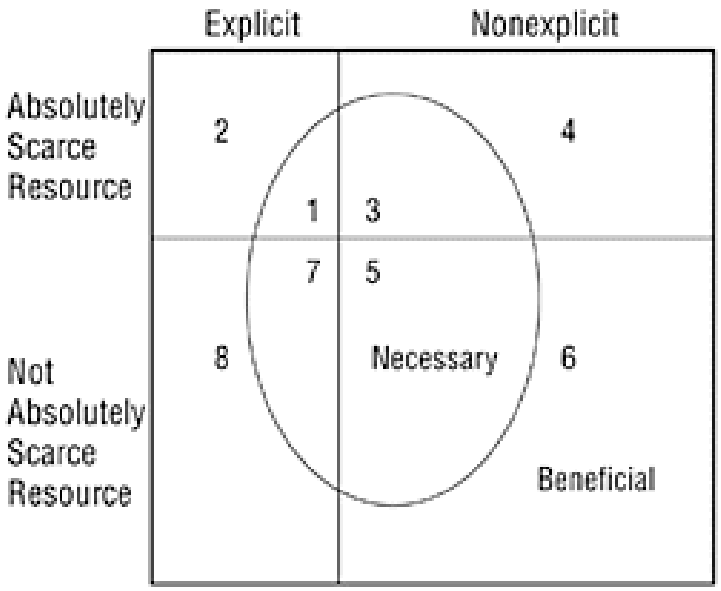
- **Complexity**

  –Study of collective processes should be 'based on the dynamics of non-equilibria, with its emphasis on multiple futures, bifurcation and choice, historical dependence (and) intrinsic and inherent uncertainty' (Wallerstein, 1996: 61)

Durham University
School of Applied Social Sciences

Health care rationing

- Rationing: Restriction of the supply of any commodity or service (OED)
- Implicit HCR: ‘moral categorisation’, clinical judgement of need
- Explicit HCR: the use of institutional procedures for the systematic allocation of resources within health care systems.
  - (Priority-setting)



Ubel and Goold Arch Intern Med. 1998;158(3):209-214

Perspectives on HCR

- Philosophy/medical ethics:
  - Substantive principles (Cookson & Dolan, 2000)
  - Deliberative procedures (Daniels & Sabin, 2008)
- Economics
  - Market processes vs. Market failure
  - Problem of allocation of scarce resources
  - Methods that might assist allocative decisions (Donaldson, Bate, Brambleby, & Waldner, 2008)
- Health policy
  - Institutional and political processes that sustain or challenge systems (Crinson, 2004; Ham & Roberts, 2003; Milewa, 2006).
- Sociology
  - Tension between the rhetoric of rationing and the multiple rationalities that underpin decisions in local contexts (e.g. Light & Hughes, 2001).

Models of HCR: Expertise in Society

Public Education Model	Public Dialogue Model	Co-production Model
• Science is a robust system of rational enquiry • Ignorance and mistrust addressed by policies and programmes of scientific education • Clear boundary between experts and public views.	• Science can be enhanced by public debate. • Science gains public legitimacy from integrating values and perspectives • Forums to harness and manage the contributions of multiple groups.	• Science and society are intimately linked • recognition of increasing uncertainties about the knowledge base for collective decision making • Public controversies on technical matters are sign of a healthy democratic life.
Norway's commissions on health care prioritisation	Most common: e.g NICE, Sweden Medicines Board	Public Controversies about rationing decisions (dementia, breast cancer, etc)

HCR Controversies and uncertainty

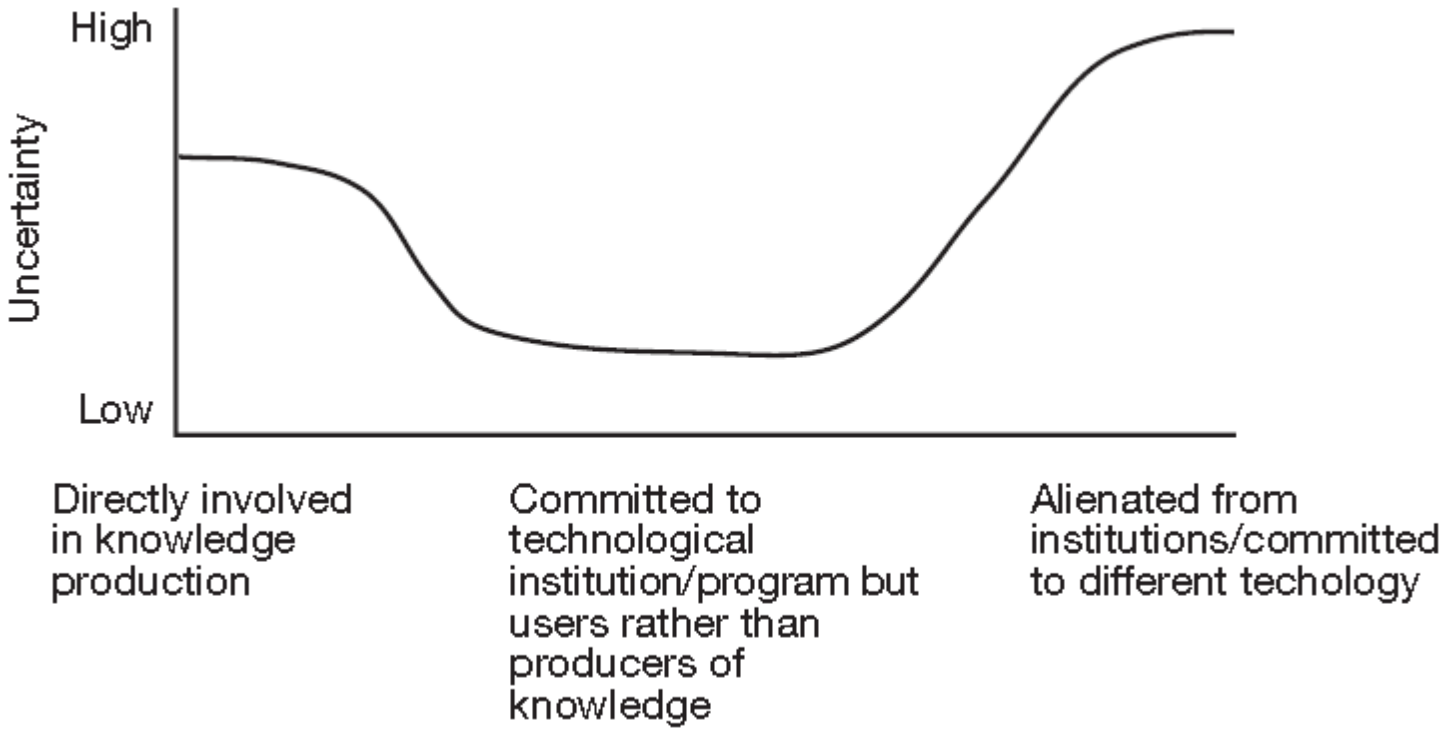
Three conditions:

- Loose institutional framing of discussions often shifting from formal procedures to adhoc debates and interventions.
- Membership within the collective negotiation process about evidence is open to experts, interested parties, political actors and common citizen alike.
- Discussions tend to focus on the explorations of links between the technical and the political within knowledge claims.

<u>Controversies make uncertainties of knowledge base visible</u>

Mackenzie's certainty trough

FIGURE 1
Mackenzie's certainty trough (MacKenzie, 1990: 372).



Source: MacKenzie, 1990. © MIT Press.

Distribution of uncertainty in HCR processes

Table 1
Distribution of uncertainty in health care priority setting.

Disease-specific	Closed	Open
Standard: Closed	1	2
Standard: Open	3	4

Distribution of uncertainty in HCR processes

1	Both standard-related and disease-specific knowledge bases remain closed to public exploration despite controversy between experts • groups are likely to pursue divergent paths such as the withdrawal /switching health care provision • Eg. Homoeopathic treatments
2	Standard-related knowledge remains closed but disease-specific knowledge becomes fraught with uncertainties • the application of impersonal rules is facilitated and likely to become publicly accepted
3	Disease-specific claims are left unexamined and standard-related knowledge is weakened in public discussion • opening a 'local' or individual exception is likely to be seen to be the solution
4	Both standard related and disease specific knowledge bases are opened to debate • **<u>Uncertainty guides process to seek to establish 'common good'</u>**

Durham University
School of Applied Social Sciences

Regimes of justification

In situations of open uncertainty individuals or groups draw on ideals of common good and associated ways of knowing to support their arguments and actions:

- ‘forms that channel uncertainty into coordination frames appropriate for public judgment and that imply a dynamic of critique and justification’ (Thevenot, 2007)

- “the mobilisation of moral and cognitive frames to entrench policies and programmes within social relationships. They are attempts to bring such actions onto common understandings of ways of living together; they propose a version of what health care is for and distribute rights and responsibilities across actors engaged in achieving this ‘good’. […] by drawing on established, agreed ideals of moral and social order, they justify change by appealing to conventional, customary rules.”

Durham University
School of Applied Social Sciences

See Moreira, T. T (2012) The transformation of contemporary health care, New York, Routledge: 56.

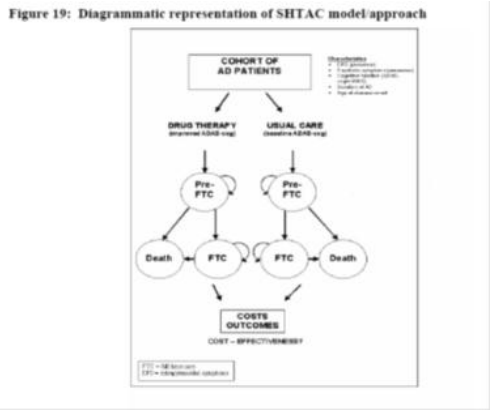
Regimes of Justification in Health Care

The market: attempts to embed principles of economic rationality and efficient use of resources in the shaping and delivery of health care;

The laboratory: concerted actions that emphasise the value of science, experiments and 'evidence' in the management of research, practice and policy;

The forum: the application of deliberative procedures and other forms of public consultation to decision making on health technologies/services

See Moreira, T. T (2012) The transformation of contemporary health care, New York, Routledge: 56.

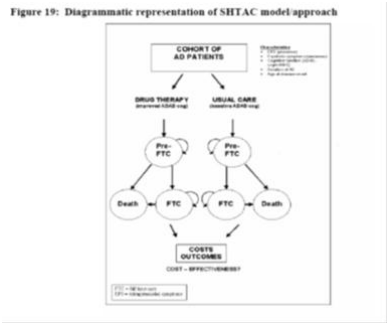


Dementia drugs controversy (2005-08)

2001: NICE recommends dementia drugs should be available on the NHS drawing on clinical trial data as QoL measurement in dementia is 'uncertain'

- **2005** draft revision of the guidance: new analysis of the evidence suggests drugs were not cost effective
  - a strong media and public reaction, a campaign supported 100 UK MPs, Secretary of State for Health asks NICE to reassess its cost-effectiveness analysis
- **Jan 2006**: After consultation with 'stakeholders' and an appraisal of new evidence, cholinesterase inhibitors reccommended "as options in the management of people with Alzheimer's disease of moderate severity only" (NICE, 2006).
  - More controversy
- **May 2006**, NICE published the Final Appraisal Determination and did not change its decision of January 2006.
- **July 2006** Appeal Panel.
  - After a longer than usual period of consideration, the appeals were rejected and the advice upheld.
- **November 2006,** Esai/Pfizer to apply for judicial review
  - protest marches organised by the Alzheimer's Society all across the country.
- **June-August 2007** The judicial review hearing
  - The High Court decided in August 2007 to uphelp the NICE's advice except in relation to where it contravened anti-discrimination (MMSE)
- **May 2008**, the Court of Appeal found that the companies were treated unfairly in not having had access to the 'fully executable economic model' but did not quash NICE's recommendation
  - increasing the complexity and duration of other drug appraisals

Durham University
School of Applied Social Sciences



The Market

•SHTAC HTA summary (2005):

Consistency of effectiveness of ChEIs on cognition and global measures;

•Economic model: Can drugs delay institutionalisation?

•Model based on equivalence cognition-QoL

Model accounts for costs for NHS/Social care only: Full time care (FTC)

• Evaluation puts costs of ChEIs above cost-per-QUALY threshold

When good evidence exists of the therapeutic equivalence between two or more clinical management strategies the cheaper option is preferred […] However, in most instances NICE is confronted with a clinical management strategy that is better than current standard practice but which costs more. NICE must then decide what increase in health (compared with standard practice) is likely to accrue from the increase in expenditure. This is the **incremental cost effectiveness ratio.** Such ratios can be expressed in many ways. NICE's preferred measure is the **cost per quality adjusted life year**. (Rawlins and Culyer, *BMJ* 2004, 224)

The Laboratory

R]emoval of the anti-dementia drugs will significantly impair our ability to care for people with Alzheimer's disease. [This] will leave private prescriptions the only recourse available to patients and their families to obtain a licensed and proven treatment. This is not only against the ethos of the NHS but leaves vulnerable patients open to the vagaries of the market place. (Burns et al, 2005)

There is no real consistency there. […] In that situation we think that other factors should be given more weight, and that has been outlined by Sir Michael Rawlings in the BMJ amongst others when uncertainties exist around the qualities it is important to look at other aspects […] (Appeal Hearing Transcripts, July 13 2006: 6-7: my emphasis)

NICE do not question the safety and efficacy of these drugs but, on a model of cost effectiveness, they conclude that the drugs have failed to meet the level which would justify their prescription on the NHS. However, the model used is largely based on measures that do not have validity in Alzheimer's disease and did not take into account the effects of the disease on carers nor the specific positive benefits of the medications on psychiatric symptoms and behavioural disturbances. The assessment of quality of life in Alzheimer's disease and its economic equivalent quality of life years (QALY's) is not well developed, the model does not do justice to the myriad aspects of the disease and insufficient data are available to support the assumptions presented by NICE. They have carried out a thorough review of the available literature, but what is striking from this is the lack of evidence available on which to base the cost models […] (Burns et al., *BMJ* 2005)

The Forum

"The [Alzheimer's] Society believes that NICE's work must reflect the value placed on the drugs' impact on the disease by **people with dementia themselves and their carers** [which emphasise the importance of behaviour]

It is of considerable concern that their views are rarely included in the design of clinical trials.

A summary of the Alzheimer's Society's response to draft guidance from Nice', May 2005 [my emphasis]

I am joining with the Daily Mail to challenge the government, which I believe betrayed my mother. When she died aged 85, I, a former Labour MP, wanted to write on her gravestone: ''Betrayed by the NHS and a Labour Government''

Helen Clark (*Daily Mail*, February 28, 2007)

So what?

•Model supports an understanding of health care priority setting as underpinned by the framing and distribution of uncertainty.

•Where there is disagreement, it is recommended that decision makers and stakeholders should be required to pre-emptively account for their reasoning to a non-expert audience.

•Established view: different regimes can be thought of as different functions of health care: to deliver objective health outcomes, in the most economical manner, through programmes that are significantly aligned with public values

•The gearing of institutions towards the reduction of epistemic and moral uncertainty plays a key role in the entrenchment of policy ideals in health care

- Exploration of boundaries between regimes

Durham University
School of Applied Social Sciences

Moreira, T (2011) ‘Health care rationing in an age of uncertainty: a conceptual model’ Social Science and Medicine, 72(8): 1333-1341

Moreira, T. (2012) The Transformation of Contemporary Healthcare: the Market, the Laboratory and the Forum, New York, Routledge/Taylor Francis.

Durham University
School of Applied Social Sciences

Health care rationing: uncertainty, difference and complexity

Tiago Moreira (Durham University)

ABSTRACT: Health care rationing - the use of technical and institutional procedures for the systematic allocation of resources within health care systems – has been a topic of heightened academic and policy debate since at least the 1970s. This debate can broadly be divided into three positions: those proposing that efficiency can be achieved through market mechanism; those recognising the normative dimensions of the issue and proposing aggregative or deliberative solutions for it; and those remarking on the inexorably political or situated character of concrete allocative decisions. In this paper, I will argue that an empirical analysis of rationing decision making processes can equip institutions to better manage the complexity of health care priority setting. I will suggest that this complexity stems from the way in which knowledge-making practices and grammars of the public good are multifariously interlocked in health care rationing. I will explore how the gathering of evidence, the gauging of health preferences/capacities and the use of deliberative procedures, often employed together by priority setting institutions, bring different, contradictory epistemic and normative assumption to bear. I will propose that rather than smoothing over such differences, priority setting institutions should monitor their usage and relative position in decision making as a form of institutional learning.