

SOCIAL VALUES AND CLINICAL COMMISSIONING

A SUMMER SCHOOL WORKSHOP

**School of Medicine King's College London
School of Public Policy University College London**

12-13 September 2012

**Location: School of Public Policy, University College London
Rubin Building, 29-30 Tavistock Square
London WC1H 9QU**

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PRE-WORKSHOP PACK

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Background and Aims of the Workshop

Clinical commissioning groups will soon acquire responsibility for commissioning services for their populations. When they do, they will face familiar problems in healthcare priority setting, including the tension between meeting need and maximising benefit, identifying exceptional cases and securing overall fairness. In addition, a new value-based pricing regime is due to come into effect for pharmaceuticals in 2014.

How will clinical commissioning groups fare in this new world? Increasingly, those responsible for setting health care priorities are recognising the role of social values, like justice and accountability, as central to good decision making. At the national level in the UK's National Institute for Health and Clinical Excellence has formally recognised this with its own statement of Social Value Judgements. But how will values like accountability and justice fare in clinical commissioning? Will clinical commissioning meet standards of public justifiability and relevance?

The purpose of this summer school workshop is to consider these questions. It follows up the inaugural summer school in June 2012, and is devoted to enabling participants to identify the key challenges of social values under the new regime. It will bring together those who will an interest in or responsibility for clinical commissioning with academic researchers working on healthcare priority-setting.

Main features include:

- A combination of lectures and interactive seminars, with an emphasis upon discussion of the practical examples that participants bring to the event.
- Introduction to a new web-based tool, the Catalogue of Cases and Decisions, intended to provide an aide to decision analysis.
- An introduction to a new Framework tool for Social Values Analysis, discussed by international participants in the latest issue of the *Journal of Health Organization and Management*.

Participants include: Alena Buyx, who leads an Emmy Noether Research Group on Bioethics and Political Philosophy at Münster University and is an Honorary Senior Research Associate Fellow in the School of Public Policy at UCL; Sarah Clark, Research Associate, School of Public Policy, UCL; Peter Littlejohns, Professor of Public Health, King's College London; Shepley Orr, Lecturer in Ethics and Policy Appraisal, UCL; and Albert Weale, Professor of Political Theory and Public Policy, UCL.

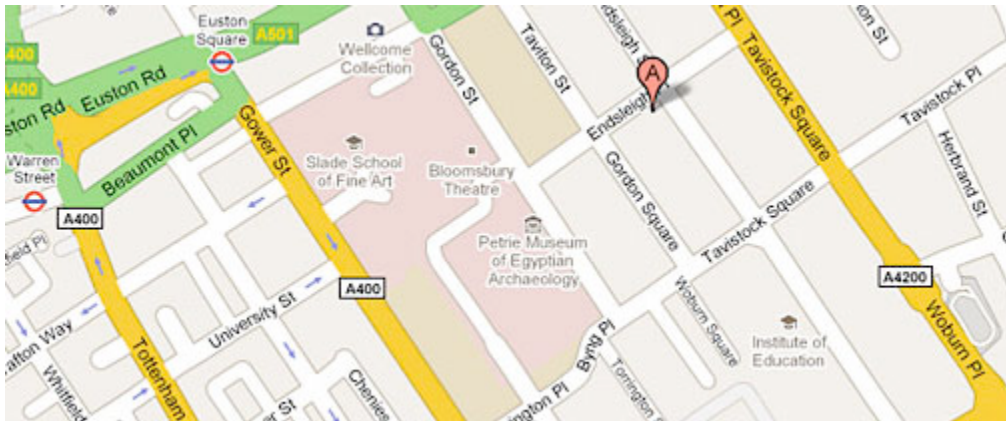
Thanks to generous support by the Economic and Social Research Council, there is no charge for the event.



Location and Directions

Venue:

**School of Public Policy
University College London
Rubin Building
29-30 Tavistock Square
London
WC1H 9QU**



See also <http://www.ucl.ac.uk/find-us/downloads/ucl-bloomsbury-campus-map>

The School of Public Policy is located on the corner of Tavistock Square, opposite the entrance to Endsleigh Road (in the exact location shown on the map above).

The main door is operated by controlled entry - if you do not have a UCL pass, please press the buzzer, wait, and you will be let in.

Nearest tube stations

Euston Square and Goodge Street are the nearest tube stations and are within 5-10 minutes walk of the School of Public Policy.

King's Cross and Warren Street are also nearby and are 10-15 minutes walk away.

Contact

If you need to contact us on the day of the workshop or beforehand, please telephone Sarah Clark on **07981130302**.

PROGRAMME

Wednesday 12 September

- 0930: Arrival and coffee
 1000: Welcome and Introduction, The Challenge of Social Values and Clinical Commissioning: Peter Littlejohns and Albert Weale
 1015: Accountable and Integrated Care Systems:
 Anant Jani
 1130: Break
 1145: Break-out Group Work:
 Values at the CCG Level
 1300: Lunch
 1400: The Geography of Abiraterone Decision Making:
 Peter Littlejohns
 1515: Tea
 1545: Value-Based Pricing:
 Shepley Orr
 1700: Round-up and Review of the Day
 1900: Dinner for participants.

Thursday 13 September

- 0930: Arrival and coffee
 1000: The Case of Novo Seven:
 Alena Buyx
 1115: Coffee
 1145: What Would Accountability for Social Values Mean in Clinical Commissioning?
 Albert Weale
 1300: Lunch
 1400: Roundtable Discussion: Values and Accountability in CCGs
 Anant Jani, Peter Littlejohns, Shepley Orr
 1515: Tea
 1545: The Catalogue of Cases and Decisions
 Sarah Clark
 1630: Round up and Next Steps
 Peter Littlejohns and Albert Weale

Participant Leads

Dr Alena Buyx has a background in medicine, philosophy and sociology. She leads an Emmy Noether research group on Bioethics and Political Philosophy at Münster University and is an Honorary Senior Research Associate in the School of Public Policy, University College London. Until May 2012, she was Assistant Director at the Nuffield Council on Bioethics, leading projects on ethical issues in Novel Neurotechnologies, Biofuels, and on Solidarity as an emerging concept in Bioethics. Prior to that, she worked at the Harvard Program in Ethics and Health, with her research focus mainly on medical ethics and questions of justice in health care and public health.

Dr Sarah Clark is Research Associate in the School of Public Policy, University College London, working on the ESRC Professorial Fellowship Programme 'Social Contract, Deliberative Democracy and Public Policy'. She did her PhD at the University of Essex, where she worked on altruism and public policy in gamete transfer. She took the lead in developing the Social Values analysis described in the special issue of the *Journal of Health Organization and Management* (26:3) on Social Values and Healthcare Priority-Setting as well as producing a number of published papers and policy briefs on priority-setting and health care.

Professor Peter Littlejohns is Professor of Public Health at King's College London. Between 1999-2011 he was the founding Clinical and Public Health Director of the National Institute for Health and Clinical Excellence (NICE) in the UK. He is a Fellow of the Royal College of Physicians, Fellow of the Faculty of Public Health and Fellow of the Royal College of General Practitioners. His research interests are aimed at improving the cost-effectiveness of health care and understanding the role of "values" in the fair allocation of health care resources

Dr Anant Jani was born and raised near Chicago, IL and trained in the natural sciences at Brandeis University and then at Yale University. My experience in health care stems from my work in Sir Muir Gray's QIPP Right Care program, where I am helping localities across the UK design and implement high value population-based Accountable Integrated Care Systems. This workstream relies on helping localities build strong local networks that promote and pursue shared decision making, population medicine and programme budgeting.

Katharina Kieslich is a PhD Candidate in Political Science at the University College London (UCL). As part of her PhD research, she is conducting a comparative analysis of the decision-making processes, methods and outcomes of health technology assessments (HTA) in Germany and England. She has recently published an article on social values and health priority setting in Germany in the latest issue of the *Journal of Health Organization and Management* (26:3). Prior to her PhD studies, she worked as a researcher for the Christian Democratic Party (CDU) in Bremen, Germany. Her research fields included health, social, labour, family and European policy matters.

Dr Shepley Orr is Lecturer in Ethics and Policy Appraisal at University College London in the Department of Civil and Environmental Engineering. His research interests include the relationship between political philosophy and economic policy, measuring benefits for purposes of policy appraisal, and philosophical and experimental approaches in decision theory. His current research projects in the health sector include: eliciting preferences over health states using condition-specific information for a general public sample (with colleagues in UCL's Institute of Ophthalmology); using the person trade-off and related methods to elicit public preferences over risk reductions in the NHS (with Brunel's Health Economics Research Group), and a project on

the inclusion and trading-off of different values in models of value based pricing (with Jonathan Wolff).

Professor Albert Weale is Professor of Political Theory and Public Policy at University College London. He has published widely on principles of priority-setting in health care including *Cost and Choice in Health Care* (King Edward's Hospital Fund, 1988), for which he was editor, and *Risk, Democratic Citizenship and Public Policy* (ed.) (Oxford University Press, 2002) as well as a number of journal papers and chapters. He was one of the organisers of the international workshop on Social Values and Healthcare Priority-Setting, papers from which have been published in the latest issue of the *Journal of Health Organization and Management* (26: 3). Between 1986 and 1990 he was a member of the Advisory Board of the King's Fund Health Policy Institute and chaired the King's Fund Grants Committee between 1997 and 2001. Between 2008 and March 2012 he chaired the Nuffield Council on Bioethics.

Executive Summary of ‘Commissioning for value’
By Littlejohns, P, Weale, A and Clark, S (2012), *Health Services Journal*
(forthcoming on 13 September, 2012)

- The aspiration for a locally led patient focussed NHS will only be realised if each of the new CCGs can demonstrate the legitimacy of their decision-making processes to professionals, patients, and the public.
- How this will be achieved remains unclear - there is no “blue print”, and the indications from both Government and commissioning organisations are that local solutions are strongly favoured over downward directives.
- In this new world, commissioners will face difficult challenges of health care prioritisation, needing to balance the objectives of securing high quality, comprehensive health care within limited resources.
- One approach to these challenges is to search for greater 'value for money' through evidence-based assessment of interventions. But hard trade-offs and tragic choices can rarely be overcome merely by greater efficiency, so priority setting resulting in the dilution, delay or denial of NHS services is likely for years to come.
- How commissioners make these priority setting decisions will involve not only judgments of clinical and cost effectiveness, but also judgments of social values such as justice, solidarity and autonomy. Commissioners will be accountable to local populations and thus their judgements must reflect the social values of their communities.
- This will be difficult - despite years of striving to address this issue, NICE remains controversial. However, help is at hand in the shape of a new policy and research network - Social Values and Health Priority Setting <http://www.ucl.ac.uk/socialvalues> - whose aim is to suggest a check-list for analysis of social values which can provide the basis of a “value profile” for CCGs.

Scenario-based exercises

The following scenarios are fictional but offer examples of the kind of priority setting choices which may face clinical commissioners. They are designed to prompt you to consider the issues of social values that arise and to think about and discuss what should be taken into account in the decision-making process in each case.

The group discussions on Day 1, Session 2 of the Workshop will be based around these scenarios.

You might wish to use the following to help you consider the issues raised by each scenario:

- What values strike you as being relevant in the scenario? For example, values of cost-effectiveness, clinical effectiveness, justice/equity, solidarity, autonomy?
- Which specific features of the scenarios alert you to these values? For example:
 - Features of the patient population: eg. are they predominantly young/old, male/female, vulnerable or not? Is this patient population particularly significant in terms of the community served by the CCG?
 - Features of the condition: is it, for example, a life-threatening, life-limiting or particularly severe condition? Is it chronic or acute? Is it a condition to which social stigma or cultural sensitivity attaches? Are there any associated public health issues?
 - Features of the benefit provided by the interventions: are benefits only to local populations or also spread more widely? Is it only patients themselves who benefit or others in society - eg. carers, families, communities? How certain are the benefits to be provided? Are there associated public health benefits?
 - Features of the intervention itself: eg. is it innovative? To what degree is it clinically effective? How certain is the clinical effectiveness? To what degree is it clinically/medically necessary?
- Is there anything that you would want to take into account in terms of the decision-making *process*? For example, the involvement of pressure groups or stakeholders, the transparency and publicity of decisions, the relevance of any commitments made in previous decisions?

Scenario 1

A local autism clinic has become a national centre of excellence and is researching and pioneering new behaviour and language therapies for autistic children, enabling them to manage social situations and to integrate and perform better at school. This improved social functioning has also been shown to significantly reduce stress on the families of these children and reduce the associated risk of family breakdown. The therapies are intensive, lengthy and therefore expensive. The interventions have been shown to have the best outcomes when used with younger children, but children and adolescents of all ages benefit. The CCG currently spends around £500,000 per year on the clinic. The clinic has said that without this funding it will have to scale back its services and reduce its research programmes and is arguing that this will disadvantage not only local children with autism, but those who come from other parts of the country too.

At the same time, unplanned hospital admissions amongst the elderly have risen, putting strain on the local hospitals and causing significant additional spending for the CCG. The kind of events - falls etc. - that lead to these unplanned admissions also tend to increase the chance of loss of independence and admission of elderly patients to residential care, thereby increasing costs in the local social care budgets as well as increasing costs for those families who are liable for care home charges. It has been proposed that for an investment of around £350,000, the CCG could implement a computerised risk assessment system and increase numbers of community matrons, both of which measures would facilitate early identification of at-risk elderly patients. It is estimated that this investment could save the CCG around £350,000 per year in future years. The area served by the CCG is popular for retirement, and the elderly were identified as a priority patient group in the CCG's most recent strategic needs assessment.

It has been proposed by one member of the CCG that the funds needed for the initial investment in interventions to reduce unplanned hospital admissions amongst the elderly could be found by introducing more restrictive guidelines for referrals to the autism clinic, such that only those with more severe autistic disorders and only children under 10 would be eligible.

What are the main issues of social values that arise here?

What should the CCG do and what should it take into account in its deliberations?

Scenario 2

A CCG has received an individual funding request from a 37 year old woman with a rare cancer for a new and very costly drug. The drug has not been assessed for clinical or cost effectiveness by NICE but early use in the US has shown positive results, although it is used in combination with other chemotherapy drugs and its independent clinical effect has not yet been established. Without the drug, the woman is expected to live for another 6 months-1 year. With the new drug, results from the US suggest that life can be prolonged for an additional 6 months-1 year on top of what can be expected from the existing treatment alone. However, in one case a US patient survived for an additional 2.5 years.

The drug is thought to be most beneficial to patients with a particular genetic profile, which this woman has, and consequently her treating oncologist believes that she will benefit more than other patients with the same cancer. The woman is a single parent with children aged 16 and 12, the youngest of whom has a moderate learning disability. She is likely to need repeated cycles of the drug over as many years as she survives. A CCG in another part of the country has recently agreed to an individual funding request from a patient in similar circumstances in their area, and the woman (and the Rarer Cancers Forum patient group) is using this to support her case. Her case is also being supported by her own GP, a member of the lead practice in the CCG.

At the same time, the CCG has received a proposal from a local drug and alcohol rehabilitation centre to increase their inpatient capacity by 5 beds, and to extend their outreach services to target sex workers in the area. The centre has a good record on the effectiveness of their interventions in the short term, with patients on average remaining drug- or alcohol- free for around 6 months after interventions, but relatively few patients stay clean for longer than 1 year. However, patients usually remain in contact with the centre and receive support services - using the drop-in centre, needle exchange, health information etc. - on an ongoing basis after initial treatment. In the 3 years since the centre has been open, crime rates in the town centre area it serves have dropped by 15%.

It is coming towards the end of the financial year and the CCG has funds available to pay the costs of the first year of one of the two options, but not both.

What are the main issues of social values that arise here?

What should the CCG do and what should it take into account in its deliberations?

Scenario 3

The CCG is under financial pressure and is looking for areas in which it can make substantial savings. It has noticed that the cost of funding IVF has risen markedly over the last few years and is significantly higher than in the surrounding CCGs. It currently funds up to three cycles of treatment in line with the recommendations by NICE, and has imposed an upper age limit for women of 39. It provides this treatment to any patient, whether or not they or their partner already has a living child. It does not impose any other conditions on eligibility for treatment.

On investigation, the CCG learns that neighbouring CCGs vary significantly in the terms on which they provide IVF treatment. One offers no funding at all for IVF. Another offers a maximum of two cycles, but only where the patient does not have a living child, and where neither the patient or her partner is a smoker, and where the woman is under 37. Another CCG offers only one cycle of IVF and only in circumstances where neither the patient nor her partner has a living child, and only where neither are smokers and where the woman is under 35 and has a BMI score of less than 30.

The CCG knows that the effectiveness of IVF declines as women get older, with chances of success decreasing over the age of 35. It also knows that chances of success are reduced if either partner is a smoker or if the woman is overweight.

The CCG does not feel it could abolish funding for IVF services altogether, but recognizes that there are substantial savings to be made by imposing conditions on, for example, age, lifestyle and existence of living children, as well as on the number of cycles of treatment it funds. Patients in other CCG areas clearly are used to these terms and few complaints seem to have been made. In this CCG however, individual GPs are worried about the effect any move to restrict referrals will have on patients' perceptions of them, and how they will justify any such decision to potential parents who cannot conceive naturally.

What are the main issues of social values that arise here?

What should the CCG do, and what should it take into account in its deliberations?

Useful Web Links

Klein, R and Maybin, J (2012) 'Thinking about Rationing' (London: King's Fund)
Available at: www.kingsfund.org.uk/document.rm?id=9528

Clark, S and Weale, A (2012) 'Social Values in Health Priority Setting: A Conceptual Framework', Journal of Health Organisation and Management 26:3

Available at:

<http://www.emeraldinsight.com.libproxy.ucl.ac.uk/journals.htm?issn=1477-7266&volume=26&issue=3>

UCL Social Values and Health Priority Setting Research Project

See: <http://www.ucl.ac.uk/socialvalues>

Catalogue of Cases on Social Values and Health Priority Setting

Available at:

<http://www.ucl.ac.uk/socialvalues/case-studies>