Regulating for the public good

HTA review of the year event
15 July 2014
Regulating for the public good

Sharmila Nebhrajani
HTA Chair
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<th>Time</th>
<th>Event Description</th>
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<tr>
<td>14.00</td>
<td>Introduction: <strong>Sharmila Nebhrajani</strong>, Chair, HTA</td>
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<td>14:15</td>
<td>Keynote speaker: <strong>Dr Katherine Rake</strong>, Chief Executive, Healthwatch</td>
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<td>14:30</td>
<td>Question and answer session</td>
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<td>14:40</td>
<td>Panel discussion: Regulating for the public good</td>
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<td>• <strong>Professor Jim Smith</strong>, Deputy Chief Executive and Chief of Strategy, Medical Research Council</td>
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<td>• <strong>Christine Braithwaite</strong>, Director of Standards and Policy, Professional Standards Authority</td>
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<td>• <strong>Maggie Wilcox</strong>, patient advocate</td>
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<td>• <strong>Sally Sykes</strong>, Executive Director, Parliamentary and Health Service Ombudsman</td>
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<td>• <strong>Sarah Bedwell</strong>, Director of Regulation, HTA</td>
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<td>15:10</td>
<td>Table discussion and feedback</td>
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<td>15:45</td>
<td>Closing remarks: <strong>Dr Alan Clamp</strong>, Chief Executive, HTA</td>
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Regulating for the public good

Dr Katherine Rake
Chief Executive, Healthwatch
Regulating for the public good
Dr Katherine Rake OBE,
Chief Executive, Healthwatch England
Stronger together

National insight → National impact
Local impact ← Local insight
Our impact

A national voice for consumers

An active and inclusive network

A consumer view on complaints

Using our advisory powers
Working with our regulatory partners: Healthwatch involvement in the CQC inspection process

- **Registration and surveillance**
  - Healthwatch shares insight, data and intelligence across both organisations to improve the identification of risk across the system

- **Pre and during inspections**
  - Healthwatch provides CQC inspectors with a community narrative and context ahead of inspections and updates the community during inspections

- **Post-inspection and improvement journey**
  - Healthwatch are part of the improvement journey, contributing to ensuring action is taken in light of the inspection report and ratings
Healthwatch Bradford

Uncovered serious concerns around overcrowding, staffing and lack of privacy at Bradford Royal Infirmary A&E, leading to an inspection by the CQC
The importance of candour

• It is important that staff feel able to ‘blow the whistle’, but this is a last resort

• We know that openness and honesty within organisations is crucial to ensure that early warning signals are picked up, and to prevent the kinds of events we have seen in Mid Staffordshire and Alder Hey

• A statutory duty of candour is an important step but more needs to be done to strengthen it

• There is also work to be done to ensure that the public understand the duty of candour
Supporting whistle-blowers

• New ‘fundamental standards’ legislation

• This legislation will introduce criminal penalties for failing to meet some of them

• Robert Francis QC is chairing Independent Review on Whistleblowing in the NHS review, looking at how to create culture of openness and honesty
Thank you for listening
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Professor Jim Smith
Deputy Chief Executive and Chief of Strategy, Medical Research Council
Research perspective on public/patient engagement

Jim Smith
Director, MRC National Institute for Medical Research
Deputy CEO and Chief of Strategy, Medical Research Council
Strategic aim 2—Research to People

- We have a duty to engage with the public and other groups, to give an account of our research and to ensure that public views and concerns are reflected in our decision-making

- Objective: To enhance engagement and communication with our scientists and partners, policy makers and parliamentarians, and the public
Human Developmental Biology Resource

Welcome

The MRC-Wellcome Trust Human Developmental Biology Resource (HDBR) is organised from two sites: the Institute of Genetic Medicine, Newcastle, and the Institute of Child Health, London. The HDBR is an ongoing collection of human embryonic and fetal material ranging from 3 to 20 weeks of development. Tissue, slides, RNA/DNA and tissue arrays are available to the International scientific community. Material can either be sent to registered users or our In House Gene Expression Service (IHGES) can carry out projects on user's behalf, providing high quality images and interpretation of gene expression patterns. Gene expression data emerging from HDBR material is added to our gene expression database which is accessible via our HUDSEN (Human Developmental Studies Network) website.

For further information about the Human Developmental Biology Resource or the In House Gene Expression Service (IHGES), please contact us.

If you're looking for the HDBR logo or acknowledgement slide, they can be downloaded from our FAQ section here.

News & Publications: September 18, 2013 - NEW PUBLICATION - The Early Fetal Development of Human Neocortical GABAergic Interneurons

A collaboration between:

Institute of Genetic Medicine, International Centre for Life, Newcastle upon Tyne NE1 3BE - email: hdbrer@ncl.ac.uk
UCL Institute of Child Health, 30 Guilford Street, London WClN 1EH - email: hdbr@ucl.ac.uk
The power of engagement

Aims

• To investigate, with the public, the acceptability of donating samples for research and attitudes to different models of consent

• Explore attitudes in the NHS to collecting samples for research
Conclusions

- High general level of support for use of samples
- Consent viewed as important
- Most of those surveyed wanted to retain control over the use to which their samples were put
- But those involved in focus group discussions were happy with less restrictive consent models
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Christine Braithwaite
Director of Standards and Policy, Professional Standards Authority
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Maggie Wilcox
Patient advocate
Maggie Wilcox
A Patient Perspective

HTA Annual Review event
15 July 2014
The public does understand the need for research to improve outcomes for cancer patients and willingly donates to funding.

However, public understanding of the need for human tissue in this research is minimal.

Understanding the need would make tissue donation as “normal” as blood donation.
Informed Patient View...

We feel that there is an important role for PPI
In training for professionals so that they feel
more comfortable when approaching
potential donors
And raising public awareness of the need for
tissue donation
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Sally Sykes
Executive Director, Parliamentary and Health Service Ombudsman
Our role and approach
Our role: Leading improvements in the complaints system

• **Casework**- creating more impact for more people.

• **Ombudsman reform**- a more effective Ombudsman’s service.

• **Research and insight**- sharing learning and encouraging continuous improvement.
When we receive a complaint we have to consider....

- Is it in remit, ie; can we look at the complaint by law?
- Is the complaint properly made?
- Has local resolution been completed?
- Time bar (1 year) and alternative legal remedy
- Has there been maladministration, service failure or failure to provide a service?
- Is there unremedied injustice or hardship?
Interventions, resolutions and outcomes

• Intervention occurs when the body complained about agrees to take action to resolve the complaint without the need for an investigation

• Resolutions will normally focus on obtaining a clear, simple and achievable remedy for an individual

• Outcomes may include: apology, acknowledgement of error and/or possible financial compensation
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Sarah Bedwell,
Head of Regulation, HTA
If a member of the public donates their body, tissue or organs for medical research, transplantation or training, we make sure their wishes are respected.

Our regulation ensures:

- Proper consent is given for the use of organs, tissue and cells
- High quality tissue and cells are used for treatment
- The safety and quality of organ transplants
- Research into causes of and treatments for illnesses
- Mortuaries operate to the highest standard
Background and context

• HTA future secure after ALB review
• 2013 evaluation showed that whilst we do a lot of things well, we can improve public confidence in our work
• Francis report; increased transparency and candour
• HTA has worked to involve/engage the public in our work – in 2014-17 our focus is on improving confidence and ensuring awareness amongst the interested public
• Interested public - those who have been or may be in contact with the services that we regulate, and public groups who have or may have an interest in our work
HTA public focus in 2014/15

- New public section of the website
- Making sure the information we publish is transparent and accessible
- Campaigns/awareness raising on issues of concern to the public
- Discussion about how to increase public involvement in our regulation
- How we share information with the public and other organisations
Questions for discussion

1. How could the HTA increase public and patient involvement in its regulation of establishments or activities:
   a) where the public has a choice in which service they use and those where they don’t
   b) that don’t provide a direct service to the public

2. What information should the HTA publish about the establishments it licenses? And how should we do this?
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Dr Alan Clamp
Chief Executive, HTA
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Thank you