

EMERGING SCIENCE AND BIOETHICS ADVISORY COMMITTEE (ESBAC)

ESBAC FORUM - SUMMARY

INTRODUCTION

ESBAC held its first open Forum event for stakeholders on Monday 13 May at the Department of Health, Skipton House.

PRESENTATION SUMMARIES

ESBAC: background, role and where are we now?

Dr Mark Bale (Director of Health Science and Bioethics, Department of Health)

- Dr Bale provided the background to ESBAC being established as an expert committee in 2012.
- ESBAC's role was described and its multidisciplinary membership highlighted, including ex-officios and representation from all UK health departments.
- In selecting topics for consideration, the criteria taken into account would include relevant, applicable to policy, timely, realistic, and unique.
- To date ESBAC has held three full Committee meetings and smaller focus groups have scoped out potential work in three areas. An approach to horizon scanning has also been developed.
- The purpose of the Forum was to 'sense-check' the proposals with stakeholders and to seek feedback on the horizon scanning approach.
- In working with other bodies, and recognising its place in the wider landscape where a range of organisations are involved in ethics, different approaches may be taken to partnership working and engagement is likely to be topic specific. Flexibility in approach will be important, given limited resources.

ESBAC's Horizon Scanning function

(Professor Peter Littlejohns & James Peach, ESBAC Members)

- Professor Peter Littlejohns introduced the role of ESBAC's Horizon Scanning Steering Group (HSSG), its membership and proposed method of working.
- ESBAC would essentially act as a receiver of referrals, rather than 'another' horizon scanner. The HSSG would seek referrals from key organisations and ESBAC Members via the completion of a pro-forma and topics/issues highlighted would then be cross-referenced with ESBAC's terms of reference.
- James Peach outlined the pro-forma and explained that areas identified should (i) involve a new advance in health-related science and/or clinical application (ii)

raise a relevant ethical, legal, social or economic issue (as set out in ESBAC's terms of reference) and (iii) be applicable to policy-making.

Keynote speech

(Professor Dame Sally Davies, Chief Medical Officer)

- CMO was impressed by the calibre of the Membership and also the enthusiasm and commitment that both the Chair and Members have demonstrated in the short time the Committee has been up and running
- Encouraged stakeholders to engage with and help shape the Committee's work going forward as the Committee firmly establishes itself
- Provided a brief update on the 100,000 genomes work (more to follow in the coming weeks), explaining why the ESBAC Genomics Focus Group had been put on hold, to avoid any duplication.
- CMO referred to the new Government Chief Scientific Adviser, Sir Mark Walport, who highlighted 5 key themes for scientific advice in Government at the recent Centre for Science and Policy Annual Conference:
 - Ensuring that scientific knowledge translates to economic growth
 - Strengthening infrastructure resilience for the engineered world of transport, energy, the built environment and telecommunications and also the natural world
 - Underpinning policy with evidence
 - Harnessing science for emergencies
 - Providing advocacy and leadership for science
- Being CMO presents a strong opportunity to interpolate into the process science and evidence.
- CMO outlined her vision for ESBAC, including:
 - An interactive Committee that draws on the full range of its Members' expertise and the expertise of others (cross-fertilisation).
 - Operating in accordance with government rules for Scientific Advisory Committees (SACs)
 - Contributing to making a difference in science and evidence.
 - ESBAC specifically tasked with looking at emerging healthcare developments and their ethical, legal, social and economic implications
 - Highlighted the uniqueness in linking science with ethical, legal and social, economic perspectives
 - Benefits of ESBAC's varied membership – and its interdisciplinary lens to examine problems and Members being able to contribute a variety of perspectives to any work undertaken
 - Inevitably there will be things that may be interesting that the Committee will not be able to do. ESBAC will not cover work that others are doing.
 - Consideration of what is important now and in the future

- Important contribution to make, but prioritisation will be essential – bounded by prioritisation and resources, recognising that ESBAC is not a ‘commission’.
- Importance of ESBAC Members scanning, and using their networks and identifying what could be important to CMO and Ministers.

ESBAC’s emerging work strands: Focus Group proposals

Dementia (Diana Sternfeld, ESBAC Member)

- The size of the dementia challenge was outlined using facts and figures from the Alzheimer’s Society, including highlighting that one in three people will die with dementia.
- Brief outline of how dementia fits with ESBAC’s topic selection criteria
- The proposed work aims to develop a broad landscape of the scientific advances being made in the diagnosis for dementia and the direction in which therapeutics responses are developing
- It would then explore the ethical, legal, social and economic issues raised by the future scenario of being able to diagnose the presence of dementia earlier on in the disease progression and in younger age groups than is currently possible.
- The ethical imperative underpinning this work is the need to prepare individuals and society as a whole for making qualitatively different decisions in relation to the diagnosis and treatment of dementia.

Innovative governance (Julian Hitchcock, ESBAC Member)

- Reference was made to the tensions and interactions arising in development of appropriate and adaptive regulatory responses to emerging biomedical sciences.
- The competing governance drivers were outlined including, improving public health, efficacy and morality
- How to improve and expedite responsible translation, without compromising safety, in the UK
- The objectives were outlined as:
 - Identifying governance opportunities for simplifying, rationalising and expediting the responsible translation of biomedical innovation
 - Developing an integrative framework to guide and optimise regulatory and policy decision-making; taking into account various interactions
 - Assessing how regulation can better reflect changes in risk
 - Validating the framework using test cases

Technologies to optimise treatment (Professor Sir Alasdair Breckenridge)

- A project based primarily on emerging technologies which might have a direct effect on patient treatment.
- Instead of merely using more technology, we should aim to optimise the use of the technology in question.
- Delivery of innovation and innovation of delivery
- Three types of technology had been considered by the Focus Group:
 - technologies to improve patient adherence
 - technologies to optimise treatment in other ways
 - technologies that monitor overall health status (out of scope)
- Examples of technologies to improve adherence range from the simple (email reminder) to the sophisticated (smart chips in medicines)
- Ethical aspects include:
 - Personal freedom v social responsibility
 - Consent to treatment
 - Health professional/patient relationship
- Examples of technologies to optimise treatment in other ways include blood sugar monitors, disposable delivery systems for devices, smart syringes for auto injection
- Proposed deliverables:
 - Workshop with experts to develop ideas
 - Peer reviewed report or framework including map of technology examples and framing of the issues raised.

SUMMARY OF FEEDBACK, COMMENTS AND DISCUSSION

Horizon scanning:

- Discussion around how open the horizon scanning referral system would be for people to submit suggestions, how to avoid duplication (how would people know if someone else had already submitted a particular issue).
- Peter Littlejohns explained that it could not be a completely open system (to avoid being flooded with suggestions and not being able to manage expectations, given limited resources). Instead, the approach would be to invite organisations to submit referrals so as to funnel suggestions to ESBAC in a way that was more likely to be manageable.
- Transparency in filtering topics was recognised as important. It was envisaged that completed forms would be assessed by the Horizon Scanning Steering Group initially, and a report that included all pro-formas received would be prepared and submitted to ESBAC before each of their Committee meetings in order to agree what action is required.

Dementia:

- Care needs and quality of care was raised as an important issue.
- What are the emerging care technologies e.g. 'smart' home monitoring, social network technologies
- Use of robotics in social care
- Recommendation that ESBAC joins the Dementia Action Alliance
- Broad governance around technologies for early detection more generally
- The list of potential stakeholders for this work is lacking a nutrition stakeholder
- Should 'prevention' or 'delay of onset' be in scope of the project?
- Would like to see strong alliance with PM's Dementia Challenge Research Group
- Ethical consideration of informed consent to early diagnosis and impact on life and restrictions
- How to chisel out ESBAC's contribution in this area

Innovative Governance:

- Suggestion that the definition of regulation used was limiting (e.g. did not include the issues around patenting, funding etc).
- Think more about governance issues – 'democratic' should be stated in the drivers
- The work should build on other frameworks (e.g. Responsible Research and Innovation EU framework)
- Take a wider view of regulation. Be realistic about the global context. Take notice of the 'ungovernable' e.g. how internet/social networking can circumvent. Seek to 'export' good UK models (e.g. research ethics practice)

Technologies to Optimise Treatment:

- Consideration of patient-led innovation?
- Improving adherence was recognised as important
- Emphasis is on helping patients; not 'snooping'
- Other than the 'smart chip' drugs are these technologies new?

General:

- Suggestion that when ESBAC revisits genomics it should look at it more broadly (e.g. proteomics) and consider what other technologies might be important.
- Challenge of securing sustainability in a policy context (moving goalposts with change of administration)

CLOSING COMMENTS

- All comments and feedback received will be reviewed as part of taking the work forward
- Attendees were encouraged to complete the comments form and indicate if they would like to be involved as work progresses.