

AGENDA ITEM 4

Emerging Science and Bioethics Advisory Committee

Discussion paper by the Secretariat

Horizon scanning proposal

BACKGROUND

1. At its first meeting on the 17 July, ESBAC discussed horizon scanning as an essential aspect of its role and as such, it is reflected in ESBAC's Terms of Reference. Members agreed that horizon scanning would include an international dimension. However, the actual horizon scanning process was not discussed in any detail, other than recognising that ESBAC will not have the resources to commission horizon scanning externally.
2. The Committee is now asked to discuss a proposal by the Secretariat on how the horizon scanning function may be set up and run. The proposed approach is not horizon scanning in the conventional sense. Instead, it reflects ESBAC's spirit of providing a networking forum to consider and develop coordinated advice across the wider science, health and academic communities, to help discuss priorities in response to new developments. In doing so, it will be able to collect valuable intelligence on emerging science for healthcare. In the proposed approach there is more emphasis on input from Members and their networks and less on literature searches.
3. The proposal considers the architecture and mechanism for information collection and evaluation. Each aspect is flexible so it can be adapted following Members' suggestions and in the longer term adapted to better suit ESBAC's evolving needs.
4. Once agreed this proposal will develop into ESBAC's Horizon scanning protocol and will be published on the website alongside ESBAC's Code of Practice and Terms of Reference.

HORIZON SCANNING

Definition

5. In the context of this paper, the definition by Chief Scientists Advisers Committee for horizon scanning is used: “the systematic examination of potential threats, opportunities and likely developments including but not restricted to those at the margins of current thinking and planning. Horizon scanning may explore novel and unexpected issues as well as persistent problems or trends.”

Purpose

6. To gather evidence, detect signals and trends and consider their implications in healthcare science to advise ESBAC on emerging developments and their ethical, legal, social and economic implications, relevant to ESBAC’s remit. This will provide strategic early warning, challenge and test current policy thinking by acknowledging future uncertainties.

Scope

7. The suggested scope is to:
 - Gather information, detect signals and trends to identify emerging technologies in healthcare that could have implications for the health system.
 - Consider ethical, legal, social and economic implications of the technologies identified and gather further information as required.
 - Identify any gaps or areas of duplicated effort.
 - Take part in networks to gather intelligence.
 - Report to ESBAC and make recommendations on emerging issues which could be of immediate, medium or long term interest.
 - Review the effectiveness and purpose of the horizon scanning methodology.

Questions:

- 1) Do Members have any comments on the above purpose and scope?
- 2) Are there any other suggestions?

Architecture

8. No single existing horizon scanning activity has yet been found that would cover ESBAC's broad remit. It is therefore advisable to have a multi-prong approach to ensure maximum coverage of the information being collected. Existing horizon scanning activities could assist ESBAC to gather the information it requires, but would not be sufficient on its own. A broad outline of the structure and mechanism to collect information is presented in Annex A.
9. As highlighted in Annex A, sources of information identified so far are:
 - ESBAC Members reporting intelligence from their own connections and expertise.
 - Committees. Information collected via cross-membership of ESBAC members and from the Department of Health (DH) internal networks. A list of Members already sitting on Committees of interest and a list of DH Scientific Committees are in Annex B.
 - Through Member attendance at events such as workshops, conferences and meetings. Members may report from events they have attended or recommend attendance to the Secretariat. Forthcoming meetings identified so far:
 - i. MHRA and the Academy of Medical Sciences workshop on the regulation of regenerative medicine using stem cells.
 - ii. AMS stratified medicine symposium, Oct 2012
 - Policy proposals from DH or from other Government Departments. This information will usually come from policy officials networks.
 - Existing Horizon scanning networks. No single existing horizon scanning activity has been found that is likely to cover all aspects

that concern the work of ESBAC. Relevant horizon scanning activities identified so far:

- i. Go-Science's cross-departmental horizon scanning network
 - ii. National Institute for Health Research (NIHR) Horizon scanning Centre
 - iii. EUROSCAN.
- Links with key organisations via Members and the Secretariat. A list of key organisations is in Annex C.
 - The DH Library have been asked to set up a number of regular current awareness searches and alerts as outlined in Annex D which will be fine-tuned as appropriate depending on the value of the information returned over an initial period. The results output is currently being collated by the Secretariat, but given the volume, is not manageable in the long term. In isolation, reliance on literature searches and alerts cannot be expected to yield all the information required but will be one of many useful sources. In particular, when ESBAC's workplan is underway it may be possible to commission the DH Library to conduct an ad-hoc, extensive literature search on the particular topic that a working group is focusing on.

10. It is proposed that the timescale for horizon scanning is left intentionally open and is considered an ongoing activity given the area of concern, emerging science, is very broad and could lead to many applications. Members are invited to consider a trade off between the value of early uncertain information, versus the value of certain, but late information which may be of limited relevance to decision makers due to implementation of earlier decisions.

Questions:

- 1) Are there are other Committees not listed in Annex B that should be linked to the work of ESBAC? Do Members participate in any other relevant networks?
- 2) Are Members, in particular those named in Annex B, willing to provide regular updates from the meetings and events they attend to the Secretariat for rapid cascading to all ESBAC members as appropriate?

- 3) Are there any other horizon scanning activities not already mentioned that could be of interest? Are there any other activities on going or overlapping?
- 4) Members are invited to suggest additional one off or on going events in the UK or elsewhere, which could be beneficial to ESBAC's work.
- 5) Is the list of key organisations in Annex C relevant and sufficient? Others may be added as new topics are identified.
- 6) It is expected that by default the information gathered will include international developments whether scientific or regulatory. Are Members satisfied that the provisions made are sufficient?
- 7) Are Members satisfied that the proposed horizon scanning mechanism is structured to cover all relevant areas (including sciences, legal, social sciences, economics)?
- 8) Are members aware of scholarly searches similar to those that the Secretariat is currently running within their organisations and/or elsewhere to avoid duplication of effort?
- 9) Do Members have any suggestions on the timescale for horizon scanning?
- 10) Any other points?

Process

11. As it is collected, the wealth of information from the routes identified above, will have to be evaluated for validity and relevance, trends will need to be monitored and priorities assessed (aided by scoring tools if appropriate) to make recommendations to ESBAC.
12. The limited Secretariat for ESBAC cannot process such large quantities of information nor do they necessarily have the required expertise in all the areas required. Ideally each area of interest could be championed by a Member, for example, stems cells, legal framework, etc.
13. It is therefore suggested that a group be created with the expertise to collect and then appraise the relevant information. The Secretariat could support this group by feeding in relevant results output, as appropriate, from the current awareness searches and alerts it commissions from the

DH Library. This could be a Horizon scanning Working Group or Forum or similar set up.

14. If it is agreed that a Working Group should be set up, it will have the opportunity to refine its own ways of working further. Such a group could initially meet in between ESBAC meetings either in person or via teleconference and will have support from ESBAC Secretariat.

Questions:

- 1) Do Members agree with the proposed horizon scanning working group or network? Are there any other suggestions for alternative arrangements?
- 2) If ESBAC decides to have a horizon scanning working group, would it be appropriate for the Chair to be appointed from ESBAC's membership? Any other suggestions?
- 3) Do any Members wish to take part if a horizon scanning group/forum is set up? Membership could be drawn from key stakeholder organisations identified in Annex C and from the relevant existing horizon scanning centres.
- 4) What other form could this work take and how should such information be processed?

RISK

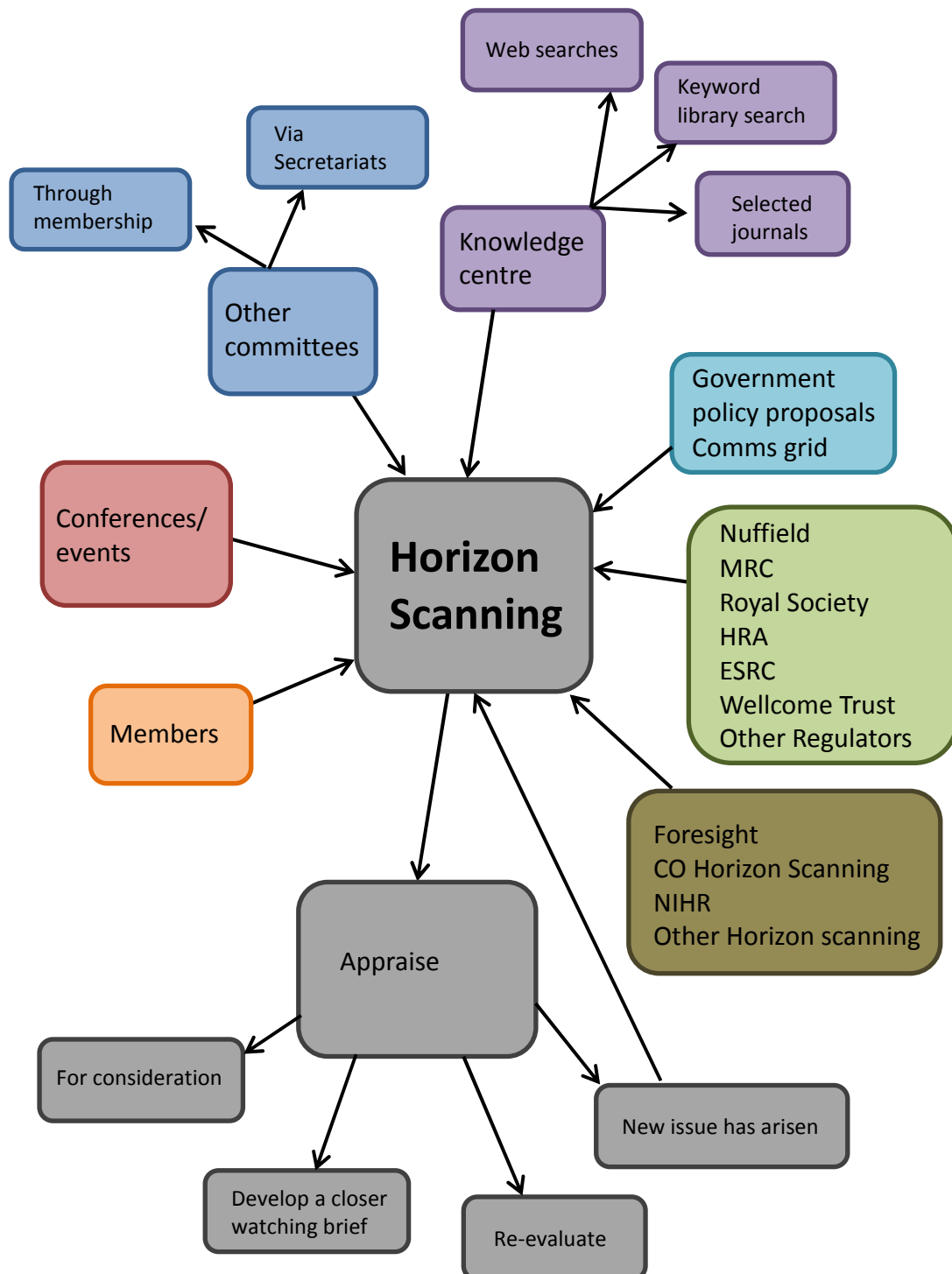
15. It seems necessary to consider the prominent risks involved with the horizon scanning activities discussed and consider mitigation strategies from the onset.
16. As already mentioned horizon scanning for ESBAC is highly dependent on individual Members' commitment and availability. This is the highest risk identified so far. However, the time requirement from Members should not be too onerous as Members are asked to share intelligence they already hold and comment on papers.
17. To enable this approach to deliver the information needed it is essential that Members are committed to this activity (in line with the Code of Practice) and Members keep abreast of developments in health related biosciences and biotechnologies and inform the Secretariat, who will then collate the information.

18. Horizon scanning is dependent on the quality of the information collected. Since ESBAC's remit is very broad, it could also suffer from being overwhelmed by too much information and/or that the information collected is not sufficiently sensitive as the searches would have to be very broad. It is therefore imperative that horizon scanning activities are set up with a clear and precise focus.

Questions:

- 1) Are there any other risks or further mitigation strategies that should be highlighted?

Annex A



Annex B

List of Committees and organisations which Members already sit on

ESRC Genomics Policy and Research Forum	Joyce Tait	
Medical Research Council	John Savill	Chief Executive
	Wendy Ewart	Deputy Chief Executive and Director of Strategy
	Bobbie Farsides	Brain Bank Network Steering Committee
	Nick Lemoine	Molecular & Cellular Medicine Board
	Duncan McHale	Pharmaceuticals Forum
	Andrew Baker	Development Pathways Funding Scheme
Nuffield Council on Bioethics	Hugh Whittall	
Wellcome Trust	Katherine Littler	
The Royal Society	Julie Maxton	
Technology Strategy Board	John Brown	Governing Board Member
	James Peach	Stratified Medicine Innovation Platform
Human Fertilisation and Embryology Authority (HFEA)	Bobbie Farsides	Donation Strategy Group
Medicines and Healthcare products Regulatory Agency	Alasdair Breckenridge	Chair
	Bella Starling	Patient and Public Engagement Expert Advisory Group
National Institute of Health Research Clinical Research Network	Nick Lemoine	
Academy of Medical Sciences	Rachel Quinn	Director of Medical Science Policy
	Helen Munn	Executive Director
	Andrew Morris	
	Nick Lemoine	

ESBAC 02(04)(01)

PHG Foundation	Julian Hitchcock	
Scottish Stem Cell Network	Joyce Tait	
The Association of the British Pharmaceutical Industry	Duncan McHale	
	Stephen Whitehead	Chief Executive
	Louise Leong	Head of R&D
	Dipti Amin	
Bioindustry Association	Diana Sternfeld	
International Risk Governance Council	Joyce Tait	
Society of Biology	Louise Leong	
CellFate	Julian Hitchcock	
Independent National DNA Database Ethics Group	Madeleine Colvin	
Research Ethics Committee (King's College Hospital)	Madeleine Colvin	
Roslin Foundation Board	Joyce Tait	
	John Brown	
Scientific Advisory Board of the Institute of Technology Assessment (Vienna)	Joyce Tait	
Scottish Science Advisory Council	John Brown	
Liberty Council	Madeleine Colvin	
Life Sciences Industry Advisory Board (Scot)	John Brown	
Scottish Life Sciences Association	John Brown	
UK Biobank	Wendy Ewart	
Scottish Executive Health Department eHealth Strategy Board	Andrew Morris	
Donation Ethics Committee	Bobbie Farsides	
Institute of Medical Ethics	Bobbie Farsides	
British Medical Association	Bobbie Farsides	Ethics Committee
BPAS Research Ethics Committee	Bobbie Farsides	

ESBAC 02(04)(01)

Core Scientific Advisory Board	Nick Lemoine	
Gene Therapy Advisory Committee	Nick Lemoine	
	Andrew Baker	
Council of the Society for Genomic Policy & Population Health	Stuart Hogarth	
Brighton and Sussex University Hospital Trust (BSUHT) Clinical Ethics Committee	Bobbie Farsides	
BSUHT Organ Donation Committee	Bobbie Farsides	
Durham Centre for Ethics, Law, and the Life Sciences	David Townend	
European Industry (EFPIA) Pharmacogenetics Group	Duncan McHale	
International Conference on Harmonization genomics group	Duncan McHale	
Standards Committees of the Royal College of Physicians and the Faculty of Public Health	Peter Littlejohns	
Helex Advisory Board	Julie Maxton	
Medical Toxicology and Information Services	Dipti Amin	
Externam Advisory Group, PEALS	Hugh Whittall	
FRSA	Hugh Whittall	
Francis Crick Institute	Wendy Ewart	
Pfizer European Oncology Advisory Board	James Peach	
NHS Tayside Board	Andrew Morris	
Diabetes UK	Andrew Morris	
American Diabetes Association	Andrew Morris	
Association of Physicians	Andrew Morris	
Royal College of Physicians of Edinburgh	Andrew Morris	
Royal College of Physicians of Glasgow	Andrew Morris	
Royal Society of Edinburgh	Andrew Morris	

ESBAC 02(04)(01)

Translational Medicine Research Collaboration	Andrew Morris	
Generation Scotland Scientific Committee	Andrew Morris	
The Health Foundation	Andrew Morris	
Health Science Scotland	Andrew Morris	
Wellcome Trust/MRC/ESRC/CR UK Expert Advisory Group on Data Access	Andrew Morris	
Council of the British Society for Human Genetics	Angus Clarke	
Council of the Association of British Neurologists (ABN)	Neil Scolding	

Annex C

Key Organisations for Horizon scanning activities

National Institute for Health and Clinical Excellence (NICE)
BBSRC
Association of Medical Research Charities
NHS Involve (patient engagement)
National Institute for Health Research (NIHR)
Information Commissioner
Parliamentary Committees at both UK and European level
European Group on Ethics
European Regulations Agency
US Food and Drug Administration (FDA)
Scottish Council on Human Bioethics
UK Medicines Information
UK PharamScan
National Prescribing Centre
Health and Safety Executive
Health Protection Agency- Rapid review panel
National Genetics Reference Laboratories
BIS Foresight Centre
International Information Network on New and Changing Health Technologies
International Network of Agencies for Health Technology Assessment
Health Technology Assessment Database
Health Technology Assessment International

Annex D

Mailing lists subscribed to:

Centre for Genetics and Society
ESRC Genomics Network
Nuffield Council on Bioethics
Wellcome Trust
Bioedge
The US Presidential Commission for the Study of Bioethical Issues
The Royal Society
Royal Society of Medicine
Bionews
PHG Foundation
Science and Innovation Network (BIS)
International Risk Governance Council
BioSciences Knowledge Transfer Network
EuroScan
National Institute of Health Research (NIHR) Horizon Scanning Centre
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Scientific Reports Weekly
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Current Biology
Trends in Biochemical Sciences
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