



**Report of the First Meeting of the Ethics and Standards Advisory Panel
(ESAP)
held on Monday 4th September 2006 at 2pm at
BMA House, Tavistock Place, London WC1H 9JP.**

Present:

Martin Bobrow (Chair) (MB)	}	The Panel
Neil Formstone (NF)		
Ruth Chadwick (RC)		
Nick Ross (NR)		

In attendance:

Brian Clark – onCore UK (BJC)
Sarah Dart – onCore UK (SD)
Anne Carter – onCore UK (AC)

Background

The purpose of the meeting was to convene a body to provide advice on ethical matters to the management and Board of Trustees of onCore UK. The members of the Panel had each been invited and had kindly accepted the invitation to fulfil this function.

Each of the attendees introduced themselves to the rest of the Panel and detailed their background and interests and experience in the area of medical ethics relevant to the work of onCore UK.

BJC introduced the Panel to the background of onCore UK and its progress to date.

Terms of Reference

The Panel were presented with draft Terms of Reference for membership of the Panel. The Panel discussed at length the provisions of the document and how these would impact the Panel working successfully with onCore UK.

The Panel suggested amendments to the Terms and requested that onCore UK amend the document accordingly and recirculate by email for comments.

The Panel agreed to adopt the name "Ethics and Standards Advisory Panel" and encouraged onCore UK to publish the names of the Panel Members, a report of each meeting and other relevant documents relating to the work of the Panel on the onCore UK Website.

Ethics and Standards Statement

The Panel considered the Interim Ethics and Standards Statement which had been previously drafted by onCore UK. onCore UK had been functioning in line with this interim statement for about 1 year prior to this meeting. The Panel were asked to comment on the content of the statement.

The Panel discussed at length the contents of this document and suggested some minor amendments. The Panel felt it was important for onCore UK to finalise this document as soon as possible and so requested that an amended document be circulated to the Panel by email for immediate comment and approval.

Guiding Principles for the Confederation of Cancer Biobanks

The Panel were asked to advise on the contents of a document which had been produced to support a new Confederation of Cancer Biobanks that was being created under the auspices of the National Cancer Research Institute and it was noted that onCore UK would be a founder member. The Confederation brought together a group of Cancer Biobanks to harmonise operations, procedures, policies and best practice in the UK. It was noted that the efforts in the UK were also linked to similar efforts on an international scale. The first meeting of the Confederation had taken place in June 2006, where this document had been discussed by the founding members. It was anticipated that the final content of the document would be agreed soon at a meeting in October where the Confederation would also be officially launched.

The Panel discussed how onCore UK were interacting with other organisations, in particular, organisations in Europe. The Panel felt it was important that onCore UK look beyond the UK and seek to interact with its European counterparts. BJC explained that onCore UK was a founding member of the Marble Arch Working Group whose remit was to harmonise best practice and accreditation of biobanking on a global scale.

The Panel made some suggested amendments to the document and asked that the document be amended and that the document adopted by the Confederation be recirculated to the Panel.

Draft Patient Consent Form and Patient Information Form.

The Panel were asked to consider a draft of a form which would be used with patients who were being asked if they would like to donate samples to onCore UK. The form was designed to be read whilst the patient was accompanied by a nurse or other healthcare professional. The form was designed to inform the patient about onCore UK, what it was created to do, what would be involved in donating, how the samples would be used, and to answer any other questions a patient may have and stimulate discussion between the Patient and the Nurse. Once this process was complete the patient would be asked to give their consent to donate to onCore UK.

The Panel felt that the form in its present state was too long, complex and could be re-ordered. The Panel considered that the form needed to be much simpler and set out first and foremost exactly what the patient was being asked to do. The Panel suggested that the form be shortened and that simpler language be used to explain the process.

The Panel believed it was important that patients be given as much information as possible upfront so they could make an informed decision. At the same time it was important that onCore UK emphasise what exactly contributing to onCore UK would mean to a patient. The Panel felt that patients should be told directly that they would not benefit from their own donation – the donation they were giving was for future the benefit of future patients.

The Panel suggested amendments to the documents and asked that the document be amended and recirculated by email for comments.

General Matters

The Panel requested that papers for the next meeting be sent by email and in hardcopy by post.

The Panel were happy to hold meetings in Central London.

The Panel suggested holding meetings every 6 months but in the initial stages of the Panel to hold meetings more frequently. The Panel requested that a meeting be set up in December 2006 or in January 2007.

Topics to be included in the next meetings agenda:

- Access Policy
- ESAP Terms of Reference
- Membership of the Panel
- Patient Consent Forms

There being no further business the meeting closed.