Minutes of the Ethics of Reproductive Testing and Fetal Therapy SIG

Wednesday, 13 July 2016
Berlin, Germany

Number in attendance: 22

At the SIG Ethics business meeting, there were 22 attendees including genetic counsellors, clinical geneticists, gynaecologists, laboratory specialists and ethicists, as well as two members of the board of ISPD. It was good to meet and see each other (again) and to think about possible activities. Unfortunately, due to extended conference sessions, we had only a brief half hour for this meeting. As there was not enough time for much discussion, attendees were asked to respond to this report with specific suggestions (see under Agenda, below).

The SIG Ethics in 2015-2016

In Washington (see report of SIG meeting on the ISPD website) we thought about possible topics to be addressed by this SIG and identified the following tasks: 1. developing educational/informational content for the website; 2. contributing ideas (topics/speakers) for the next conference; 3. developing a pre-congress course (PCC) for the next conference, ideally together with another SIG.

#1: this is something that still needs to be taken up, and would seem to require a larger group of people wanting to contribute (see also under ‘deliverables’ below);
#2: proposals were made to the board, but opportunities to provide much input seemed scarce;
#3: a detailed proposal of lectures and speakers for a PCC for Berlin on one of the topics suggested in Washington (‘ethical aspects of fetal therapy’) was worked out together with the SIG fetal therapy. However, the board feared a low uptake and therefore rejected our proposal.

Present coordinators are Wybo Dondorp (Associate Professor of Biomedical Ethics at Maastricht University, the Netherlands, and Ainsley Newson (Associate Professor of Bioethics at the Sydney School of Public Health, Australia). The board has announced terms of reference for transparent and democratic replacement for all ISPD SIGs and working groups.

Agenda for new activities

The board asked all SIGs to follow a specific agenda in their discussions, focussing on deliverables, topics to be considered for SIG-activities and gaps in the area of interest of the relevant SIG. The common aim of all SIG activities should be Education.
With regard to **deliverables**, the board asked us to consider the following possible activities:

a) write for Prenatal Perspectives, the monthly newsletter of ISPD. This could be very brief pieces announcing or reporting activities of interest for the wider ISPD community.

b) make proposals for ISPD Position Statement activities, including topics, authors, timetable etc.

c) review the website and provide website content. This may refer to the ISPD website as a whole, but more specifically to the information on the SIG pages.

d) prepare content for member-wide webinars on hot topics, at least one per year: list topics and identify presenters.

e) make proposals for preconference courses (see attached call, deadline Sept 15).

f) name a representative to work with the Membership Committee to retain and attract new members from similar discipline areas

#c Relevant information on the **website** was considered an important need. A specific idea was to have information listed about regulations in different countries regarding e.g. termination of pregnancy, screening policies etc. It was suggested that this might be done by asking SIG/ISPD members from the relevant countries to provide this information in a specific format.

#e Ideas about a **PCC for the San Diego 2017 conference** were briefly discussed. These included a retry of ‘Ethics of fetal therapy’ together with the SIG FT, a PCC on relevant ethical concepts and how these play out in relevant settings of prenatal testing, for instance ‘the right (not) to know’, a PCC on the ‘technological imperative’ and its implications (challenges of overdiagnosis and uncertainty), and a PCC together with the SIG Counseling, discussing ethical issues as they arise in connection to specific counselling cases. There was a clear preference among the Berlin attendees for this last proposal. Some of the other more theoretical topics might be considered for webinars.

#f Given that ethics does not relate to a specific professional group within the ISPD community (in fact it relates to the work of all disciplines in ISPD), it is not entirely clear how we as a SIG could contribute to the Membership Committee.

What **topics** should this SIG consider? What gaps do we see?

In the report of the Washington meeting the felt needs in this regard were summarized as follows:

i. **Concept-driven needs**: these are interests or needs that are driven by a desire to know more about particular concepts that have ethical relevance;

ii. **Practical needs**: these are interests or needs that are driven by a desire to develop practical strategies or methods for responding to ethical issues in clinical practice in the prenatal testing or therapy context; and

iii. **Educational needs**: these are interests or needs that are driven by a desire to further develop theoretical knowledge about ethics relevant to prenatal testing and therapy. This may encompass learning about ethics more generally.
Conclusions & closing

- There was a preference among the attendees for a PCC together with the SIG Counseling.
- More effort is needed to provide content to the website relevant to our SIG. Information on regulations and policies was suggested as a welcome part of this.
- For the educational tasks of the SIG (website, webinar) it would be good to have a broader working group than only the coordinators.
- Coordinator Wybo Dondorp volunteers for the Program Committee 2017 on behalf of the SIG
- NB: Ideas and suggestions are very welcome, especially with regard to possible ISPD Position Statements and Webinars on topics related to our SIG, but also more generally. Please send these to the SIG coordinators Wybo Dondorp w.dondorp@maastrichtuniversity.nl and Ainsley Newson ainsley.newson@sydney.edu.au

Minutes by Wybo Dondorp, 21 July 2016