



# European Neonatal Ethics Conference 2014

Feedback

Dr Alok Sharma

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Total Attendees including faculty **141**

Feedback forms (Conference) received (excluding 19 faculty) **103**

Feedback forms (Workshop) attendees **31**

1. What % of individuals felt they regularly discuss ethical issues at work or during training?

Yes 96.2% No 1.9% No Answer 1.9%

2. Were printed learning objectives of the conference met?

Yes 89.3% No 3.9% No Answer 6.8%

3. Was there any bias or conflict of interest evident in the course?

Yes 7.7% No 88.3% No Answer 4%

4. Were the speakers knowledgeable?

Yes 99% No 0 No Answer 1%

5. How do you rate relevance of CPD activity to your educational needs? (n=100)

Highly Relevant 79.6%

Mostly Relevant 14.5%

Fairly Relevant 2.9%

Not Relevant 0

6. How did you rate the overall quality of the conference? (n=99)

Excellent 77.7%

Good 23.2%

Satisfactory 0.1%

Poor 0

## Scores (Talks)

Scale 1 Poor 2 Satisfactory 3 Good 4 Very Good 5 Outstanding

1. Genome Testing at Birth Mean Score 4.3 Median Score 4
2. Gestational Ageism Mean Score 4.5 Median Score 5
3. Balancing Neonatal Interests Mean Score 4.2 Median Score 4
4. The Dutch Experience Mean Score 4.3 Median Score 4
5. End of Life Decisions The EPICE study Mean Score 4.1 Median Score 4
6. Case Presentations Mean Score 4.5 Median Score 5
7. Is it ethical to withhold artificial feeding Mean Score 4.5 Median 5



## How did you rate the catering?

Mean 4.1 Median 4

Outstanding 35%

Very Good 46.6%

Good 10.6%

Satisfactory 4.8%

Poor 0

No response 3%

## How did you rate the venue?

Mean 4.02 Median 4

Break Up

Outstanding 32%

Very Good 43%

Good 19.4%

Satisfactory 3.8%

Poor 1%

No response 0.5%

## How did you hear about the conference?

**WONEP website 52.4%**

Word of Mouth 20.3%

Dr A Sharma 15.5%

RCPCH website 5.8%

BAPM website 5.8%

Infant 1.9%

NICU99 (EU) 0%

## Comments

### 1. Have any particular themes emerged from the conference?

TPN - when to continue or stop now focussing on the future of the neonate rather than getting caught up with the emotion of the moment may help steer our thoughts productively.

Lots, artificial nutrition, viability.

Persistent debate and under debate in society is needed.

Just because we can doesn't necessarily mean we should!

Legal aspects use qualitative language. Medical aspects use qualitative language. More legal training for medics! As well as ethical training.

Think about prognosis rather than gestation when making decisions about resuscitation & life sustaining Rx. Learnt about different practices worldwide including Groningen protocol.

To consider other sectors when resuscitating a preterm infant, not only GA.

There are often multiple opinions when discussing ethical cases.

Best interests - what & how to judge? Doctrine of double effect.

Balancing interests in Neonatology an excellent talk. End of life decisions in newborn infants as well.

Balance Views of parents. Differing views of Drs vs. nurses.

How every situation may be different for different parents? How Holland have addressed some of the issues with a guideline that may be controversial.

Our poor evidence base for predicting outcome of serious disorders. The potential horrors of increased availability of whole genome screening.

Common sense is useful in ethical debate too.

To always think about the destinations of treatment. The importance of familial involvement. The different practices throughout Europe.

Uncertainties amongst neonatologists about the process when there is a disagreement with parents. Diversities in European practices amongst different countries.

Provided helpful advice for my next practical.

The differences in attitudes across the globe.

Variations in practice despite underlying common agreements in principle.

Ethical discussions are difficult. Good recap of legal aspects.

Very different viewpoints from Europe.



A fantastic day, very interesting, thank you.

Not to rely so heavily on GA for making decisions.

The decision around gestational age as only decider of whether to resuscitate preterm infant was enlightening.

Recent evidence about the outcome of babies with bilateral IVH (in the workshop).

I enjoyed the focus on antenatal counselling & think this is an area of evolving practice that we should continue to reflect upon.

Challenges and a way to evaluate ethical issues Do you have an online discussion group? If no forming one

Earlier notification of receipts than at the conference so that this can be reimbursed

Several very good discussions particularly artificial feeding Good idea to do group discussion post lunch

Grey areas remain grey. Good to hear + discuss differing views. Reassuring to know that others have similar views/concerns

Check tests

Enjoyed the multidisciplinary discussions and different perspectives

The consideration of withdrawal of feeding hydration and doing this as part of palliative care

Thank you to all the organisers and speakers for a very interesting day. Wish we could have had 2 days to discuss these issues in more depth

Different practices

For me withdrawing artificial nutrition was completely new -very controversial and thought provoking

Balance of interests

Good to hear that many other colleagues struggle in this area

Challenges faced by every speaker Need to consider how we address issues in wider forums

Can't treat all the babies the same regardless of gestation-lot to think about

Generally very thought provoking

Excellent variety

What is ethically acceptable?

Concept of withholding artificial nutrition Excellent case presentations Dr Wilkinson's talk very clear and interesting

Guidelines are not explicit for many ethical situations The law about best interests are not defined for 22 weeks gestation

Themes in workshops complemented conference well



I think it is extremely useful to revisit over and over the limits of gestational age with regards to initiating treatment Longer! All quite rushed not enough time to review the poster sessions

Fluid restriction for withdrawal of intensive care is an option

Uncertainty exists in ethics

Stop using the phrase child's best interests Do hold annual meeting

Excellent speakers

Multidisciplinary input in decision making key Can we have a copy of slides

Excellent workshops

Enjoyed all presentations especially gestational ageism

No It was a pleasure to attend the conference

Very knowledgeable speakers Perhaps more time needed for panel discussion and interactions after talks

Different European practices very interesting

## 2. Other Comments

Speakers from other countries SWEDEN USA Italy especially as most research takes place there, venue to small cramped

More time for discussion

Audiovisual too small Room too small Conference excellent though

Larger screen needed

Really good should run it again, perhaps advertise to an obstetric and FM AUDIENCE

Small venue, more MDT members need to be involved

More case presentations

For the course organiser's-What better opportunity could you get in such a less cost (for me personally); For hotel need larger screen

Excellent day high quality speakers, Need more time for discussion as panel discussions after each topic as for the cases; Because it was so well attended needed a bigger venue/bigger screen

That yellow fluid was not custard!!!



It was particularly useful to hear about the wide range of views throughout Europe. More time for questions/discussion/poster sessions/ Should be a 2 day conference with same number of plenary talks

Genome Testing at birth not ethically relevant; Case facilitator a little bit biased to the views presented by the case presenters

Fantastic selection of speakers

Brilliant conference Excellent speakers

Conference organisation was very good

Copy of slides with the bibliography

Excellent concept of using simulation to complement workshops





**Workshops n=31**

1. Were printed learning objectives of the workshop met?  
Yes 100% No 0% No Answer 0%
  
2. Was there any bias or conflict of interest evident in the course?  
Yes 0% No 100% No Answer 0%
  
3. Were the speakers knowledgeable?  
Yes 100% No 0% No Answer 0%
  
4. How do you rate relevance of CPD activity to your educational needs? (n=100)  
  
Highly Relevant 58%  
  
Mostly Relevant 25.8%  
  
Fairly Relevant 3.2%  
  
Not Relevant 0  
  
No Answer 16.1%
  
5. How did you rate the overall quality of the workshops? (n=99)  
  
Excellent 68%  
  
Good 25.8%  
  
Satisfactory 3.2%%  
  
Poor 0  
  
No Answer 3%
  
6. How do you rate the educational activity for CPD purposes?  
  
Very Effective 52%  
  
Definitely Effective 48%  
  
Partly Effective 0  
  
Ineffective 0

## Rating for Scenarios

Scenario	Facilitators	Mean	Median
A discussion with parents	HF/LL	3.9	4
A difficult resuscitation	SF/SB/KE	4.5	4.5
A difficult situation	SB/KD/JB	3.5	4
Differing opinions	RI/DW/KE/RG	3.5	4
We don't want our baby resuscitated	HF/LL/DW	4	4
An antenatal dilemma	AS/DW/SC/VS	3.7	4
Expert opinions	AS/SB/JB/SC	4.5	4.5
An issue of faith	AS/RG/SC	4.3	4
Transferring a sick baby	RI/RG/KE	4.3	5

## Comments Workshop

Discussion with parents best scenario A Difficult Resuscitation same repetitive info Extravasation-less relevant presenters got to hung up on their clinically interesting case-SUDI very interesting but less to do with ethics Catering could be improved

Topics covered that are often not addressed Interesting



discussions generated in the  
extravasation scenario

Well supported and  
very stimulating  
Definitely influence  
future practice

Use  
fewer  
slides  
please

Counselling Scenario-was very useful to hear  
varying opinions Tracheal atresia very  
interesting scenario TPN extravasation-Felt  
slightly confused Overall very enjoyable and  
helpful thank you

Certainly some faculty were better than others at creating initiating discussion  
Really good morning session's Average afternoon sessions IVH-Excellent and  
well thought 1st scenario Issue of Faith well thought and played. Really  
highlighted the issues with realistically face in NICU's Post signs to the venue

IVH very relevant to practise  
Issue of Faith very relevant to  
practise Transport-  
discussion after was very  
good

Scenario on IVH  
was excellent  
and slides were  
excellent

The balance of staff roles in groups allowed for a broad spectrum of thoughts and  
ideas and will definitely modify what I do. The sim on issue of faith could have been  
done without an interpreter and been just as effective in English The scenario on  
transporting sick baby was very thought provoking but need a circle to discuss to be  
more inclusive

Reduce time spent  
on simulation,  
Increase time spent  
on discussion

Very constructive; very good to have summary slide after the scenarios. The scenario on IVH  
was very effective scenario, realistic and helpful discussion with knowledgeable credible faculty  
and participants. For issue of faith see above comments it was excellent



I appreciate that difficult but a room to have refreshments clearer timings for rotation would be good. Extremely good day though

Good ethical debates/missed out on an international perspective More clinical scenarios =actual resuscitation 'when to stop' Scenario 2 and 3 were similar

Discussions very good. Especially enjoyed listening to Dominic Wilkinson

Scenario CLD a lot of time taken up in getting the information.

I would love to have a forum to discuss difficult ethical dilemmas in our practise.

Learnt a lot about ethical dilemmas and the different approaches No other courses/workshops similar to this are around-Well done for the initiative Very interactive and loved the concept of combining simulation with ethics

Scenario 2 and 3 were similar.

Scenario of counselling overseas parents was very interesting but overlapped with scenario 2.

The scenario with Indian parents was very interesting; useful discussions regarding liaising with the obstetric team and clearly documenting plans and consideration of parallels.

Good opportunities to discuss practise/observe counselling Excellent discussion with parents and team The ethical aspects of the scenarios were nicely illustrated with links to the cases discussed The scenario on differing opinions had a very good overall concept and case selection. Difficult to assimilate all that information in a short time. Could we forward some of our own cases to be used in future scenarios?

More mingling of faculty with candidates and a



place to sit down for  
lunch

All scenario's very relevant  
to clinical practice  
Interesting combination of  
clinical and ethical  
conundrum

Scenario on a difficult resuscitation  
was very relevant to future  
practice. Scenario on a difficult  
situation too doctor oriented less  
for nurses

The speakers were knowledgeable  
but everyone also acknowledges their  
own limitations in a professional  
manner being open to ongoing  
learning. As a nurse at the bedside  
we are often the first to give up but I  
was interested in gaining more insight  
into the medical rationale for  
decisions made. The scenarios a  
little bit too medical orientated for  
actual participation but felt  
comfortable with the discussions.  
Scenario on Indian parents  
emotionally eye opening. Scenario  
on CLD probably most appropriate for  
me professionally as a nurse as I  
could relate to it. Scenario on  
unintubatable baby-difficult to know  
how to participate in actual running