

APPENDIX 1: Informed consent form and interview guide second study



UNIVERSITY OF BERGEN

*Department of Public Health and Primary Health Care
Division of Medical Ethics*

CONSENT FOR PARTICIPATION IN RESEARCH

Priority Setting in Neonatal Medicine

Health care needs are usually in greater demand than can be met – sometimes leading to tragic choices. Therefore, priority setting is a serious and ongoing challenge for every health care system in the world, and at all levels of the health care system. For example, priority setting is an important aspect of expensive health care programs. In this research project we will study how decisions on distribution of resources are actually taken when considering treatment of severely sick neonates. This is important as empirical data is particularly scarce on medical decision-making in non-Western contexts. Empirical data on priority setting are important information for policy makers and guideline developers.

I agree to participate in this research study and understand that:

- The purpose of this study is to study priority setting in neonatal intensive care
- I am free to participate or not, and whether I participate or not will be disclosed to my employer
- My participation will consist of an interview, of approximately 30-40 minutes, during which I will be asked about my involvement in priority setting in my unit
- The interview will be audiotaped, transcribed and analysed
- Information I provide will not be directly provided to my employer
- In presentations of the research (in any form) my name will not be associated with any quotes or opinions
- I will not benefit directly from participating
- I will not be compensated for my participation

I further understand that the interviews and data collection will be done by Ingrid Miljeteig (MD, PhD –student) while the principal investigator in this study is Ole Frithjof Norheim, MD, PhD (Professor in medical ethics, University of Bergen, Norway and Haukeland University Hospital) and that if I have any concerns or questions about the research I may contact him at mail: ole.norheim@isf.uib.no

NAME: _____ SIGNATURE AND DATE: _____

Interview guide, second study modified 31.01.07

1. Please introduce yourself and talk about your role in treatment of premature neonates.
2. Can you tell me about your indications for treatment of premature neonates in this unit;
 - Who do you always treat?
 - Who do you never treat?
 - Who do you sometimes treat?
3. What are the criteria you emphasise in these decisions?
 - Are these criteria written in manuals or guidelines?
 - Who decided the criteria?
 - What makes the criteria change (over time)?
 - Are the treatment criteria available for the parents or others to see?
 - How do you use the Indian national guidelines for resuscitation of neonates?
4. Can you tell me more about the aspect of costs in these decisions?
 - In the decision making – if the parents do not have/do not want to pay
 - Costs of different outcomes
 - Measurements of socio economic background
 - Limits of subsidising / funds
5. How are decisions concerning treatment of premature taken?
 - Where?
 - When?
 - Who?
 - (Do you consider this decision fair?)
6. What if there is disagreement between doctors or doctors and parents?
 - Can you tell me about a concrete episode?
 - Obs- neonat.
 - Decision making within the family
7. What is done in case someone disagrees with decisions to withhold or withdraw life support of premature in your hospital?
 - Are there mechanisms for complaints today?
8. Can you tell me about your role as a doctor when you also have to deal with resource constraints and the families ability to pay?
9. What do you see as the main ethical controversies in treatment of premature neonates in India today?
10. (Child's best interest vs family and society's best interest in treatment decisions? What are your thoughts about this?)