

Table 2: Ethical issues about maternal gene therapy in pregnancy identified through qualitative stakeholder and patient interviews.

Issues	Stakeholders	Patients
Who is the patient?	Broad range of attitudes: “the fetus has no legal status” “the fetus has a moral status”	For most patients the fetus was a person: “my baby”
Maternal treatment for fetal benefit	Treatment should be permissible, after careful consideration of the balance of risks and benefits.	Mother and baby’s lives are intertwined. Decision to take part depends on the risk of the treatment.
Making a decision in an FGR pregnancy about trial participation	Concerned about the psychological stress put on the mother.	Most women felt able to make a decision at the time of diagnosis Discussed with family members and healthcare team. Need time to make rational decision.
Survival of fetus with disability	Not a new concept and applicable to most prenatal interventions.	Acceptable as long as disability is not due to the treatment itself.
Challenges of informed consent	Emphasised the need for independent advice for participants.	Almost all women would involve their partner.
Acceptability of gene therapy	The novelty of gene therapy was not a concern. The exception was stakeholders from Germany, where there is a negative societal view of gene therapy.	Most had a spontaneous positive reaction to a trial of a novel treatment. There were no concerns about the use of gene therapy.