Literature Review - A Lay Summary

As part of the EVERREST Project a literature review was carried out to assess the ethics of a clinical trial of growth factor therapy in pregnant women whose unborn babies are affected by fetal growth restriction (FGR). FGR is a serious condition and has a significant risk of stillbirth. Affected babies are small and may be born very early. This can cause them problems as a baby and later on in life. Until the trial is carried out it is not known whether this growth factor therapy will work for FGR and improve growth and whether it is safe in humans.

The literature review discussed two main questions: Firstly, whether it is ethical to treat a pregnant woman with a potentially risky treatment when she herself has no benefit from the treatment but it may improve the health and survival prospects of the unborn baby. And secondly, whether it is ethical to treat this condition of the unborn baby who may otherwise have died but with the treatment may be born with a serious disability.

The answer to the first of these questions turns largely on who is the patient in a pregnancy, whether it is the woman only or whether it is both the woman and the unborn baby. If we believe that the patient is the woman alone – which is the legal position in most countries – then it would be ethical to give her the new treatment if she herself decided in favour of it for the benefit of her unborn child. If on the other hand we believe that the patient in pregnancy is both the woman and the unborn baby then both their interests need to be protected. There would therefore be two obligations: firstly an obligation to the unborn child to authorise a treatment which is of benefit to the child and secondly an obligation not to provide such treatment if it harmed the woman. But even in this case, the woman cannot ever be forced to have the treatment for the sake of her unborn child: it is not obligatory. Whichever view of who the patient is in a pregnancy prevails, both views permit the treatment of the unborn for its own benefit.

The issue the second question addresses is the psychological burden of the woman when making her decision in favour of or against the new treatment. When she decides in favour of the treatment it may save her pregnancy but it may also lead to the birth of a seriously disabled child. The woman will be aware that, but for her choice the child would not have survived, leaving her with feelings of guilt and grief. The decision is therefore far from easy and is emotionally complex. For this reason it is suggested in the literature review that there is a need to interview women and their partners about their experiences when faced with the diagnosis of FGR.