Executive summary

The use of ultrasound scans during pregnancy can detect numerous fetal abnormalities. Some fetal diseases can even be treated before birth. The Health Council published an advisory report on these developments in 1990. This horizon scanning report gives an update on the current level of knowledge in the Netherlands and beyond. It aims to contribute to the debate on how to safe-guard high quality care in the field of fetal therapy in the future.

The most commonly performed invasive fetal treatments are intra-uterine blood transfusion for severe fetal anaemia and the fetoscopic laser coagulation of blood vessels in the placenta of twins with twin-to-twin transfusion syndrome. The number of such procedures carried out in the Netherlands each year are 100 and 45 respectively.

Non-invasive treatment of the fetus by the administration of medications to the mother can be used for conditions such as cardiac arrhythmias, thyroid abnormalities and the production of anti-platelet antibodies. Each of these disorders involves five to ten pregnancies per year. Each year, a few fetuses are treated by using a large-gauge hypodermic needie to insert a shunt (drainage tube) into their thoracic cavity or bladder. Open fetal surgery, in which the mother's abdomen and uterus are opened and then closed-up again once the operation on the fetus is complete, is not carried out in the Netherlands.

Those fetal treatments which are carried out in the Netherlands are either non-invasive or only marginally so. Such treatments pose only a very slight risk to the pregnant mothers themselves. The decision to proceed with fetal treatment

is usually only taken in cases where delaying treatment until after birth is virtually certain to lead to an adverse outcome. Furthermore, most of the children who successfiilly undergo fetal treatments in the Netherlands have a good chance of being completely healthy. One promising new application is the pre-natal treatment of rare metabolic diseases. This involves keeping pregnant mothers on a special diet or giving them food supplements.

Research is currently being conducted abroad into treating fetuses for diaphragmatic hernias, spina bifida and heart valve stenosis. However, the results of this work will not be available for another three to five years. Should these studies produce favourable results, then the Netherlands will also experience increasing demand for these procedures. Stem cell therapy and gene therapy are still in the laboratory stages, but it seems sensible to assume that these techniques too will eventually be applied to the treatment of human fetuses.

Given the complexity of fetal therapy (and of invasive fetal therapy) and the small numbers involved, the preconditions for such treatment would be concentration in a small number of centres, complete and transparent reporting, sound scientific research, and cooperation at national and international level. Any proper assessment of the pros and cons of fetal therapy requires that the children receiving treatment be monitored for many years and that they be tested from time to time as they grow up.