

Response to the National Institute for Health and Clinical Excellence (NICE) consultation on the draft scope for: Guideline on antenatal care for uncomplicated pregnancies update

April 2018

- 1 This response provides comments on the draft scope for an update of the NICE guideline on antenatal care for uncomplicated pregnancies. For the draft scope, see: <https://www.nice.org.uk/guidance/indevelopment/gid-ng10096/consultation/html-content>

Title of guideline

- 2 Page 1, line 10: This line suggests that the new guideline will cover all aspects of antenatal care. The guideline is referred to as the guideline on ‘antenatal care’ in other places as well (e.g. page 5, line 26). However, in several other places, the consultation states that the new guideline will focus on antenatal care in uncomplicated pregnancies only, and will not cover the care of women with complicated or multiple pregnancies (e.g. page 5, line 24). It would be helpful if the scope of the guideline was clarified at the beginning and a descriptive title used throughout.

The care of women who continue their pregnancy following a diagnosis of fetal anomaly

- 3 General comment: We strongly urge NICE to expand this guideline to include the care of women who continue their pregnancy following a diagnosis of fetal anomaly, or to produce a separate guideline on this area of care.
- 4 Women with high-chance combined test screening results will be able to access non-invasive prenatal testing (NIPT) in the NHS later in 2018. The introduction of NIPT as a second stage test is likely to lead in numerical terms to both more terminations of pregnancy following a diagnosis of Down’s, Edwards’ or Patau’s syndromes, and more pregnancies being continued than is currently the case.¹ Both NICE and the Royal College of Obstetricians and Gynaecologists (RCOG) have produced professional guidance on termination of pregnancy. However, there are no NICE guidelines on the care of women who continue their pregnancy following a diagnosis, and the RCOG guidelines on this are sparse and hidden in its guidance on termination of pregnancy.

¹ Nuffield Council on Bioethics (2017) *Non-invasive prenatal testing: ethical issues*, paragraph 2.43, available at: www.nuffieldbioethics.org/NIPT

- 5 A need for better professional guidance on continuing a pregnancy following a diagnosis of fetal anomaly was identified in a recent inquiry on NIPT by the Nuffield Council on Bioethics. The Council recommends that such guidance should include the care of women who receive a high chance or positive NIPT result, as well as those who undergo invasive diagnostic testing. It should be emphasised that following a diagnosis or a high chance NIPT result, women should have access to advice from a wide range of experts, including those with first-hand knowledge of children and adults with genetic conditions and impairments and their families, and they should have the option of receiving specialist care and support throughout their pregnancy or remaining on the standard antenatal care pathway.²

Inclusion of antenatal screening

- 6 Page 5, line 6: We recommend that antenatal screening is included in the key areas to be covered in the update. Although it is stated that the guideline will signpost to the NHS antenatal screening programmes (page 3, line 9), it would be helpful if NICE also considered recent changes to the screening programme in this update, given that the forthcoming introduction of NIPT will lead to a significant change in the information to be provided to pregnant women about screening, and the choices that they might be asked to make. Antenatal screening is included in the current NICE guideline on antenatal care for uncomplicated pregnancies and the removal of this area from the updated guideline is not explained.

Contact details:

Catherine Joynton

Assistant Director, Nuffield Council on Bioethics

cjoynton@nuffieldbioethics.org

² For more information, see Nuffield Council on Bioethics (2017) *Non-invasive prenatal testing: ethical issues*, available at: www.nuffieldbioethics.org/NIPT.