human reproduction

# **SUPPLEMENTARY DATA**

**Supplementary Table SI** Overview of the 38 statements divided over the four basic ethical themes that formed the basis of this Delphi study. In the first Delphi round 2 new statements were added (statement 39 and 40).

#### THEME I: BENEFICENCE

- I Infertility in women with Turner syndrome leads to psychological harm.
- 2 Patients with Turner syndrome rate their own infertility as their primary concern.
- 3 The risk of infertility in patients with Turner syndrome has a negative impact on their intimate relationships and their chances at marriage.
- 4 Fertility is an essential element of femininity and is linked to a woman's sense of identity.
- 5 There are other ways to become a parent besides having genetically own children.
- 6 Most women prefer biologic offspring.
- 7 It is more difficult for women with Turner syndrome to adopt a child.
- 8 Live birth rates are doubled in woman with Turner syndrome who used donor oocytes to become pregnant.
- 9 Oocyte donation in women with Turner syndrome leads to significantly less chromosomal abnormalities in their offspring
- 10 Intrafamilial oocyte donation offers woman with Turner syndrome an option for genetically related offspring with reduced foetal risks.
- II Intrafamilial oocyte donation could lead to imbalances in the relationship between patient, donor and child.
- 12 Cryopreservation of oocytes is an established fertility preservation method for woman and post-pubertal girls, whereas ovarian tissue cryopreservation is still experimental.
- 13 Cryopreservation of oocytes requires ovarian stimulation with exogenous FSH, whereas ovarian tissue cryopreservation does not.
- 14 Cryopreservation of oocytes requires transvaginal ultrasound guided oocyte retrieval, whereas ovarian tissue cryopreservation does not.
- 15 Cryopreservation of oocytes can be performed only in girls who have had a spontaneous menarche, whereas ovarian tissue cryopreservation can be performed in both pre- and post-pubertal girls.
- 16 Ovarian tissue preservation has been demonstrated as a successful fertility preservation option in other patient groups.
- 17 The germ cell loss will continue after auto transplantation of cryopreserved ovarian tissue.
- 18 The attempt to preserve a patient's fertility decreases the patient's psychological distress and promotes her psychological comfort.

## THEME 2: AUTONOMY

- 19 Most patients diagnosed with premature ovarian insufficiency express a desire for future offspring.
- 20 Patients and parents are motivated to try experimental fertility preservation methods.
- 21 Young patients with Turner syndrome might be too immature to give informed consent for experimental fertility preservation methods.
- 22 Regardless their age, girls with Turner syndrome should be included in the consent process for ovarian tissue cryopreservation.
- 23 Fertility preservation could create expectations for the child to reproduce.

### THEME 3: NON-MALEFICENCE

- 24 Pregnancies in women with Turner syndrome show higher rates of foetal complications.
- 25 Oocyte genetics or pre-implantation genetic screening can be used to screen oocytes and embryos.
- 26 Pregnancies in women with Turner syndrome show higher rates of maternal complications.
- 27 Furthermore, pregnant women with Turner syndrome are at risk of severe cardiac complications and mortality.
- 28 Ovarian tissue cryopreservation requires laparoscopic surgery.
- 29 Experimental fertility preservation options could create false hope, which could lead to psychological harm in the future.
- A decisional conflict between the child and the parents could cause harm to their relationship.
- 31 Performing ovarian tissue cryopreservation in paediatric patients upon parents' consent, may lead to both positive and negative feelings during adolescence of adulthood.

(Continued)

## **Supplementary Table SI** Continued.

#### **THEME 4: JUSTICE**

- Reproduction is a fundamental human right.
- 33 Patients at risk of premature ovarian insufficiency should have equal access to counselling and fertility preservation options.
- 34 Fertility preservation is a typical instance of 'medicalization'.
- 35 Ovarian tissue cryopreservation is also performed for non-medical reasons and social indications.
- 36 In some countries, ovarian tissue cryopreservation is already experimentally offered to girls with Turner syndrome.
- 37 Ovarian tissue cryopreservation remains financially out of reach for some patients.
- 38 Girls with Turner syndrome are less likely to get sexual education from their parents, due to their infertility.

### **ADDITIONAL STATEMENTS**

- Each girl with TS interested in OTC, should be discussed within a multidisciplinary expert team, after psychosocial and cardiologic screening have taken place.
- Fertility preservation options might make us unhappier in the long run, because they contribute to a society where tragedy and human limitations are not accepted and are insurmountable problems.