

# International consensus: Ovarian tissue cryopreservation in young Turner syndrome patients

## Outcomes of an ethical Delphi study including 55 experts from 16 different countries

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### INTRODUCTION

- Cryopreservation of ovarian tissue (OTC) is a valid option for preserving the fertility of young females at risk of iatrogenic premature ovarian insufficiency.
- One of the most common genetic disorders related to premature ovarian insufficiency is Turner Syndrome (TS).
- Ovarian tissue cryopreservation appears to be a promising technique to preserve the fertility of females with TS, as it can be performed regardless of the patient's age or ovarian activity.
- However, offering OTC as a fertility preservation option to patients with TS raises some ethical issues with which we believe clinicians should be familiar with before OTC is routinely performed in this specific patient group.

### OBJECTIVE

To reach group consensus and form an international standpoint on ovarian tissue cryopreservation in young females with TS

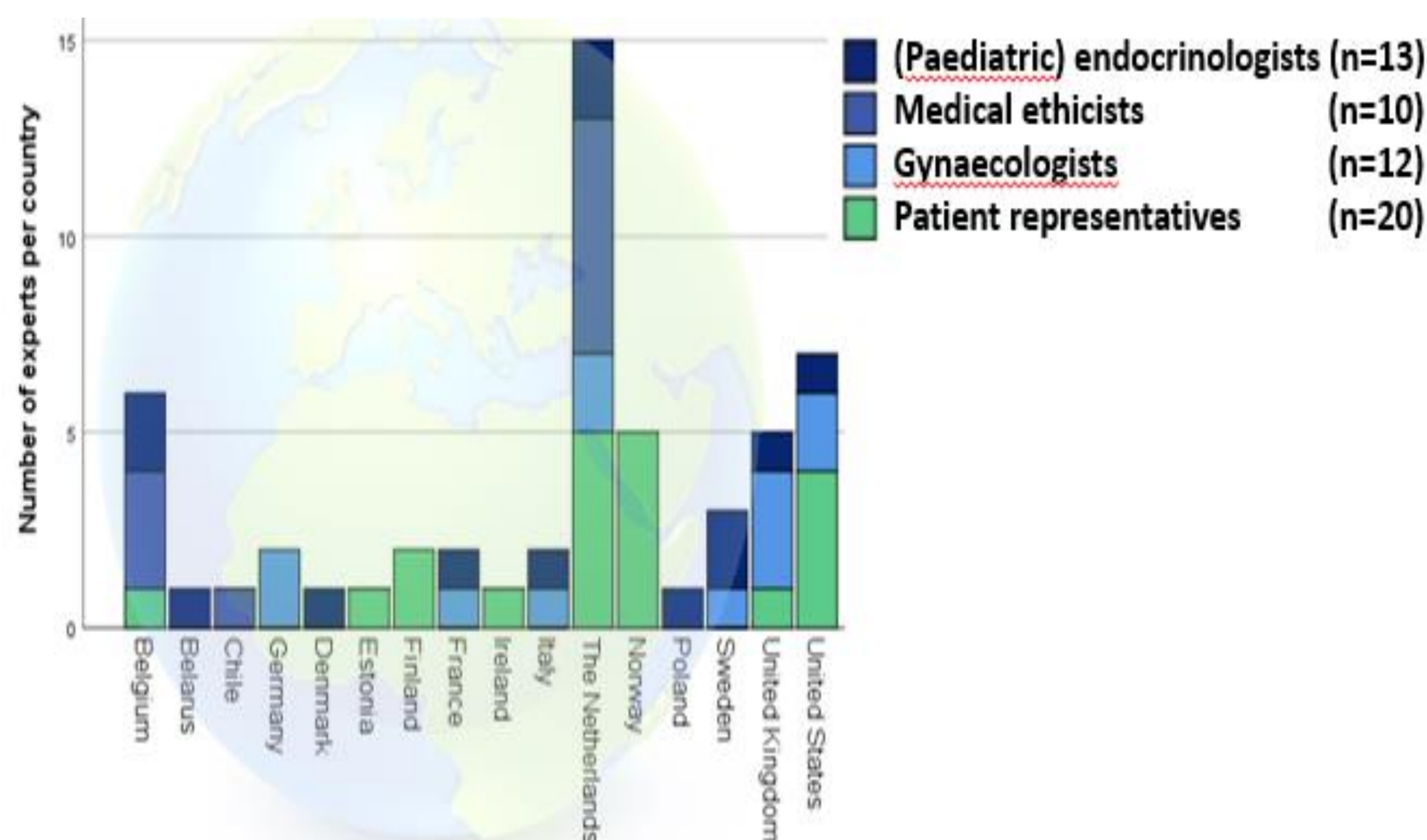
### METHODS

#### Study design

A three-round ethical Delphi study was conducted to systematically discuss the advantages and disadvantages of ovarian tissue cryopreservation in young females with TS

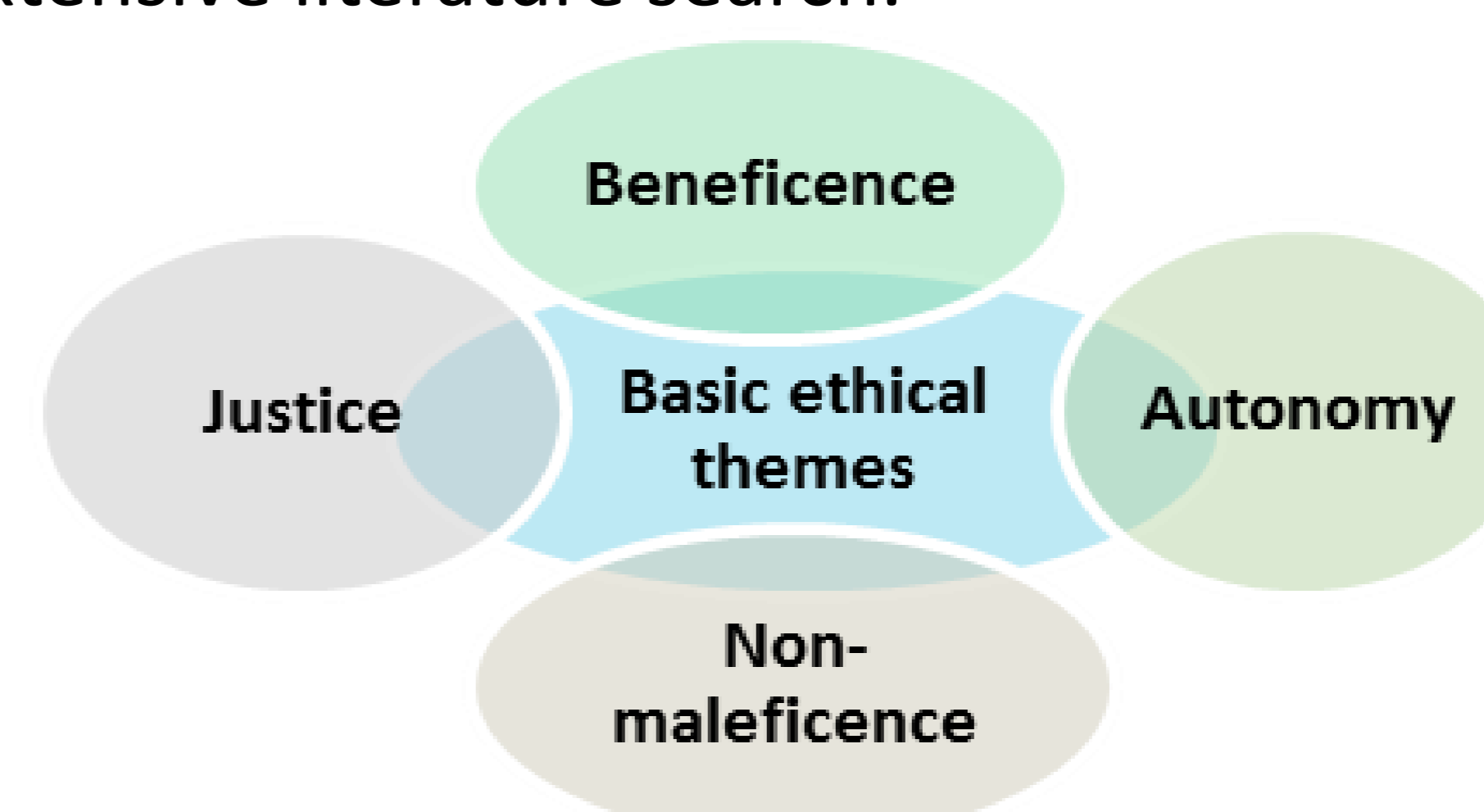
#### Participants

A mixed panel of gynaecologists, (paediatric) endocrinologists, medical ethicists and patient representatives from 16 different countries with expertise in TS gave consent to participate in this international Delphi study.



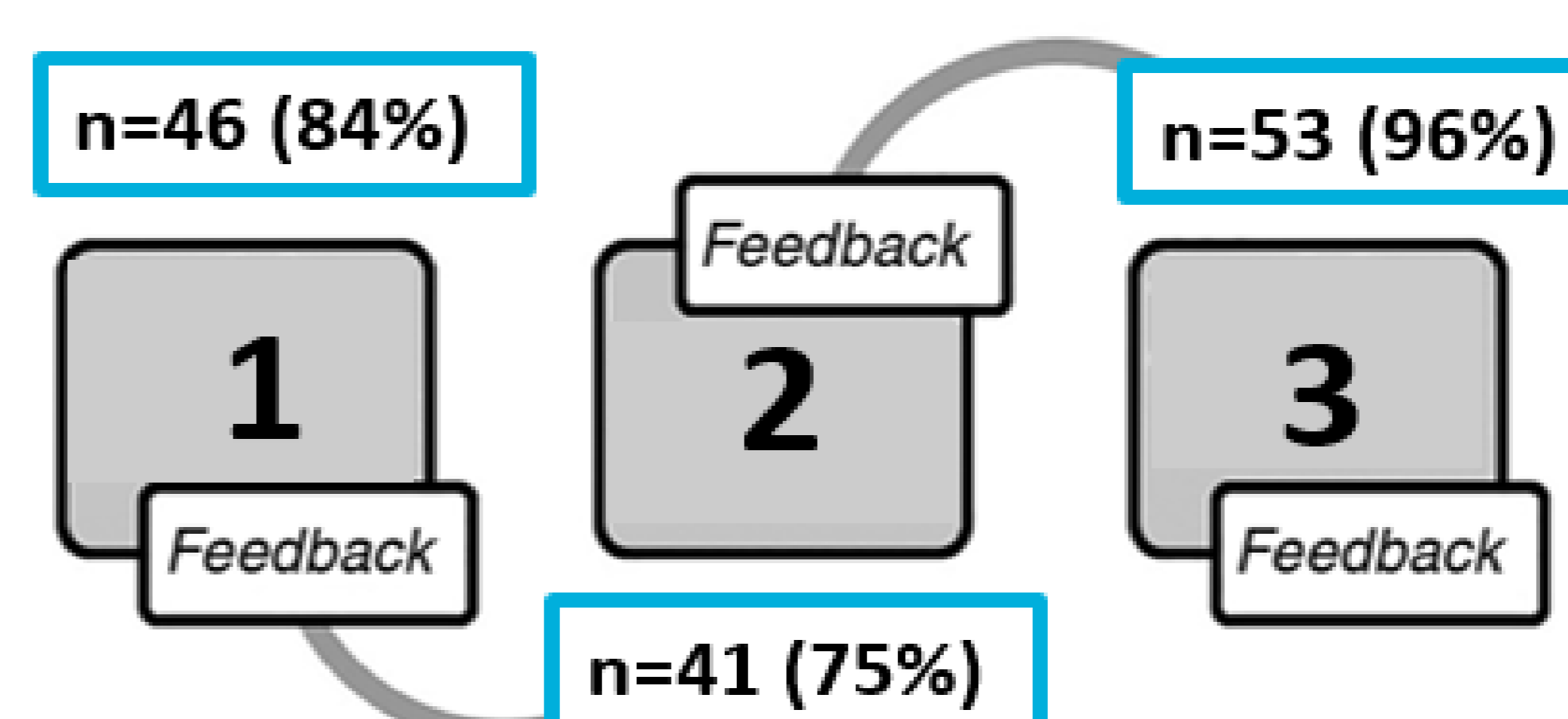
### Selection of key statements and formulation of a common standpoint

- In the first two rounds, the expert panel rated 38 statements that were based on extensive literature search.



- The selection of key statements was based on the ranking position, median score and level of agreement.
- After each round, opinions were swayed with the aim to reach group consensus.
- An overview of the selected key statements and the expert panel's standpoint was sent out by E-mail to all 55 experts to reach the final approval.

### RESULTS



### Key statements

#### Theme 1: Beneficence

1. Infertility in women with Turner syndrome leads to psychological harm.
2. Patients with Turner syndrome rate their own infertility as their primary concern.
3. There are other ways to become a parent besides having genetically own children.

#### Theme 3: Non-maleficence

5. Pregnancies in women with Turner syndrome are associated with higher rates of maternal complications.
6. Pregnant women with Turner syndrome are at risk of severe cardiac complications and mortality.

#### Theme 2: Autonomy

4. Regardless their age, girls with Turner syndrome should be included in the consent.

#### Theme 4: Justice

7. Patients at risk of premature ovarian insufficiency should have equal access to counselling and fertility preservation options

#### Additional statements

8. Each girl with Turner syndrome interested in OTC should be discussed within a multidisciplinary expert team, after psychosocial and cardiologic screening have taken place.

### CONCLUSION AND DISCUSSION

- This international standpoint is the first step in the global acceptance of OTC in females with TS. Future collaborative research with focus on efficacy and safety, with long-term follow-up are urgently needed.
- The selection of experts was based on their willingness to participate. The fact that not all panelists took part in all rounds, may have resulted in selection bias.

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