

# Adolescent Turner Syndrome – Service Evaluation at a UK Tertiary Teaching Hospital Clinic

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## Background

Turner Syndrome (TS) is a genetic disorder affecting only females which is associated with a range of symptoms and characteristics including affected sexual development and subfertility.

70-80% of TS women don’t undergo spontaneous puberty and so pubertal induction plays a key role. Only 2-5% can conceive naturally. Fertility treatment is an option for some TS women, but they must be identified and counselled early to maximize its benefits.

## Aims

Our aim was to assess whether we are meeting the standards of best practice for management based on the 2016 Cincinnati Guidelines for adolescent TS patients. We focused on:

1. Appropriate pubertal induction
2. Fertility preservation and counselling
3. Continuity of care during transition from paediatric to adult TS clinic

## Methods

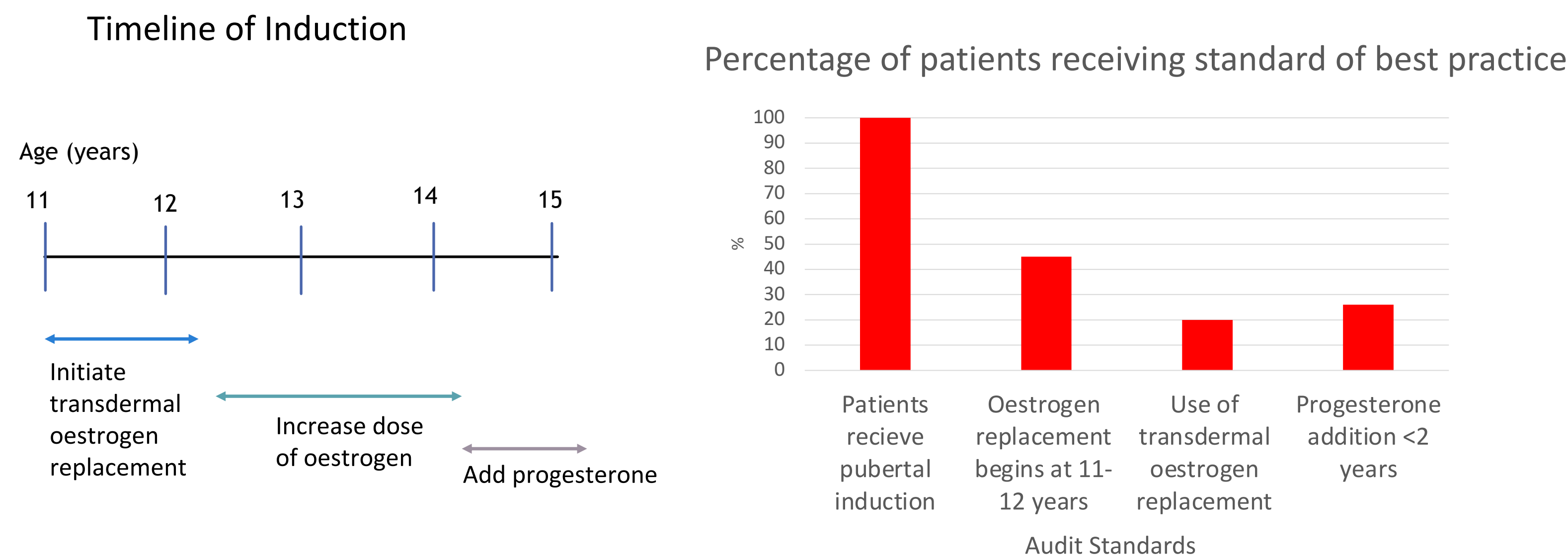
Service evaluation project that looked at 31 patients aged between 11 and 30 who had attended the child and adolescent TS clinic at a UK teaching hospital from 2005-2020.

Clinic notes were reviewed and a standardised proforma filled in for each patient. Data collected included: karyotype; age of patient when commenced oestrogen and progesterone treatment, method of administration of oestrogen replacement, discussions about fertility, evaluation of ovarian reserve and fertility preservation.

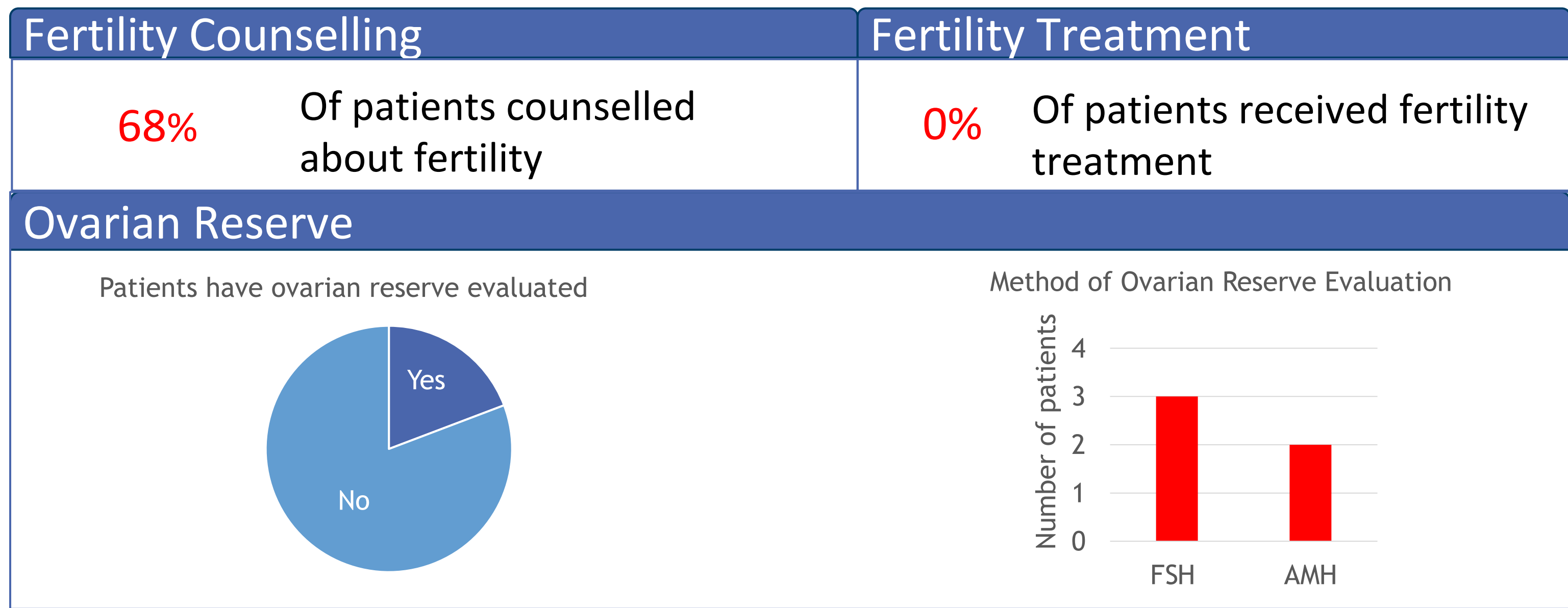
Data was subsequently analysed in Excel and R Statistics

## Key Results

### 1. Pubertal induction



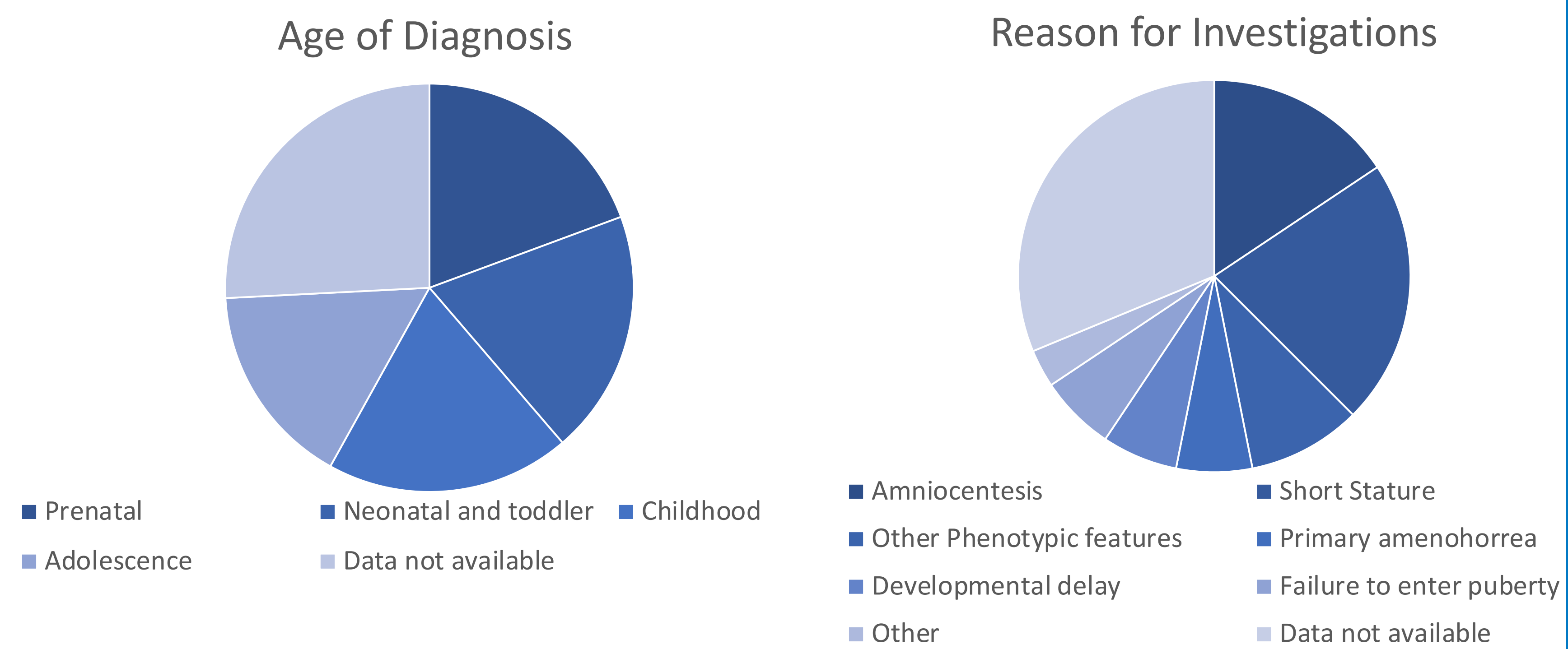
### 2. Fertility



### 3. Transition

| Audit Criteria                                   | Standard to Meet (%) | In Practice (%) |
|--------------------------------------------------|----------------------|-----------------|
| Transition from paediatric to adult clinic       | 100                  | 100             |
| Use of online resource tools to aid transition   | 60                   | 0               |
| Counselling on specific topics during transition |                      |                 |
| a. Lifestyle                                     | 60                   | 10              |
| b. Cardiovascular health                         | 60                   | 75              |
| c. Psychosocial issues                           | 60                   | 46              |

## Demographics



## Conclusions

This study demonstrated the complexities in managing adolescent patients with TS, particularly in terms of their reproductive health.

All patients received pubertal induction and no patients were lost in transition from child to adult TS clinic. Fertility counselling, which has its challenges in this age group as they may not be considering their options, occurred in nearly 70% of patients.

This project also demonstrated significant room for improvement in managing these patients in line with guidance.

We aim to disseminate our results to all medical professionals conducting these clinics to improve adherence to guidance and reassess in 6 months. We also aim to conduct a patient satisfaction questionnaire, particularly for those who have transitioned from paediatric to adolescent care.