

# The perception of adult females diagnosed with CAH on childhood feminising surgery.

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The perception of adult females diagnosed with CAH, who underwent genital surgery in childhood, on early feminizing surgery.

<b>Ethical review</b>	Approved WMO
<b>Status</b>	Pending
<b>Health condition type</b>	Endocrine disorders congenital
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON57042

### Source

ToetsingOnline

### Brief title

Perception of females with CAH on childhood feminising surgery

### Condition

- Endocrine disorders congenital
- Adrenal gland disorders

### Synonym

congenital adrenal hyperplasia - CAH

### Research involving

Human

### Sponsors and support

**Primary sponsor:** Erasmus MC, Universitair Medisch Centrum Rotterdam

**Source(s) of monetary or material Support:** Ministerie van OC&W

## Intervention

**Keyword:** CAH, feminising surgery, focus group, women's experiences

## Outcome measures

### Primary outcome

focus group discussion - interview content

### Secondary outcome

none

## Study description

### Background summary

In congenital adrenal hyperplasia (CAH), the 21-hydroxylase enzyme is missing or present at low levels. As a consequence, the adrenal glands are unable to produce cortisol and aldosterone. All cholesterol will be metabolized into androgens. In fetuses with 46, XX karyotype, the excessive amounts of circulating androgens will lead to masculinization of the developing external genital. About 70 years ago medical treatment became available. Infants born with CAH obtained good opportunities to survive and CAH became a congenital condition for life [1-3].

In individuals with 46,XX CAH the development of the internal genital is unaffected and patients are fertile as females. Infants with 46,XX CAH therefore, are assigned and reared as females. For many years, feminizing surgery of the masculinized external genital was conducted in order to facilitate menstrual discharge and penile-vaginal intercourse and to give the genital a female appearance. As surgeons got more experienced, feminizing surgery was often conducted in infancy [1,2].

For more than 25 years, feminizing surgery in childhood is under debate. It is argued that feminizing surgery in children too young to give their informed consent is unethical and harmful; it is disrespectful to the person with CAH (your genital is not good) and harms the child's body and sexuality. Advocates (united in Organisation Intersex International;

[https://en.wikipedia.org/wiki/Organisation\\_Intersex\\_International](https://en.wikipedia.org/wiki/Organisation_Intersex_International)) consider feminizing surgery as genital mutilation and call for a prohibition of all elective genital surgery until the adolescent - young adult is old enough to decide herself [4,5].

In this scenario, girls with CAH have to live with a genital with an atypical appearance. Particularly for girls with born with severe genital

masculinization (Prader stages 4-5) the atypical genital may lead to difficulties in acceptance of the female gender (by the child herself, the parents or the social network) and in exploring her sexuality as a female. Proponents of early genital surgery argue that adjustment will facilitate acceptance and will enable girls to take part in all types of social activities without fear for undue curiosity, injurious remarks, harassment or isolation [4,6-9].

In several countries elective genital surgery in children is not possible anymore [4]. In The Netherlands and in Belgium advocates ask the Ministries of Health to reform the law in order to prohibit feminizing and masculinizing surgery in under-aged children.

Evaluation of elective genital surgeries in childhood in relationship to gender, sexual functioning and psychosocial wellbeing in adulthood did not reveal an obvious advantage for early or delayed surgical intervention [10-23]. This study aim to explore the perception of young adult females diagnosed with CAH, who underwent genital surgery in childhood, on the discussion described above. According to them, what are advantages and disadvantages of early feminizing surgery? What would they decide for their own daughters? For this purpose, we will organize two focus groups, one in Ghent and one in Rotterdam.

## **Study objective**

The perception of adult females diagnosed with CAH, who underwent genital surgery in childhood, on early feminizing surgery.

## **Study design**

Non-interventional prospective study (observational)

## **Study burden and risks**

Single 3 hours participation in a focus group or individual interview. Minimal mental health risk.

# **Contacts**

## **Public**

Erasmus MC, Universitair Medisch Centrum Rotterdam

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## **Scientific**

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## Trial sites

### Listed location countries

Netherlands

## Eligibility criteria

### Age

Adults (18-64 years)

### Inclusion criteria

46,XX CAH

Aged 18-50

Feminising surgery in childhood

### Exclusion criteria

A potential subject who is insufficient fluent in the Dutch language

## Study design

### Design

**Study type:** Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

## Recruitment

NL  
Recruitment status: Pending  
Start date (anticipated): 01-03-2025  
Enrollment: 10  
Type: Anticipated

## Ethics review

Approved WMO  
Date: 08-10-2024  
Application type: First submission  
Review commission: METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)

## Study registrations

### Followed up by the following (possibly more current) registration

No registrations found.

### Other (possibly less up-to-date) registrations in this register

No registrations found.

## In other registers

Register	ID
CCMO	NL87059.078.24