

Youth with Gender Incongruence: Culture and Future

Henriette Delemarre Memorial Lecture

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Epath, Ghent, March 12 2015

Henriette Delemarre-van de Waal



Henriette Delemarre-van de Waal

(1952 – 2014)



- Pediatric endocrinologist

Professor of Pediatrics

- VU University Medical Center 1982-2008
- Leiden University Medical Center 2008-2014

Henriette Delemarre-van de Waal

(1952 – 2014)

- Patient care
 - Teaching
 - Committees, boards
 - Awards
 - Research → 230 PubMed
-
- Expert on puberty (GnRH; precocious puberty)
 - **Transgender youth → the Dutch protocol**



Transgender Care for Youth: European roots

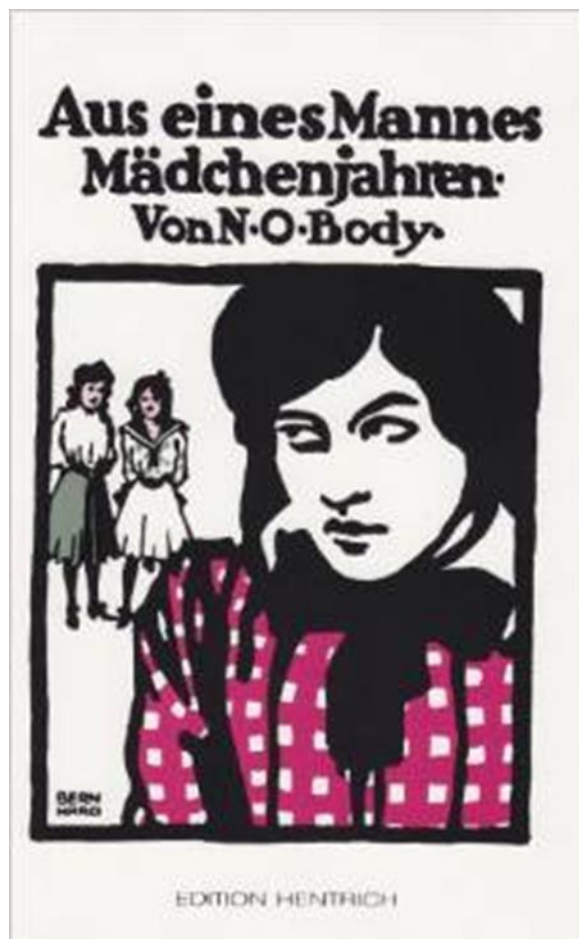
Transgender Care in Europe

Hirschfeld (1868 – 1935)

- Institut für Sexualwissenschaft



First gender affirming treatments



Karl Baer (N.O. Body) (1885 -1956)

- “About the girl’s years of a man”
- First operation 1906
- Legal recognition 1907

Lili Elbe(1886 – 1931)



Discovery of Sex Hormones

The New England Journal of Medicine

Copyright, 1944, by the Massachusetts Medical Society

Volume 230

May 18, 1944

Number 20

THE HISTORY OF THE DISCOVERY AND ISOLATION OF THE FEMALE SEX HORMONES

GERHARD J. NEWERLA, M.D.*

WALTHAM, MASSACHUSETTS

Transgender Care in Europe 2

- First hormone treatment by Christian Hamburger (Denmark)
- Christine Jorgensen
“Classic treatment”



CHRISTIAN HAMBURGER



Omikron Omikron via Getty Images

First European Care Providers

Acta psychiatr. scand. 1987;75:176-182

Key words: transsexualism; sex reassignment programs; overview.

Sex reassignment surgery in Europe: A survey

P. T. Cohen-Kettenis and J. Wålinder

Department of Social Sciences (Head: Professor J. Dijkhuis), University of Utrecht, The Netherlands and Department of Psychiatry (Head: Professor G. d'Elia and Professor J. Wålinder), University Hospital, Linköping University, Sweden

Participating 10 countries

Table 1

Number of transsexual patients treated in different countries

	Men	Women	Total
Belgium	93	10	103
Denmark	60	20	80
Finland	5	3	8
France	23	19	42
Germany	711	377	1088
Italy	40	6	46
The Netherlands	315	188	503
Sweden	104	49	153
Switzerland	38	17	55
United Kingdom (incl. Northern Ireland)	920	89	1009

European Transgender Care

- Requirements diverse (procedure and personal characteristics), but psychotherapy usually obligatory
- Reimbursement in most countries
- **Nothing** mentioned about persons < 18 years

Cultural Climate

Resistance

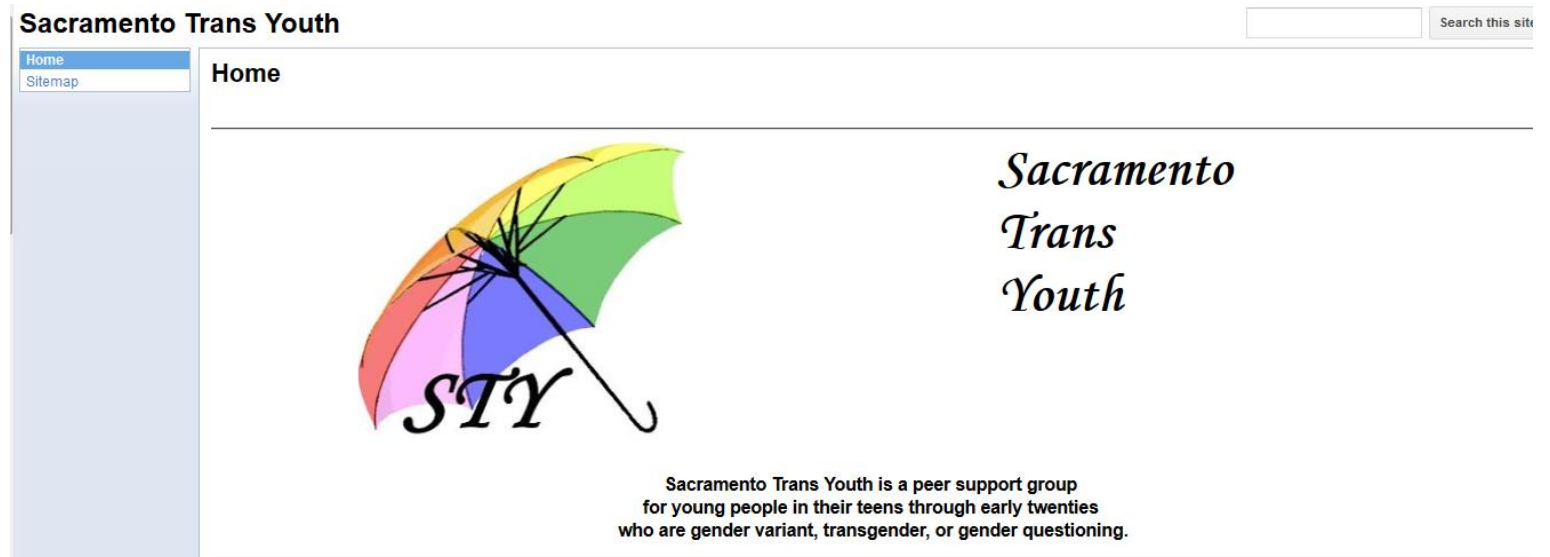
- Personal
 - Confusion / Uneasiness / Feelings of threat
 - Moral
 - Religious
- Theoretical / professional

Negative Attitudes

- Health Council, the Netherlands (1965): “In severe cases there is a **deep-rooted delusion** related to belonging to the opposite sex. It is mainly these **seriously disturbed patients** that have led doctors to perform surgical interventions.”

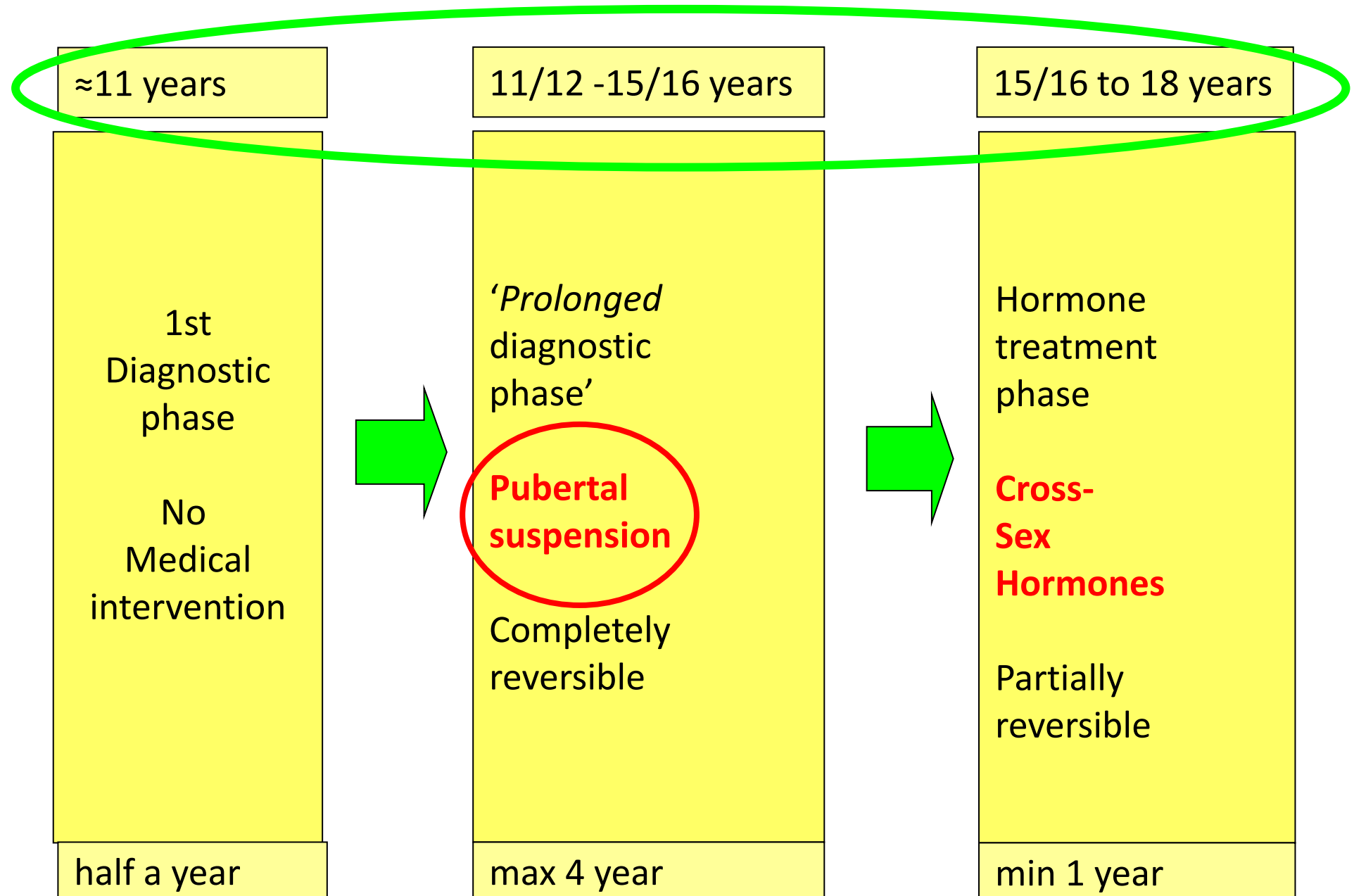
Adolescents?

- MH institutions no experience
- Medical doctors rejecting
- No place to go
- No subculture / Internet
- Waiting...



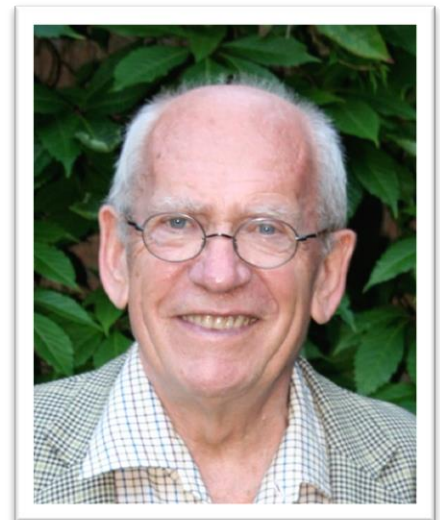
“The Dutch Protocol”

Current Treatment Protocol Adolescents

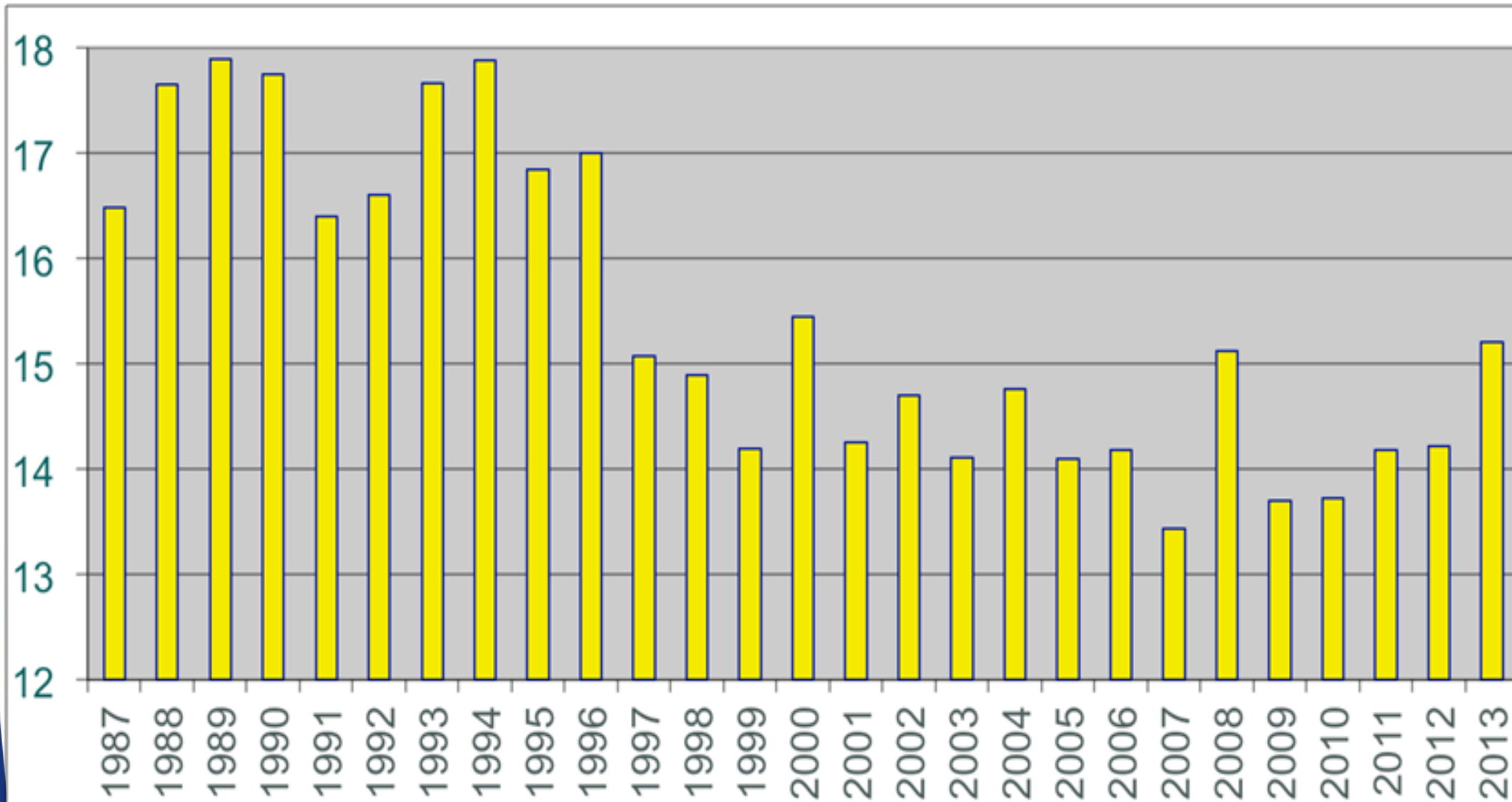


Development of “the Dutch Protocol” (1)

- 1987: Start C&A Gender Identity Clinic
 - Referrals mostly >16 years
 - Within department of child psychiatry → only MH care
 - In collaboration with prof. Louis Gooren at VU University medical center
 - Lowering age of cross-sex hormones (18 → 16 years)



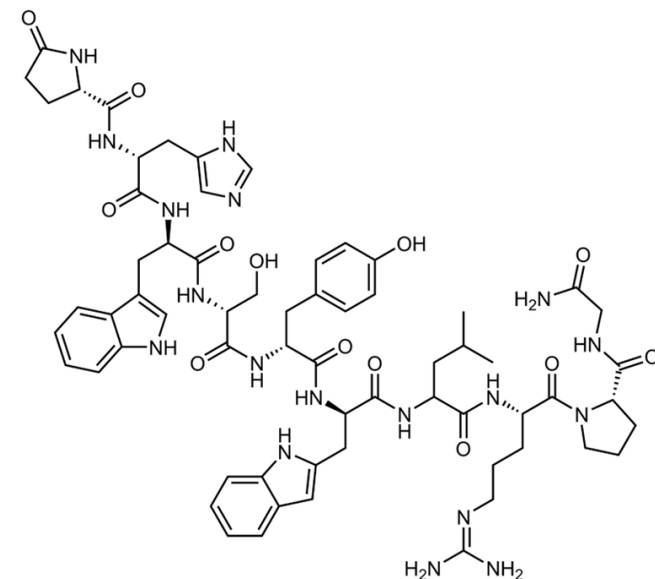
Mean Age at Referral



Development of “the Dutch Protocol” (2)

- 2002 *Multidisciplinary* service for adolescents
- Involvement of pediatric endocrinology →
Henriette Delemarre-van de Waal

GnRH analogues



Guidelines

- Standards of Care 7 (WPATH, 2012)
- Clinical practice guidelines (Endocrine Society, 2009)

Criticism 1

At first:

Too progressive

- “Abuse of medical science”
- “Today’s hype is tomorrow’s scandal”
- Nazi’s experimenting with children



- Data base from the beginning
- Monitoring the adolescents clinically
- Follow-up studies

Criticism 2

Now:

- Age limits puberty blockers
- Age limits cross-sex hormones
- Age limits surgery (Milrod: How young is too young? JSM 2014)
- Involvement of mental health practitioners
- Cultural US vs Europe ?

Where Do We Stand Now?

Cultural Changes

- Openness (media)
- Attitudes (shame vs proudness)
- Empowerment

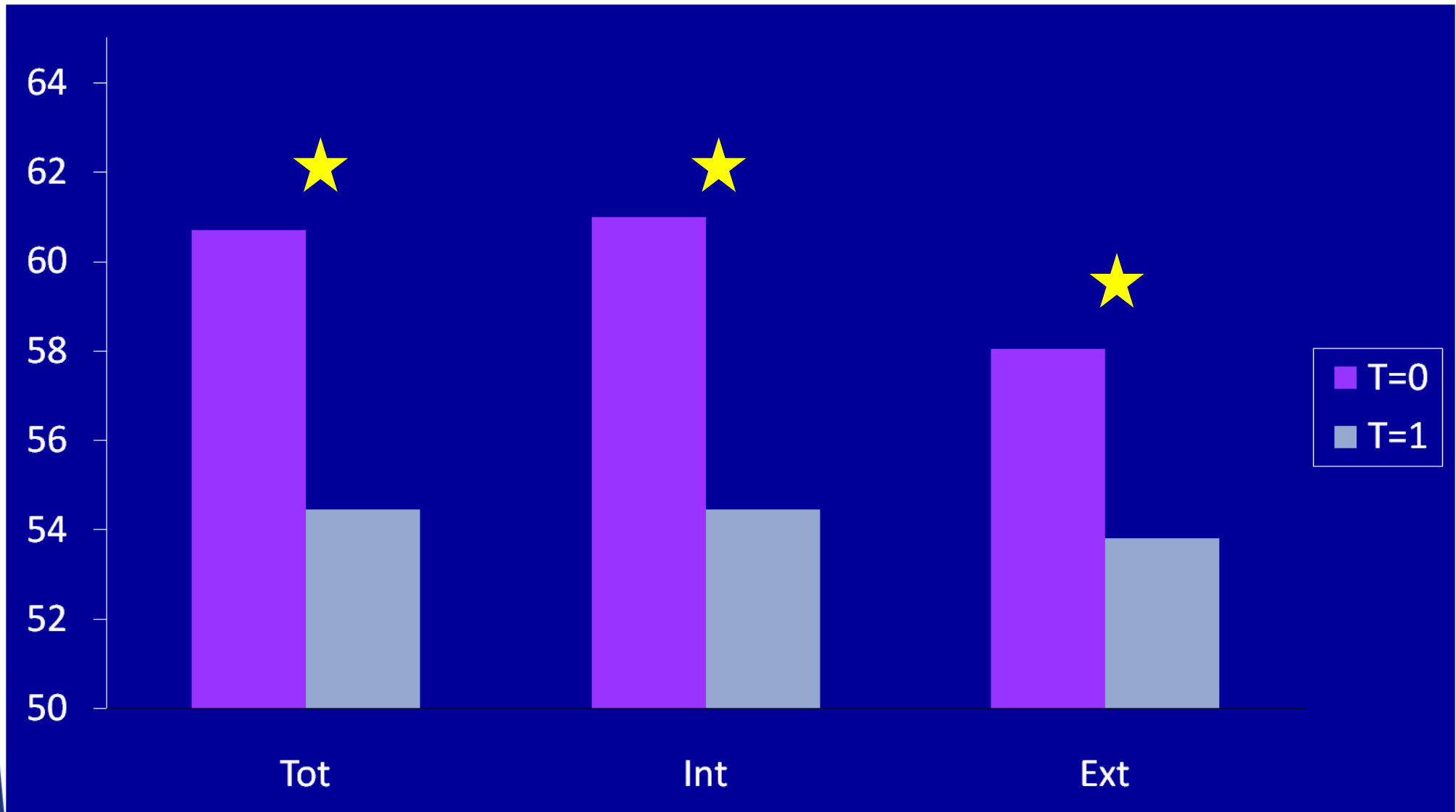


No Concerns?

Main clinical concerns

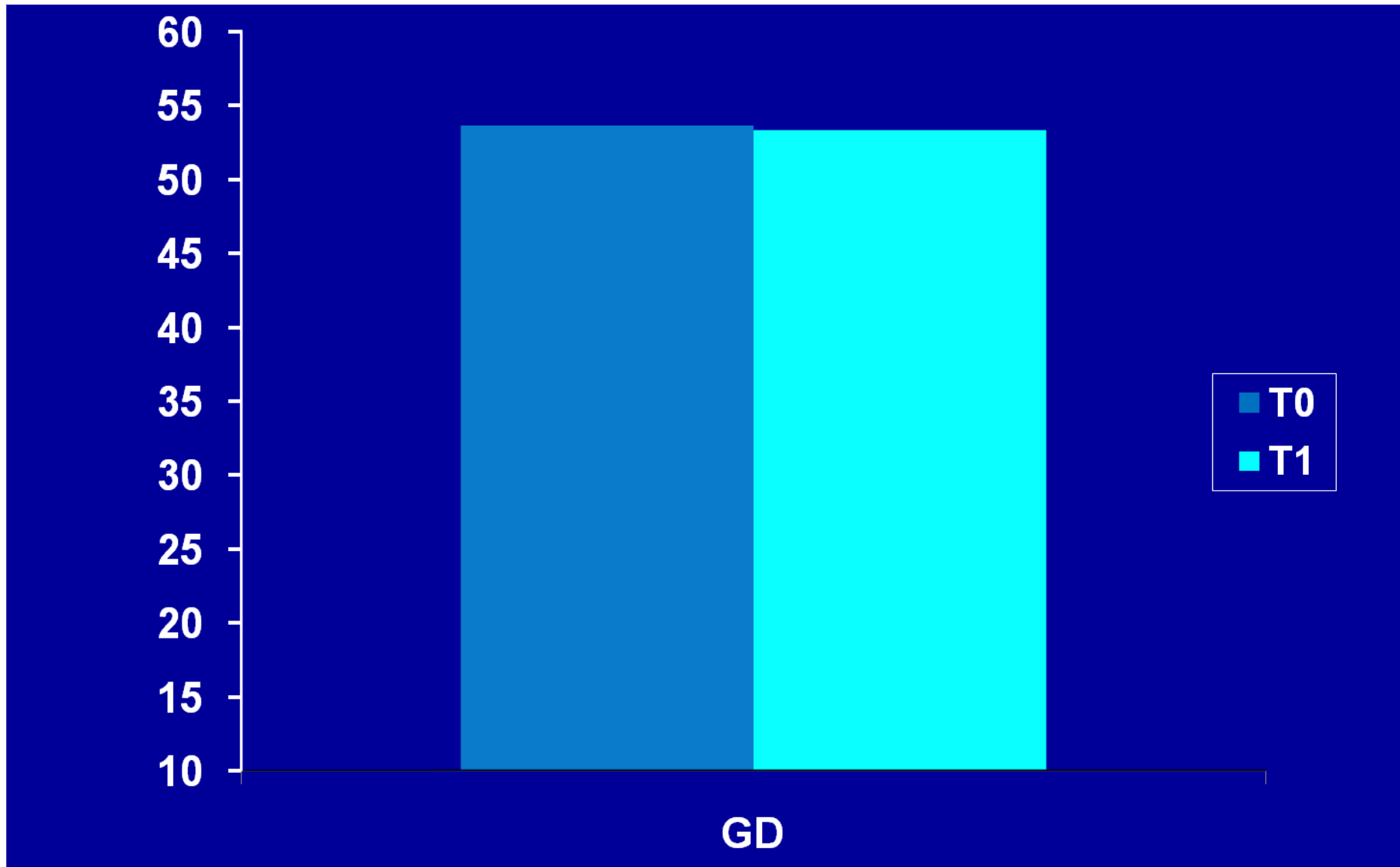
- How to deal with complex cases (ASD; ADHD; switching identities)? → exchange clinical experiences
- Does a treatment starting with GnRH analogues at a young age result in good outcome?
 - Mentally
 - Physically

Psychological functioning before and after puberty suppression (CBCL / parent report)



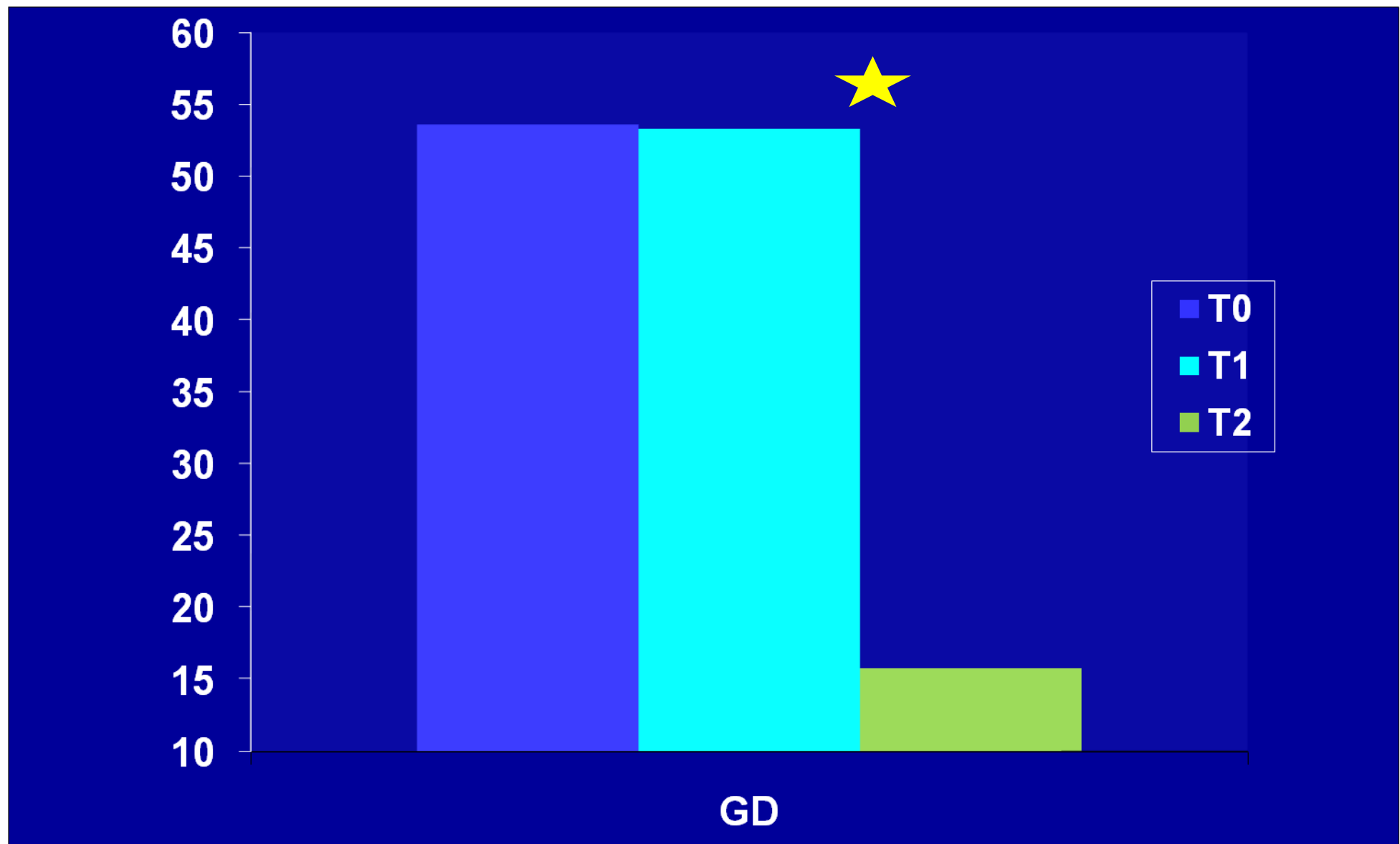
De Vries et al, 2011

Gender Dysphoria before and after puberty suppression



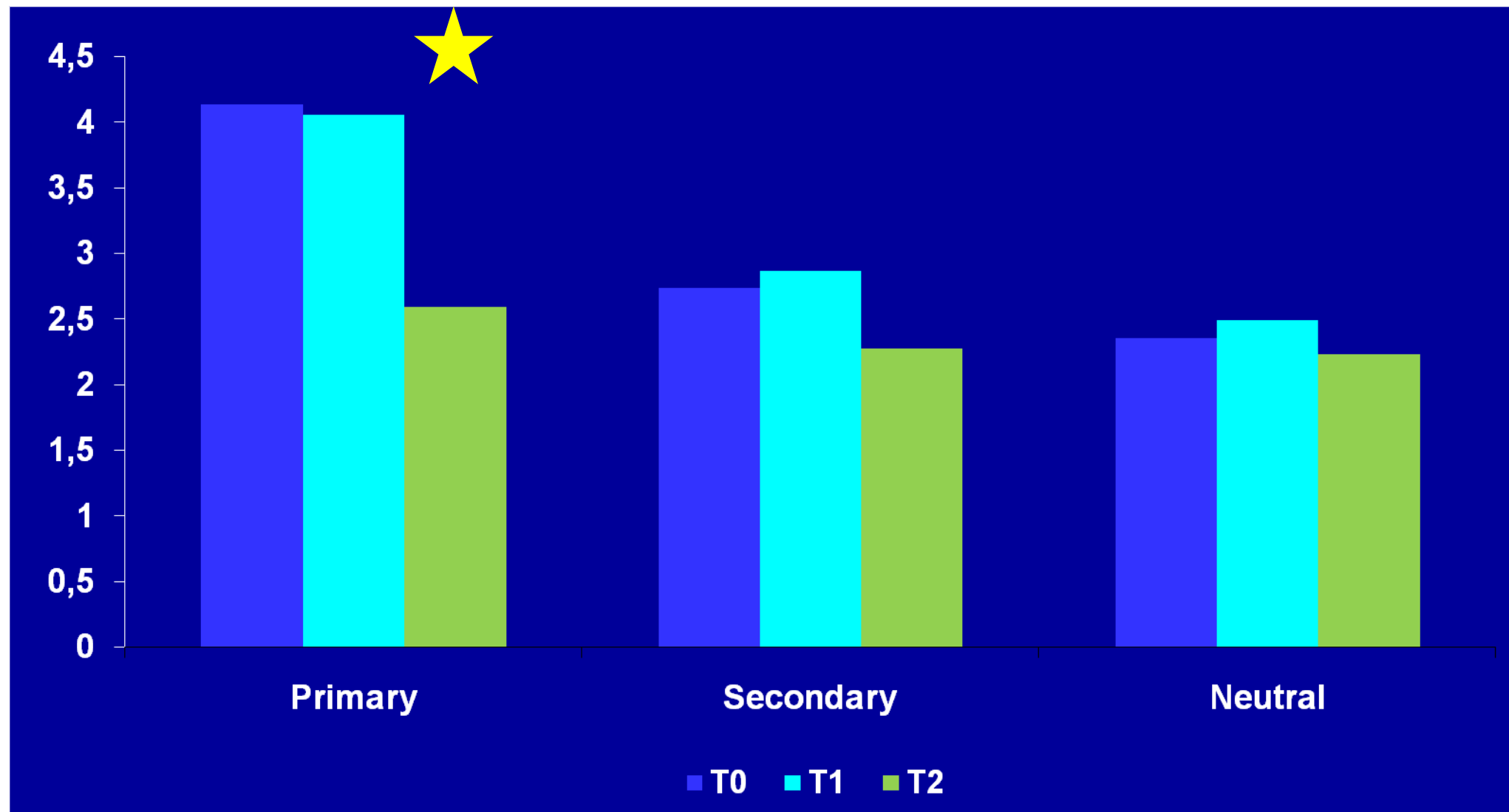
De Vries et al, 2011

GD before and after puberty suppression, and 1 year post surgery



De Vries et al, 2014

Dissatisfaction with body before and after puberty suppression and 1 year post surgery (T0, T1, T2)



De Vries et al, 2014

Post-operative Follow-up

- No gender dysphoria
- Psychological functioning improved
- Subjective well-being comparable to general population of young adults

De Vries et al.,2014

No Concerns?

(1)

- Only *one* prospective follow-up study
- Period of only one year post-surgery
- Selected and closely monitored group
- Physical effects?

No Concerns? (2) (bone mass density)

- Bone mass should increase from start puberty until about 25 years
- Puberty suppression also suppresses bone mass development

No Concerns? (3) (bone mass density)

Arch Sex Behav

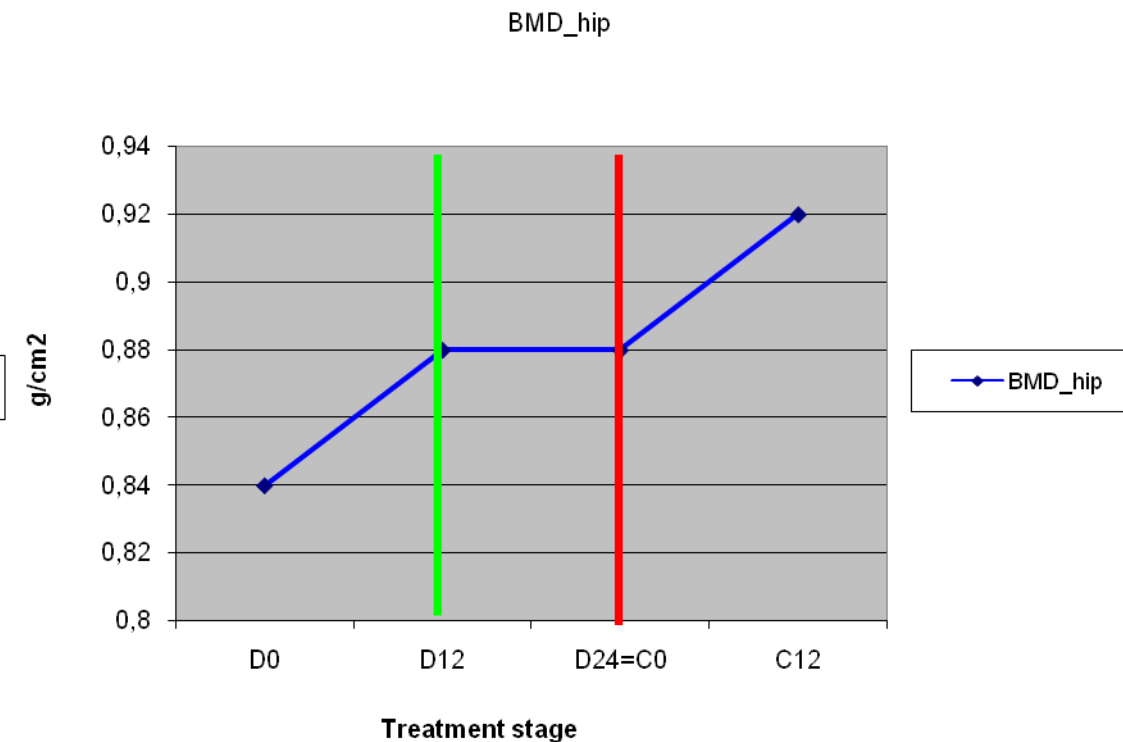
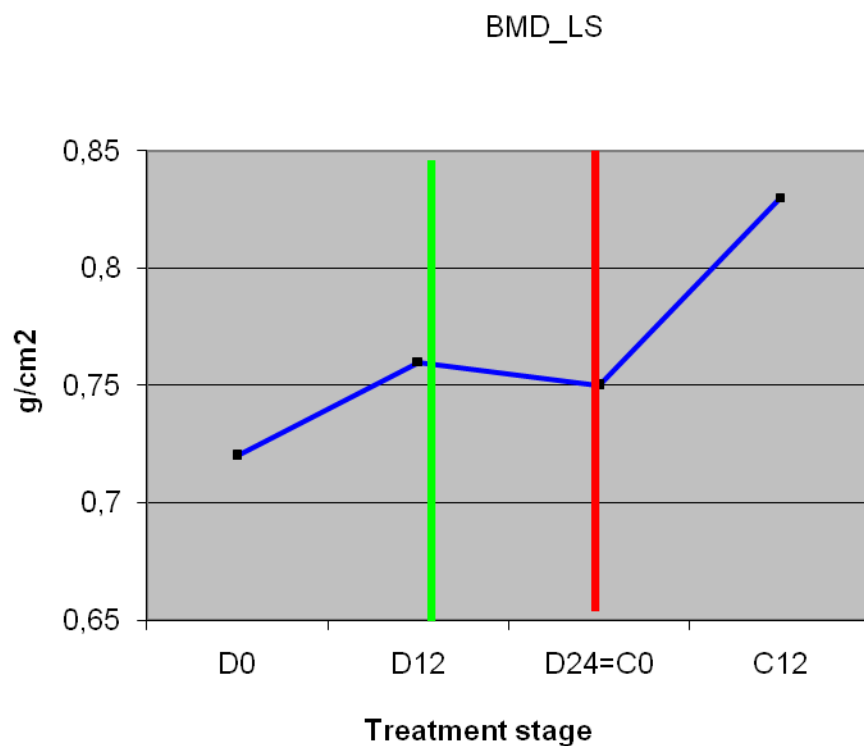
DOI 10.1007/s10508-011-9758-9

CLINICAL CASE REPORT SERIES

Puberty Suppression in a Gender-Dysphoric Adolescent: A 22-Year Follow-Up

**Peggy T. Cohen-Kettenis • Sebastiaan E. E. Schagen •
Thomas D. Steensma • Annelou L. C. de Vries •
Henriette A. Delemarre-van de Waal**

Bone Mass Density (BMD)



Delemarre van de Waal et al., 2004
Delemarre-van de Waal et al., 2006



No Concerns? (4)

J C E M O N L I N E

B r i e f R e p o r t — E n d o c r i n e R e s e a r c h

Bone mass in young adulthood following gonadotropin releasing hormone analogue treatment and cross sex hormone treatment in adolescents with gender dysphoria.

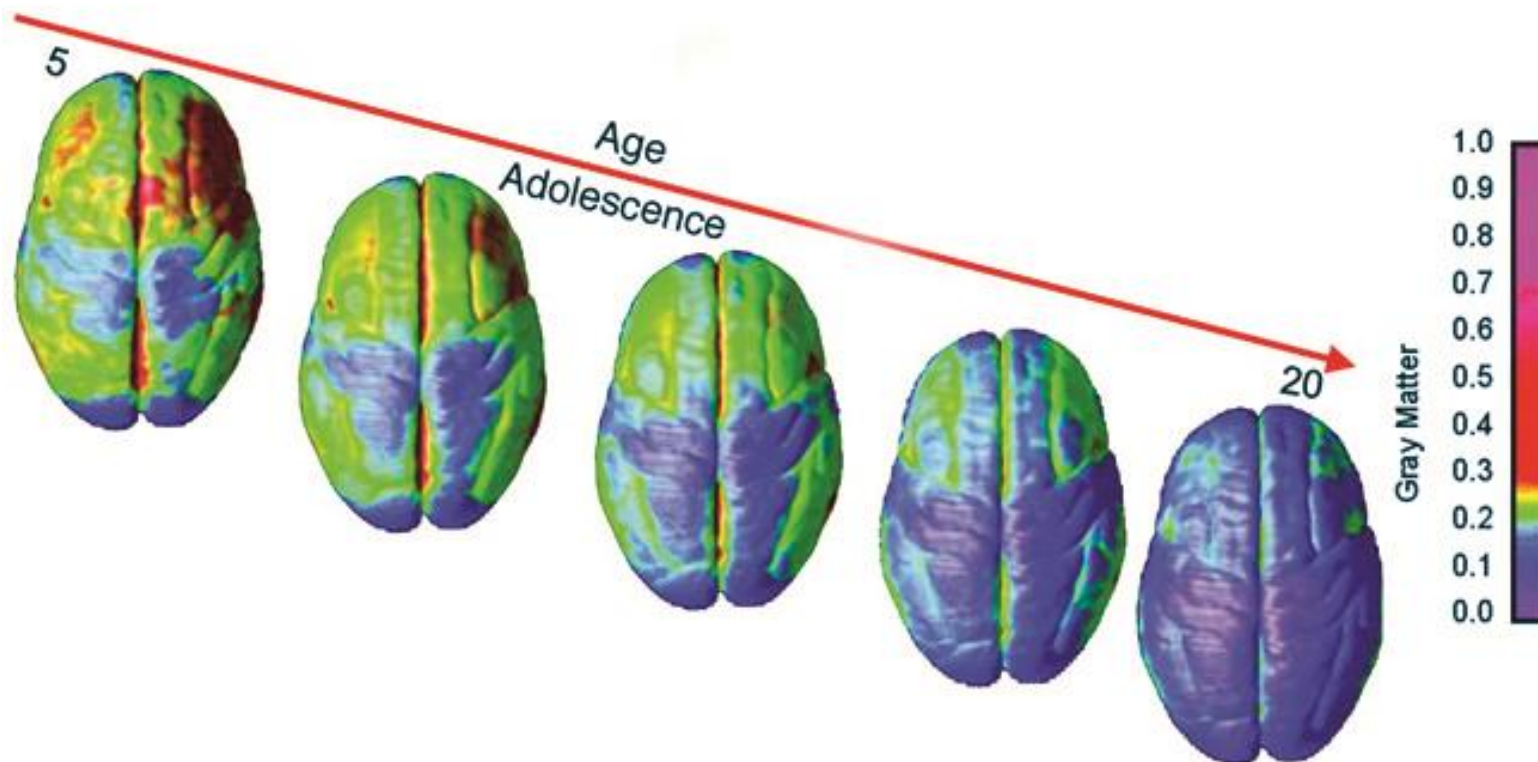
Daniel Klink^{1,2}, Martine Caris², Annemieke Heijboer³, Michael van Trotsenburg^{1,4}, Joost Rotteveel^{1,2}

¹Center of Expertise on Gender Dysphoria, VU University Medical Center, De Boelelaan 1118, 1081 HZ Amsterdam, The Netherlands;; ²Department of Pediatrics, Division of Endocrinology, VU University Medical Center, De Boelelaan 1117, 1081 HV Amsterdam, The Netherlands; ³Department of Clinical Chemistry, VU University Medical Center, De Boelelaan 1118, 1081 HZ Amsterdam, The Netherlands; ⁴Department of Obstetrics and Gynaecology, VU University Medical Center, De Boelelaan 1117, 1081 HV Amsterdam, The Netherlands

In transgirls (22y) peak bone mass delayed or peak bone mass attenuated (Klink et al., JCEM, 2014)

Peak bone mass 25 years → longer follow-up

Other Effects?



CAUTION

ACHTUNG!

CUIDADO

UWAGA!

POZOR!

VIGYÁZAT!

注意

ВНИМАНИЕ!

FORSIGTIG

Transgender adolescent care around the world



C & A GI services

- Africa?
- Latin America?
- Japan (Psychiatria et Neurologia Japonica, 2012)
- Australia
- New Zealand
- US 35 providers (Hsieh & Leininger, 2014)
- Canada
- **Europe** → Survey by Riittakerttu Kaltiala-Heino (Tampere, Finland)

C & A Specialized GI Services: European Survey

1. Belgium (1)
2. Finland (2)
3. Germany (3)
4. Italy (4)
5. Netherlands (2)
6. Northern Ireland (1)
7. Serbia (>16 years) (1)
8. Spain (3)
9. Sweden (2)
10. Switzerland (2)
11. UK (2)

12. Austria

- Croatia (0)
- Denmark (planning)
- France (0)

Total = 24 services

Costs Covered by National Health Insurance or Private Health Insurance

1. Belgium
2. Finland
3. Germany
4. Italy
5. Netherlands
6. Northern Ireland
7. Serbia
8. Spain
9. Sweden
10. Switzerland
11. UK

C&A Multidisciplinary team

C&A Psychologists, psychiatrists, pediatric endocrinologists

1.Belgium

2.Italy

3.Netherlands

4.Northern Ireland

5.Serbia

6.Spain

Others providers: network

Specific Legislation on Clinical Work

On assessment

- Spain
- Finland
- Sweden
- Serbia

On surgery (18)

- Spain
- Finland
- Sweden
- Serbia
- Italy
- N-Ireland

Specific Legislation on Clinical Work (2)

- **Hormonal treatments not** regulated by law (except in Serbia)
 - In practice cross-sex from 16y (15 Germany)
 - Puberty blocking from 12y or 14y

Legislation (documents)

- Lowest age of change legal documents 18 years
- In Netherlands: Lowest age of change legal documents 16 years

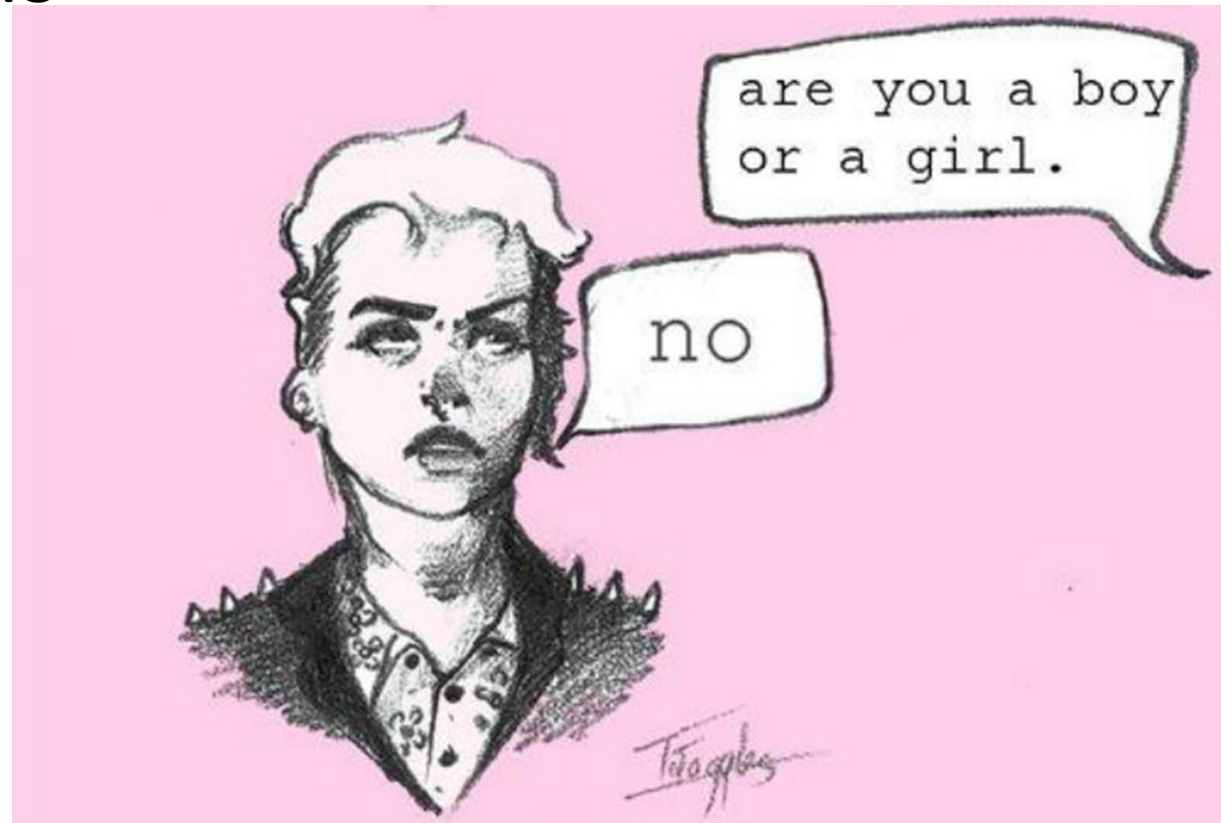
Future developments

Factors Influencing TG Care in Future

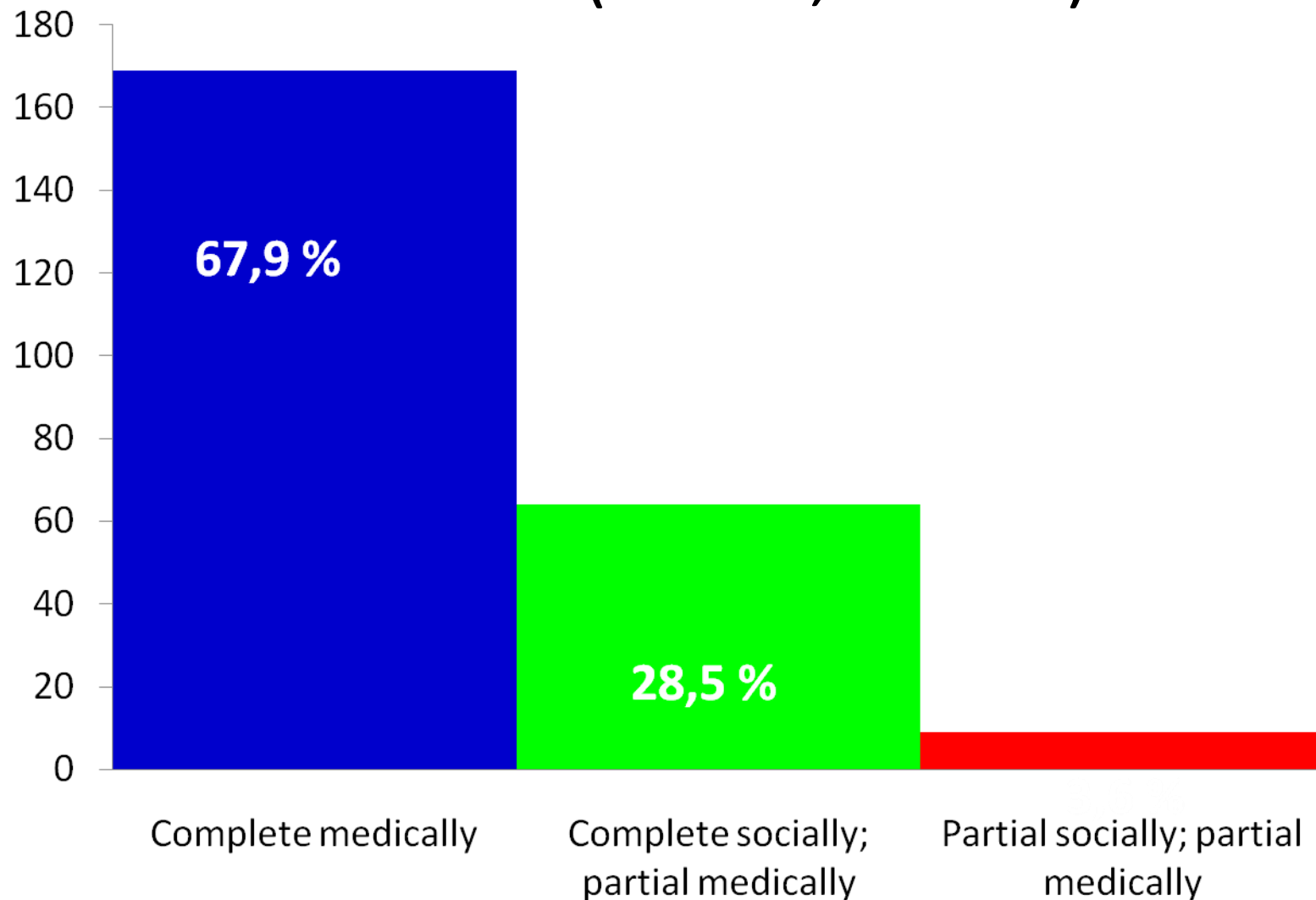
- **Effects of new diagnostic criteria**
- New laws
- New research

Effects New DSM-5 Criteria

- Only 2 indicators required for GD diagnosis
- More referrals?
- More heterogeneous referrals?
- Treatment desires
→ more diverse



Desire for type of treatment in 2013 (adults; N=249)



Titia Beek, 2014

ICD-11 (2017)



World Health
Organization

Field trials ICD-11

- Questionnaire on diagnosis among adolescents
 - name
 - psychiatric diagnosis
 - criteria
 - stigma



Factors Influencing TG Care in Future

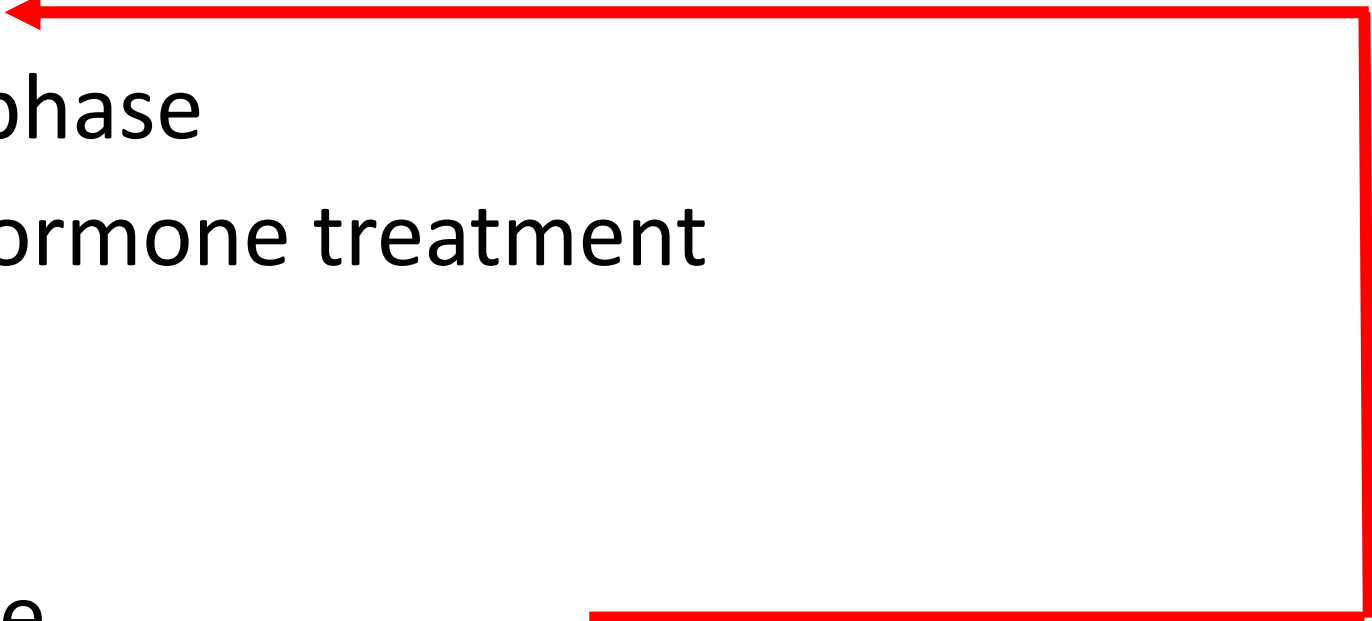
- Effects of new diagnostic criteria
- **New laws**
- New research

New laws

- Legal document changes without medical treatment
- Age < 18y (sometimes younger)



Treatment steps

- 
- Diagnostic phase
 - Cross-sex hormone treatment
 - Surgery
 - Legal change

Factors Influencing TG Care in Future

- Effects of new diagnostic criteria
- New laws
- **New research**

New research

- Studies on development of gender identity (relevant for deciding on social transitioning)
- Long term clinical follow-up studies of various kinds of treatment
 - Effects on quality of life
 - Effects on health
 - Effects on brain development
- How to deal with preservation of fertility

New Research (2)

- Cross-clinic, cross-national studies
- Networks of researchers
Adolescent Gender Identity Research Group
(AGIR; coordinator Thomas Steensma)

CHANGE
is
good.



Thank you

