Intersex Genital Mutilations

Human Rights Violations Of Children With Variations Of Reproductive Anatomy

Intersex UK
PROTECT EVERY BODY

UKIA
UK Intersex Association

HUMAN RIGHTS FOR HERMAPHRODITES TOO!
StopIGM.org

NGO Report (for Session)
to the 6th Report of the United Kingdom
on the Convention against Torture (CAT)

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Executive Summary

All typical forms of IGM practices are still widespread in the United Kingdom today, facilitated and paid for by the State party via the National Health Service (NHS), with statistics indicating about 2,900 involuntary, non-urgent interventions practiced annually.

The United Kingdom is thus in breach of its obligations under CAT to **(a)** take effective legislative, administrative, judicial or other measures to **prevent involuntary, non-urgent surgery and other medical treatment on intersex persons** without the effective, informed consent of those concerned, causing severe mental and physical pain and suffering, and **(b) to ensure impartial investigation, access to redress**, and the right to fair and adequate **compensation** and **rehabilitation for victims** (arts. 2, 12, 14 and 16, General Comments 2 + 3).

This Committee has repeatedly recognised IGM practices to constitute ill-treatment, and called for **legislation** to **(a)** end the practice, **(b)** ensure redress and compensation, and **(c)** to provide access to free counselling (CAT/C/DEU/CO/5, para 20; CAT/C/CHE/CO/7, para 20; CAT/C/AUT/CO/6, paras 44-45; CAT/C/DNK/CO/6-7, paras 42-43; CAT/C/CHN-HKG/CO/4-5, paras 28-29; CAT/C/FRA/CO/7, paras 32-33; CAT/C/NLD/CO/7, paras 52-53).

In addition, **CRC** has already **considered IGM in the UK** as a **harmful practice** (CRC/C/GBR/CO/5, paras 46-47) and **CRPD** as a **violation of the integrity** (CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41). Also **CCPR**, **CEDAW**, **SR Torture**, **SR Violence against Women**, **SRSG Violence against Children**, **UNHCHR**, the Council of Europe (**COE**), the Inter-American Commission on Human Rights (**IACHR**), the African Commission on Human and Peoples' Rights (**ACHPR**) and the World Health Organisation (**WHO**) recognise IGM practices as a **serious violation of non-derogable human rights**, calling for **legislative remedy** and **access to redress and justice**.

Intersex people are born with **Variations of Reproductive Anatomy**, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. While intersex people may face several problems, in the "developed world" the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations.

IGM Practices include **non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical treatments** that would not be considered for "normal" children, without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs. **Typical forms** of IGM include "masculinising" and "feminising", "corrective" genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, human experimentation and denial of needed health care.

IGM Practices cause known **lifelong severe physical and mental pain and suffering**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, urethral strictures, impairment or loss of reproductive capabilities, lifelong dependency of artificial hormones, significantly elevated rates of self-harming behaviour and suicidal tendencies, lifelong mental suffering and trauma, increased sexual anxieties, less sexual activity, dissatisfaction with functional and aesthetic results.

This **Thematic NGO Report** has been compiled by intersex NGOs **IntersexUK**, **The UK Intersex Association** and **StopIGM.org**. It contains **Suggested Recommendations (p. 19).**

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A. Introduction

1. Intersex, IGM and Human Rights in the United Kingdom

The United Kingdom has been reviewed by **CRC** (2016), and **CRPD** (2017), with both Committees **recognising** IGM in the UK as constituting a **harmful practice**, **cruel, inhuman or degrading treatment**, and a **violation of integrity**.

In countries allover the world, **UN treaty bodies including CAT** are regularly denouncing IGM as a **serious violation of non-derogable human rights.** [1] [2]

Nonetheless, **the UK fails to recognise** the serious nature of the violations constituted by IGM practices, and **fails to undertake effective measures**, including legislation, to protect intersex children from the daily mutilations. This NGO Report demonstrates that the current **harmful medical practice on intersex persons in the UK** – advocated, facilitated and **paid for by the State party** – constitute **serious breaches** of the UK's obligations under the Convention.

To this day the United Kingdom undeviatingly not only does nothing to prevent this abuse, but **continues to directly finance it via the public National Health Service (NHS)** and via funding the public university clinics and paediatric hospitals, thus **violating its non-derogable duty** to prevent inhuman treatment of intersex children, to guarantee access to **justice, redress and compensation** to IGM survivors, as well as access to **adequate counselling and consensual needed health care** for intersex people and their families.

2. About the Rapporteurs

This NGO report has been prepared by the **Intersex NGO Coalition UK:**

- **StopIGM.org / Zwischengeschlecht.org,** founded in 2007, is an international Human Rights NGO based in Switzerland. It is led by intersex persons, their partners, families and friends, and works to end IGM Practices and other human rights violations perpetrated on intersex people, according to its motto, *"Human Rights for Hermaphrodites, too!"* [3] According to its charter,[4] StopIGM.org works to support persons concerned seeking redress and justice, and regularly reports to UN treaty bodies on IGM practices. StopIGM.org has been active in the UK since 2011[5] [6] [7] [8] [9].

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[1] Currently there are **38 UN Treaty body Concluding Observations** explicitly condemning IGM practices as a **serious violation of non-derogable human rights**, see: http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

[2] **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

[3] http://Zwischengeschlecht.org/, English pages: http://stop.genitalmutilation.org/

[4] http://zwischengeschlecht.org/post/Statuten

[5] http://zwischengeschlecht.org/pages/Open-Letter-ISHID-2011-18-09

[6] Margaret Simmonds, "Girls/women in inverted commas – facing 'reality' as an XY-female", PhD Thesis University of Sussex, p. 208 (PDF p. 214), http://sro.sussex.ac.uk/43431/1/Simmonds,_Margaret.pdf

[7] Australian Senate Hearing, 28.03.2013, Testimony G. Ansara, p. 11 (PDF p. 15), http://parlinfo.aph.gov.au/parlInfo/download/committees/commsen/86ba4480-36ef-4e72-b25e-9fa162f9a4ae/toc_pdf/Community%20Affairs%20References%20Committee_2013_03_28_1856_Official.pdf;fileType=application%2Fpdf#search=%22committees/commsen/86ba4480-36ef-4e72-b25e-9fa162f9a4ae/0000%22

- **IntersexUK (iUK)**, founded in 2011, is an NGO led by UK intersex persons and survivors of IGM practices working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues, including in regional and international media. They deliver educational training in universities and political consultancy to public sector bodies, particularly in England and Scotland.[10] [11]
- **The UK Intersex Association (UKIA)**, founded in 2000, is an NGO led by UK intersex persons and survivors of IGM practices working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues.[12] [13]

In addition, the Rapporteurs would like to acknowledge the work of the **Androgen Insensitivity Syndrome Support Group UK (AISSG UK)**[14] and **Margaret Simmonds**.[15] We would like to acknowledge the work of **Leslie Jaye**[16] and of **Michel O'Brien**.[17] We would like to acknowledge the work of **Ellie Magritte**[18] and **dsdfamilies.org**.[19] And we would like to acknowledge the work of Daniela Crocetti, Surya Monro, and Tray Yeadon-Lee with Fae Garland and Mitch Travis at the University of Huddersfield's **Intersex/DSD Human Rights, Citizenship and Democracy [EUICIT] Project**.[20]

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[8] http://stop.genitalmutilation.org/public/Open-Letter_I-DSD_2013.pdf

[9] http://www.ias.surrey.ac.uk/workshops/intersex/papers/Intersex%20programme%20brochure.pdf

[10] https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex
http://www.independent.co.uk/news/uk/home-news/special-report-intersex-women-speak-out-to-protect-the-next-generation-8974892.html

[11] http://intersexuk.org

[12] https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex
https://www.vice.com/en_uk/read/the-group-campaigning-for-better-intersex-rights

[13] http://ukia.co.uk

[14] http://www.aissg.org/

[15] Margaret Simmonds: 'Girls/women in inverted commas – facing "reality" as an XY-female', University of Sussex 2012, http://sro.sussex.ac.uk/43431/1/Simmonds,_Margaret.pdf

[16] https://intersexday.org/en/language-truth-jaye/

[17] http://oiiinternational.com/653/holistic-for-whom/

[18] http://www.dsdfamilies.org/docs/conf/working_together.pdf

[19] http://www.dsdfamilies.org/

[20] https://research.hud.ac.uk/institutes-centres/ccid/projects/intersex-dsd_human_rights/

3. Methodology

This thematic NGO report is in part based on the **2016 CRC UK NGO Report**,[21] the **2017 CRPD UK PSWG NGO Report**,[22] the **2017 CRPD UK NGO Report**,[23] and the **2018 CEDAW UK PSWG NGO Report**[24] by the same rapporteurs.

It includes **10 anonymised personal testimonies of UK survivors of IGM practices** originally compiled for the 2016 CRC UK Thematic Intersex NGO Report by the same Rapporteurs,[25] based on (a) written submissions solicited by the Rapporteurs and IntersexUK, (b) interviews conducted for this NGO report, and (c) written testimonies available online via AISSG UK[26] and Hypospadias UK[27] (see source given at the end of each testimony). They show in an exemplary manner how different forms IGM are practiced in the UK without informed consent by the persons concerned and/or their parents, and cause **severe physical and mental pain and suffering**.

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[21] http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

[22] http://intersex.shadowreport.org/public/2017-CRPD-PSWG-UK-NGO-Coalition-Intersex-IGM.pdf

[23] http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf

[24] http://intersex.shadowreport.org/public/2018-CEDAW-PSWG-UK-NGO-Coalition-Intersex-IGM.pdf

[25] http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

[26] http://www.aissg.org/41_STORIES.HTM

[27] http://www.hypospadiasuk.co.uk/life-stories-of-men-with-hypospadias/

B. Non-derogable Protections denied: The Misrepresentation of IGM as "LGBT" or "Health Care" Issue

1. Intersex is NOT THE SAME as LGBT or SOGI

Unfortunately, there are often interrelated **harmful misconceptions about intersex** still prevailing in public, with often **serious legal consequences**, notably if intersex is falsely labelled as being the same as or a subset of LGBT or SOGI, e.g. if intersex and/or intersex status are **misrepresented as a sexual orientation** (like gay or lesbian), and/or as a **gender identity**, as a subset of **transgender**, as the same as **transsexuality**.

The underlying reasons for such harmful misconceptions include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**[28] [29] for their own agenda, and State parties **trying to deflect** from criticism of involuntary intersex treatments.

Intersex persons and their organisations have spoken out clearly against instrumentalising or misrepresenting intersex issues,[30] maintaining that IGM practices present a **distinct and unique issue** constituting significant human rights violations, which are different from those faced by the LGBT or SOGI community, and thus need to be **adequately addressed in a separate section** as **specific intersex issues.**

Also **human rights experts** are increasingly warning of the **harmful conflation** of intersex and LGBT.[31]

Particularly **State parties** are constantly **misrepresenting intersex and IGM as sexual orientation or gender identity issues** in an attempt to **deflect from criticism** of the serious human rights violations resulting from IGM practices, instead referring to e.g. *"gender reassignment surgery"* (i.e. voluntary procedures on transsexual or transgender persons) and *"gender assignment surgery for children"*,[32] *"a special provision on sexual orientation and gender identity"*, *"civil registry"* and *"sexual reassignment surgery"* [33], transgender guidelines[34] or *"Gender Identity"* [35] [36] when asked about IGM by e.g. Treaty bodies.

Regrettably, **these harmful misrepresentations seem to be on the rise also at the UN**, for example in recent **UN press releases** and **Summary records** misrepresenting IGM as *"sex alignment surgeries"* (i.e. voluntary procedures on transsexual or transgender persons),

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[28] CRC67 Denmark, http://stop.genitalmutilation.org/post/CRC67-Intersex-children-used-as-cannon-fodder-LGBT-Denmark

[29] CEDAW66 Ukraine, http://stop.genitalmutilation.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics

[30] For references, see 2016 CEDAW France NGO Report, p. 45. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

[31] For example ACHPR Commissioner Lawrence Murugu Mute (Kenya), see http://stop.genitalmutilation.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT

[32] CRC73 New Zealand, http://stop.genitalmutilation.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child

[33] CCPR120 Switzerland, http://stop.genitalmutilation.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120

[34] CAT56 Austria, http://stop.genitalmutilation.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations

[35] CAT60 Argentina, http://stop.genitalmutilation.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture

[36] CRPD18 UK, http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD

IGM survivors as *“transsexual children”*, and intersex NGOs as *“a group of lesbians, gays, bisexuals, transgender and intersex victims of discrimination”*,[37] and again IGM survivors as *“transgender children”*,[38] *“transsexual children who underwent difficult treatments and surgeries”*, and IGM as a form of *“discrimination against transgender and intersex children”* [39] and as *“sex assignment surgery”* while referring to *“access to gender reassignment-related treatments”*.[40]

What’s more, **LGBT organisations** (including “LGBTI” organisations without actual intersex representation or advocacy) are using the ubiquitous misrepresentation of intersex = LGBT to **misappropriate intersex funding**, thus depriving actual intersex organisations (which mostly have no significant funding or public representation, if any) of much needed resources.[41]

On a **legislative level**, the wilful misrepresentation of intersex as a LGBT or gender issue inevitably perpetuates the **denial of intersex children’s non-derogable rights,** including the right to **protection from inhuman treatment**, genital mutilation or involuntary sterilising procedures, and the **right to justice, redress and compensation** of those submitted to such harmful medical practices.

2. Misrepresenting Genital Mutilation as “Health Care”

An interrelated, alarming new trend is the **increasing misrepresentation of IGM as *“health-care issue”*** instead of a serious human rights violation, and the **promotion of *“self-regulation”* of IGM by the current perpetrators** [42] [43] [44] – instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee).

Even worse, **Health** ministries construe UN Treaty body Concluding Observations falling short of explicitly recommending legislation to criminalise or adequately sanction IGM as an **excuse for “self-regulation” promoting state-sponsored IGM practices to continue with impunity.**[45]

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[37] CAT60 Argentina, http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60

[38] CRC77 Spain, http://stop.genitalmutilation.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children

[39] CRC76 Denmark, http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CRC-Denmark-UNCRC67

[40] CAT/C/DNK/QPR/8, para 32

[41] For example in Scotland (UK), LGBT organisations have so far collected at least £ 135,000.– public intersex funding, while actual intersex organisations received ZERO public funding, see 2017 CRPD UK NGO Report, p. 14, http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf
Typically, during the interactive dialogue with CRPD, the UK delegation nonetheless tried to sell this glaring misappropriation as “supporting intersex people”, but fortunately got called out on this by the Committee, see transcript (Session 2, 10:53h + 11:47h), http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD

[42] For example Amnesty (2017), see http://stop.genitalmutilation.org/post/Amnesty-Report-fails-Intersex-Children-and-IGM-Survivors

[43] For example FRA (2015), see StopIGM.org (2015), Presentation at OHCHR Intersex Expert Meeting, slide 8, http://stop.genitalmutilation.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

[44] For example CEDAW Italy (2017), see http://stop.genitalmutilation.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN

[45] See for example Ministry of Health Chile (2016), http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile

C. IGM in the UK: State-sponsored and pervasive, Gov fails to act

1. Overview: IGM practices in the UK: Pervasive and unchecked

In the **United Kingdom** (see CRC/C/GBR/CO/5, paras 45-46, CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41), same as in *Germany* (CAT/C/DEU/CO/5; para 20; CRPD/C/DEU/CO/1, paras 37-38; CEDAW/C/DEU/CO/7-8, paras 23-24), *France* (CAT/C/FRA/CO/7, paras 32–33; CRC/C/FRA/CO/5, paras 47-48; CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f), *Switzerland* (CAT/C/CHE/CO/7, para 20; CCPR/C/CHE/CO/4, paras 24-25; CRC/C/CHE/CO/2-4, paras 42-43; CEDAW/C/CHE/CO/4-5, paras 38-39), and in **many more State parties**,[46] there are

- **no effective legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and **to prevent IGM**
- **no measures** in place to ensure **systematic data collection and monitoring** of IGM
- **no legal or other measures** in place to ensure the **accountability** of IGM perpetrators
- **no legal or other measures** in place to ensure **access to redress and justice** for adult IGM survivors.

To this day, the **UK government fails to recognise the serious human rights violations**[47] and the lifelong, severe suffering caused by IGM practices, let alone to ***"take effective legislative, administrative, judicial or other measures"*** to protect intersex children.

What's worse, this continues **after the State party has already been reprimanded** by **CRC in 2016**, and by **CRPD in 2017** for IGM practices, with both Committees calling for **legislative measures** including to ensure access to **redress**, and to provide **adequate support.**

UK doctors are very outspoken about their determination to continue with involuntary surgeries etc. on intersex children ***"[u]ntil such time as there is a change in law"*** (see p. 14).

To this day, in the UK **all forms of IGM practices remain widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by state funded University and public Children's Hospitals, and **advocated and paid for** by the public **National Health Service (NHS):**

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[46] See http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

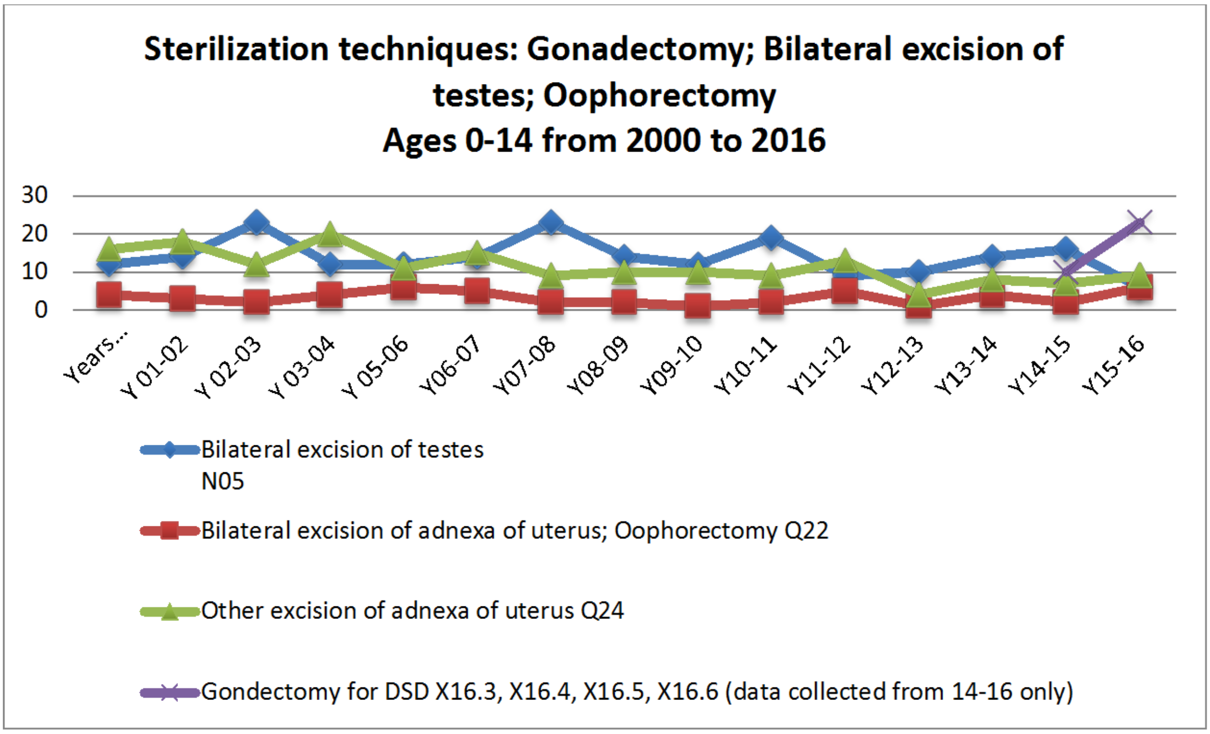
[47] **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

2. Most common IGM Forms advocated by NHS Doctors and Clinics

While there is no data available on IGM practices in the whole of the UK, **statistics based on NHS England Hospital Episode Statistics (HES)** and published in a research report of the University of Huddersfield indicate **annually up to 2,900** non-urgent genital surgeries on intersex children in England alone.

a) IGM 3 – Sterilising Procedures:

Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones [48]



Source: Huddersfield UK Intersex Report 2017, p. 13[49]

Removal of testes, as advocated in the 2013 ***"ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)",***[50] co-authored by Dr Peter Malone (University College Hospital UCLH, University College London Hospitals NHS Foundation Trust / Royal Berkshire Hospital, Royal Berkshire NHS Foundation Trust):

> ***"Testes are*** *either brought down in boys or* ***removed*** *if dysgenetic with tumour risk or* ***in complete androgen insensitivity syndrome or 5 alpha reductase deficiency.*** *Testicular prostheses can be inserted at puberty at the patient's request.****"***

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[48] For general information, see 2016 CEDAW NGO Report France, p. 47. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

[49] Monro, Surya, Crocetti, Daniela, Yeadon-Lee, Tray, Garland, Fae and Travis, Mitch (2017), Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report. University of Huddersfield, http://eprints.hud.ac.uk/id/eprint/33535/

[50] P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf

Similarly, the **"2016 Global Disorders of Sex Development Consensus Statement",**[51] co-authored by Prof S. Faisal Ahmed (Paediatric Endocrinology, School of Medicine, University of Glasgow / Royal Hospital For Children, NHS Greater Glasgow and Clyde) still advocates "gonadectomy" – even when admitting *"low"* cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)[52].

Accordingly, around **450 times annually** the NHS England facilitates and pays for **removal of testes of children 0–14 years, including unnecessary removal in intersex children age 0-14**.[53]

And around **5 times annually** the NHS England regularly facilitates and pays for **unnecessary removal of "atypical" gonadal tissue of intersex children age 0-14 ("excision of ovotestes")**.[54]

In addition, as the more refined statistics 2014-2015 for "gonadectomies" show, in England **often gonadectomies, including excision of ovotestes, still happen very early from 0-4 years,** when in any case actual cancer risk is hardly an issue.[55]

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation[56]

The ***"Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015)"*** [57] generally advocates early unnecessary surgeries as legitimate, framing the human rights issues involved as *"controversies":*

> ***"Some parents may consider early genital surgery as a mechanism that could possibly protect their child from the risk of future stigma.*** *This will require a thorough discussion with several members of the MDT team including the clinical psychologist, surgeons, gynaecologist and nurses so that the parents are fully informed of the* ***controversies around undertaking or withholding early genital surgery."***

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[51] Lee et al., "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care", Horm Res Paediatr 2016;85:158–180, https://www.karger.com/Article/Pdf/442975

[52] ibid, at 180 (fn 111)

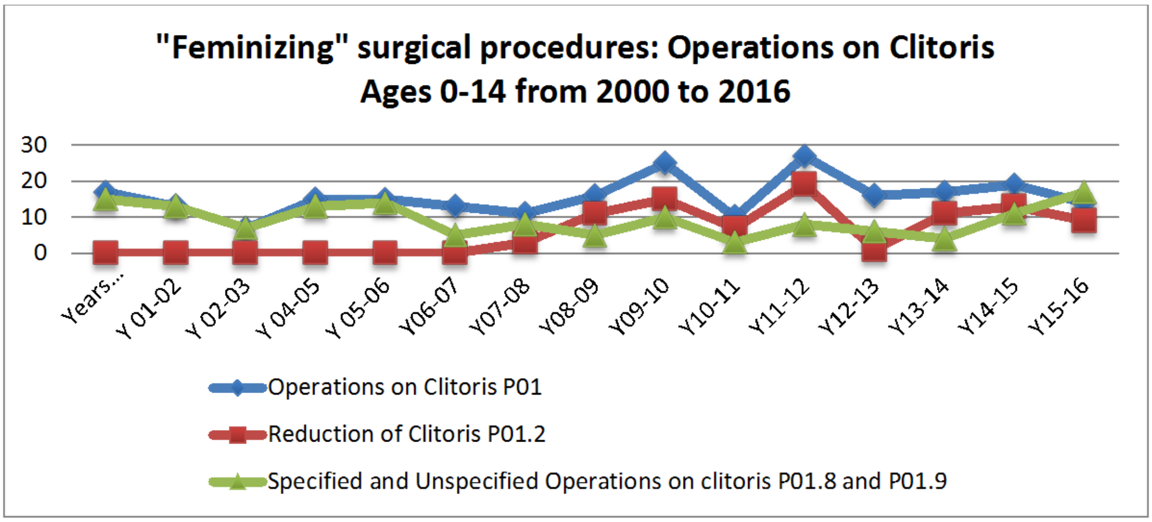
[53] Figure derived from Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2000-2014: "Main procedures and interventions: 4 character", N05.2, N06.3. 2014-15: N05.2, N05.3, N06.3, N06.6. Note: Numbers also include necessary treatments of non-intersex children.

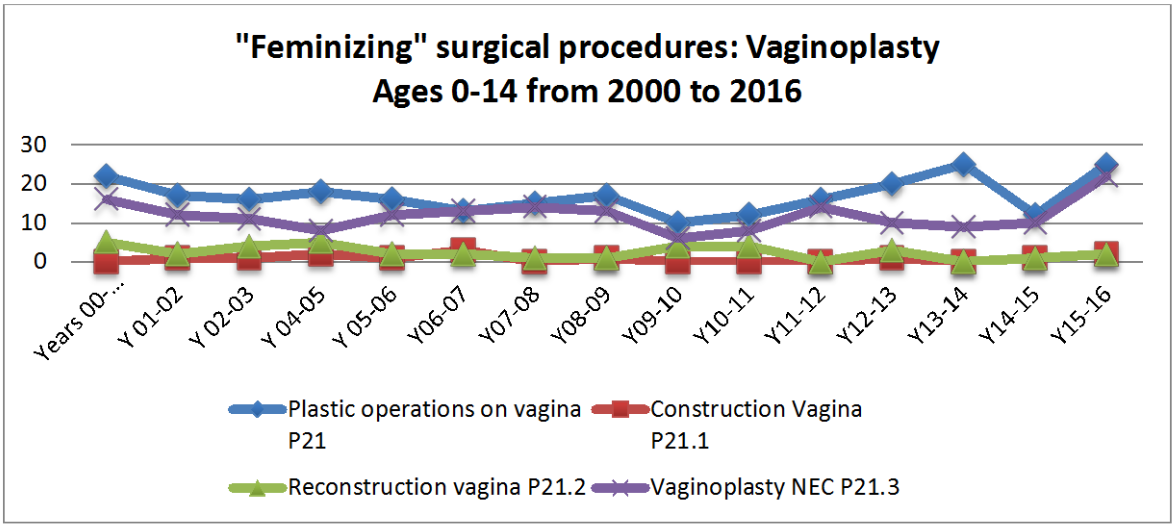
[54] Figure derived from Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2000-2014: "Main procedures and interventions: 4 character", X15.3. 2014-15: X16.3-6 (see next example).

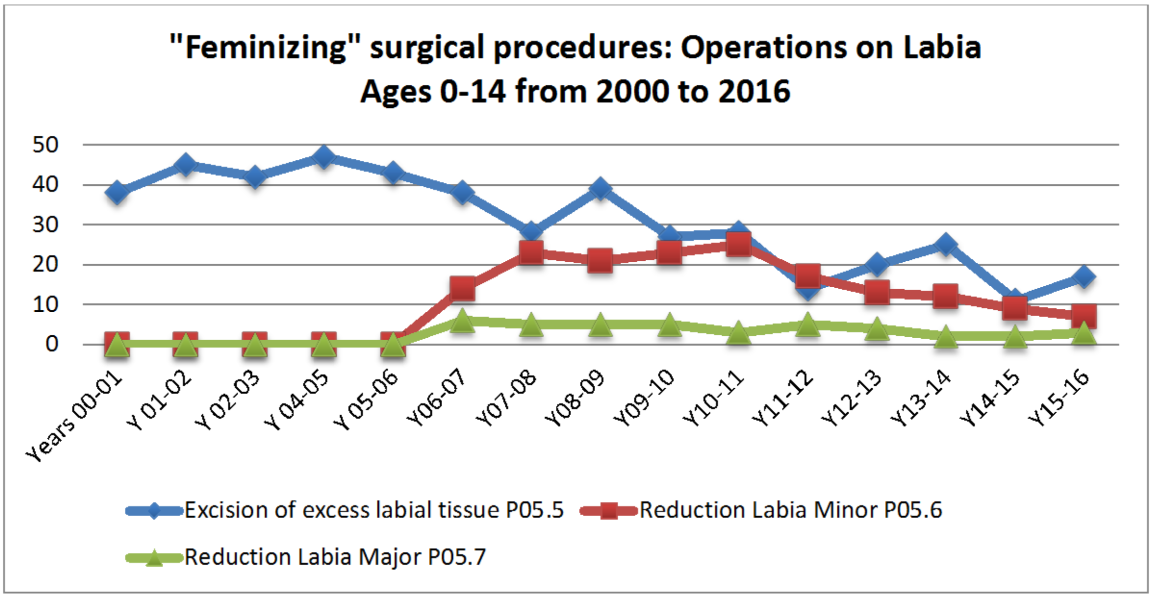
[55] From Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2014-15: "Total procedures and interventions: 4 character". Note: These procedures may not all constitute unnecessary treatments.

[56] For general information, see 2016 CEDAW NGO Report France, p. 48. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

[57] S. Faisal Ahmed et al., "Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015)", Clinical Endocrinology (2016) 84, 771–788, http://onlinelibrary.wiley.com/doi/10.1111/cen.12857/pdf







Source: Huddersfield UK Intersex Report 2017, p. 14[58]

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[58] Monro, Surya, Crocetti, Daniela, Yeadon-Lee, Tray, Garland, Fae and Travis, Mitch (2017), Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report. University of Huddersfield, http://eprints.hud.ac.uk/id/eprint/33535/

Above UK Endocrinology *"guidance"* remains remarkably similar to the 2011 ***"best practice by a multidisciplinary team (MDT) dedicated to children with DSD"*** as promoted by paediatric urologist Dr Imran Mushtaq (Great Ormond Street Hospital for Children GOSH NHS Foundation Trust / Senior Lecturer Institute of Child Health, London): [59]

> ***"There is no subject that creates more controversy and debate*** *than that relating to 'feminising' genital surgery in infants and children with DSD. [...]"*
>
> ***"Many parents of children with DSD continue to express deep concerns about the appearance of the genitalia*** *and these concerns need to be taken seriously and managed in an appropriate manner. [...]"*
>
> ***"Clitoral surgery is generally considered when the clitoris is larger than 'normal'.*** *[...] "*
>
> ***"In girls with severe clitoral enlargement we remain happy to undertake clitoral reduction surgery,*** *provided the family are fully informed and cognisant of the potential risks and benefits."*
>
> ***"Until such time as there is a change in the law, parents will continue to have the right to decide*** *if their child should or should not have genital surgery in infancy or childhood. [...]"*

Accordingly, the NHS England persistently facilitates and pays for **clitoral surgery on children 0–14 years** around **15 times annually** – despite all ethics and human rights *"controversy and debate"*.[60]

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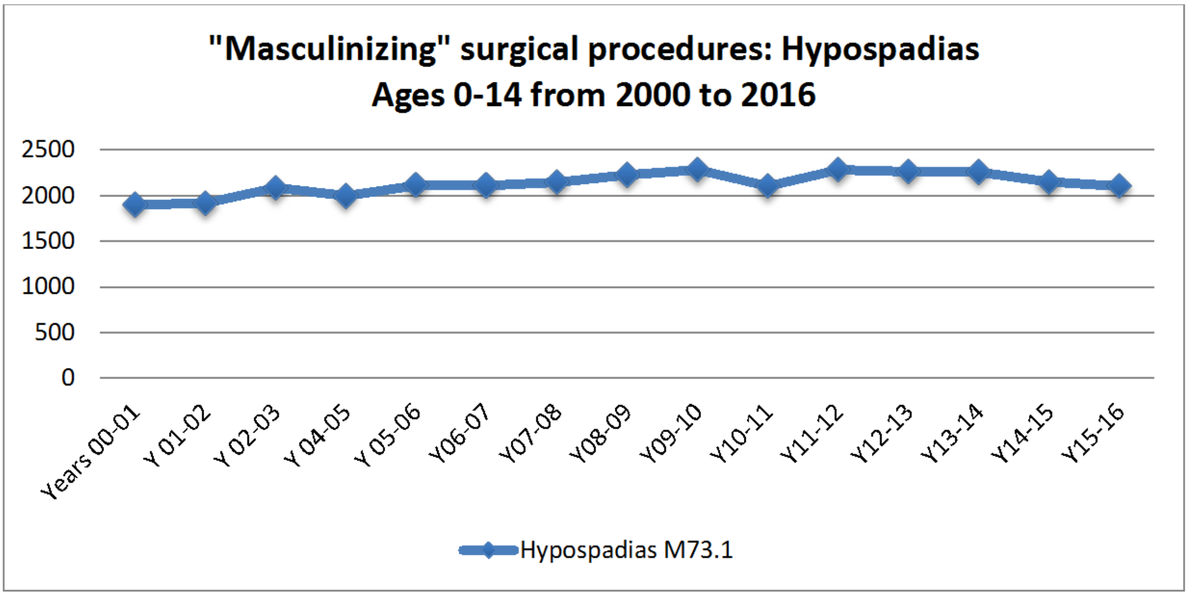
[59] Imran Mushtaq, "Surgery in infants and children with DSD" (2011), http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf

[60] Figure derived from Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2000-2012: "Total procedures and interventions: 3 character", P01. 2012-15: "All procedures and interventions: 4 character" P01.1, P01.2, P01.8.

c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”[61]



Source: Huddersfield UK Intersex Report 2017, p. 15[62]

Hypospadias “repair”, as advocated by the “British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS)” in their online ***“Procedure Guide Hypospadias”***: [63]

> *“There is no urgency to treat this condition, but once recognised you will be referred to a specialist to discuss surgery to correct the problem. […]”*
>
> ***“What surgery is available, and what techniques are involved?***
>
> *Surgery is recommended to make the penis look as natural as possible and to enable the child to stand up to pass urine.* ***Corrective surgery for the treatment of hypospadias is often carried out 12 months after birth but can be done earlier or later.*** *[…].”*
>
> ***“Is this surgery available on the NHS?***
>
> *Surgery to correct hypospadias is widely available on the NHS.”*

UK NHS medical bodies and children’s clinics generally **advocate early hypospadias “repair” justified by psychosocial “indications”.** For example the **“Norfolk and Norwich University Hospitals NHS Foundation Trust”** and **“Ipswich Hospital NHS Trust”** in their *“Information Leaflet on Hypospadias for Parents”*: [64]

> *“WHAT AGE WILL MY SON BE?”*
>
> *“We prefer to perform the operation at* ***about 12 months of age*** *or above.”*

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[61] For general information, see 2016 CEDAW NGO Report France, p. 48-49. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

[62] Monro, Surya, Crocetti, Daniela, Yeadon-Lee, Tray, Garland, Fae and Travis, Mitch (2017), Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report. University of Huddersfield, http://eprints.hud.ac.uk/id/eprint/33535/

[63] http://www.bapras.org.uk/public/patient-information/surgery-guides/hypospadias

[64] http://www.nnuh.nhs.uk/publication/download/hypospadias-29-0-14

Or the **"University Hospitals Bristol NHS Foundation Trust"** in its *"Surgery for Hypospadias Family information leaflet"*: [65]

> ***"Surgery usually takes place at 10-18 months of age** [...]"*

Accordingly, up to **2400 times annually** the NHS England facilitates and pays for **hypospadias "repair" on intersex children 0–14 years.**[66]

3. UK NHS Doctors consciously dismissing Intersex Human Rights Concerns

It must be duly noted that **UK paediatric surgeons** are **adamant advocates** of IGM practices, **consciously dismissing to consider any human rights concerns, despite openly admitting to knowledge of relevant criticisms** by human rights and ethics bodies.

For example, the 2013 *"ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)"*, co-authored by Dr Peter Malone (University College Hospital UCLH, University College London Hospitals NHS Foundation Trust / Royal Berkshire Hospital, Royal Berkshire NHS Foundation Trust) dismissed both the **2013 Report by the Special Rapporteur on Torture** and the 2012 Recommendations by the Swiss National Advisory Commission on Biomedical Ethics as ***"inappropriate and biased statements"*** and ***"biased and counterproductive reports"***, while insisting on continuing with IGM practices.[67]

And paediatric urologist Dr Imran Mushtaq (Great Ormond Street Hospital for Children NHS Foundation Trust / Senior Lecturer Institute of Child Health, London) freely admits **only *"a change in law"*** would prevent the hospital's *"multidisciplinary team (MDT) dedicated to children with DSD"* from continuing with IGM practices: [68]

> *"**Until such time as there is a change in the law, parents will continue to have the right to decide** if their child should or should not have genital surgery in infancy or childhood. [...]"*

This is the more severe, since over a decade of ongoing research published by **clinicians from the UCLH Middlesex Clinic caring for adult intersex persons** clearly documents the disastrous effects of non-consensual, unnecessary childhood treatments in the UK, so UK paediatric doctors specialising in such treatments are obviously fully aware of the severe pain and suffering caused by their actions,[69] as are Government bodies.

Nonetheless, so far Government bodies fail to take appropriate action, but continue to ignore intersex human rights, and allow IGM doctors to continue practicing with impunity.

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[65] http://www.drmark.info/Dr_Mark/Information_leaflets_files/Hypospadias%20surgery_one%20and%20two%20stage_2012.pdf

[66] Figure derived from Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2000-2012: "Main procedures and interventions: 4 character", M73.1. 2012-15: "All procedures and interventions: 4 character" M73.1.

[67] P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf

[68] Imran Mushtaq, "Surgery in infants and children with DSD" (2011), http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf

[69] see e.g. Sarah M. Creighton et al., (2013), Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same?, Psychology & Sexuality 5(1):34-43
For a list of older relevant Middlesex publications, see http://www.intersexinitiative.org/articles/minto-creighton.html

D. Conclusion: UK must "take effective measures" to end IGM

For many years, the **UK government has been called upon** to

- undertake **legislation to prohibit** IGM practices
- guarantee **access to justice and redress** for IGM survivors
- ensure **adequate support** for intersex children and their families
- systematically **collect disaggregated data**,

including by UN Treaty bodies **CRC** and **CRPD**, which have expressed **concern** about

> ***"[c]ases of medically unnecessary surgeries and other procedures on intersex children*** *before they are able to provide their informed consent, which often entail* ***irreversible consequences*** *and can cause* ***severe physical and psychological suffering****, and the* ***lack of redress and compensation*** *in such cases"*,

and have **urged the UK**, inter alia, to

- ***"[e]nsure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood"***
- ***"[provide] protection and care to the child victims and the prosecut[e] those found guilty of perpetrating such acts"***
- ***"[e]stablish measures to ensure equal access to justice"***
- ***"[p]rovide redress to the victims of such treatment"***
- ***"[e]ducate medical and psychological professionals […] on the consequences of unnecessary interventions for intersex children"***

Since then, on the positive side the **current UK Government** has to be commended for being the **very first** to

- publicly **acknowledge the call for legislative measures** to prevent IGM practices (CEDAW/C/GBR/Q/8/Add.1, para 46)
- publicly **admit that it is wrong to conflate intersex with transgender**,[70] [71]
- undertake a **Call for Evidence on Variations in Sex Characteristics** in consultation with intersex advocates.[72]

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[70] *"I draw the committee's attention to a couple of drafting points in relation to the policy memorandum. The first is that it* ***incorrectly includes intersex people under the umbrella term "trans"****. That was an unfortunate action during drafting in relation to an area that is constantly developing. We recognise that the needs of trans people and of* ***intersex people are different****. We will ensure that any future documentation does* ***not include intersex people under the trans umbrella."*** Fiona Hyslop, Cabinet Secretary for Culture, Tourism and External Affairs, Scottish Government, at the 34th Meeting of the Culture, Tourism, Europe and External Affairs Committee, 20.12.2018, column 28, http://www.parliament.scot/parliamentarybusiness/report.aspx?r=11864&mode=pdf

[71] *"The sex characteristics of focus here are* ***naturally occurring genetic, chromosomal, gonadal, anatomical and hormonal variations.*** *It includes diagnoses such as Congenital Adrenal Hyperplasia (or CAH), Hypospadias, Androgen Insensitivity Syndrome (AIS), Klinefelter syndrome and Turner syndrome, as well as many others****. This is distinct from being transgender or non-binary,*** *which are to do with a person's gender identity."* Government Equalities Office (2019), Variations in Sex Characteristics. A Call for Evidence, p. 3, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/771459/VSC_call_for_evidence_Web_Accessible.pdf

[72] https://www.gov.uk/government/news/government-calls-for-evidence-on-people-who-have-variations-in-sex-characteristics

Unfortunately, there are also still serious **shortcomings, gaps, concerns and challenges.**

To this day, UK doctors, hospitals, the NHS and still far too many Government officials **fail to recognise the serious human rights violations**[73] and the lifelong, severe suffering caused by IGM practices.

To this day, the **United Kingdom is categorically failing to meet its non-derogable obligations under the Convention** towards intersex people, and in particular towards intersex children, including to take **effective legislative, administrative, judicial or other measures** to prevent acts of torture (Art. 2 CAT) or other forms of cruel, inhuman or degrading treatment (Art. 16 CAT, GC 2).

Adult victims of IGM practices unchangedly encounter **severe obstacles** in the pursuit of their right to an **impartial investigation** (Arts. 12, 13 CAT), and to **redress** and fair and adequate **compensation**, including the means for as **full rehabilitation** as possible (Art. 14 CAT, GC 3).

Also the United Kingdom's efforts on **education and information regarding the prohibition against torture in the training of medical personnel** remain grossly insufficient with respect to the treatment of intersex people (Art. 10 CAT), as evidenced by the fact that **involuntary, non-urgent interventions continue**, paid for by the National Health Service (NHS) (see p. 11-16).

The UK must finally *"take effective legislative, administrative, judicial or other measures"* to protect intersex children from ill-treatment – in line with its obligations under CAT, CRC, CRPD, CEDAW and CCPR.

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[73] **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

E. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in the UK, the Committee includes the following measures in their recommendations to the UK Government (in line with this Committee's previous recommendations, and with CRC's and CRPD's previous recommendations to the UK):

Intersex Genital Mutilation (arts. 2, 12, 14, 16)

The Committee remains concerned about reports that unnecessary and irreversible surgery and other medical treatments are performed on intersex children without their informed consent and impartial counselling. It is concerned that such procedures, which cause long-term physical and psychological suffering, have not been the object of any inquiry, sanction or reparation and that there are no specific legal provisions providing redress and rehabilitation to the victims (arts. 2, 12, 14, 16).

The Committee recommends that the State party:

(a) Take the legislative, administrative and other measures necessary to guarantee respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures without his or her informed consent;

(b) Guarantee impartial counselling services and psychosocial support for all intersex children and their parents, so as to inform them of the consequences of non-urgent, unnecessary surgery and other medical treatment and the possibility of postponing any decision on such treatment or surgery until the persons concerned are able to decide for themselves;

(c) Guarantee that full, free and informed consent is ensured in connection with medical and surgical treatments for intersex persons and that non-urgent , irreversible medical interventions are postponed until a child is sufficiently mature to participate in decision-making and give effective consent;

(d) Undertake investigation of instances of surgical interventions or other medical procedures performed on intersex persons without effective consent and prosecute and, if found responsible, punish perpetrators. Adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation.

Annexe 1 “UK Case Studies”

Case Study No. 1

Source: Written submission, interview.

Born 1963, presenting as male. After adrenal crisis diagnosed with CAH.

1966 initial reduction of clitoris at three.

1967 clitoris completely amputated before fourth birthday at Great Ormond Street Hospital for Children (GOSH).

Remembers being led in to a room, students standing in a row at the wall, staring at their shoes while she is told to stand on a table and undress.

1978 start of several exploratory surgeries to explore the internal reproductive layout.

1980 attempt to create a neo-vagina at 17 led by Sir Jack Dewhurst at Chelsea Westminster Hospital. Announced as „minor correction“ due before 18 to be paid for, the neo-vagina broke down as a consequence of not being sterile, leading to septicemia and 5 days in coma, followed by repair surgery a few weeks later.

Pre 2012, after discovering her GOSH patient number in her GP's notes, files subject access request to obtain medical records. GOSH first denies her ever having been a patient. Then says records are archived in microfilm cabinet. In September 2012, after repeated written complaints, GOSH apologises for not being able to find the records, and officially registers them as lost.

> *“I do not, and never have had a functional vagina, and nor do I have anything that could be described as a clitoris. I do have severe scarring in my groin, which gives me great pain almost every day.”*
>
> *“I have suffered a lifetime with flashbacks and nightmares about my experiences at Great Ormond Street, and the physical mutilations my body has suffered as a consequence of being born intersex. I have a formal diagnosis of PTSD in my GP’s notes, and have struggled with bouts of depression at points in my life.”*

Case Study No. 2

Source: Written submission, interview.

Born 1966 at a private hospital in the UK with abdominal testes and a micropenis with hypospadias. Transferred to a general NHS hospital in Glasgow, and after that to another General Hospital in Manchester. Doctors unsure about sex, further tests revealed male chromosomes. Later diagnosed with 5 Alpha Reductase Deficiency.

Feminising surgery during first months on penis and scrotum, removal of testes.

1976 vaginoplasty at 10. Then refused any further surgery and the prescribed hormones.

In 1997, at age 19, decides to live as man and seeks reconstructive surgery.

Soon after he had a road traffic accident, which he survived severely hurt, but is in a wheelchair since that day.

His medical records contain information about the accident, but all documents concerning intersex treatment are gone.

> *“My family objected [to feminising surgery], but were advised that my life would be a living nightmare if I grew up looking so different. It wasn't possible (or so they were told) to make me look like a ‘normal boy’ so the best thing would be to make me look like a girl (on the outside). I wouldn't remember the operation nor have any idea that I was male, so would grow up a happy, well-adjusted girl. The ‘only’ drawback was that I would be infertile.”*

> *“Some surgery was performed in the first months of life to ‘reduce’ my penis to resemble a clitoris and my scrotum split open and sutured to resemble labia. Later, one testicle was found in my groin and surgically removed (and in my case, my fertility). I had ultrasound tests and some abdominal surgery in order to find the second gonad, but this was unsuccessful. Following the surgeries, my health was poor due to what was to be a long legacy of [urethral tract] infections.”*

> *“When I first attended school, I had problems due to repeated genital and renal infections. For my first day in school I had to wear incontinence pants, [...].”*

> *“Concurrent with attending school I spent years attending hospital being prodded and poked by medics whilst a spotlight was shone on me and being made to feel like a specimen on a slab.”*

Case Study No. 3

Source: Written submission.

Born 1969 in Portsmouth, England, classified and raised as a girl.

1976 referred to Chelsea Hospital for Women in London because of abdominal pain. Professor Sir John Dewhurst diagnosis CAIS, tells parents “ovaries” have to be removed or she would die of cancer. Parents consent to surgery.

Ashamed of body after surgery, sexually abused by teenager at the age of 8.

1981 start of „hormone replacement therapy“. Drinking alcohol at 12, taking drugs from age 14. Mother leaves the family in 1983, two suicide attempts.

1994 discovers truth about gonadectomy. Psychotherapies, in recovery from addiction for 14 years, meets other intersex person in her forties.

Still suffering from trauma, afraid of hospitals, nightmares before going to the doctor. Currently on anti-depressants for anxiety and low mood.

> *“He [Dewhurst] told my parents and I that I am a "special little girl"[...]. He said I was lucky to be diagnosed [...] (implying that other girls died from it).”*

> *“Our family saw Dr Dewhurst as a God-like "saviour"figure and my parents went along with whatever he wanted from then on- as he had "saved"their little girl's life. [They] compl[ied] with his wish to see me in London every 6 months, ostensibly to check on my progress, in reality, not medically unnecessary. Although I believed these visits were to make sure the cancer wasn't active. [H]e would have between 8-15 medical students, who would all gather around my bed and examine my body- whilst he talked about me, as an interesting, rare & special specimen.”*

> *“[Later] I went to see a male gynaecologist who told me I had a small vagina and no womb and probably wouldn't grow public hair. He sent me home with an NHS kit of dildos- small to large; and told me to insert them every day. I felt so ashamed and embarrassed I threw them in the bin. I stopped doing sport at school as I didn't have periods and no pubic hair growing; and absolutely no support structure.”*

Case Study No. 4

Source: Written submission.

Born 1984 at Edinburgh Western General Hospital, classified and raised as girl.

1987 referred to Edinburgh Sick Kids Hospital for routine hernia operation, where the doctors found abdominal testes and removed them without consulting the parents first.

Diagnosis „Testicular Feminisation“ was later changed to „Partial Androgen Insensitivity Syndrome“, and finally to „Intersex“.

1992 surgery to lengthen the vagina.

1994 (age 10) parents tell her that she cannot have children, but there is no counselling from constultant of Edinburgh Sick Kids Hospital.

1998 (age 14) learns she had been born with testes.

> *“[A]s my Mother awaited me coming out of surgery, the surgeon approached her and told her that whilst they were operating, they had discovered two internal undescended testes, and had removed them due to an alleged cancer risk. This was done with absolutely no consent from anyone, informed or otherwise, from either my parents or (obviously) myself - as I was three. The Surgeon who operated on myself informed my Mother about this in a hospital waiting room with around three or four people sitting nearby, who heard everything. She became rather upset and began crying.”*
>
> *“My parents continued to raise me as a girl, and a later operation were scheduled, without my consent, at the age of eight, to lengthen the vagina. I can remember all of my hospital stays vividly, and the first one in particular was horrendous. To say that I was only three, my memory of it was surprisingly vivid, as I screamed in terror, cried, and retched as the doctors attempted to administer the old-fashioned style of anaesthetic, with a mouth piece. To this day that hideous smell haunts me, the very memory of this incident sickens and upsets me.”*

Case Study No. 5

Source: Written submission.

Born 1988 in Leamington Spa England with a Cloacal Exstrophy, no visible genitalia, sex unknown. Given a boy's name. Later transferred to Birmingham Children's Hospital for first emergency surgery to close abdomen.

At ten months old first appointment with urologist of Great Ormond Street Hospital for Children (GOSH) in London to perform surgery to close abdomen and pelvis. Urologist persuades parents to also perform feminising surgery and to remove reproductive organs to avoid cancer risk.

Around 18 months surgery to close abdomen and pelvis, removal of reproductive organs. No further genital surgeries were performed. Raised as a girl.

1992 mother tells him that he originally was a boy. Growing up confused, always feeling like a boy.

„Hormone replacement therapy“ during teenage years. Depression, suicide attempts, self harm.

Later in life routine chromosome test reveals XY chromosomes. Obtained medical records show that healthy testes were removed during childhood.

> *“[When the consultant urologist at GOSH explained] my parents should raise me as a girl, naturally*

> *they immediately dismissed his idea, they had had a little boy for almost a year, so where was the sense in changing that now. The consultant sat them down and explained that babies born with Cloacal Exstrophy were almost always raised female as being raised male had a massive detrimental effect on the physical and emotional wellbeing of the child."*
>
> *"He went on to explain that as a male I wouldn't have a penis and that the psychological effect would lead to depression and maybe even suicide and that surgically reconstructing a penis wasn't viable. He explained that as a female he could construct a vagina and that with the right hormones I would grow up like any other little girl."*
>
> *"Some soul searching later and my parents decided, that, if my life would be so much more difficult as a boy then raising me as a girl was the only option. They were told to pick a day to make the transition, they chose my first birthday. The night before my birthday they put me to bed then began changing all of my clothes from blue to pink [...]."*
>
> *"Unfortunately there are many cases of Cloacal Exstrophy males who have been castrated and raised female, it was and still is depending on where you are born the standard practice of care."*
>
> *"Though it is too late to fix the damage of the past, it is vital that we protect these children in the future."*

Case Study No. 6

Source: Written submission.

Born 1991 at the Sandwell Hospital, West Midlands, UK, classified and raised as girl.

1996 at the age of five referred to Birmingham Children's Hospital for surgery to fix a hernia. Doctors find an abdominal testis and performed a biopsy. Parents are coerced to make the decision to perform a gonadectomy to avoid high cancer risk. Both testes removed during another surgical procedure shortly after.

2002 at 11 told about her diagnosis, start of „hormone replacement therapy“. Finally also had to deal with a doctor without any knowledge about her condition, which prescribed hormonal medication detrimental to bone health, leading to low bone density. Today on the correct medication, but has to pay up monthly for two separate forms of medication for the rest of her life. Recently been diagnosed with Generalised Anxiety Disorder and moderate to severe depression.

> *"One vivid memory is when I was roughly about 7 or 8 years old, I remember feeling cornered in a room of around 8 adults. I felt on display for some kind of exhibition which I had no idea was about. I was asked questions by doctors, nurses and medical students, but I remember feeling unbelievably anxious and shy and I simply could not speak. At this point, I was asked to leave while the adults talked about my health, something I was kept in the dark about. I knew there was something wrong with me, but I was always told by professionals that it was "just a check-up for your hernia"."*
>
> *"I went for annual check-ups in order for Dr. Kirk to review my progress with regards to pubescent changes, particularly breast growth. [...] [I]t felt wrong that I had to sit there while he examined closely and touched my breasts. When I was around 14, I was referred to Birmingham Women's Hospital. Mrs Blunt, the specialist I was in contact with at this time, was helpful and seemed to know quite a lot about my individual case. However, I remember having to have the length of my vagina examined, which was measured by Mrs Blunt penetrating a finger inside of my vaginal opening. [...] I was prescribed with dilators to stretch my vaginal opening so that I could have sexual intercourse in the future."*

> *“[I] was persuaded not to tell anyone about my condition because nobody would accept me for the way I am. [...] I was never offered any form of psychological support, and [...] my parents found it difficult and uncomfortable to talk about. [...] I used to sit in my room and sometimes self-harm, feeling suicidal.”*

> *“Since reaching out to support networks on social networking sites that I found by myself, I feel so much more accepting of myself and realise that I’m not as abnormal and alone as first believed. In hindsight, I wish that my family and I were provided with more informative, psychological support to allow an autonomous decision with regards to life-changing surgery and other aspects.”*

Case Study No. 7

Source: http://www.aissg.org/stories/sophia.htm

Born 1964, diagnosed with 5-alpha reductase deficiency.

Hypospadias repair at age of 18 months.

Learning about her diagnosis in her forties.

Later in life, after many painful complications, opting for feminising surgery.

Angry about parent's and doctor's mismanagement, and about secrecy.

> *“I describe myself as someone who was the victim of a misinformed medical profession and a conformity obsessed society. The problem is not one of "social interactions"or "sexology." The problem with me was being born with a metabolic condition that has symptoms people were all confused about. I never felt like a "little girl"or a "little boy." It was at an early age I just became numb to such notions. I actually thought the rest of the world was pathologically obsessed. I was sort of living in some nightmare populated by blank eyed zombies who saw nothing other than "sex"and "gender." And let's be honest here, was that the sort of thing a child should have to put up with?”*

> *“My body is still a mess with numerous scars, my mind is also scarred by what happened to me as a child.”*

Case Study No. 8

Source: http://www.aissg.org/stories/sam.htm

Born 1985, diagnosed with PAIS, gonadectomy at 18 months old, vaginoplasty at 1 ½ years old.

Under doctors' care at UCLH (Elizabeth Garrett Anderson Hospital) since about 14 or 15 years old.

In 2004 another surgery is performed to correct the poor results of the vaginal surgery as a toddler, with disastrous outcome: unable to place the vaginal opening where planned, the surgeons proceeded anyway. Complications, urethral problems, severe pain, also in the abdomen due to repeated laparoscopic examinations, followed by a bad infection, and a 4-5 month healing process.

The result is a ring of large scars, dilation doesn't work because of scaring, the vagina shrinks again.

Later another vaginoplasty is performed in Brazil, with better results, but still leaving the traces of the other surgeries on the exterior.

> *“Due to my anatomy downstairs they put the vagina where my perineum [area between labia/vulva and anus] once was, and in my opinion too far back and behind my vulva lips. It literally looked like I had*

> *sat on a metal fence spike and it was an injury!"*

Case Study No. 9

Source: http://www.aissg.org/stories/liam.htm

Born 1986 with hypospadias, hypospadias „repair“ surgery during childhood, discovers to have PAIS and hypospadias over the internet at the age of 25. The trigger was a psychotic episode and him starting to think he was a woman, and an admission to a psychiatric hospital. Suffers from psychosocial problems and incontinence.

> *"It was amazing, life changing, life affirming when the truth has finally come out. I've been admitted to a physchiatric hospital for psychosis and I'm now in a theraputic community in Scotland (...). I've never known that I had a defect at birth and not until I had my psychotic episode did I start to think I was a woman. Since then I've asked my dad (a GP) about it and my mum - but it became obvious that they weren't telling me what was going on; it's only till I typed in my symptoms to a google search did I find out about all the information firstly about hypospadias and then about Partial AIS and CAIS - when I did this 4 hours ago everything clicked into place and the relief of the truth came out. I'm writing to you because I fear that I may never get to meet any other sufferers or come to the meeting annual because of the cloak of deceipt that has been around me since my conscience and because of the lack of trust of those around me: and fear too partly because of psychosis."*

> *"None of the medical professionals have been honest about [having hypospadias], and I would also like to get a full copy of my medical records now that I feel I'm in a position so that it will not affect my mental health so that I can see exactly what went on."*

Case Study No. 10

Source: 48 years old in the UK, http://www.hypospadiasuk.co.uk/life-stories-of-men-with-hypospadias/

Three-stage surgery between age 3 and 5 at Great Ormond Street Hospital for Children (GOSH) in London, surgery seemingly successful.

Discharged from aftercare at age 7.

During adolescence problems become more obvious, but unable to talk to parents or doctor about it. Years after the first complications, a diverticulum (sort of pocket our pouch off the urethra, where urine collected) developed, causing frequent pain and tendency to empty urine later, causing embarassement.

Physical problems getting worse in his 30s and 40s, stone in diverticulum, chronic urinary tract infections.

In 2007 finally seeking medical advice, GP's refers him immediately to consultant urologist at Guy's Hospital, which refers him to specialist at UCLH. Two-stage repair surgery followed to remove stone and diverticulum and rebuild urehtra.

> *"I feel much better, both physically and personally. Physically, because I realise that the stone had been causing me a lot of low-level, chronic infections which were making me feel generally unwell. It was also quite uncomfortable during sex. Personally, because I have finally faced up to my "dark secret" and done something about it. It's hard to describe how great this feels – it's like a big weight being taken off my shoulders. Anyone who's gone through similar experiences will understand."*

> *"I've had tremendous support from a couple of other men with HS whom I met through the old Yahoo groups. It was this experience, of meeting "sufferers", that initiated the whole process of being able to*

face up to my HS, tell my partner about it and seek medical advice.”

“I’ve received very little information about what was going to happen to me, and absolutely no counselling whatsoever. I’ve been badly handled by incompetent hospital administrations who have routinely cocked up appointments, and then don’t understand when I get angry or upset. There is absolutely no recognition of the fact that it’s hard for a man to deal with issues relating to his genitals; you’re expected to breeze through it exactly as you would if you were having your tonsils removed.”

“I’ve been told now that anyone who had HS surgery in infancy is very likely to need a further repair in adulthood – but I had never heard that before. If that was more widely known, I would have consulted a doctor years ago, and saved myself a lot of unhappiness. I also think that any surgery which involves a man’s genitals should be accompanied by some form of pre- and post-operative counselling.”