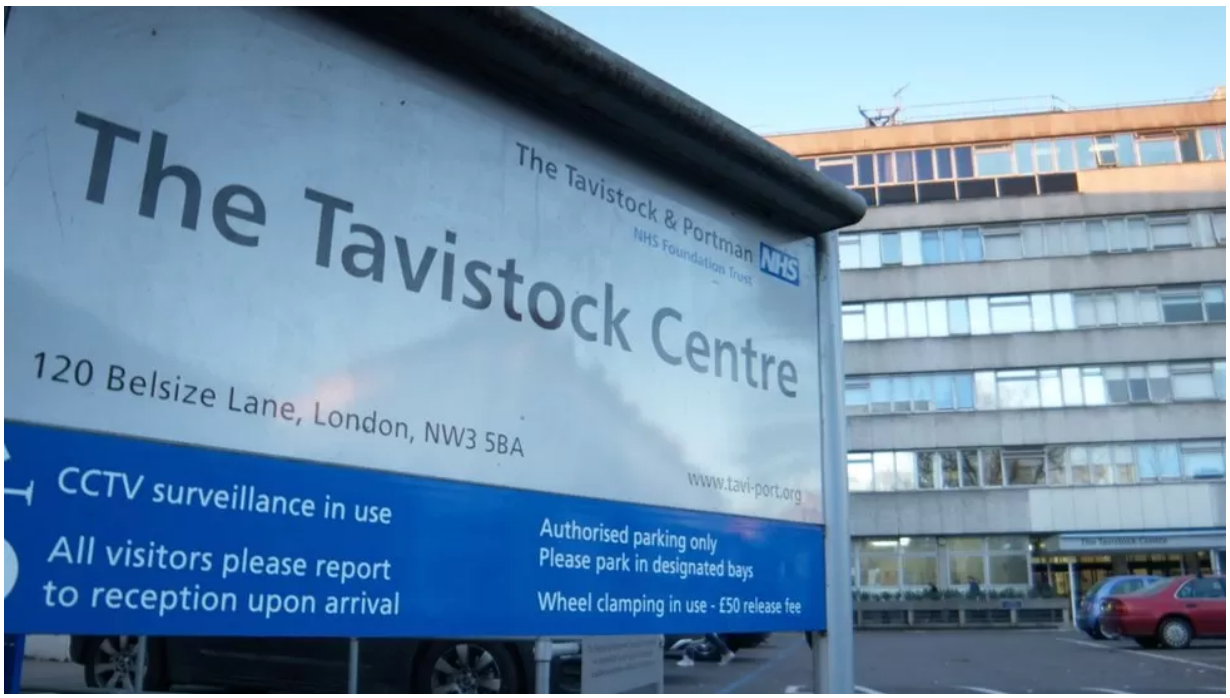
Transgender treatment: Puberty blockers study under investigation

22 July 2019



By Deborah Cohen and Hannah Barnes
BBC Newsnight

England's only NHS youth gender clinic lowered the age at which it offers children puberty blockers, partly based on a study now being investigated.

The study's full findings have not been published - but early data showed some taking the drugs reported an increase in thoughts of suicide and self-harm.

The clinic said data was from a "small sample" and so no "meaningful conclusion" could be drawn from it.

Children as young as 11 are now being offered these hormone-blocking drugs.

Experts on clinical trials have criticised the design of the study, which they say makes it hard to tell if the reported effects were due to the puberty blockers or something else. But experts said they warranted further investigation.

The Health Research Authority - which ensures medical studies are ethical and transparent - is now investigating claims brought to them by the BBC's Newsnight programme about the early findings from the study - and the information that is understood to have been shared with patients and parents about the possible effects of puberty blocking drugs.

- **Transgender kids 'need help from all sides'**
- **Transgender teen care 'needs regulation'**
- **NHS child gender reassignment 'too quick'**

When a child in the UK is questioning their gender, they can be referred to the Gender Identity Development Service (Gids) at the Tavistock and Portman NHS Foundation Trust in London and Leeds.

One treatment on offer is puberty blockers. They work on the brain to stop the eventual release of oestrogen or testosterone - the sex hormones that increase during puberty. This prevents the development of sex characteristics such as periods, breasts or voice-breaking.

Before 2011, Gids would give puberty blockers to children only once they had turned 16.

But as gender clinics around the world began providing blockers to those who had just begun puberty, reports grew of UK children going overseas to buy the drugs.

And in 2011, a medical study was approved through which younger children could access these drugs.

'A life-changing step'

Acknowledging the weak evidence for the drugs, the research team, made up of Gids and University College Hospitals staff, set out to "evaluate the psychological, social and physical effects" of the blockers on a carefully selected group of young people.

Details about risks - such as potential adverse effects on bone strength, the development of sexual organs, body shape or final adult height - were provided in a patient information sheet. But Newsnight found certain information had not been included.

Previous research had suggested all young people who took the blockers went on to take cross-sex hormones - the next stage towards fully transitioning to the opposite gender. But patients and parents were not told this in the information sheet.

"I don't see that the parents and their children could really have given informed consent given the lack of information that was provided," said Michael Biggs, associate professor of sociology at Oxford University.

Prof Biggs, who has attracted criticism from some in the transgender community for his views, added: "They were not given the information they needed in order to take this momentous life-changing step."

He gave Newsnight a series of documents relating to the research study he had obtained via freedom of information requests, which were independently looked at.

Gids, together with lead investigator Prof Russell Viner, said: "We are confident that informed consent was obtained."

He said the "possibility that blocking puberty may crystallise gender identity" had been raised with the patients and parents.

Preliminary data for 30 of the 44 young people on the study was made available to the Tavistock's board in 2015. **It showed** that after a year on

puberty blockers, there was a significant increase found in those answering the statement "I deliberately try to hurt or kill myself".

Prof Susan Bewley, who chairs Healthwatch, a charity for science and integrity in healthcare, is one of a number of doctors raising concerns about the lack of evidence in this area of medicine.

She said seeing any change around suicidal thoughts "is very worrying".

"Good medical practice would normally be very reflective about an increase in harms," she added.

Because of flaws in how the study was set up, it is not possible to infer cause and effect or even to say whether rates of suicidal thoughts are higher or lower in this group than in children with gender dysphoria who don't take puberty blockers.

The study had no control group, of children not taking the drugs, to compare results with. In addition, the outcomes it was measuring were unclear.

Nevertheless, experts say these observations should have given Gids pause for thought.

Gids told Newsnight: "All patients were seen regularly by mental health professionals. They concluded that there was no evidence of harms that could be directly attributed to the treatment and that continuation of the study was appropriate."

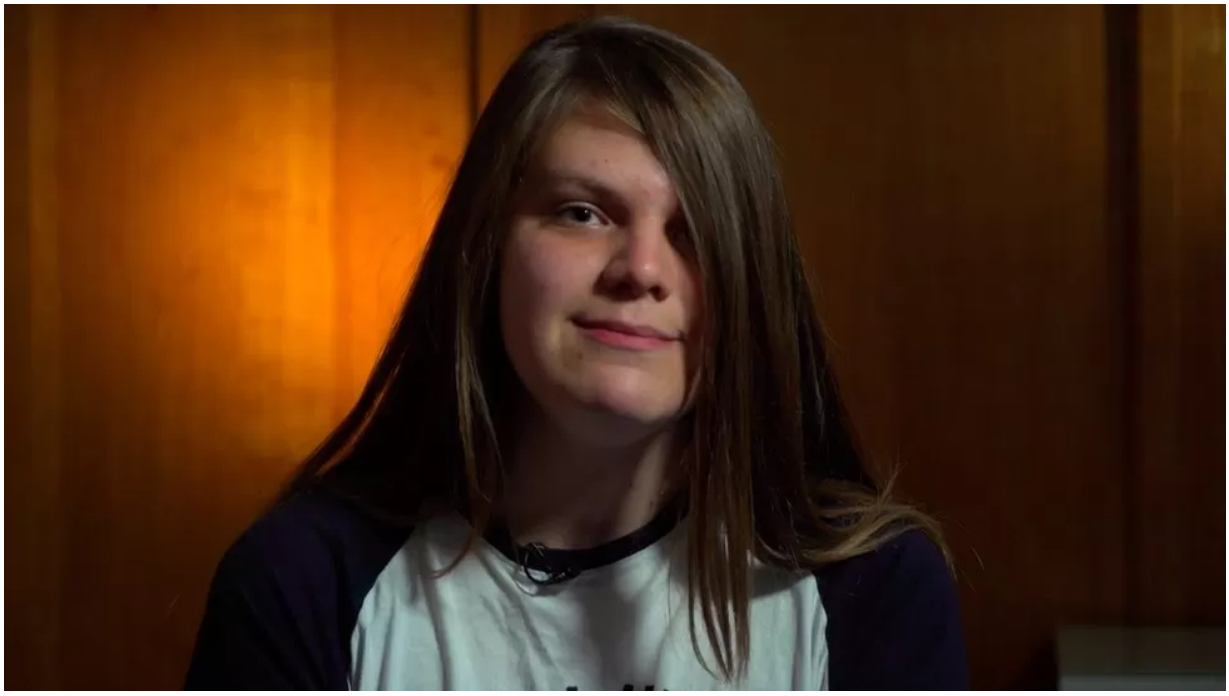
This early data was not shared with the Health Research Authority, despite its demands for updates on the study over a period of three years.

In response to Newsnight sharing this preliminary data and other concerns about the study, Teresa Allen, chief executive of the HRA, said: "The information that Newsnight has brought to our attention has not been raised with us before.

"We will therefore investigate further, which may include a review of the original ethics opinion."

The HRA told Newsnight they do not currently have all the information they need. They have reviewed minutes from the ethics committee that approved the study and these have not raised a specific concern.

'Nothing could have stopped me'



Hannah Phillips, 19, started taking puberty blockers when she was 16. She said the doctors had been clear about how little was known about the treatment and explained that it was "in testing".

"I don't think there could have been anything that the doctors could have said to stop me from wanting to go on to hormone blockers," the Youtuber told Newsnight.

While acknowledging the need for more research, Ms Phillips said there shouldn't be a halt to the current rules that allowed young people access to puberty blockers.

Receiving treatment "feels as if someone's just finally listening to you", she said.

Newsnight's investigation comes amid growing concern over the way Gids is operating.

In **an open letter** last week, former Gids clinician Dr Kirsty Entwistle raised concerns over the way puberty blockers were being presented to children as "fully reversible", when their long-term impact was unknown.

She also said staff were unable to raise concerns without risking being branded transphobic.

Tavistock and Portman Trust chief executive Paul Jenkins told BBC Radio 4's Today programme: "Puberty blockers are reversible."

He said Gids was looking at processes to make it easier for clinicians to focus on their work, "rather than being swayed or influenced by the very heated debate", but concerns over staff being falsely accused of transphobia had not been raised in the organisation.

However, a former Gids member of staff told Newsnight: "Myself and countless colleagues raised concerns in all the forums available to us."

And in **a statement last year**, the trust said concerns that staff were facing allegations of transphobia revealed "a negative attitude to... gender identity".

Policy change

In 2014, despite the patchwork of information about the study - which was still running - a change in Gids' policy was approved by NHS England: children with gender dysphoria, who were just beginning puberty, could now be eligible for blockers.

Gids' data suggests that between 2012 and 2018, 267 people under the age of 15 started using the blockers.

The service told Newsnight the use of hormone blockers at this earlier age "remains only available to a carefully selected group".

NHS England says the policy change followed an evaluation of the study. Newsnight has asked for a copy of this evaluation - but none was provided.

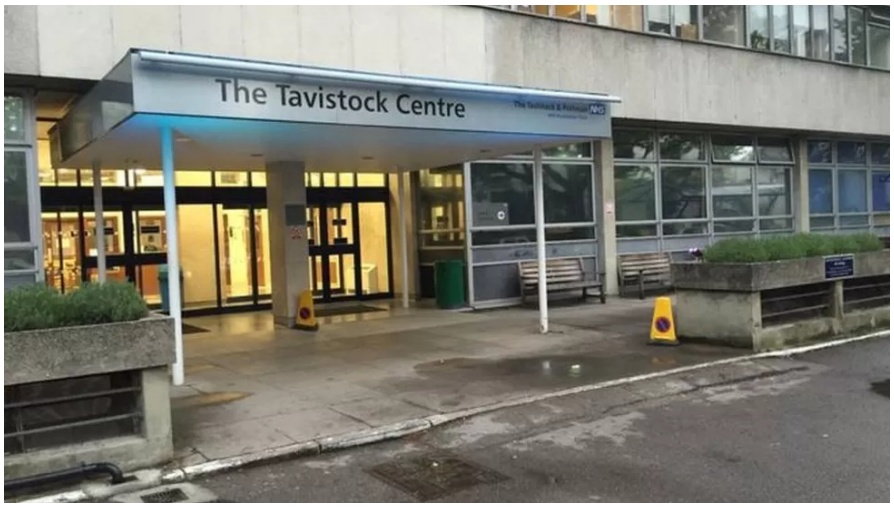
An NHS England official said its "2016 service specification for gender identity services was based on international evidence and developed with clinical experts and publicly consulted on".

"The specification will be reviewed," they added, which would include "a review of the most up-to-date research... and advice from clinical and academic experts".

If you are affected by any of the issues raised in this article, you can find support and advice via BBC Action Line.

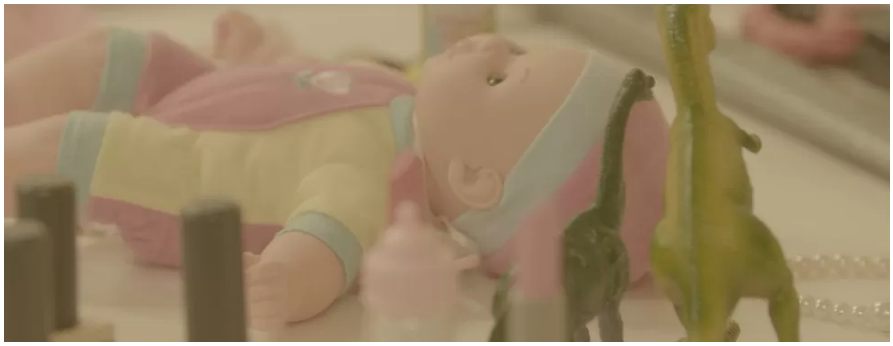
You can watch* Newsnight *on BBC Two weekdays at 22:30 or on* iPlayer*, subscribe to the programme on* YouTube *and follow it on* Twitter*.

More on this story



NHS child gender reassignment 'too quick'

25 February 2019



Top Stories

At least 59 migrants killed in shipwreck off Italy

1 hour ago

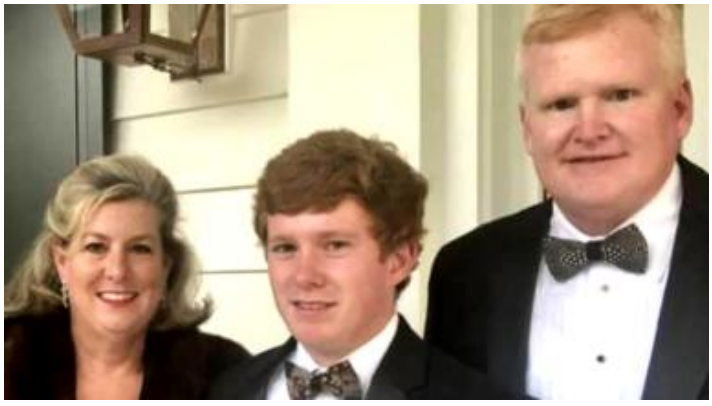
Power, privilege and murder - the downfall of a dynasty

19 hours ago

British and EU leaders to meet over NI Brexit deal

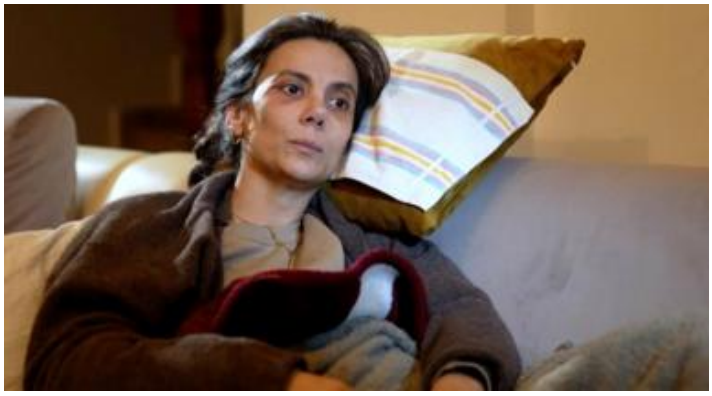
42 minutes ago

Features



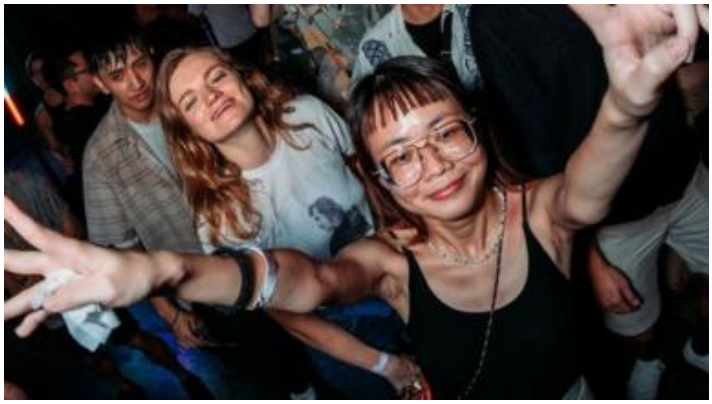
Power, privilege and murder - the downfall of a dynasty

Five must haves for reporting from the red carpet



The mission to save the biggest frog on earth

Five takeaways from the Berlin Film Festival



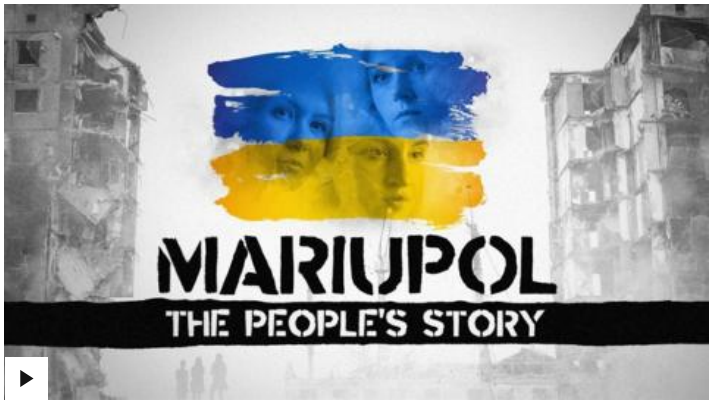
'Revenge partying' in strait-laced Singapore

'I am blind - let me show you how I live in Delhi'

Ghana's love affair with reggae and Jamaican Patois

The story of Scottish independence - what next?

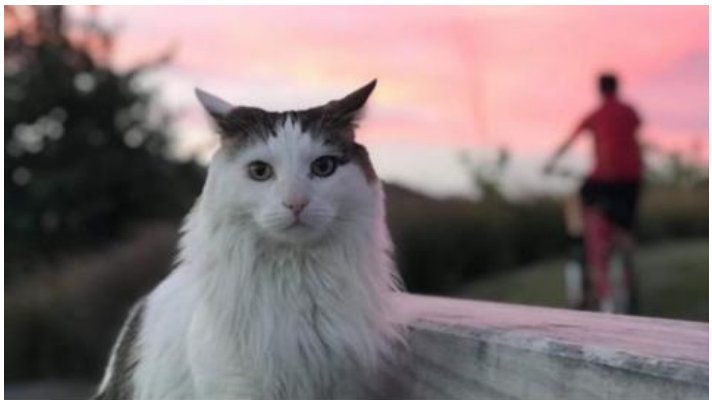
Elsewhere on the BBC



"We lived through hell"

Mariupol: Tragic deaths and daring escapes

Why Gen Z are feeling stressed at work



NZ's battle with a ruthless predator

Most Read

1 Madonna's brother Anthony Ciccone dies aged 66

2 Power, privilege and murder - the downfall of a dynasty

3 US media drop Dilbert comics over racist tirade

4 At least 59 migrants killed in shipwreck off Italy

5 Netflix cuts prices in more than 30 countries

6 Olivia Newton-John honoured at Australia memorial

7 Ukraine's Banksy stamps depict Putin being thrown

8 Rare winter storm wreaks havoc in California

9 Early results arriving from tight Nigeria election

10 Archaeologists freed in Papua New Guinea