General Medical Council

Response to NHS England consultation to seek views on a proposed interim service specification for services for children and young people with gender dysphoria

December 2022

Our response

Sent via email

We're aware that you recently published a consultation on the interim service specification for specialist gender dysphoria services for children and young people. We agree that it's important that doctors have clarification in certain areas. As you know, we don't set clinical standards or have a role in service provision. It is therefore beyond our remit to provide comment on the large parts of the proposed specification, given its focus in these areas.

However, it is our role to set the professional standards expected of all doctors registered in the UK, including those working in both the public sector and private practice. We therefore felt it important to highlight several principles from our ethical guidance that may relate to the application of the proposed specification in practice. We hope these are helpful and we'd be happy to answer any questions and to talk through the information below.

Prescribing

We note the proposal that *"NHS England will only commission GnRHa in the context of a formal research protocol"*. We recognise that you're still in the process of developing this proposal and will consult on the details in due course. However, we wanted to highlight several areas of our ethical guidance focused on research. In paragraph 13d of our guidance on *Decision making and consent*, we say that in supporting patients to make decisions about their treatment, doctors should make them aware of their right to refuse to take part in teaching or research and in paragraph 69 we're clear that nothing should influence a patient to such an extent that they can't exercise free will. Whilst we appreciate the importance of research and data in medicine it would appear that this proposal may not be compatible with principles about patients freely consenting to take part in research. Building on this, we provide further guidance on *Consent to research*, including principles on research involving children or young people, as well as paragraphs 36-40 of our *0-18: guidance for all doctors*.

On the proposals set out by the consultation around "*prescribing from unregulated sources and unregulated providers",* we wanted to highlight paragraph 57 of *Good medical practice*, which says that the investigations or treatment doctors provide or arrange must be based on the assessment they and their patient make of their patient's needs and priorities, and on their clinical judgement about the likely effectiveness of the treatment options. Doctors must not refuse or delay treatment because they believe that a patient's actions or lifestyle have contributed to their condition. We recognise the aim of these updated guidelines to *"provide greater clarity"*, but – in line with our guidance – it will be necessary to guide doctors on what services they could provide, or signpost patients to, in a situation in which a patient had accessed *"GnRHa from unregulated sources or unregulated providers"*.

Involving those close to the patient

The consultation stipulates that standardised comprehensive assessments will focus on a range of factors, including:

- *"…Their hopes and expectations and that of their family members/carers and their stance towards the child / young person's gender identification"*
- *"…Exploration of parent/carer and family views on the child or young person's gender identity journey and family support"*
- *"…Family's spiritual, cultural, or religious beliefs"*

We have several principles in our *0-18: guidance for all doctors*, which provide information around involving parents and others close to the child or young person. In paragraph 4, we say that when treating children and young people, doctors must also consider parents and others close to them; but their patient must be the doctor's first concern. Building on this, in paragraph 12, we make clear the range of factors that doctors should consider in assessing the best interests of the patient – this includes the views of the child or young person, their parents and those close to them, and the cultural, religious or other beliefs and values of the child or parents.

However, we also make clear that children and young people are individuals with rights that should be respected. This means listening to them and taking into account what they have to say about things that affect them. It also means respecting their decisions and confidentiality (paragraph 7). In addition, doctors should make it clear that they are available to see children and young people on their own if that is what they want. Doctors should avoid giving the impression (whether directly, through reception staff or in any other way) that they cannot access services without a parent. Doctors should think carefully about the effect the presence of a chaperone can have. Their presence can deter young people from being frank and from asking for help (paragraph 15).

Information sharing and confidentiality

Finally, we note the proposal that *"The Service will take part in continuous data collection"*. We therefore wanted to signpost to the principles in our *0-18: guidance for all doctors* focused on the principles of confidentiality and the steps that doctors should take. We also thought it may be helpful to signpost to our broader guidance on *Confidentiality: good practice in handling patient information*, which includes sections on disclosing patients' personal information, using and disclosing patient information for direct care, disclosures for the protection of patients and others, and using and disclosing patient information for secondary purposes.