

## Consultation Report

### Topic details

<b>Title of policy or policy statement:</b>	Surgery for pectus deformity (all ages)
<b>Programme of Care:</b>	Cancer
<b>Clinical Reference Group:</b>	Specialised Cancer Surgery
<b>URN:</b>	1675

### 1. Summary

This report summarises the outcome of a public consultation that was undertaken to test the policy proposal.

### 2. Background

Pectus deformity is a term used to describe a group of conditions associated with the malformation of the chest wall which are more common in males than females. Most people will not undergo surgical intervention because only mild physical or psychological symptoms are experienced. Other non-surgical treatment forms are available, including posture and exercise programmes, bracing and psychological support.

Surgery is a current treatment option for people with pectus deformity although it possible that access arrangements may vary across the country and there is no clinical commissioning policy in place. Although surgery can take place at any time, people undergoing corrective surgery for pectus deformity are usually either teenagers or young adults as this is the time of life when the deformity becomes more obvious.

As part of the policy development process, both the clinical and psychological benefits of the treatment have been carefully considered and it has been determined that there is insufficient evidence to continue to commission the intervention.

Stakeholder testing was completed as part of the policy development process.

### 3. Publication of consultation

The policy was published and sign-posted on NHS England's website and was open to consultation feedback for a period of 30 days from 3<sup>rd</sup> August 2018 to 2<sup>nd</sup> September 2018. Consultation comments have then been shared with the Policy Working Group (PWG) to enable full consideration of feedback and to support a decision on whether any changes to the policy might be recommended.

Respondents were asked the following consultation questions:

- Has all the relevant evidence been taken into account?
- Do you agree, that based on the evidence, this procedure should not be routinely commissioned?
- Does the impact assessment fairly reflect the likely activity, budget and service impact? - If you selected 'No', what is considered to be inaccurate?

- Please describe any equality or health inequality impacts which you think we should consider in relation to the proposed policy, and what more might be done to avoid, reduce or compensate for them?
- Is there anything else you feel NHS England should have considered as part of developing this clinical commissioning policy?

#### **4. Results of consultation**

Thirty-two responses were received in response to public consultation; of these responses, 16 responses were from either patients or relatives of patients and the remainder were from either providers or clinicians delivering this service.

Eight respondents were fully supportive of the policy proposition and agreed that the evidence base presented recommended a not for routine commissioning policy. The remaining respondents raised the following issues:

- Based on the findings presented, some respondents agreed that the evidence base appeared to be weak. However, these respondents felt that there were a small sub-group of patients with severely compromised cardiac function and psychological concerns could benefit from corrective surgery. Respondents suggested that the service should be made available for these sub-groups of patients through specialist centres and further research into the intervention should be supported by commissioners.
- One respondent queried the evidence base and research papers used to develop the clinical commissioning policy proposition. This respondent outlined a series of alternative papers that in their opinion supported the use of surgery for the treatment of pectus deformity.
- Patients, carers and sufferers of pectus deformity felt the psychological impact of pectus deformity had not been fully considered in developing the policy proposition. Respondents raised concerns regarding the mental health and well-being of people with pectus deformity and the impact the lack of corrective surgery could have on an individual's ability to participate fully in society in their adult years.
- Two respondents felt the policy proposition had been developed in order to save money.
- One stakeholder raised an issue regarding equity of access stating the procedure would now only be available to patients who could afford to pay privately for treatment.

#### **5. How have consultation responses been considered?**

Responses have been carefully considered and noted in line with the following categories:

- Level 1: Incorporated into draft document immediately to improve accuracy or clarity
- Level 2: Issue has already been considered by the PWG in its development and therefore draft document requires no further change
- Level 3: Could result in a more substantial change, requiring further consideration by the PWG in its work programme and as part of the next iteration of the document
- Level 4: Falls outside of the scope of the policy and NHS England's direct commissioning responsibility

All responses to public consultation have been graded as Level 2 responses.

## **6. Has anything been changed in the policy as a result of the consultation?**

Feedback from public consultation has been considered by as follows:

- Although it is possible that there may be a sub-group of patients (with severe cardiac and/or respiratory conditions) that could benefit from surgery for pectus deformity, no sub-groups were identified in the existing literature and the evidence review. In addition, no relationship was found in the evidence between the extent of the deformity and overall outcomes. NHS England only considers peer-reviewed, published evidence when developing a clinical commissioning policy in line with the published Methods. The PWG have advised the Programme of Care that they would be supportive of further evaluative research taking place to identify any potential sub-groups that could benefit with surgery in the future.
- The additional papers submitted by one respondent have been reviewed. The papers referenced did not meet the PICO criteria and therefore do not alter the policy proposition.
- Impact on psychological outcomes was considered as part of development of the policy proposition. A review of existing evidence found insufficient evidence to demonstrate that surgery for pectus deformity had a large enough impact on change in psychological outcomes to support the routine commissioning of this treatment.
- In line with NHS England's published Methods, the decision to progress a policy for not routine commissioning is based on the evidence of clinical effectiveness and safety presented and cost impact is not considered until after a commissioning position has been agreed and approved by Clinical Panel.
- The PWG and Programme of Care is aware that surgery for pectus deformity may continue to be offered through private practice and note the potential access issue that this could create. However, currently access to surgery for pectus deformity varies across the country. Development and implementation of a clinical commissioning policy will ensure equal access across England to this treatment on the NHS.

As a result, no changes have been made to the policy proposition.

## **7. Are there any remaining concerns outstanding following the consultation that have not been resolved in the final policy proposal?**

None.