National Institute for Health and Care Excellence

Fetal alcohol spectrum disorder

Stakeholder engagement – deadline for comments 5pm on 08/10/19
email: QStopicengagement@nice.org.uk

Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline.

We would like to hear your views on these questions:

1. What are the **key areas for quality improvement** that you would want to see covered by this quality standard? Please **prioritise up to 5 areas** which you consider as having the greatest potential to improve the quality of care. Please state the specific aspects of care or service delivery that should be addressed, including the actions that you feel would most improve quality.

Organisation details

Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank)	**CoramBAAF**
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	**None**
Name of person completing form	**Ellie Johnson Health Consultant**

Supporting the quality standard Would your organisation like to express an interest in formally supporting this quality standard? More information.	**Yes**
Type	**[Office use only]**

Quality improvement comments

Key area for quality improvement	**Why is this important?**	**Why is this a key area for quality improvement?** Evidence of information that care in the suggested key areas for quality improvement is poor or variable and requires improvement?	**Supporting information** If available, any national data sources that collect data relating to your suggested key areas for quality improvement? Don't paste other tables into this table as your comments could get lost. Type directly into this table.
Separately list each key area for quality improvement that you would want to see covered by this quality standard. **Example:**	**Example:** There is good evidence that appropriate and effective pulmonary rehabilitation can drive significant improvements in the quality of life and health status of people with COPD. Pulmonary rehabilitation is recommended within NICE guidance. Rehabilitation should be considered at all stages of disease	**Example:** The National Audit for COPD found that the number of areas offering pulmonary rehabilitation has increased in the last three years and although many people are offered referral, the	EXAMPLE: Please see the Royal College of Physicians national COPD audit which highlights findings of data collection for quality indicators relating to pulmonary rehabilitation.

Pulmonary rehabilitation for chronic obstructive pulmonary disease (COPD)	progression when symptoms and disability are present. The threshold for referral would usually be breathlessness equivalent to MRC dyspnoea grade 3, based on the NICE guideline.	quality of pulmonary rehabilitation and its availability is still limited in the UK.	http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit
Key area for quality improvement 1 Prevention of FASD by ensuring that all women of childbearing age are aware of the risks of any alcohol consumption in all stages of pregnancy.	FASD is preventable Need to increase public awareness and young people should receive education at school Health and social care staff need to give consistent messages.	Reduce morbidity	Relevant publications that have informed our response for the quality improvement standards suggested:- Adoption and Fostering Journal 3/15 vol 39 October 2015 .Special Edition FASD CoramBAAF Dealing with Foetal Alcohol Spectrum Disorder. Good Practice Guide (Mather 2018) CoramBAAF
Key area for quality improvement 2		Improve timely access to assessment.	

Identification of infants, children and young people at risk of FASD. Health , social care and education professionals can recognise/ identify children who require assessment for FASD.	Information regarding alcohol use during pregnancy is required during diagnostic process. This information is sometimes not available particularly for children who no longer live with their birth parents. Midwives and other health and social care professionals should record this information clearly and the information should be available in the childs health and social care record.	Need to increase professional awareness of presentation of FASD.	
Key area for quality improvement 3 Assessment and access to diagnostic services are available via clear pathways of care, in all areas of England. Agreed diagnostic criteria and terminology. Care pathway and diagnostic criteria to include those children where there is missing or unknown information	Specific interventions / support are available for children/ YP with FASD so diagnosis confers benefit. Prevention of secondary problems in circumstances where children/young people are not assessed or have a long wait for assessment this can include both physical and mental health complications.	Terminology confusion, lack of clarity re diagnostic criteria and diagnostic services required have left many children and families with inappropriate assessment and support historically	

regarding alcohol exposure in pregnancy.			
Key area for quality improvement 4 Children /YP / adults with FASD and their parents and carers are able to access appropriate support and interventions.	To improve outcomes in areas of physical and mental health , education, social inclusion and equality.		
Key area for quality improvement 5 Policy/Engagement with health/social care/education colleagues/ commissioners on the diagnostic value of FASD	- FASD is a diagnosis in its own right with a specific profile of need which should be considered in the overall SEND profile and in the commissioning of services Services should be commissioned and integrated within neurodevelopmental paediatric services	Historical lack of commissioner engagement in planning diagnostic and support services.	
Additional developmental areas of emergent practice			

Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.

- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- Please provide concise supporting information for each key area. Provide reference to examples from the published or grey literature such as national, regional or local reports of variation in care, audits, surveys, confidential enquiries, uptake reports and evaluations such as impact of NICE guidance recommendations
- For copyright reasons, do not include attachments of **published** material such as research articles, letters or leaflets. However, if you give us the full citation, we will obtain our own copy
- Attachments of unpublished reports, local reports / documents are permissible. If you wish to provide academic in confidence material i.e. written but not yet published, or commercial in confidence i.e. internal documentation, highlight this using the highlighter function in Word.

Please return to QStopicengagement@nice.org.uk

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.