Liver disease

NICE National Institute for Health and Care Excellence

Stakeholder engagement – deadline for comments 5pm on 2nd September 2016
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. 2. You may also wish to highlight any areas of practice that might be considered as emergent, are only currently being done by a minority of providers but which have the potential to be widely adopted and drive improvements in the longer term. Please note, these areas should be underpinned by NICE or NICE-accredited guidance
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	**CoramBAAF Adoption and Fostering Academy** CoramBAAF, 41 Brunswick Square, London WC1N 1AZ Phone: 020 7520 0300 www.corambaaf.org.uk
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	**Nil**
Name of person completing form:	**Florence Merredew** **Health Group Development Officer**

Supporting the quality standard - Would your organisation like to express an interest in formally supporting this quality standard? More information.		**No**	
Type		[for office use only]	
Key area for quality improvement	**Why is this important?**	**Why is this a key area for quality improvement?** Evidence or 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? Do not paste other tables into this table, as your comments could get lost – type directly into this table.

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 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.

Separately list each key area for quality improvement that you would want to see covered by this quality standard. **EXAMPLE:** **Pulmonary rehabilitation for chronic obstructive pulmonary disease (COPD)**	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 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.	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 quality of pulmonary rehabilitation and its availability is still limited in the UK. Individual programmes differ in the precise exercises used, are of different duration, involve variable amounts of home exercise and have different referral criteria.	EXAMPLE: Please see the Royal College of Physicians national COPD audit which highlights findings of data collection for quality indicators relating to pulmonary rehabilitation. http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit

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 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.

General			This response is being submitted on behalf of the CoramBAAF Health Group, which is also a special interest group of the Royal College of Paediatrics and Child Health (RCPCH). The Health Group was formed to support health professionals working with children in the care system, through training, the provision of practice guidance and lobbying to promote the health of these children. With over 500 members UK-wide, an elected Health Group Advisory Committee with representation from community paediatricians working as medical advisers for looked after children and adoption panels, specialist nurses for looked after children, psychologists and psychiatrists, the Health Group has considerable expertise and a wide sphere of influence. Our area of concern is the particularly vulnerable group comprised of looked after and adopted children and young people. The main risk of liver disease in this population is from acquiring a blood borne infections (BBI) related to parental substance misuse or sexual abuse and from high risk behaviour in adolescence leading to a blood borne infection.

Key area for quality improvement 1 Universal screening for hepatitis C in pregnancy should be considered.	Universal prenatal screening is an ideal opportunity to determine the hepatitis C status of pregnant women, facilitating maternal treatment where needed and to prevent transmission to the foetus.	We know from statutory assessments on looked after children that often their mothers are in an at-risk group but have not been tested for hepatitis C during pregnancy.	Recommendation 4 of PH 43 published in 2012 states "*Staff providing antenatal services, including midwives, obstetricians, practice nurses and GPs, should ask about risk factors for hepatitis C during pregnancy and offer testing for hepatitis C to women at increased risk"*. However when our members undertake statutory health assessments on looked after children they still come across looked after infants whose mothers are in an at-risk group but have not been tested for hepatitis C during pregnancy. This recommendation does not highlight the risk in mothers who are historical IV drug users, sex workers, etc, or address the fact that mothers may deny current or historical risk-taking behaviour. Also no mention of postnatal testing in infants. Statutory assessments on looked after children provide a second opportunity to consider risk status however children with vertically acquired hepatitis C who don't become looked after will likely not be identified. With improved treatment for hepatitis C now available, is there now a case for universal antenatal screening, as is already in place for hepatitis B and HIV?

Key area for quality improvement 2 The importance of and need for training in various areas should be addressed and the resource implications acknowledged if NICE recommendations are to be carried out effectively.	If existing NICE guidance and the QS to be developed are to be effective, health and social care professionals need a good understanding and expertise in the following areas which may be particularly complex where looked after children are concerned: -Consent to test for BBI -Information sharing -risk factors for BBI - addressing stigma	Our members continue to report difficulties in these areas due to poor understanding of the issues outlined, compounded by insufficient capacity to deal with these complex and sensitive issues which take time to address. It has been documented that drug and alcohol services fail to take into account the welfare of children of substance misusing parents, and that health services for children may not be aware that these children are at high risk. All involved need training to raise awareness and to develop skills and pathways of communication and referral and support. It is therefore essential to add to this list that drug services staff should routinely consider the needs of the children of their clients who have hepatitis B and C risk factors so that appropriate action re testing, referral and support can be offered.	

Key area for quality improvement 3 Communication between professionals	With regard to looked after children it is essential that health and social care work together to identify and screen those children at risk, which involves dealing with the issues noted in key area 2 above	As noted above, communication and referral pathways should be improved between adult drug and alcohol services and children's services.	
Key area for quality improvement 4			
Key area for quality improvement 5			
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

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 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.

- 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 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.