

Consultation on draft guideline - Stakeholder comments table 17/04/23 – 02/05/23

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Stakeholder	Document	Page No	Line No	<b>Comments</b> Please insert each new comment in a new row	<b>Developer's response</b> Please respond to each comment
British dietetic association	Evidence review	005	General	It is fantastic to see a recommendation for research in enteral nutrition. However, I wonder if one of the reasons no evidence was found or included on the topic of nutrition and management of luminal obstruction is because of the strict criteria of the protocol such as having to adjust for the 7 confounding factors listed on page 5. I wonder if all these confounding factors are important for lifestyle research where RCTs are rare and therefore limit the research pool for making nutrition related recommendations.	Thank you. The committee would not be confident to make recommendations based on this lower quality research due to the uncertainty associated with poorer quality studies. The committee agreed that it would be better to make a research recommendation that might prompt research funding and interest in higher quality studies.
British dietetic association	Evidence review	023	004	Databases such as AHMED and CINAHL would be good to include to help get a wider reach for nutrition and quality of life studies	We used intelligence from the previous Oesophago-gastric cancer guideline to inform the most efficient combination of databases, prioritising those that were most likely to offer unique results without adding too greatly to the sifting burden. However, as a result of this comment, searches have been tested in AMED and EMCARE (an alternative to CINAHL available via the Ovid interface) which led to no further papers that met the inclusion criteria.
British Society of Gastrointestinal and Abdominal Radiology	General	General	General	BSGAR are broadly supportive of the guideline update. We do not envisage any impact on radiology service delivery.	Thank you for your support.



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Guts UK	Guideline	General	General	As there is a change (withdrawal) in the treatment external beam radiotherapy (which does not improve survivorship or quality of life for those without bleeding or bleeding disorders), which was advised in the earlier version, I wonder if it would be helpful to patients and their carers if the changes to the guidance could be explained in lay terms in the information for the public area of the website.	Thank you. The information for the public will be updated when this guideline is published.
Guts UK	Guideline	007	009	Consider adding 'or do not have a known bleeding disorder' to this line. As the addition will make this a long sentence separate the sentence into two.	Thank you. We have added text to this effect.
Heartburn Cancer UK	Guideline	General	General	An appropriate review with a slight alteration in care as to who to give external beam therapy to if stented and palliative. The change makes sense based on the evidence and the two recommendations for research are sensible.	Thank you for your support.
Liverpool University Hospitals NHS Foundation Trust	General	General	General	Nil other comments, agree with document	Thank you for your support.
Liverpool University Hospitals NHS Foundation Trust	Guideline	005	012	We agree that enteral feeding is an option to consider when first line management of dysphagia has failed/contraindicated.	Thank you for your support.



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NHS England	Evidence review	008	000	Is there any data or studies looking at high grade palliative radiotherapy given first with NJ feeding to delay stent insertion versus stent insertion immediately?	Thank you. Studies reporting this would have been identified during our searching and included in the systematic review, however we did not find any studies that reported this intervention.
NHS England	Guideline	General	General	<ul> <li>The Kings College London LeDeR report 2021 highlighted that:</li> <li>Cancer is the 4th biggest killer for people with a learning disability in 2021 with 11.4% of people with a learning disability dying from cancer in 2021. Of these the leading cancers were of the digestive organs (24.7%) (with 13.6% being of the colon and rectum). The second most common cancers were Lymphoid, haematopietic and related tissue (11.3%), followed by cancer of the respiratory and intrathoracic organs. (8.4%) (with 7.7% being of the lung and bronchus).</li> <li>Given this, we suggest specific reference and reminders are given to the following:</li> <li>Make reasonable adjustments: This is a legal requirement and is important to</li> </ul>	Thank you. This generic advice is captured in the NICE documents that are hyperlinked from the introductory box of the guideline. For further information see <u>NICE's information on making decisions about your care</u> .



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	Bootanioni	i ugo ito		Please insert each new comment in a new row	Please respond to each comment
				help you make the right diagnostic and	
				treatment decisions for an individual.	
				You can ask the person and their carer or	
				family member what reasonable	
				adjustments should be made.	
				Adjustments aim to remove barriers, do	
				things in a different way, or to provide	
				something additional to enable a person	
				to receive the assessment and treatment	
				they need. Possible examples include;	
				allocating a clinician by gender, taking	
				blood samples by thumb prick rather than	
				needle, providing a quiet space to see the	
				patient away from excess noise and	
				activity.	
				Example that all initial deviations around a series	
				- Ensure that clinical decisions around care	
				and access to treatment are made on an	
				individual basis. Every person has	
				individual needs and preferences which	
				must be taken account of, and they	
				should always get good standards and	
				quality of care. It is also important not to	
				make generalised judgements or	



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				assumptions about people's vulnerability or frailty based on their dependence on others for support in daily living.	
				<ul> <li>Communication: Communicate with and try to understand the person you are caring for. Check with the person themselves, their family member or carer or their hospital or communication passport for the best way to achieve this. Use simple, clear language, avoiding medical terms and 'jargon' wherever possible. Some people may be non-verbal and unable to tell you how they feel. Pictures may be a useful way of communicating with some people, but not all.</li> </ul>	
NHS England	Guideline	General	General	We strongly suggest there is reference to raising and listening to feedback and concerns from people and family members and the availability of <u>Ask Listen Do resources</u> .	Thank you. Making recommendations about organisational feedback mechanisms is beyond the remit of this update. Please see the <u>scope</u> document for details of the update.



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Royal College of Nursing	General	General	General	We have had no member comments this time.	Thank you for your support.
Royal College of Physicians	General	General	General	The NCRI-ACP-RCP-RCP is grateful for the opportunity to respond to the below. We have liaised with our experts and would like to respond as follows Our experts are agreed this revision is sensible and reflects current practice in specialist centres. It was felt that an update to NICE guidelines, as proposed, would be helpful to reduce the number of patients referred for radiotherapy after being stented- where there is no evidence of benefit. In terms of evidence the ROCS trial demonstrated that radiotherapy did not add anything to stenting in a palliative setting. Therefore, our experts are supportive of this amendment.	Thank you for your support.
Together Support Group	Guideline	004	012	I agree with the recommendation and the wording	Thank you for your support.



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Together Support Group	Guideline	004	014	I agree with the recommendation and the wording	Thank you for your support.
West Yorkshire and Harrogate Health and Care Partnership	General	General	General	I agree with the statement 1.5.11 Do not routinely offer external beam radiotherapy after stenting for people with oesophageal and oesophago-gastric junctional cancer. This would be consistent with the ROCS study published by Hurt et al 2021	Thank you for your support.
West Yorkshire and Harrogate Health and Care Partnership	General	General	General	The research question below may be interesting to formally evaluate the role of enteral feeding in selected patients particularly with regards to the impact on quality of life and survival. In people experiencing partial or complete luminal obstruction resulting from incurable oesophago- gastric cancer, is enteral feeding an effective and cost-effective method of preserving quality of life and survival, when the first line management of dysphagia (for example, self-expanding stents) has failed or is contraindicated?	Thank you for your support.
West Yorkshire and Harrogate Health and Care Partnership	General	General	General	we have no concerns with the guidance	Thank you for your support.