Appendix A: Stakeholder consultation comments table

2019 surveillance of Transient loss of consciousness ('blackouts') in over 16s (2010)

Consultation dates: 3 to 16 January 2019

Do you agree with th	o you agree with the proposal to not to update the guideline?			
Stakeholder	Overall response	Comments	NICE response	
British Geriatrics Society	Yes	No comments provided	Thank you.	
Association of British Neurologists	Yes	From our perspective, this is appropriate as there is really little new that could be added.	Thank you for your comment.	
Resuscitation Council	No The guideline requires limited revision but not a full evidence review. Please see detailed comments.	 Unfortunately, your 2019 surveillance proposal consultation document, shows that you misinterpreted our attached response, sent to you in 2014, in which we drew attention to the omission from the original guideline of a common presentation of TLoC to the ambulance service via 'telephone triage'. Our feedback in 2014 appears to have prompted an assumption that you should 	Thank you for your comments. 1. The evidence search for the 2014 surveillance review covered all sections of the guideline, including initial assessment. No new evidence was identified about ambulance telephone triage and how to determine, via this medium, whether or not a patient requires urgent assessment for TLoC in emergency care. The guideline was developed for use by healthcare professionals, commissioners and providers, and people with suspected or	

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look for new published evidence relating to 'telephone triage', leading you to find one study relating to 'tele-cardiology', of no relevance to the point that we were making. You considered that topic to have 'indirectness to the UK setting', but our feedback in 2014 was unrelated to 'tele- cardiology' and has huge relevance to the UK setting, since all the UK ambulance services use 'telephone triage' via either NHS Pathways or AMPDS. Again we must emphasise that, as written, the guideline makes it virtually impossible for UK ambulance telephone triage systems to be compliant with CG109. This was not addressed	diagnosed TLoC and their families and carers. As such, it does not make specific recommendations for non-clinicians, which may include telephone triage call handlers. We have raised your concerns with topic experts, including those with paramedic expertise. The collective feedback indicates that that the outcome from the initial call to the ambulance service would be the most appropriate response for the individual patient according to evidence based protocols or algorithms, and would not necessarily result in an emergency ambulance if not warranted. There is an option for clinical support and assessment if needed for calls that do not fit straightforward criteria. Experts did suggest an amendment to the relevant recommendation (1.1.4.6) to clarify the issue and cross refer to NICE's guideline on <u>emergency and urgent</u> <u>care</u> for further advice on providing emergency and acute medical care in the community to reduce the need for hospital admissions.
specifically in the scope, but also was not recognised by the GDG (of which I was a member) when we considered the different ways in which TLoC may present to healthcare providers. We developed the guideline as if all presentations of TLoC are face-to-face, when that is clearly not the case. As a result, the guideline refers to 'presentation to the ambulance service', without recognising or	This amendment will be considered by NICE. At a broader level, NICE also recognises the importance of clinical and non-clinical call handlers in the aforementioned guideline on <u>emergency and urgent care</u> , including the <u>research recommendation</u> : What is the most clinically and cost-effective use of clinical call handlers in a telephone advisory service in terms of i) the ratio of clinical to non-clinical call handlers and ii) point of access to clinical call handlers in a telephone advisory service pathway? New evidence on telephone triage call handling, in general and
acknowledging that in many instances the ambulance service will receive contact about a person with TLoC via a (111 or 999) call to one of its call handlers. These are non-clinicians and follow a menu of prompts and responses to	 specific to TLoC, will be assessed at the next review point for the respective guidelines. 2. In 2014 NICE responded to the comments from the Resuscitation Council (UK) and the joint letter with NHS Pathways through a phone call, follow up emails and the published <u>stakeholder</u>

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achieve 'telephone triage'. They are not able to carry out many of the actions recommended in 1.1 <i>Initial assessment</i> . For those to be carried out promptly and effectively, their only option would be to commit an emergency ambulance crew or first-responder paramedic to attend many low-risk cases of TLoC and for the majority of those to be taken to the nearest hospital emergency department (ED), adding unnecessary burdens to the workload of both the ambulance service and the ED, with no benefit to the patient, and clear compromise to their ability to deliver prompt treatment to others.
The Resuscitation Council (UK) believes that the failure to recognise and address the presentation of TLoC to the ambulance services via 'telephone triage' reduces the guideline's credibility and effectiveness, and destroys any chance that it can be implemented for a substantial number of people who experience TLoC.
This problem does not warrant a full review of the published evidence since 2010, but does warrant limited revision of the guideline to address how people whose TLoC is reported to the ambulance service by telephone can be assessed and treated safely and effectively, without disadvantaging patients and healthcare provider services by generating huge numbers of totally inappropriate

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		 hospital attendances Involvement of one of the telephone triage providers (e.g. NHS Pathways) in that revision will be crucial. 2. Please note that the above problem was raised in August 2013 in a joint letter from Dr Peter Fox and Dr Fiona Jewkes on behalf of NHS Pathways and from me on behalf of the RC (UK). A copy of the final draft of that letter is attached. We have never received a reply. 	
NICE Quality and Leadership Programme	Yes	No comments provided	Thank you.
Medtronic	Yes	Thank you for the opportunity to comment. We support NICE's proposal not to update the guideline on transient loss of consciousness.	Thank you for your comments.
East Midlands Ambulance Service NHS Trust	No	It needs to have more involvement with the ambulance service with pathways for non-life threatening or incidental findings. The ambulance service can also screen for potential undiagnosed cardiac conditions with forwarding all ECGs taken from young adults between 16 and 35 years old. This of course would be with the consent of the patient or parents/guardians. All that is available for the ambulance service is a training PowerPoint slide set.	Thank you for your comments. Recommendation 1.1.4.6 advises that if the person presents to the ambulance service, they should be taken to the Emergency Department unless a diagnosis of an uncomplicated faint or situational syncope is clear. This is supported by the <u>PowerPoint implementation tool</u> you refer to. This tool aims to ensure that the relevant recommendations are made available to ambulance services in a digestible format. Throughout the presentation additional information sections have been added to the notes. These are not NICE guidance but have

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			been included to help in the application of the recommendations to practice. NICE recognises that the ambulance service staff are often present during or just after a patient has experienced TLoC. They are responsible for ensuring the patient is directed towards the appropriate pathway to make sure the person receives the correct
			diagnosis quickly and efficiently leading to a suitable management plan. However, new recommendations you suggest for ambulance teams to screen for potential undiagnosed cardiac conditions via ECGs would require supporting evidence in local settings to demonstrate the benefits. In the absence of such evidence, no impact on the guideline is anticipated at this time. Any new evidence will be considered at the next review point.
Royal College of Nursing	No Comments	Nurses caring for people with Transient loss of consciousness have reviewed the proposal and have no comments to submit at this stage.	Thank you.
Department of Health and Social Care	Not answered	I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.	Thank you.
Are you aware of any	v significant new e	vidence on implantable event recorders that could imp	pact on the guideline? If so, please provide citation details.
Stakeholder	Overall response	Comments	NICE response

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British Geriatrics Society	No	No comments provided	Thank you.
Association of British Neurologists	No	No comments provided	Thank you.
Resuscitation Council	No	No comments provided	Thank you.
NICE Quality and Leadership Programme	No	No comments provided	Thank you.
Medtronic	No	Medtronic will keep NICE posted with regards to any new significant evidence on implantable event recorders that has the potential to impact the guideline. We are aware of two new publications (outlined below) that reinforce the current recommendations thus, will not impact the current guidelines however we wanted to bring new clinical evidence to NICE's attention:	Thank you for your comments and submission of evidence that reinforces the current recommendations. Both of the studies are included in the Cochrane review (<u>Solbiati et al. 2016</u>) covered in the surveillance report, which is not considered to have any impact on the guideline recommendations.
		 Podoleanu C, DaCosta A, Defaye P, Taieb J, Galley D, Bru P, Maury P, Mabo P, Boveda S, Cellarier G, Anselme F. Early use of an implantable loop recorder in syncope evaluation: a randomized study in the context of the French healthcare system (FRESH study). Archives of cardiovascular diseases. 2014 Oct 1;107(10):546-52. 	

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		 Sulke, N., Sugihara, C., Hong, P., Patel, N. and Freemantle, N., 2015. The benefit of a remotely monitored implantable loop recorder as a first line investigation in unexplained syncope: the EaSyAS II trial. Europace, 18(6), pp.912-918. 	
East Midlands Ambulance Service NHS Trust	No	No comments provided	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided.	Thank you.
Should the scope of t significant evidence y			lowing diagnosis? If so, please provide citation details of any
Stakeholder	Overall response	Comments	NICE response
British Geriatrics Society	No	No comments provided	Thank you.
Association of British Neurologists	No	No comments provided	Thank you.

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Resuscitation Council	No	but a specific NICE guideline on the management of syncope would be a valuable resource. If you are going to include guidance on the management of syncope in a guideline about TLoC, you will also have to include guidance on the management of all other types and causes of TLoC.	Thank you for your comment. The scope of the guideline states that it does not cover the treatment of syncope or epilepsy following diagnosis, but will signpost existing NICE guidance where this is available. As such, the guideline links to the NICE guideline on <u>epilepsies: diagnosis and management</u> . In the absence of NICE guidance on syncope, some experts considered that an extension to the scope could potentially add value in this area. However, we recognise your point that this may cause an imbalance if all other types and causes of TLoC are not included as well. A specific guideline on the management of syncope may be considered at a future point.
NICE Quality and Leadership Programme	No	Management of syncope was not raised during the development of the transient loss of consciousness quality standard (QS71), and there are no placeholder statements on this area.	Thank you for your comment.
Medtronic	No	No comments provided	Thank you.
East Midlands Ambulance Service NHS Trust	No	No comments provided	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided	Thank you.

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Do you have any com	o you have any comments on areas excluded from the scope of the guideline?			
Stakeholder	Overall response	Comments	NICE response	
British Geriatrics Society	No	No comments provided	Thank you.	
Association of British Neurologists	No	No comments provided	Thank you.	
Resuscitation Council	Yes	Please see our detailed comments against (1) above.	Thank you for your comments. Please see the response above.	
NICE Quality and Leadership Programme	No	No comments provided	Thank you.	
Medtronic	No	No comments provided	Thank you.	
East Midlands Ambulance Service NHS Trust	Yes	As the ambulance service has the opportunity to incidental findings, the service needs have more robust and accessible pathways to refer patients directly with a recognised referral pathway flowchart.	Thank you for your comments. Please see the response above regarding the <u>PowerPoint</u> <u>implementation tool</u> for ambulance services.	
Royal College of Nursing	Not answered	No comments provided	Thank you.	
Department of Health and Social Care	Not answered	No comments provided	Thank you.	

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Do you have any com	Do you have any comments on equalities issues?			
Stakeholder	Overall response	Comments	NICE response	
British Geriatrics Society	No	No comments provided	Thank you.	
Association of British Neurologists	No	No comments provided	Thank you.	
Resuscitation Council	Yes	Only that many of or all those individuals whose TLoC is reported to the ambulance service by telephone will be disadvantaged by the problem identified in (1) above.	Thank you for your comment. The medium of patient presentation, in this case telephone, would not constitute an equality issue in the context of NICE's duty to have due regard to the need to eliminate unlawful discrimination, advance opportunity and foster good relations. NICE needs to consider the protected characteristics defined in the Equality Act 2010 and other factors such as socioeconomic status or other forms of disadvantage.	
NICE Quality and Leadership Programme	No	No comments provided	Thank you.	
Medtronic	No	No comments provided	Thank you.	
East Midlands Ambulance Service NHS Trust	No	No comments provided	Thank you.	
Royal College of Nursing	Not answered	No comments provided	Thank you.	

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Department of Health	Not answered	No comments provided	Thank you.
and Social Care			

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