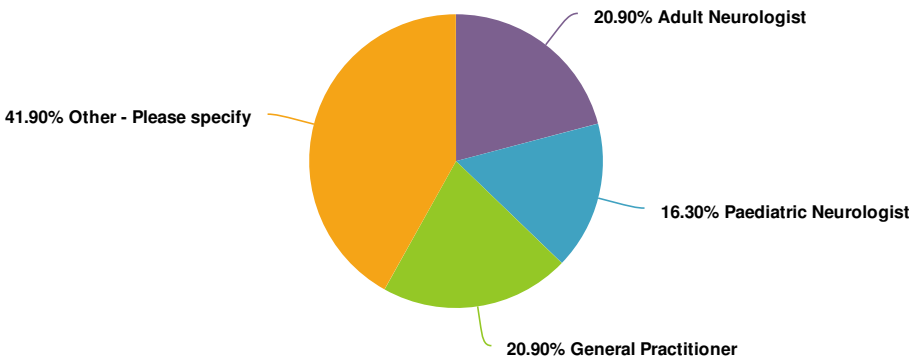
Report for NICE Suspected Neurological Conditions guideline: Targeted engagement, January 2017

Response Counts

Completion Rate:	**65.1%**		
	Complete		28
	Partial		15
			Total: 43

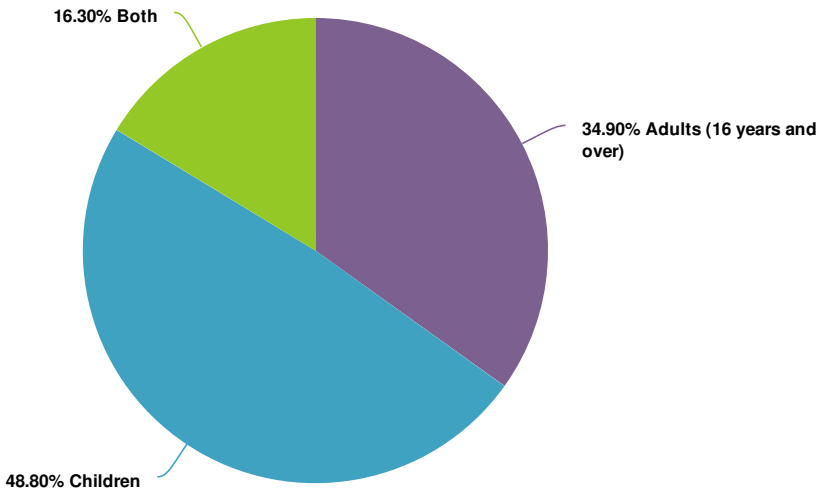
1. Please tell us your profession. Please remember that this guideline is aimed at non-specialists (principally GPs and emergency department clinicians) so if you are a specialist, please bear this in mind when commenting on the recommendations.



Value	Percent	Responses
Adult Neurologist	20.9%	9
Paediatric Neurologist	16.3%	7
General Practitioner	20.9%	9
Other - Please specify	41.9%	18

Total: 43

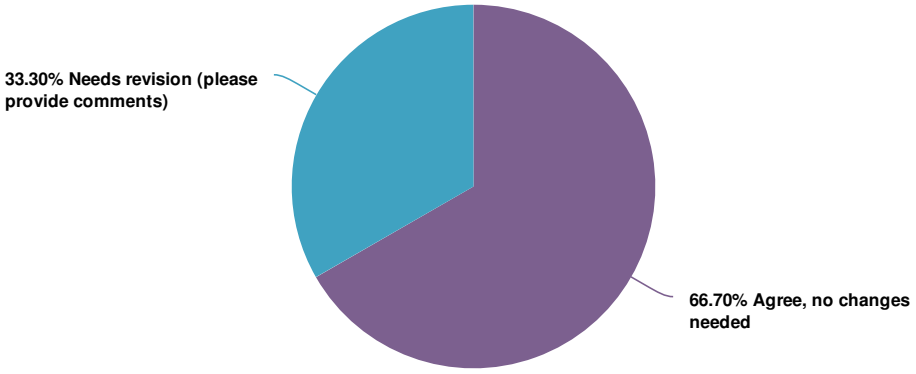
2. Do you wish to complete the survey for adults (16 years and over), children, or both? Please note that your answer will streamline the questions that will be presented to you, so you will not see the recommendations for children if you select adults, and vice versa.



Value	Percent	Responses
Adults (16 years and over)	34.9%	15
Children	48.8%	21
Both	16.3%	7

Total: 43

3. To what extent do you agree with the following recommendation? For children with acute confusion: refer for immediate hospital assessment and arrange an emergency transfer to hospital and measure blood glucose.



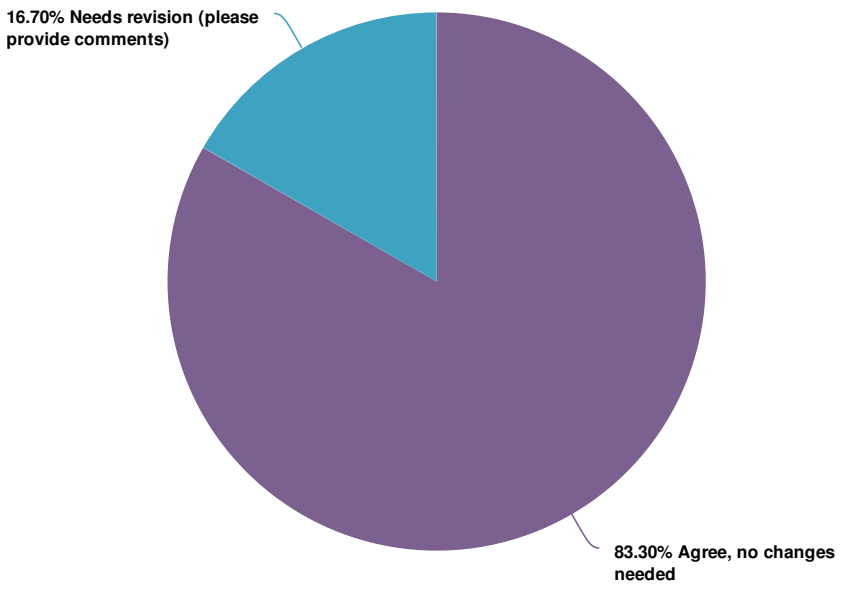
Value	Percent	Responses
Agree, no changes needed	66.7%	16
Needs revision (please provide comments)	33.3%	8

Total: 24

4. To what extent do you agree with the following recommendation? For children with acute confusion:refer for immediate hospital assessment and arrange an emergency transfer to hospital and measure blood glucose.

Count	Response
1	'Measure blood glucose' perhaps should be listed as the 1st or 2nd amongst the 3
1	Also enquire about possible alcohol ingestion/intoxication or other substance abuse.
1	Consider alcohol intoxication/other substance poisoning Consider post-ictal state
1	I think blood sugar assessment may be more appropriate as first bullet-point (as a reversible cause). In some instances, it is quicker for a child to be conveyed from a GP surgery in a carer's car, rather than wait for an ambulance to attend, who will then take the same route. So ... how about '... ensure immediate transfer to hospital, using emergency ambulance if intervention may be required enroute'.
1	Pulse, BP, oxygen saturation
1	The guideline should indicate definition and management of hypoglycaemia in primary care or community. There should be a caveat for children with conditions known to be associated with episodes of confusion eg diabetes or epilepsy, and child may have a personal care plan .
1	might need to provide a definition of confusion especially for infants
1	please define confusion esp in context of young child or infant

5. To what extent do you agree with the following recommendation? Be aware that acute confusion in children can be a symptom of meningitis, encephalitis or poisoning. If sepsis is suspected, follow the recommendations on identifying people with suspected sepsis and face-to-face assessment of people with suspected sepsis in the NICE guideline on sepsis (recommendations in sections 1.1 and 1.3)



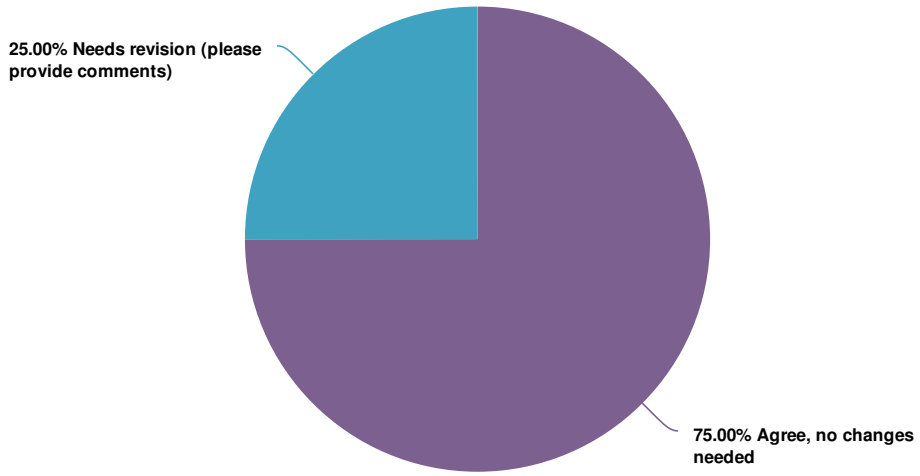
Value	Percent	Responses
Agree, no changes needed	83.3%	20
Needs revision (please provide comments)	16.7%	4

Total: 24

6. To what extent do you agree with the following recommendation? Be aware that acute confusion in children can be a symptom of meningitis, encephalitis or poisoning. If sepsis is suspected, follow the recommendations on identifying people with suspected sepsis and face-to-face assessment of people with suspected sepsis in the NICE guideline on sepsis (recommendations in sections 1.1 and 1.3)

Count	Response
1	Encephalitis needs to be seen as including both infective and non-infective causes (such as autoimmune); also consideration of metabolic causes (high ammonia, high lactate etc) needs to be mentioned
1	I think Head Injury might be included here? In the rationale, the NICE states that fever is not always present, so it might be better not to suggest absence of fever reduces likelihood of sepsis.
1	Strongly agree
1	a symptom of meningitis, encephalitis, sepsis or poisoning.
1	meningitis, encephalitis, sepsis or poisoning

7. To what extent do you agree with the following recommendation? For children with acute confusion who have a non-blanching rash and symptoms suggestive of meningococcal septicaemia: give parenteral antibiotics and arrange an emergency transfer to hospital, in line with the recommendations on symptoms, signs and initial assessment and pre-hospital management in the NICE guideline on meningitis and meningococcal septicaemia in under 16s.



Value	Percent	Responses
Agree, no changes needed	75.0%	18
Needs revision (please provide comments)	25.0%	6

Total: 24

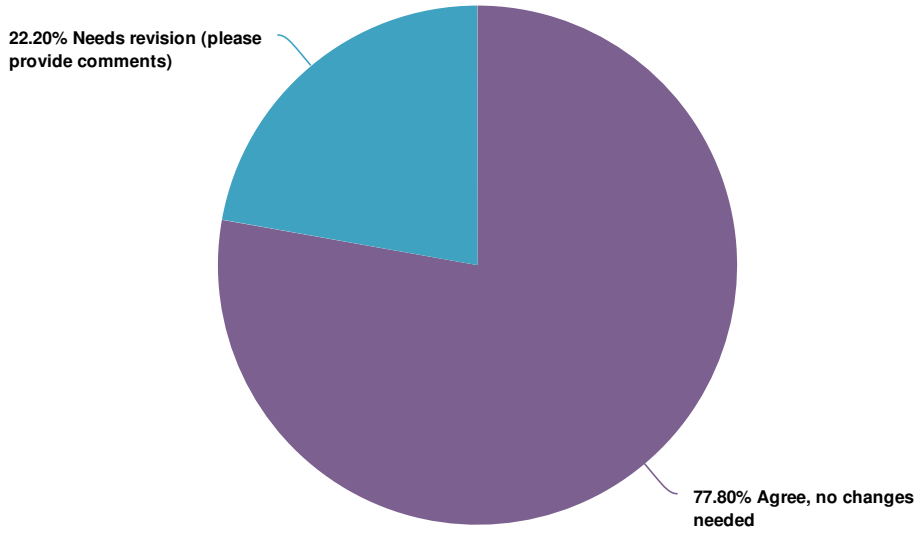
8. To what extent do you agree with the following recommendation? For children with acute confusion who have a non-blanching rash and symptoms suggestive of meningococcal septicaemia: give parenteral antibiotics and arrange an emergency transfer to hospital, in line with the recommendations on symptoms, signs and initial assessment and pre-hospital management in the NICE guideline on meningitis and meningococcal septicaemia in under 16s.

Count	Response
1	I think the recommendation should err on the side of overcalling meningococcal disease - am worried that symptoms may be subtle/late/absent
1	Nice suggest antibiotics in both meningococcal meningitis and septicaemia, so suggest same wording - as the rationale section includes both. The final sentence saying "non blanching rash on it's own ....." could cause uncertainty - because this section is on the Acutely Confused child, so the rash wouldn't be an isolated finding in this situation.
1	Often the onset of Meningococcal septicaemia can be as a blanching rash so this would also need incorporating somehow.
1	have a non blanching rash OR symptoms suggestive of meningococcal septicaemia
1	non blanching rash OR symptoms suggestive of meningococcal septicaemia
1	symptoms may not be apparent initially and I think it would be safer to treat all children w confusion & rash

9. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	'However, body temperature should distinguish poisoning from meningitis and encephalitis.' - It might not always be possible to distinguish - e.g. MDMA toxicity. Hence suggest wording as 'might help' rather than 'should'
1	?need definition of acute as opposed to subacute encephalopathy
1	As above, a differential diagnosis has to be considered and appropriate tests considered including metabolic workup and autoimmune CNS antibodies.
1	As not all children present with a rash, consider giving antibiotics if febrile and unwell.
1	Consider post epileptic phase, if known epileptic.
1	Consider same causes as for decreased consciousness guidelines
1	In rural areas, the therapy free interval may be improved by carers conveying the child. It may be prudent to weight up the benefit of ambulance transfer (ie. what will they bring to the management of this child), with the inherent delay of waiting for one.
1	Out of my scope for comment
1	Request information regarding pre- existing conditions and look for personal care plan . Seek information regarding misuse of drugs or alcohol.
1	might need to specify that some long term conditions may have paroxysmal self resloving condition such as known epilepsy and post ictal state
1	reference the RCPCH evidence based guideline: "The management of children and young people with an acute decrease in conscious level." 2015 update. RCPCH, London.
1	should acute confusion be distinguished for a more subacute change in behaviour - I am not sure how acute is being defined in this context
1	taht can be in context of post ictal state and known epilepsy
1	would be helpful to define confusion, especially in the context of very young children

10. To what extent do you agree with the following recommendation? Refer adults with transient loss of consciousness (‘blackouts’) accompanied by seizure markers urgently for neurological assessment, in line with the recommendation for people with suspected epilepsy in the NICE guideline on transient loss of consciousness in over 16s .



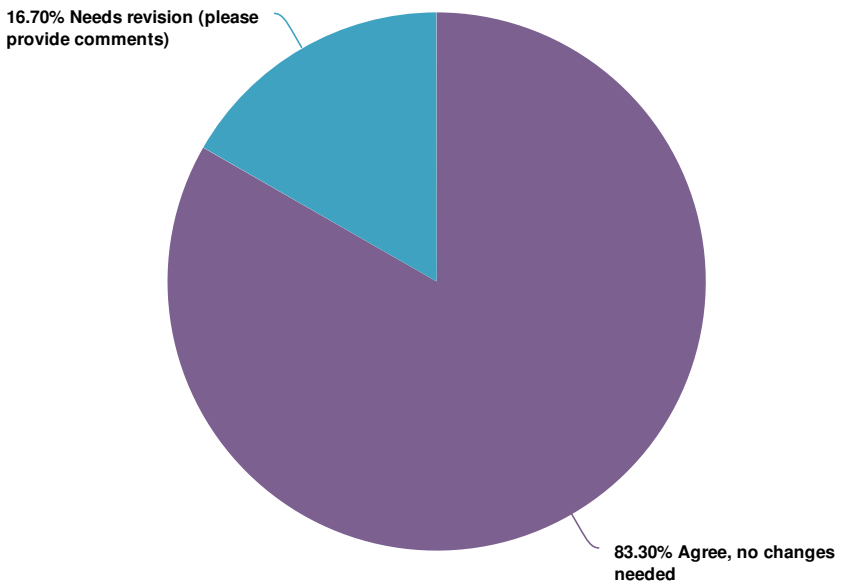
Value	Percent	Responses
Agree, no changes needed	77.8%	14
Needs revision (please provide comments)	22.2%	4

Total: 18

11. To what extent do you agree with the following recommendation? Refer adults with transient loss of consciousness (‘blackouts’) accompanied by seizure markers urgently for neurological assessment, in line with the recommendation for people with suspected epilepsy in the NICE guideline on transient loss of consciousness in over 16s .

Count	Response
1	Needs clarification about repeated presentations, suggest need to add that this should be for first presentation in someone not previously assessed by specialist services
1	Neurologist must be able to interview witness in person or on telephone
1	Of note, national ambulance services guidance advocate paramedics to convey first-time seizures to ED for same day assessment.
1	Perhaps it is worth specifying that this is for 'new' or 'first time' suspected seizure with LOC.
1	Should make clear first episode rather than in someone who has a known existing diagnosis of epilepsy
1	consider more specific advice on updated classification of epilepsy, otherwise agree with current guidance

12. To what extent do you agree with the following recommendation? For adults with suspected vasovagal syncope, follow recommendation 1.2.2.1 for people with suspected epilepsy in the NICE guideline on transient loss of consciousness in over 16s.



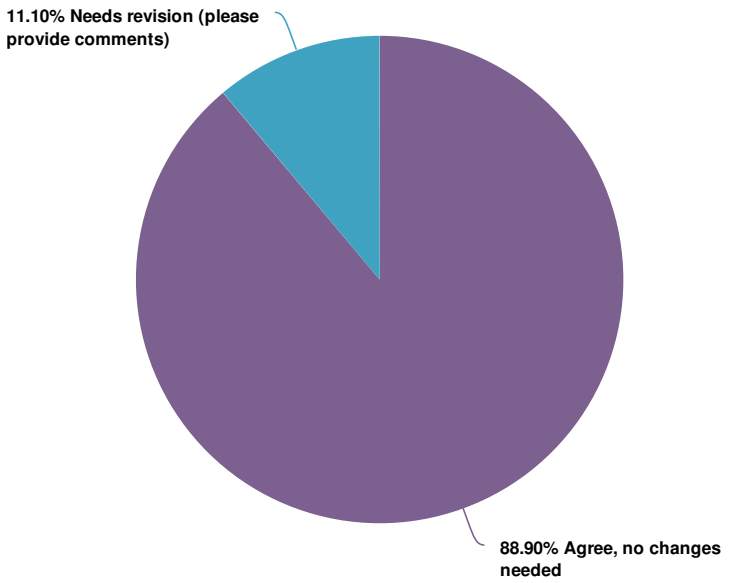
Value	Percent	Responses
Agree, no changes needed	83.3%	15
Needs revision (please provide comments)	16.7%	3

Total: 18

13. To what extent do you agree with the following recommendation? For adults with suspected vasovagal syncope, follow recommendation 1.2.2.1 for people with suspected epilepsy in the NICE guideline on transient loss of consciousness in over 16s.

Count	Response
1	I agree the statement is a little vague. Perhaps it should read: For adults with suspected vasovagal syncope, follow recommendation 1.2.2.1 for epilepsy should be suspected if there are any of the features listed in the the recommendation 1.2.2.1 etc.....
1	Is the question about suspecting vasovagal syncope or suspecting epilepsy? Perhaps the wording needs reviewing, I am not sure what the statement is trying to recommend.
1	Vasovagal syncope and orthostatic hypotension are not synonyms; the former does not require demonstration of the latter
1	from current referrals often non specialists not confident to exclude epilepsy despite clear vasovagal syncope history

14. To what extent do you agree with the following recommendation? Do not refer adults with transient loss of consciousness associated with jerking of the limbs if there are clear features of vasovagal syncope. See recommendation 1.2.2.1 for people with suspected epilepsy in the NICE guideline on transient loss of consciousness in over 16s.



Value	Percent	Responses
Agree, no changes needed	88.9%	16
Needs revision (please provide comments)	11.1%	2

Total: 18

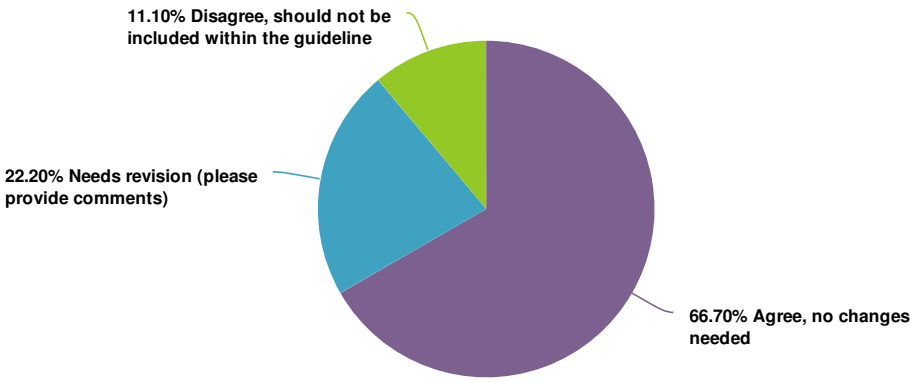
15. To what extent do you agree with the following recommendation? Do not refer adults with transient loss of consciousness associated with jerking of the limbs if there are clear features of vasovagal syncope. See recommendation 1.2.2.1 for people with suspected epilepsy in the NICE guideline on transient loss of consciousness in over 16s.

Count	Response
1	"clear features of vasovagal syncope" requires clarification e.g. to include prodrome/posture/pallor
1	Not what T LoC guideline says! It says don't refer foe epilepsy assessment. Certain patients with VV syncope my need referral esp if doubt and/or recurrent. However they need to go to cardiology
1	from a practical perspective often primary care and A&E still feel uncomfortable not to seek advice for syncope related limb jerks
1	specialists not confident to exclude epilepsy despite clear vasovagal syncope history suggesting syncopal seizure

16. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Emphasis importance of a full sequential history from pt and informant
1	Ensure patient has had an ECG prior to referral
1	If the blackout occurs during or after a medical procedure, including a peripheral cannula (which might have been open to air), the possibility of air embolism should be considered.
1	No
1	With regards to 8. - I would highlight the need to refer to the appropriate specialty or initiate investigation initially in primary care if any red flags e.g. arrhythmias, exertional symptoms.
1	Yes as above. The key is the witness description which is sadly so often not planned on referral.
1	re-iteration of this guidance within electronic directory of services where choose and book clinics take place may aid demand mangement

17. To what extent do you agree with the following recommendation? Refer adults with new-onset difficulty writing for a neurological assessment.



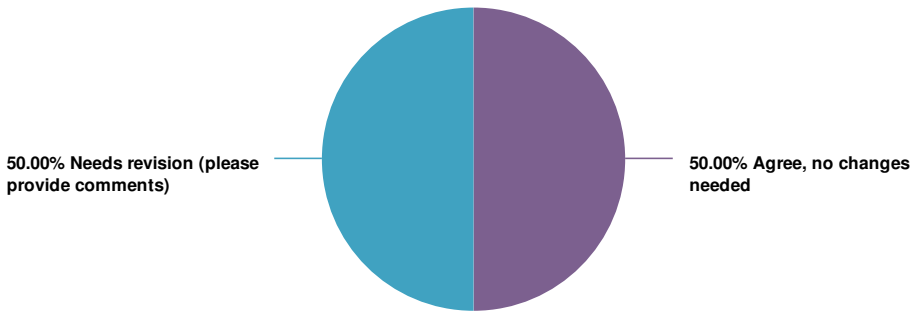
Value	Percent	Responses
Agree, no changes needed	66.7%	12
Needs revision (please provide comments)	22.2%	4
Disagree, should not be included within the guideline	11.1%	2
	Total: 18	

18. To what extent do you agree with the following recommendation? Refer adults with new-onset difficulty writing for a neurological assessment.

Count	Response
1	Acute onset (less than 2 weeks)with focal neurological signs should be referred and seen within 2 weeks
1	I would add a clause about possible musculoskeletal causes (traumatic shoulder injury, carpal tunnel syndrome, repetitive strain injury at wrist, cramp etc etc) e.g: Refer adults with new-onset difficulty writing with no apparent musculoskeletal or other cause for a neurological assessment.
1	This is a very rare referral agenda
1	This statement seems somewhat vague- I note from the linked document that this mainly refers to dystonia/Parkinson's disease, but it could also refer to a multitude of other conditions (anywhere from carpal tunnel syndrome to a primary language disorder, hand pain, deformities due to osteoarthritis, stroke, decline in visual acuity.....etc), so perhaps further detail should be given acompanying the statement. I don't agree that all adults with new onset writing difficulty need to be referred to a neurologist- I only think this is necessary when an underlying neurological condition is suspected, or when the referring doctor has doubts.
1	Too non-specific needs much more clarification and will confuse GPs and encourage inappropriate referrals
1	specify the need to exclude other focal neurology symptoms, which may affect the decision for urgency of referral.

Count	Response

19. To what extent do you agree with the following recommendation?Ask adults with difficulty writing to demonstrate their writing and: if the difficulty is specific to the task of writing and examination shows no other abnormalities, suspect focal dystonia. Refer adults with suspected focal dystonia for an assessment and consideration of botulinum toxin treatment. if the person's writing is small and slow, suspect Parkinson's disease and follow the recommendations on tremor in adults in this guideline*. if the person has a problem with language rather than hand function, suspect neurodegenerative disease. * Please note that not all recommendations on tremor are included for this targeted consultation as not all are consensus-based.



Value	Percent	Responses
Agree, no changes needed	50.0%	9
Needs revision (please provide comments)	50.0%	9

Total: 18

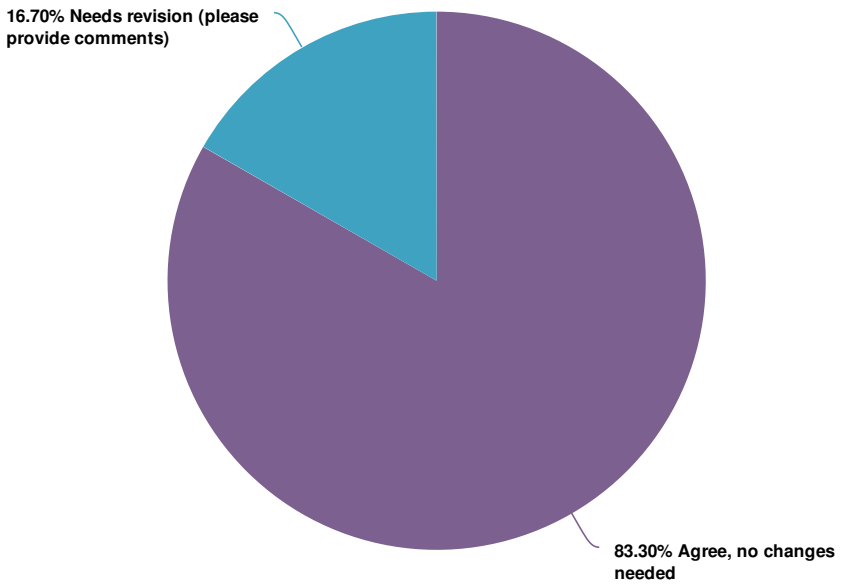
20. To what extent do you agree with the following recommendation?Ask adults with difficulty writing to demonstrate their writing and:if the difficulty is specific to the task of writing and examination shows no other abnormalities, suspect focal dystonia. Refer adults with suspected focal dystonia for an assessment and consideration of botulinum toxin treatment. if the person's writing is small and slow, suspect Parkinson's disease and follow the recommendations on tremor in adults in this guideline*. if the person has a problem with language rather than hand function, suspect neurodegenerative disease.* Please note that not all recommendations on tremor are included for this targeted consultation as not all are consensus-based.

Count	Response
1	.... suspect neurodegenerative disease like dementia and consider referral to the memory clinic
1	Handwriting can become small and slow as part of normal ageing so there must be additional features for GP to refer for ? P D
1	May need caveat dependent on local service eg if if satellite clinic and centre where botox offered significant distance away all 3 may be seen in a general clinic and may be able to be managed locally in DGH neurology. The DGH clinic may then triage when appropriate onto botox clinic. There will likely be regional variations in service
1	PD is of course a neurodegenerative disease, which leads to this wording being in conflict with the wording of the next phrase "if the person has a problem with language rather than hand function, suspect neurodegenerative disease". Perhaps this would be better worded as "....., suspect other cause, including dementia"; the umbrella term 'neurodegenerative disease' includes PD but this would not ordinarily be associated with language problems of this nature
1	Second bullet point, Parkinsons disease may present with writing difficulties but not a tremor, so referring clinicians to a tremor guideline may not always be appropriate in this situation.
1	T ask specific dystonia must be <0.1% of referrals. If we could get away from the PD-tremor association and start to think of PD as a disorder of motor slowness we would be making good progress
1	agree with above if there are clearly defined separate services . At a DGH all 3 scenarios may be seen directly within the same clinic and potentially then a patient needing botox to be sent onto specialist clinic. I think it is potentially a challenge for the GP tp differentiate and may lead to large travelling distance to specialist centre for botox when in fact it may not be indicated
1	regarding the 3rd sentence: "if the person has a problem with language rather than hand function, suspect intracranial lesion, psychiatric conditions or neurodegenerative disease" (psychiatric symptoms such as ambivalence, poverty of speech, disorganised speech etc may affect the language production)
1	regards to focal dystonia, could the difficulty writing be elaborated- i.e. pain with writing, increasingly eligible writing etc.

21. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Perhaps remind GPs to ask patients for any history of anosmia or REM behaviour sleep disorder in patients with small and slow handwriting
1	no

22. To what extent do you agree with the following recommendation?Suspect cervical dystonia in adults who have persistent abnormalities of head or neck posture with or without head tremor, especially if the symptom improves when the person touches their chin with their hand.



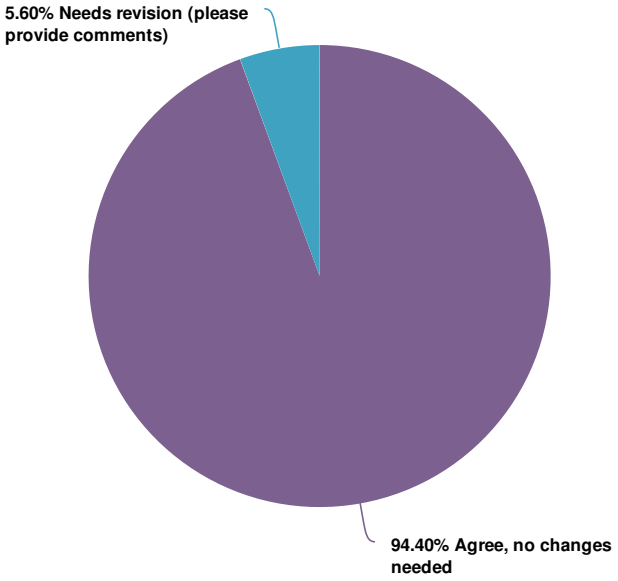
Value	Percent	Responses
Agree, no changes needed	83.3%	15
Needs revision (please provide comments)	16.7%	3

Total: 18

23. To what extent do you agree with the following recommendation?Suspect cervical dystonia in adults who have persistent abnormalities of head or neck posture with or without head tremor, especially if the symptom improves when the person touches their chin with their hand.

Count	Response
1	"with or without head tremor" brings no added value. You might as well say "with or without pain" or "with or without muscle hypertrophy"
1	Specify a time frame for 'persistent' as we see many patients with torticollis. Should we refer if persistent for >6 weeks?
1	please define the duration of 'persistent'

24. To what extent do you agree with the following recommendation? Do not offer cervical imaging before referring adults with suspected cervical dystonia.



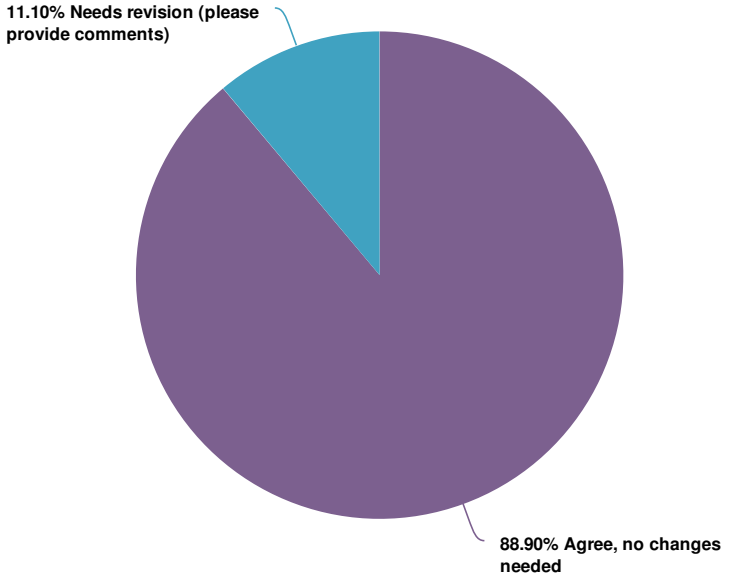
Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

25. To what extent do you agree with the following recommendation? Do not offer cervical imaging before referring adults with suspected cervical dystonia.

Count	Response
1	I agree imaging not evidence based however it is difficult for GPs to resist ordering a neck xray in possible dystonia. In fact the commonest pathway is through physio which is inappropriate resource use and therefore perhaps should also receive comment
1	Unable to comment

26. To what extent do you agree with the following recommendation? Be aware that focal dystonia may affect other parts of the body (for example, in-turned posture of the foot).



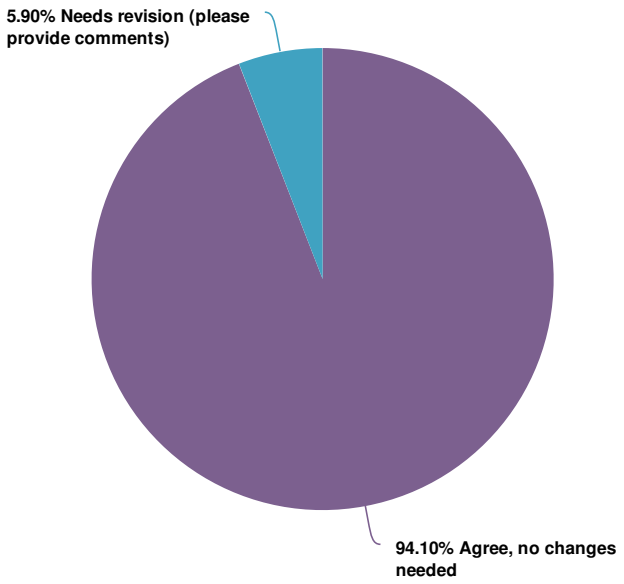
Value	Percent	Responses
Agree, no changes needed	88.9%	16
Needs revision (please provide comments)	11.1%	2

Total: 18

27. To what extent do you agree with the following recommendation? Be aware that focal dystonia may affect other parts of the body (for example, in-turned posture of the foot).

Count	Response
1	In-turned posture of the foot does just make me wonder whether there needs to be reference here to a functional neurological disorder being a consideration
1	Why then is it called focal dystonia? This is neurological nit-picking of no relevance to referral guidelines

28. To what extent do you agree with the following recommendation? Refer adults with suspected focal dystonia to have an assessment for diagnosis and to assess the suitability of botulinum toxin treatment.



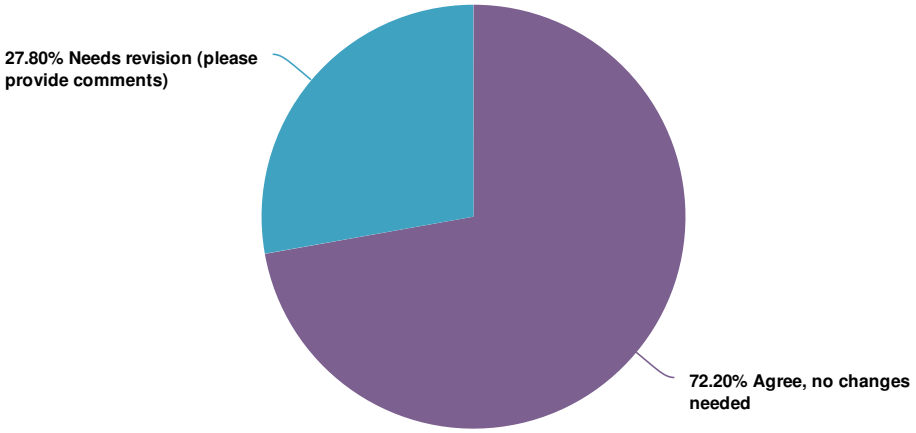
Value	Percent	Responses
Agree, no changes needed	94.1%	16
Needs revision (please provide comments)	5.9%	1

Total: 17

29. To what extent do you agree with the following recommendation? Refer adults with suspected focal dystonia to have an assessment for diagnosis and to assess the suitability of botulinum toxin treatment.

Count	Response
1	... and for consideration of leaving relatively well alone in non-disabling cases (bot tox services are severely oversubscribed)

30. To what extent do you agree with the following recommendation? Be aware that antipsychotic and anti-emetic medication can trigger or exacerbate dystonia in adults.



Value	Percent	Responses
Agree, no changes needed	72.2%	13
Needs revision (please provide comments)	27.8%	5

Total: 18

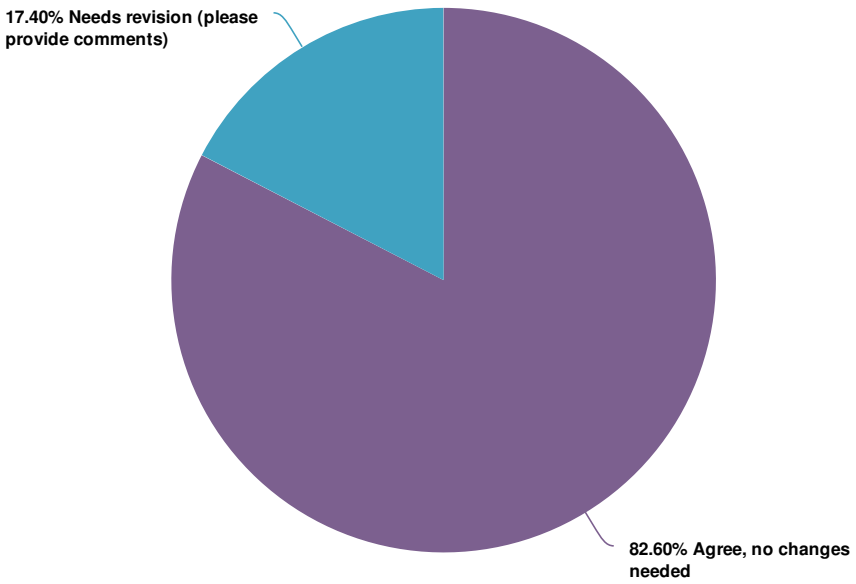
31. To what extent do you agree with the following recommendation? Be aware that antipsychotic and anti-emetic medication can trigger or exacerbate dystonia in adults.

Count	Response
1	"Be aware that dystonia in adults on antipsychotic or antiemetic medication is probably a side effect of that medication"
1	Perhaps give examples of biggest culprits?
1	agreed but the rationale in the document then talks about tar dive dsykineia which is as I understand it different to dystonia. It doesnt elaborate. But it might be useful to discuss both acute and chronic drug induced dystonia and if procyclidine use is recommended.
1	consider advice regarding anticholinergic therapy as may significantly benefit symptoms pending review in neurology services
1	could add considering anticholinrgic medication for symptom management, as may be delay for OPD appointment while symptoms may be managed /improved

32. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	As per previous - will the rationale sections be included in the guideline as presented here? If so, I would have some comments.
1	Which anti-emetics? Is it all of them even though they work differently?

33. To what extent do you agree with the following recommendation? In children with abnormal neck posture, check whether painful cervical lymphadenopathy is the cause.



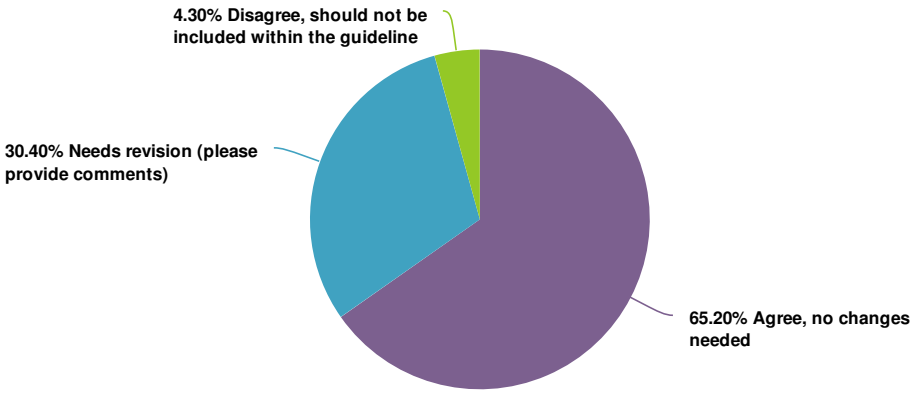
Value	Percent	Responses
Agree, no changes needed	82.6%	19
Needs revision (please provide comments)	17.4%	4

Total: 23

34. To what extent do you agree with the following recommendation? In children with abnormal neck posture, check whether painful cervical lymphadenopathy is the cause.

Count	Response
1	Agree but cervical lymphadenopathy may be associated with a life- threatening infective or neurological pathology eg Lemmiere's Syndrome
1	Although painful and suspected cause the key and needs to be followed closely by point 13 below
1	Cervical lymphadenopathy is very frequent in young children and should not be presumed if present to account for abnormal neck posturing hence I think the above statement could lead to a lower threshold for consideration of other serious underlying pathology.
1	Or airway problems are the cause e.g. laryngeal inflammatory
1	Painful with direct cause is the key here, but may need to refer to excluding red flags symptoms of brain tumour as per headsmart or malignancy as per suspected cancer guidelines. number 13 needs to be but closely after this.
1	and if persisting more than 48 hours with no explanation refer for paediatric assessment and MRI brain.

35. To what extent do you agree with the following recommendation? Refer children with abnormal neck posture and a recent history of head or neck trauma immediately for neurological assessment.



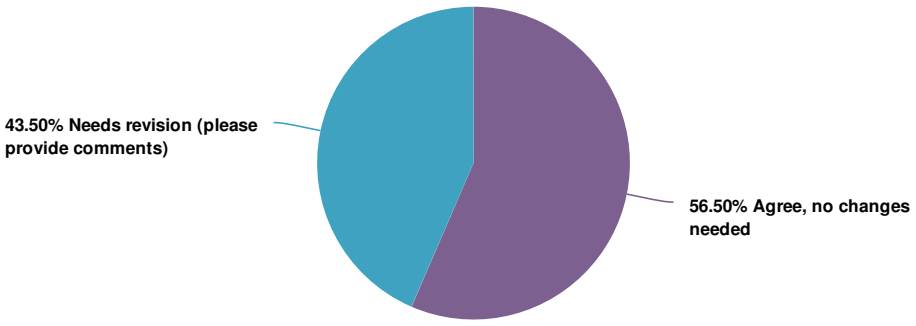
Value	Percent	Responses
Agree, no changes needed	65.2%	15
Needs revision (please provide comments)	30.4%	7
Disagree, should not be included within the guideline	4.3%	1

Total: 23

36. To what extent do you agree with the following recommendation? Refer children with abnormal neck posture and a recent history of head or neck trauma immediately for neurological assessment.

Count	Response
1	Ensure neck is stable. Do we need to say neurological - might be spinal or other orthopaedic?
1	Guideline should include advice regarding stabilisation of neck (APLS guidelines)
1	Higher incidence of cervical instability in certain genetic conditions ,for example in Down's syndrome, so must be referred for specialist assessment.
1	How much do we need to refer to trauma guidance, neck stabilisation, imaging, spinal or other surgical review etc?
1	I don't know what it is getting at, but am happy to be educated
1	To consider stabilisation of neck if h/o trauma
1	need to include comment re stabilising the neck
1	needs to include statement re stabilising the neck
1	neurological assessment. Should this not be neurosurgical assessment.

37. To what extent do you agree with the following recommendation? Refer children who develop abnormal posture of a limb for neurological assessment.



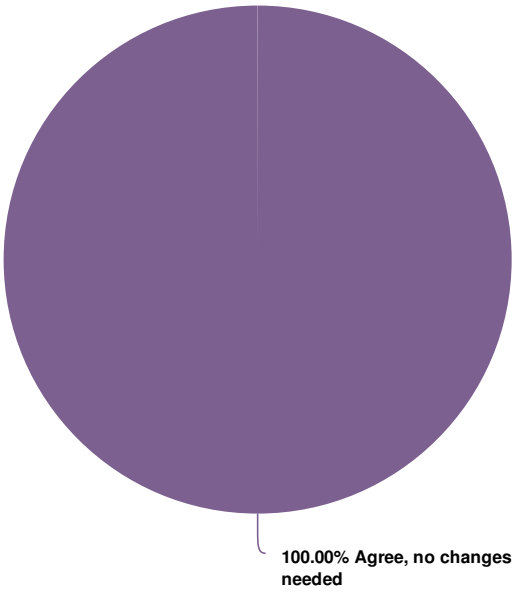
Value	Percent	Responses
Agree, no changes needed	56.5%	13
Needs revision (please provide comments)	43.5%	10

Total: 23

38. To what extent do you agree with the following recommendation? Refer children who develop abnormal posture of a limb for neurological assessment.

Count	Response
1	'Abnormal posture' is too vague a term. Does it mean weakness/dystonic posturing/ clumsiness? I would suggest an asymmetry either witnessed or as per parental report his can often be transient eg parents having noted a floppy arm and transient facial droop which is no longer apparent by the time they are seen but still warrants Ix and imaging. That this could be transient/intermittent should not be dismissed by the clinician.
1	?need to specify time frame
1	Caveat regarding evidence or suspicion of injury (trauma)
1	Certain exceptions might apply- e.g. an immobile child where safeguarding concerns might come to light
1	Clearly this can occur post trauma, should we say unexplained abnormal posture. Need to be clear that not necessarily mitigating neurological review in the first instance, exam could be done by paediatrician then refer/investigate as necessary - e.g joint inflammation, reactive arthritis, fracture in very young children may present in this manner though pain/discomfort may well be present.
1	Consider possibility of a fracture in preverbal and younger children with associated pain along with abnormal posture.
1	Evaluate signs and symptoms and possible impact of other emotional, behavioural factors. Sometimes this can be functional.
1	does time frame need to go in here?
1	limb/or limbs. Dystonia not always isolated to one limb.
1	persistentt abnormal posture
1	would suggest immediate

39. To what extent do you agree with the following recommendation? Be aware that abnormal head tilt in children can be a symptom of posterior fossa tumour.



Value	Percent	Responses
Agree, no changes needed	100.0%	23
	Total: 23	

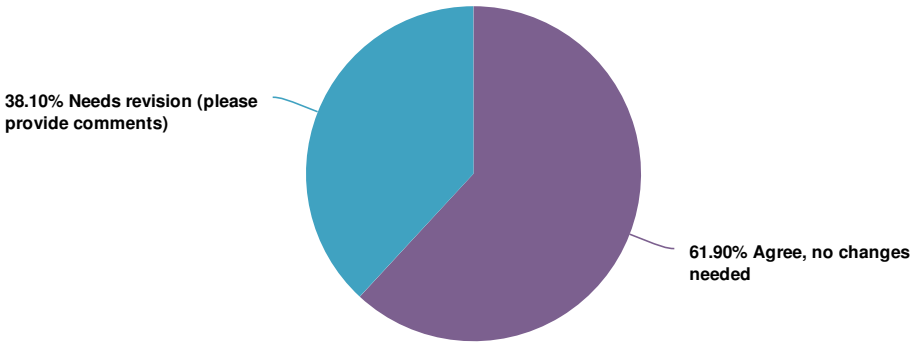
40. To what extent do you agree with the following recommendation? Be aware that abnormal head tilt in children can be a symptom of posterior fossa tumour.

Count	Response
1	Refer to Headsmart guideline for red flag symptoms and signs of brain tumour in children
1	This needs to be more closely linked to number 10 as per my comments there

41. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Children with neurodevelopmental conditions may adapt abnormal postures, but this is usually not an acute presentation.
1	I would recommend additional comment regarding the consideration of an abnormal head tilt secondary to sternomastoid tumours if presenting in infancy. If suspected onward referral to physiotherapy at the earliest stage possible is most effective. I am unsure of the protocol around ultrasound scan as this appears to occur inconsistently but this also could be considered as part of the guideline.
1	In infants consider birth history and possibility of brachial plexus trauma
1	for Q 24. should that not also apply to adults as well?
1	just that examination of the child and any relevant factors such as pain, trauma systemic illness and emotional and behavioural disturbance needs to be elicited
1	no
1	or can be due to Chiari or to a gaze palsy

42. To what extent do you agree with the following recommendation? Be aware that dizziness in children: is unlikely to be a symptom of a brain tumour if there are no accompanying symptoms is often a symptom of migraine and may be the predominant feature.



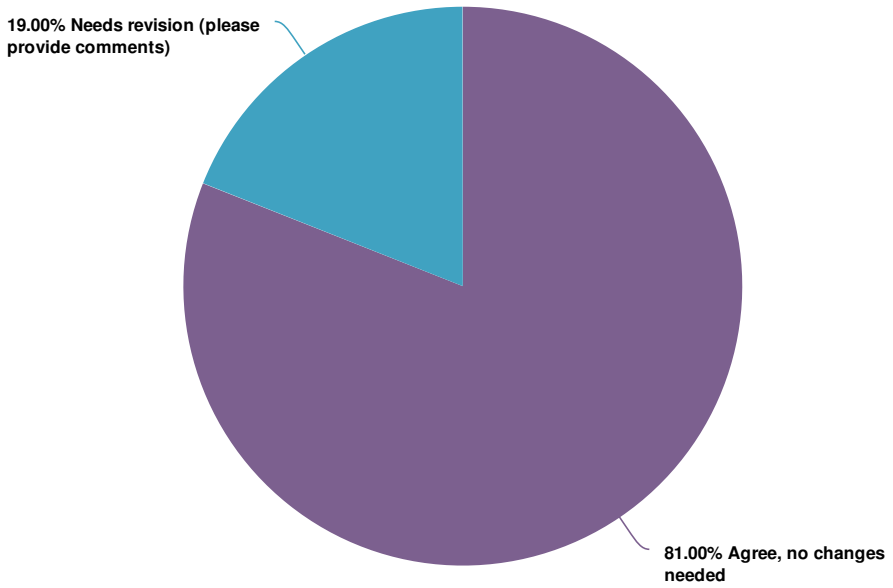
Value	Percent	Responses
Agree, no changes needed	61.9%	13
Needs revision (please provide comments)	38.1%	8

Total: 21

43. To what extent do you agree with the following recommendation? Be aware that dizziness in children: is unlikely to be a symptom of a brain tumour if there are no accompanying symptoms is often a symptom of migraine and may be the predominant feature.

Count	Response
1	"or other clinical signs"
1	Comment is re - 'is often a symptom of migraine and may be the predominant feature'- Migraine associated dizziness although is recognised, is less so predominant, when compared to the vasovagal symptoms seen e.g. in adolescents.
1	Firstly the word 'dizziness' needs defining (by both clinicians and sufferers) as it is often incorrectly used and does not always refer to 'a sensation of self motion' but can instead be used to mean a host of various symptoms/sensations and feeling of unsteadiness/disequilibrium. Clarifying the definition and meaning of the word is the FIRST step to guide the differential diagnosis process and any Ix if warranted.
1	Need definition of "dizziness" which is a vague symptom,- may be include definition of "vertigo"
1	Should this be "Isolated" or "non recurrent"? As a GP, I felt confused by this and the subsequent section on "paroxysmal" -
1	add "is often a symptom of pre-syncope"
1	again would suggest defining the term
1	need a definition of dizziness if not already provided

44. To what extent do you agree with the following recommendation? Be aware that in older children (usually aged over 8 years), dizziness related to change in posture is most often caused by postural hypotension.



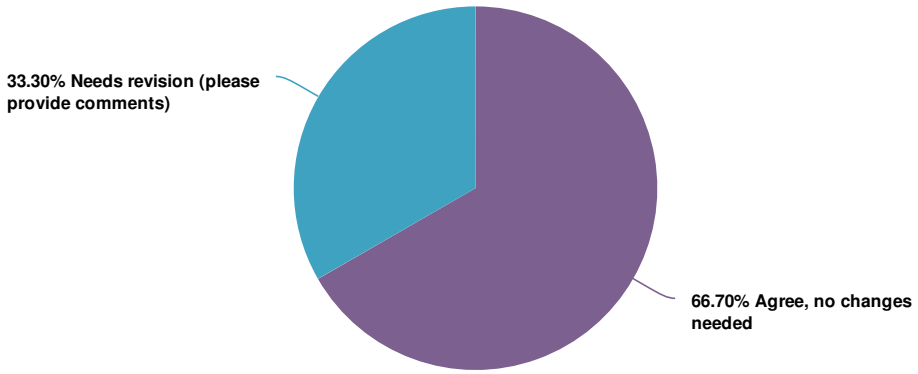
Value	Percent	Responses
Agree, no changes needed	81.0%	17
Needs revision (please provide comments)	19.0%	4

Total: 21

45. To what extent do you agree with the following recommendation? Be aware that in older children (usually aged over 8 years), dizziness related to change in posture is most often caused by postural hypotension.

Count	Response
1	Consider vestibular causes in this group. Enquire about antecedent URTI/ear infection.
1	Feeling lightheaded on standing is not the correct definition of 'dizziness' see above comments hence this is rather redundant and is due to misuse of the term 'dizziness'.
1	Unable to comment
1	is there evidence to say most often rather than often
1	is there evidence to support "most often" rather than "often:

46. To what extent do you agree with the following recommendation? For children with paroxysmal dizziness: arrange an ECG, which may need interpretation by a specialist with expertise in paediatric ECGs, and exclude cardiac dysrhythmias, recurrent middle-ear infections and anaemia.



Value	Percent	Responses
Agree, no changes needed	66.7%	14
Needs revision (please provide comments)	33.3%	7

Total: 21

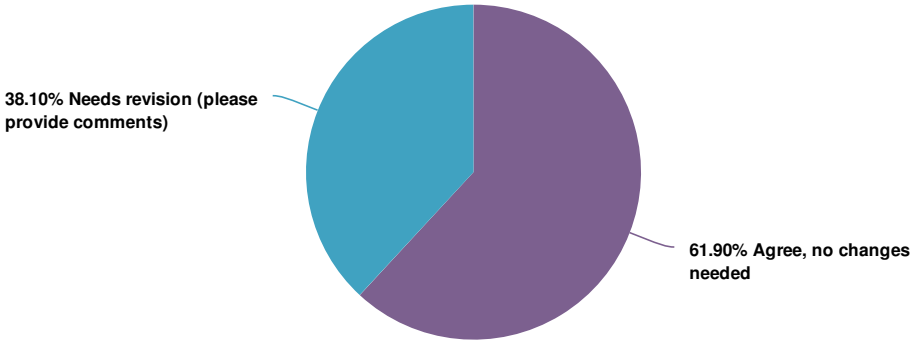
47. To what extent do you agree with the following recommendation? For children with paroxysmal dizziness:arrange an ECG, which may need interpretation by a specialist with expertise in paediatric ECGs, and exclude cardiac dysrhythmias, recurrent middle-ear infections and anaemia.

Count	Response
1	
1	'exclude cardiac dysrhythmias, recurrent middle-ear infections and anaemia' - perhaps rephrase as consideration will be needed for cardiac arrhythmia, the potential for arrhythmia, and cardiac outflow obstruction being some of the cardiac causes of syncope.
1	But note above comment
1	I am not sure of the meaning of the term 'paroxysmal dizziness' is that occasional dizziness v/s chronic dizziness??? Arent most cases of dizziness paroxysmal by the very nature of the problem? Needs rethinking and reformulating and firstly working definition of dizziness needs to be stated.
1	I don't like the word "exclude" in guideline. Anaemia might be "excluded" by standards of Hb level (except possibly in haemolytic crisis if blood is taken after resolution of event. A cardiac dysrhthymia may be missed unless the child has a prolonged or "event" ECG. I think "recurrent middle ear infections" should be omitted unless there is a history of vertigo during an illness with symptoms/signs of acute otitis mediaor labyrinthitis
1	The rationale for this needs clarifying: There are a range of possible causes of paroxysmal dizziness in children, including for example anaemia, dehydration, viral illness and ear infection. Electrocardiography can help to identify some of these causes and rule out the need for referral to neurology. two things an ecg can't identify any of the causes mentioned and rule out the need for neurology referral? I can't really see how unless a clear dysrhythmia or long qt etc is found and attributed as the cause of the intermittent dizziness.
1	how is "exclude cardiac dysrhythmia" different from "arrange ECG" - the repetition is confusing
1	how is exclude cardiac dysrhythmia different from arrange ECG - the reiteration is confusing
1	this seems too vague, I think exclude other symptoms & signs, this really relates to "pure" dizziness" which is an unusual history in a child

48. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Dizziness requires a detailed history and a careful interpretation as to what the child refers to as 'dizziness'.
1	Is there any possibility of clarifying, medically, what dizziness means in this context as it can mean so many different things particularly to the non-medical person? If the patient has dizziness at the time of examination and it is clear there is a spontaneous nystagmus, for example (say worse on leaning on one side), what then? [I once had an adolescent with this, 1-2 day history, and a diagnosis (by me) of a vestibular neuronitis, with no other abnormal findings at the time, the family later went to A&E after low grade pyrexia developed and the young man was diagnosed with a UTI (despite lack of any urinary symptoms or evidence from what I could tell) and given antibiotics. If diagnosis is difficult there will be pressure on GPs to refer immediately via A&E to prevent litigation if the wrong diagnosis has been made, to prevent complaints, and to prevent parental concern if/when other clinicians come up with wildly varying diagnoses. During my Clinical Skills Assessment (CSA) for my
1	No
1	Out of scope
1	Referral to secondary care/ neurologist may be necessary if the above are normal, as the child may have vertebro basilar migraine, and may need treatment if recurrent and disabling.
1	This is fraught as 'dizziness' is an often misused word to describe a host of various feelings and only rather infrequently in children does it equate with its actual meaning of the patient having a sensation of 'self-motion'. IF this term is not clarified then all of the above statements (technically incorrect) would seem 'reasonable'
1	in the first rationale. statement: undertake the appropriate screening tests to investigate migraine before deciding whether referral to paediatric neurology not very useful appropriate screening test? I would examine but not do any " screening tests" these need to be elaborated on.
1	see above

49. To what extent do you agree with the following recommendation?Be aware that hypotonia (floppiness) in babies aged under 6 months may be the presenting symptom of a significant disorder of the brain or peripheral nervous system, or of a dysfunction of the heart, liver, muscle or kidneys.



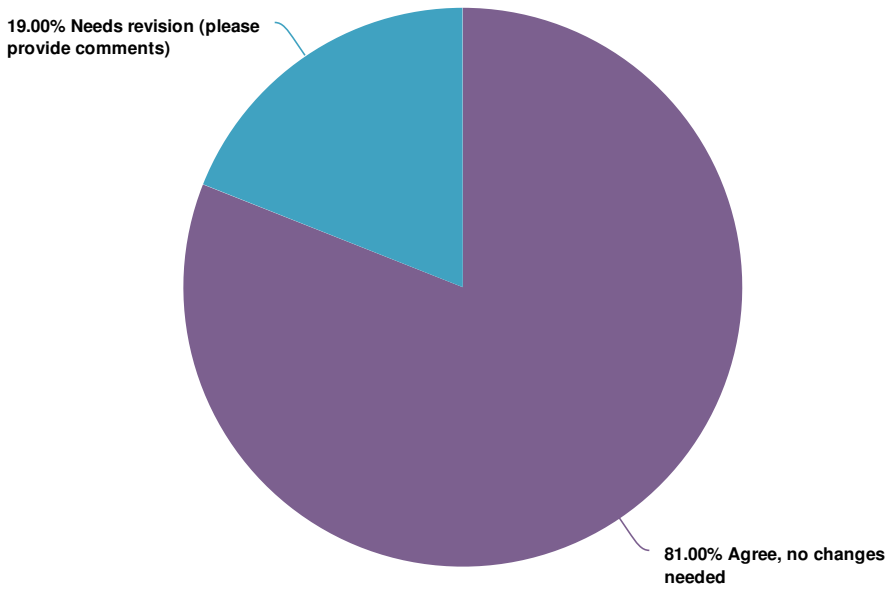
Value	Percent	Responses
Agree, no changes needed	61.9%	13
Needs revision (please provide comments)	38.1%	8

Total: 21

50. To what extent do you agree with the following recommendation?Be aware that hypotonia (floppiness) in babies aged under 6 months may be the presenting symptom of a significant disorder of the brain or peripheral nervous system, or of a dysfunction of the heart, liver, muscle or kidneys.

Count	Response
1	?include chromosomal disorder??
1	Many causes are benign or genetic/metabolic/perinatal. Perhaps should say may be benign but may also be the symptom of the brain or peripheral nerve system or other condition.
1	Recent onset hypotonia, may be the presenting .....
1	Suggest " Be aware that hypotonia (floppiness) may be the presenting symptom of a significant disorder of the brain or peripheral nervous system or muscle. Dysfunction of the heart or liver or kidneys may also present with floppiness so the baby should be carefully examined for signs of cardiac failure and enlargement of liver or kidneys- with relevant investigations .
1	can also be feature of a chromosomal disorder eg Downs
1	can be benign, or often more in context of genetic. Perhaps could put may be benign but could be the sign of neuromuscular, genetic or other condition
1	consider changing use of the word THE to A PRESENTING SYMPTOM
1	define 'paediatric services' is this neurology consultant or would referral to a children's physiotherapist be considered.
1	or combination of the above

51. To what extent do you agree with the following recommendation? Refer children with unexplained hypotonia to paediatric services as follows: routine referral if there are no accompanying symptoms urgent referral if hypotonia is accompanied by weakness immediate referral if hypotonia is accompanied by an altered level of consciousness because this may indicate a neurometabolic disorder, meningitis, encephalitis or raised intracranial pressure.



Value	Percent	Responses
Agree, no changes needed	81.0%	17
Needs revision (please provide comments)	19.0%	4

Total: 21

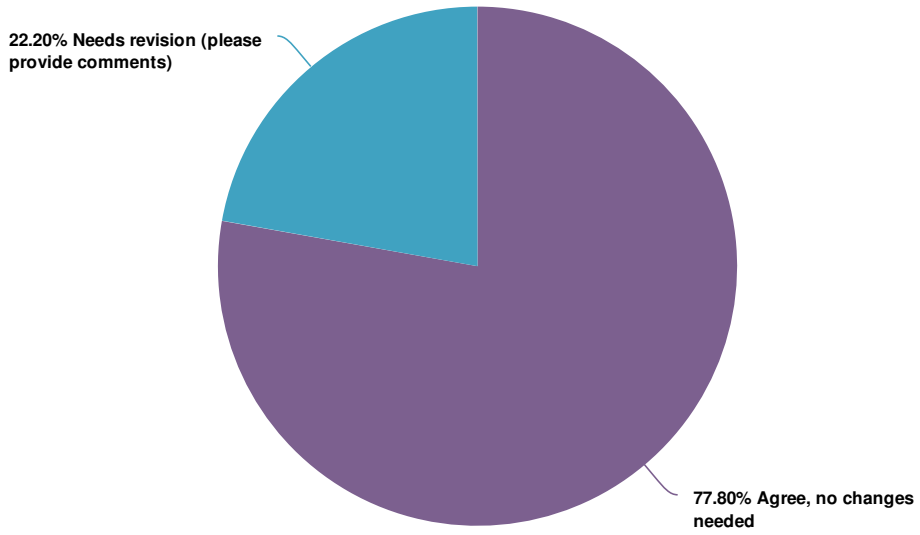
52. To what extent do you agree with the following recommendation? Refer children with unexplained hypotonia to paediatric services as follows:routine referral if there are no accompanying symptoms urgent referral if hypotonia is accompanied by weakness immediate referral if hypotonia is accompanied by an altered level of consciousness because this may indicate a neurometabolic disorder, meningitis, encephalitis or raised intracranial pressure.

Count	Response
1	Follow the protocol for sepsis and or give antibiotics if the symptoms suggest meningococcal meningitis
1	If hypotonia is "unexplained" ie not a benign cause or related to child's overall developmental level then referral to paediatric services should be "urgent" , I would not recommend "routine referral"
1	It is not always easy to distinguish 'hypotonia with weakness' from that without as I've seen numerous experienced paediatricians delay referral because of this, hence would not make above so strict and would add if in doubt urgent referral.
1	It is unclear where the referral destinations should be for routine or urgent cases. In my experience, wait times to see paediatric neurologists are long and often originate from other consultants initially. Perhaps the guideline should be more specific in directing referrals into general paediatrics initially who may be able to see sooner than neurologists?

53. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Family history of consanguinity; of any other siblings with delayed development, etc
1	May be explain standards of a "routine referral"
1	No

54. To what extent do you agree with the following recommendation? Be aware that involuntary movements in adults that can be temporarily suppressed at the expense of mounting inner tension are likely to be tics, and do not refer unless the tics are severe and disabling.



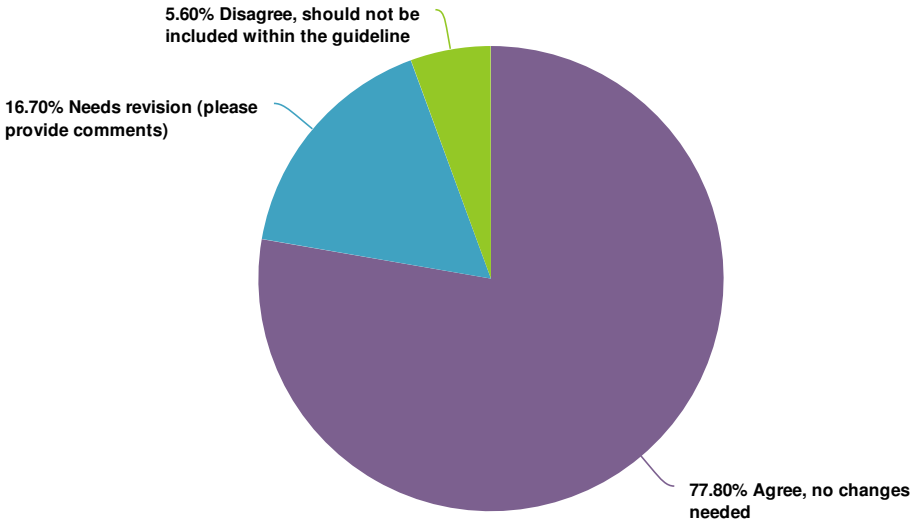
Value	Percent	Responses
Agree, no changes needed	77.8%	14
Needs revision (please provide comments)	22.2%	4

Total: 18

55. To what extent do you agree with the following recommendation? Be aware that involuntary movements in adults that can be temporarily suppressed at the expense of mounting inner tension are likely to be tics, and do not refer unless the tics are severe and disabling.

Count	Response
1	I am more in agreement with 20. It depends on what is meant about "severe and disabling" versus "distress"
1	I would omit 'at the expense of mounting inner tension' as this is too wordy and too specific. Just ' temporarily voluntarily supressed' is sufficient.
1	I wouldn't discourage referrals as tic disorders can be quite difficult to diagnose. Eg treatable conditions such as blepharospasm or hemifacial spasm are often mistaken for tics. Perhaps instead of the words "severe" and "disabling", the word "intrusive" could be considered.
1	re write for clarity. consider the wider audience, perhaps at the expense of mounting inner tension could be clarified by mounting inner tension/ psychological discomfort. also may I suggest, and do not normally need referral to neurology unless the tics.....

56. To what extent do you agree with the following recommendation? Consider referring adults with a tic disorder for psychological therapy if the disorder distresses them.



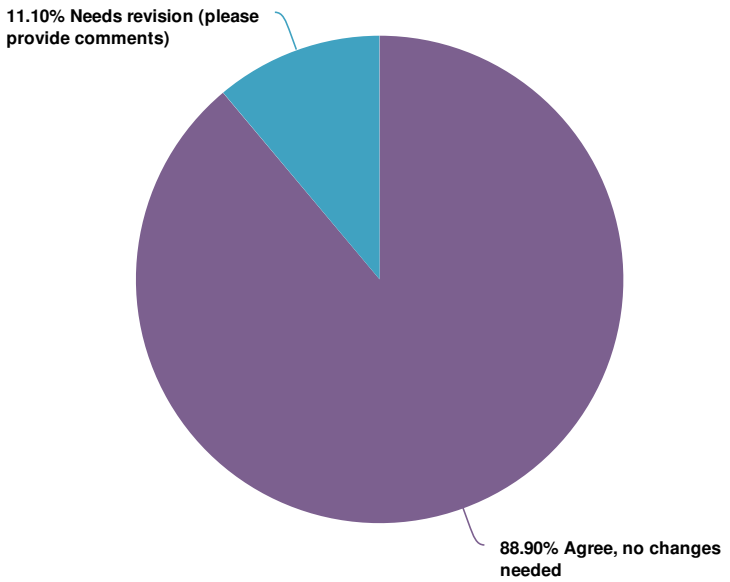
Value	Percent	Responses
Agree, no changes needed	77.8%	14
Needs revision (please provide comments)	16.7%	3
Disagree, should not be included within the guideline	5.6%	1

Total: 18

57. To what extent do you agree with the following recommendation? Consider referring adults with a tic disorder for psychological therapy if the disorder distresses them.

Count	Response
1	Consider adding a sentence on managing any co-morbid psychiatric conditions (which might include alcohol or substance misuse)? This would be different to a psychological approach via Neurology dept, and different patients might benefit from different approaches. Plus Psychology resource in acute settings has limited capacity.
1	Is there an evidence base? I suspect not
1	Perhaps greater detail as to rationale for referral
1	the rationale needs to be clarified. Habit-reversal therapy may be offered for particularLY disabling tics.

58. To what extent do you agree with the following recommendation? Consider referring adults who have completed psychological therapy for a tic disorder to have a neurological assessment if their symptoms are severe and the disorder continues to distress them.



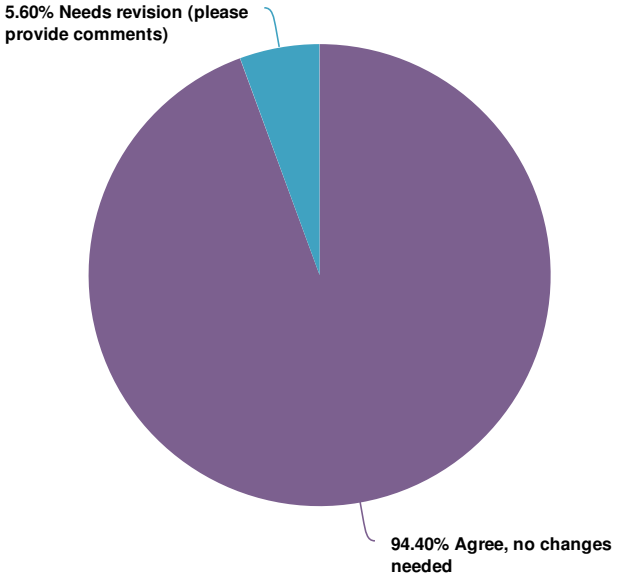
Value	Percent	Responses
Agree, no changes needed	88.9%	16
Needs revision (please provide comments)	11.1%	2

Total: 18

59. To what extent do you agree with the following recommendation? Consider referring adults who have completed psychological therapy for a tic disorder to have a neurological assessment if their symptoms are severe and the disorder continues to distress them. - comments

Count	Response
1	Although I do not disagree with the principle, I am concerned that this pathway can prolong patients' suffering and can lead to a loss in trust between patients and doctors. I doubt if patients with severe tic disorder would benefit a great deal from psychological interventions alone and would suggest to refer to neurology first
1	State that tic is almost always better tolerated than treated
1	re write rational for clarity.

60. To what extent do you agree with the following recommendation? Be aware that involuntary movements in adults that cannot be suppressed are more likely to need neurological assessment.



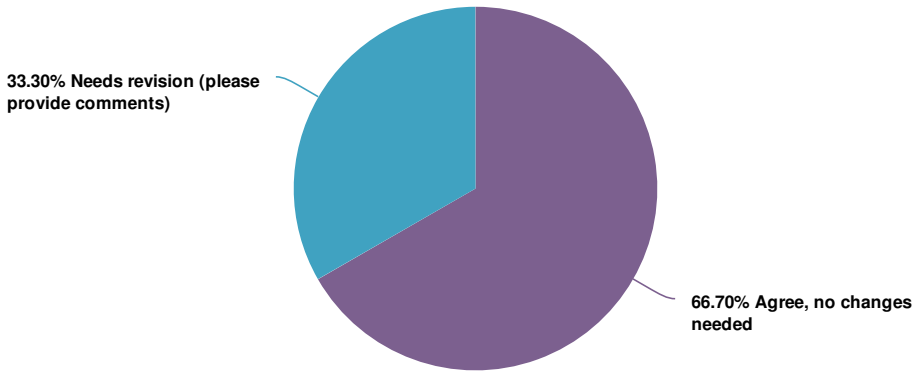
Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

61. To what extent do you agree with the following recommendation? Be aware that involuntary movements in adults that cannot be suppressed are more likely to need neurological assessment. - comments

Count	Response
1	Neuro assessment is largely to provide bottom line opinion that tic is almost always better tolerated than treated

62. To what extent do you agree with the following recommendation? Do not refer adults with involuntary movements of the eyelid that cannot be suppressed unless the movements are in both eyelids or have persisted for more than 3 months.



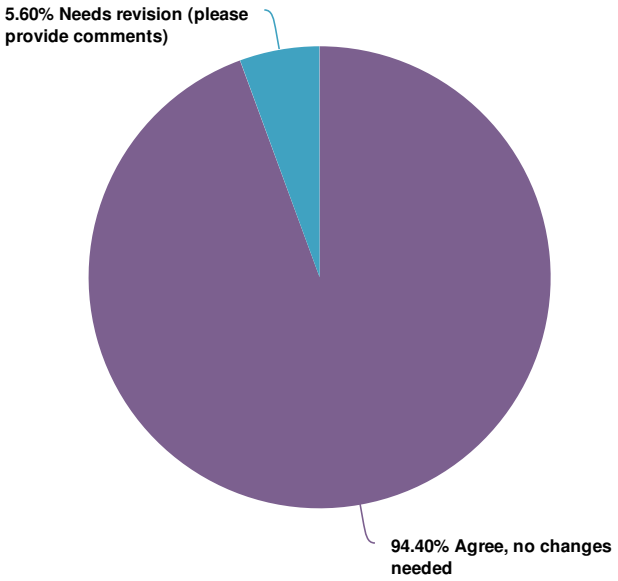
Value	Percent	Responses
Agree, no changes needed	66.7%	12
Needs revision (please provide comments)	33.3%	6

Total: 18

63. To what extent do you agree with the following recommendation? Do not refer adults with involuntary movements of the eyelid that cannot be suppressed unless the movements are in both eyelids or have persisted for more than 3 months. - comments

Count	Response
1	I wonder whether this should read 'Do not ROUTINELY refer ...'
1	I would add: "or unless there are other neurological or psychiatric symptoms" (for example movements of the eyelid together with behaviour changes or sleep difficulties or low mood or anxiety or cognitive disturbances or headaches could be the early signs of an autoimmune encephalitis)
1	Little more detail is required eg this is eyelid myokymia/blepharospasm unless atypical and give atypical features which need prompter referral
1	This statement inappropriately limits referral of hemifacial spasm (much commoner than blepharospasm)
1	Without changing meaning I would say something on lines of "...refer if symptoms have persisted for more than 3 months."
1	see below

64. To what extent do you agree with the following recommendation? Refer adults for neurological assessment if they have involuntary movements of the face, neck, limbs or trunk, or involuntary tight eye closure (blepharospasm) that cannot be suppressed.



Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

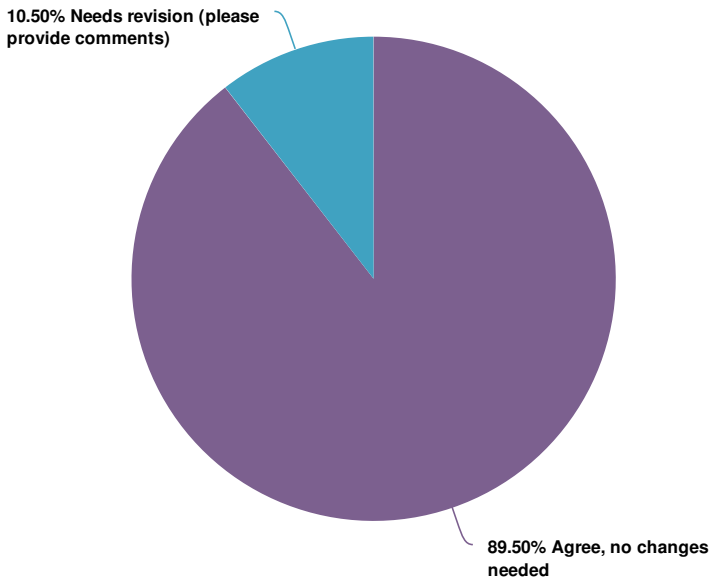
65. To what extent do you agree with the following recommendation? Refer adults for neurological assessment if they have involuntary movements of the face, neck, limbs or trunk, or involuntary tight eye closure (blepharospasm) that cannot be suppressed. - comments

Count	Response
1	I think 39 & 40 should be combined in one guidance to avoid confusion
1	add that blepharospasm is a bilateral symptom
1	perhaps the involuntary production of sounds-vocal ticks-could be added

66. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Please note that botilinum toxin injections for blepharospasm are often given by Ophthalmologists and not neurologists, but a referral to neurology for diagnostic purposes is appropriate.
1	What would be the recommendation if the involuntary movement is secondary to medication such as antipsychotics, and causing significant distress. Would a referral to neurologist still be advised?

67. To what extent do you agree with the following recommendation? Do not refer children with simple motor tics that are intermittent.



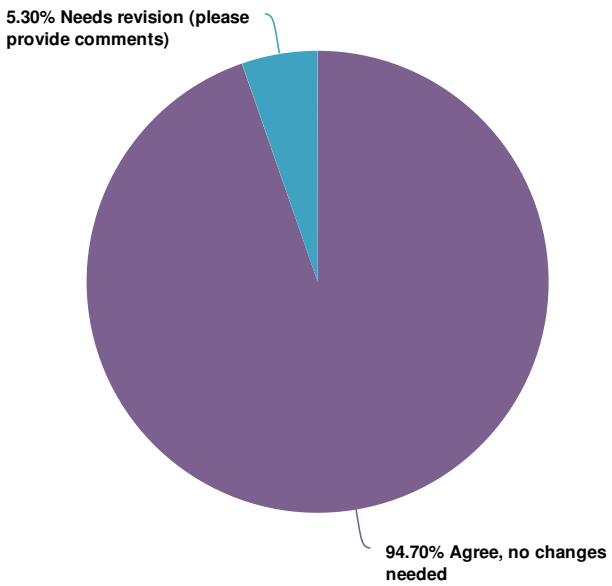
Value	Percent	Responses
Agree, no changes needed	89.5%	17
Needs revision (please provide comments)	10.5%	2

Total: 19

68. To what extent do you agree with the following recommendation? Do not refer children with simple motor tics that are intermittent. - comments

Count	Response
1	...and are not causing a problem in themselves
1	In the absence of other concerns or functional impact.

69. To what extent do you agree with the following recommendation? Advise parents or carers of children with a tic disorder to discuss the disorder with the child's school, emphasising that the tic is an involuntary movement and the child should not be reprimanded for it.



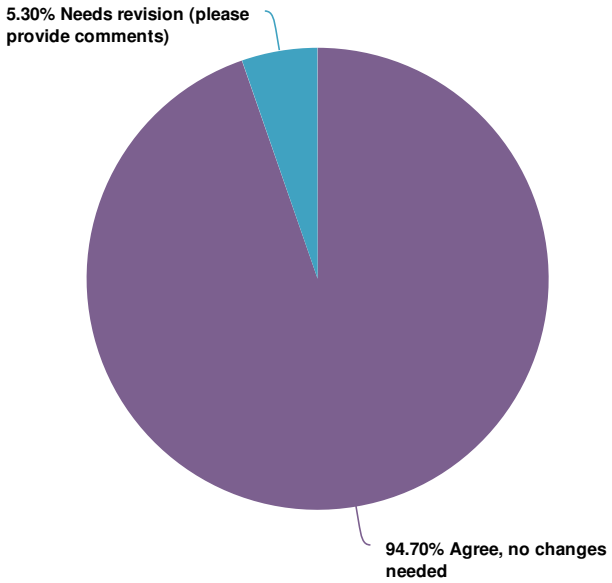
Value	Percent	Responses
Agree, no changes needed	94.7%	18
Needs revision (please provide comments)	5.3%	1

Total: 19

70. To what extent do you agree with the following recommendation? Advise parents or carers of children with a tic disorder to discuss the disorder with the child's school, emphasising that the tic is an involuntary movement and the child should not be reprimanded for it. - comments

Count	Response
1	Signpost to supporting information on tics? Royal college psych/NHS choices?
1	give advice (nhs choices, other)

71. To what extent do you agree with the following recommendation? Do not offer medication for simple motor tics in children without specialist referral and advice.



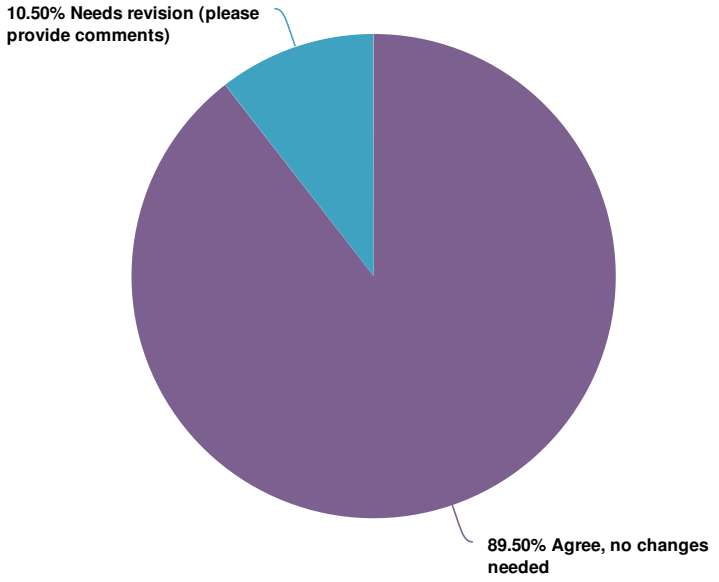
Value	Percent	Responses
Agree, no changes needed	94.7%	18
Needs revision (please provide comments)	5.3%	1

Total: 19

72. To what extent do you agree with the following recommendation? Do not offer medication for simple motor tics in children without specialist referral and advice. - comments

Count	Response
1	should this be more prescriptive. Do not offer medication. This requires specialist input.

73. To what extent do you agree with the following recommendation? Be aware that tics and stereotypies (repetitive or ritualistic movements such as body rocking) are more common in children with autism and an intellectual (learning) disability.



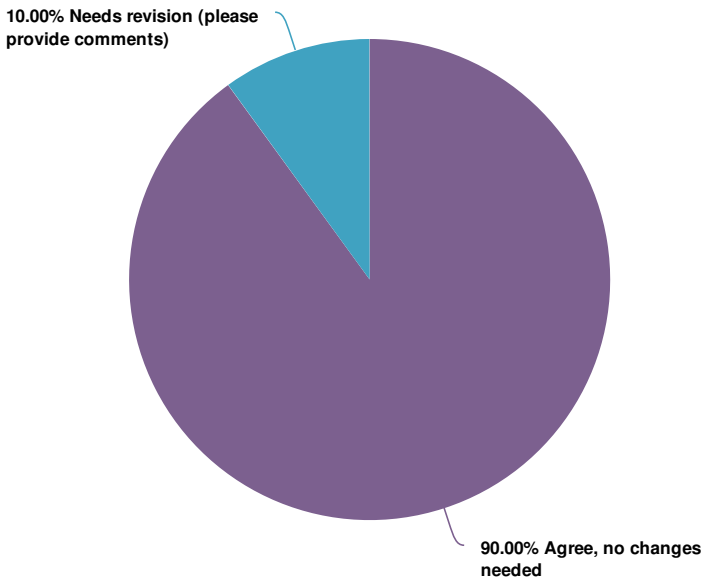
Value	Percent	Responses
Agree, no changes needed	89.5%	17
Needs revision (please provide comments)	10.5%	2

Total: 19

74. To what extent do you agree with the following recommendation? Be aware that tics and stereotypies (repetitive or ritualistic movements such as body rocking) are more common in children with autism and an intellectual (learning) disability. - comments

Count	Response
1	Tics and stereotypies can be associated with Autism and sometimes with a learning disability so children in whom these conditions are known or suspected should be referred to the Community paediatrician or ASD team in the child's locality
1	Tics are more predominant with anxiety/ ADHD/ OCD.

75. To what extent do you agree with the following recommendation? Refer children immediately for neurological assessment if they have sudden-onset chorea, ataxia, dystonia or other involuntary movements .



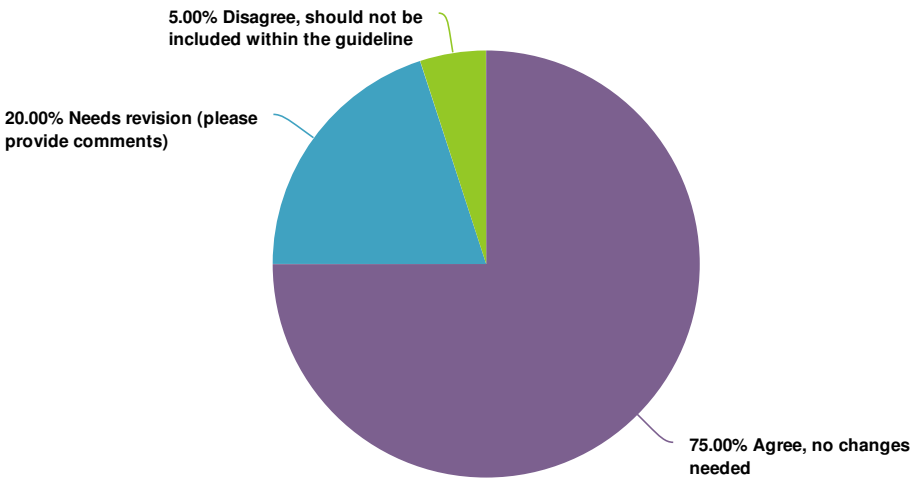
Value	Percent	Responses
Agree, no changes needed	90.0%	18
Needs revision (please provide comments)	10.0%	2

Total: 20

76. To what extent do you agree with the following recommendation? Refer children immediately for neurological assessment if they have sudden-onset chorea, ataxia, dystonia or other involuntary movements . - comments

Count	Response
1	after physical examination and history taking account of any emotional or behavioural aspects
1	but this could be through to general paediatricians initially with onward referral rather than direct to paediatric neurology
1	consider rheumatic fever if associated with temperature or rash

77. To what extent do you agree with the following recommendation? Consider referring children with a tic disorder for neurological assessment if they have any of the following: symptoms of another neurodevelopmental disorder such as autism attention and concentration difficulties an intellectual (learning) disability.



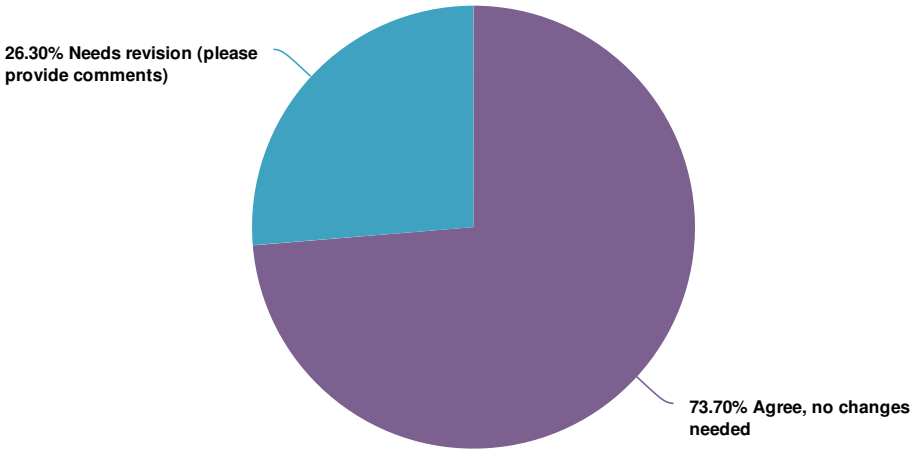
Value	Percent	Responses
Agree, no changes needed	75.0%	15
Needs revision (please provide comments)	20.0%	4
Disagree, should not be included within the guideline	5.0%	1

Total: 20

78. To what extent do you agree with the following recommendation? Consider referring children with a tic disorder for neurological assessment if they have any of the following: symptoms of another neurodevelopmental disorder such as autism attention and concentration difficulties an intellectual (learning) disability. - comments

Count	Response
1	Also if troublesome/ affecting education and self-esteem. Ofcourse seen in situations where the symptoms are far more persistent.
1	Consider also referral for appropriate multidisciplinary assessment such as educational psychology or Occupational Therapy if affecting activities of daily living
1	I would suggest initial referral pathway to Community paediatrics or multidisciplinary Autism Team established in some localities
1	i would probably state refer for review and neurodevelopmental assessment and then refere to nice gidance for recognition and referral for autism, adhd etc
1	refer to community paediatrician for that above conditions
1	should be managed by community paediatrician or neurodisability paediatrician notpaediatric neurologist, unless they have a special interest / clinic. But I am aware that pathways differ in different parts of the UK.

79. To what extent do you agree with the following recommendation? For children with a tic disorder associated with obsessive or compulsive behaviours that affect activities of daily living, refer for multidisciplinary assessment and onward referral to local services.



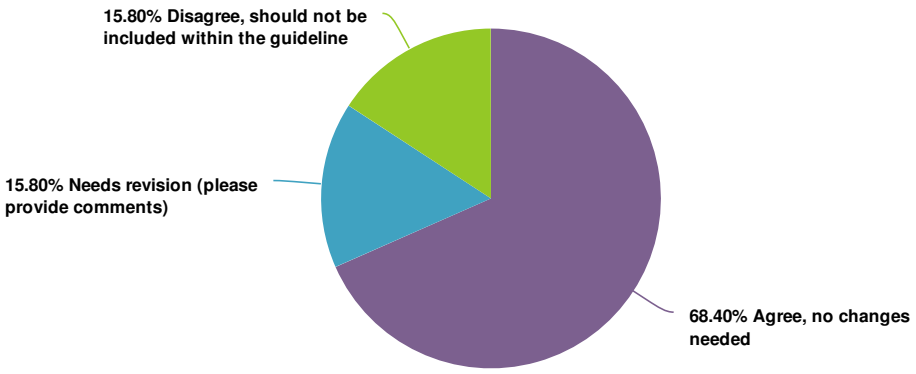
Value	Percent	Responses
Agree, no changes needed	73.7%	14
Needs revision (please provide comments)	26.3%	5

Total: 19

80. To what extent do you agree with the following recommendation? For children with a tic disorder associated with obsessive or compulsive behaviours that affect activities of daily living, refer for multidisciplinary assessment and onward referral to local services. - comments

Count	Response
1	Explain "multidisciplinary assessment". Should include Community Paediatrician and CAMHS
1	I would say impair ADL rather than affect ADL
1	not clear what is meant by local services here
1	probably need to specific mental health or other services depending on local pathways
1	should we specify child mental health services specifically or services that can evaluate child mental health conditiuons perhaps?

81. To what extent do you agree with the following recommendation? Refer children with a tic disorder and symptoms of secondary anxiety to secondary care for onward referral to psychology services.



Value	Percent	Responses
Agree, no changes needed	68.4%	13
Needs revision (please provide comments)	15.8%	3
Disagree, should not be included within the guideline	15.8%	3
	Total: 19	

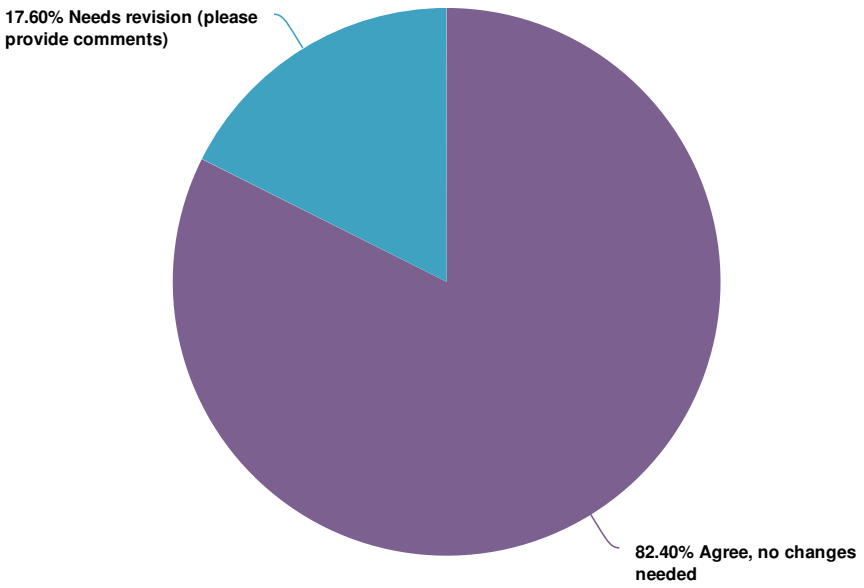
82. To what extent do you agree with the following recommendation? Refer children with a tic disorder and symptoms of secondary anxiety to secondary care for onward referral to psychology services. - comments

Count	Response
1	How do you distinguish "secondary anxiety" from anxiety causing or exacerbating tics eg in autistic spectrum disorders?
1	It is the anxiety, not the tic that indicates psychology services
1	May result in excessive numbers of referrals to psychology services, who are already struggling to cope in many areas!.
1	To psychology/psychiatry services as often these children are not seen nor offered any support (CBT etc)
1	i think incorporating this into point 28 above and/or refining some of the other points (22?) would cover this
1	incorporate into point 28

83. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Need to emphasise importance of multi-disciplinary and multi-agency (e.g. involving education) management in all these cases
1	Some questions out of scope

84. To what extent do you agree with the following recommendation? For recommendations on assessing sudden-onset limb or facial weakness in adults, see the NICE guideline on stroke and transient ischaemic attack in over 16s.



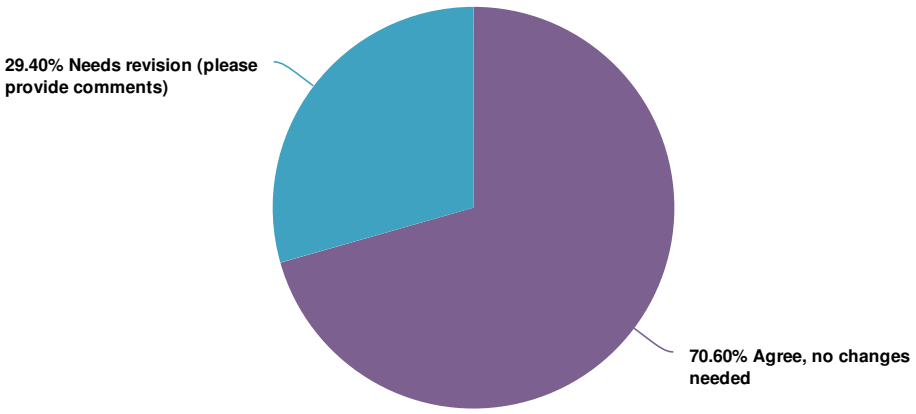
Value	Percent	Responses
Agree, no changes needed	82.4%	14
Needs revision (please provide comments)	17.6%	3

Total: 17

85. To what extent do you agree with the following recommendation? For recommendations on assessing sudden-onset limb or facial weakness in adults, see the NICE guideline on stroke and transient ischaemic attack in over 16s. - comments

Count	Response
1	If the "stroke" or TIA occurs during or after a medical procedure, including a peripheral cannula (which might have been open to air), the possibility of air embolism should be considered. URGENT IMAGING is required when air embolism is suspected, bearing in mind that air bubbles can disappear quickly. If confirmed, urgent referral for hyperbaric oxygen therapy in a suitable unit is required.
1	It is appropriate the two are sited together as significant numbers with progressive weakness sent to stroke pathway. Key issue will relate to whether locality has access to urgent 2 week wait open access imaging. I am not sure this is currently universal
1	The concept of crescendo TIA needs to be explained and clarified. If there are 2 attacks of TIA, then the GP should not be basing the referral on TIA scores. It is high risk and needs mediate referral.
1	True, but I wonder whether it might be worth adding some wording such as "It should be noted even restricted distribution weakness, such as isolated hand weakness, when of sudden onset may be due to stroke or TIA"; the justification for including such wording is that, anecdotally, this is sometimes poorly understood and can lead to isolated hand weakness being referred non-urgently (eg suspected compression neuropathy etc)

86. To what extent do you agree with the following recommendation? Do not refer adults with an isolated episode of unilateral lower motor neurone facial nerve (Bell's) palsy.



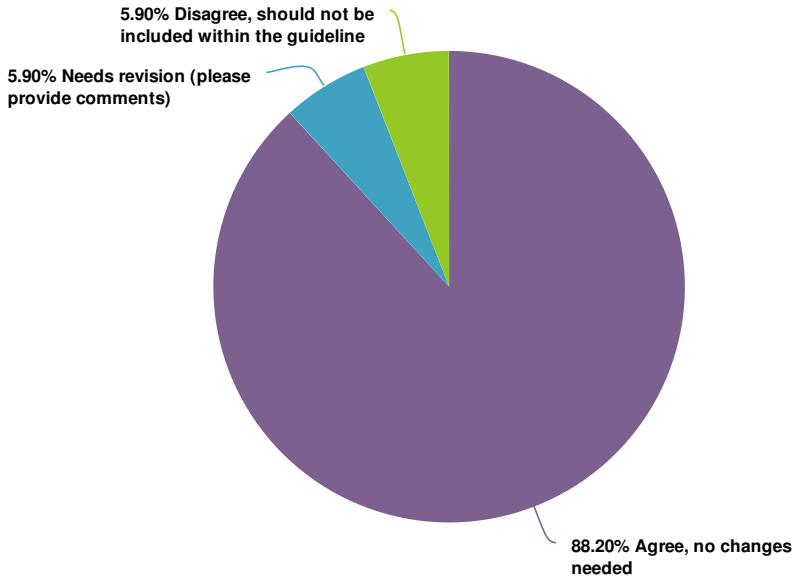
Value	Percent	Responses
Agree, no changes needed	70.6%	12
Needs revision (please provide comments)	29.4%	5

Total: 17

87. To what extent do you agree with the following recommendation? Do not refer adults with an isolated episode of unilateral lower motor neurone facial nerve (Bell's) palsy. - comments

Count	Response
1	Consider adding in recommending a time frame for referral if symptoms do not resolve despite steroid treatment.
1	I think that this can be a difficult area for many GPs and I suspect referral may often be appropriate
1	It would be helpful to clarify guidance on prescribing high dose steroids in primary care - or add a link. Also suggest advice on eye care if not to be referred (or refer to ophthalmology if needed).
1	May need qualifications here eg. there are other symptoms such as joint pain, other sensory symptoms etc. - then needs referral, if no other symptoms and no sig past medical history then does not need referral
1	consider more specific guidance on steroid dose for primary care/A&E and specific comments on eye care and risk of infection due to impaired blink
1	very useful to include to reduce hospital referral. Linked evidence and specific dose guidance and important note of advice for alert to risk of secondary eye infection secondary to corneal exposure will aid primary care

88. To what extent do you agree with the following recommendation? Refer adults with rapidly (within hours to days) progressive weakness of a single limb or hemiparesis for urgent neuroimaging, in line with the recommendation on brain and central nervous system cancers in adults in the NICE guideline on suspected cancer.



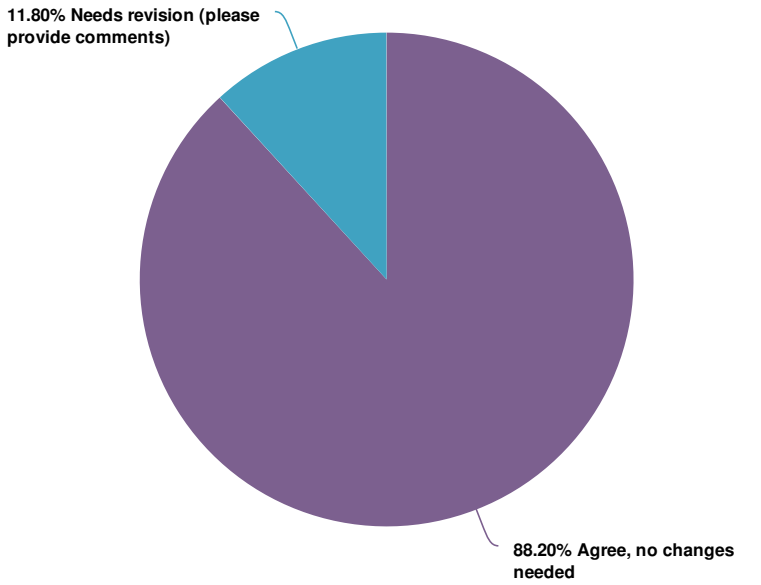
Value	Percent	Responses
Agree, no changes needed	88.2%	15
Needs revision (please provide comments)	5.9%	1
Disagree, should not be included within the guideline	5.9%	1

Total: 17

89. To what extent do you agree with the following recommendation? Refer adults with rapidly (within hours to days) progressive weakness of a single limb or hemiparesis for urgent neuroimaging, in line with the recommendation on brain and central nervous system cancers in adults in the NICE guideline on suspected cancer. - comments

Count	Response
1	Becomes confusing - if rapid then needs to go down stroke/TIA pathway. Neuroimaging may not be available to primary care. If suspected cancer then should go down 2 week cancer wait pathway
1	Progression over hours is not expected for a tumour. Progression over weeks however is.
1	Some DGHs do not currently have this in place/ is the assumption that this will happen once guidance issued?
1	need to clarify if all areas have access to imaging for this purpose as uncertain in practice at local DGH that this happens

90. To what extent do you agree with the following recommendation? Refer adults with rapidly progressive (within days - up to four weeks) symmetrical limb weakness for immediate neurological assessment and assessment for bulbar and respiratory dysfunction.



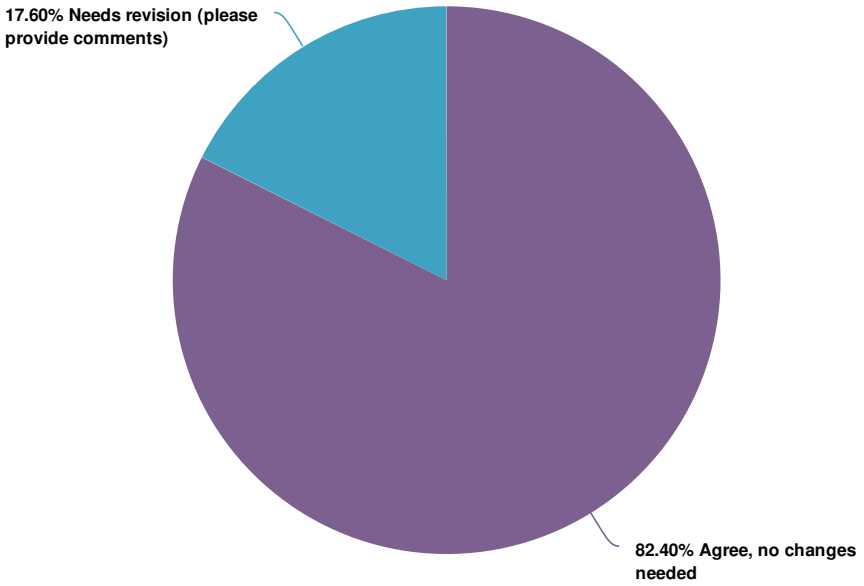
Value	Percent	Responses
Agree, no changes needed	88.2%	15
Needs revision (please provide comments)	11.8%	2

Total: 17

91. To what extent do you agree with the following recommendation? Refer adults with rapidly progressive (within days - up to four weeks) symmetrical limb weakness for immediate neurological assessment and assessment for bulbar and respiratory dysfunction. - comments

Count	Response
1	Guillain-Barre: the final e should have an acute accent
1	I agree immediate assessment is required, but an assessment by a neurologist on the same day isn't realistic. Perhaps "immediate hospital assessment" ?

92. To what extent do you agree with the following recommendation? Refer adults with slowly (within weeks to months) progressive limb weakness for neurological assessment.



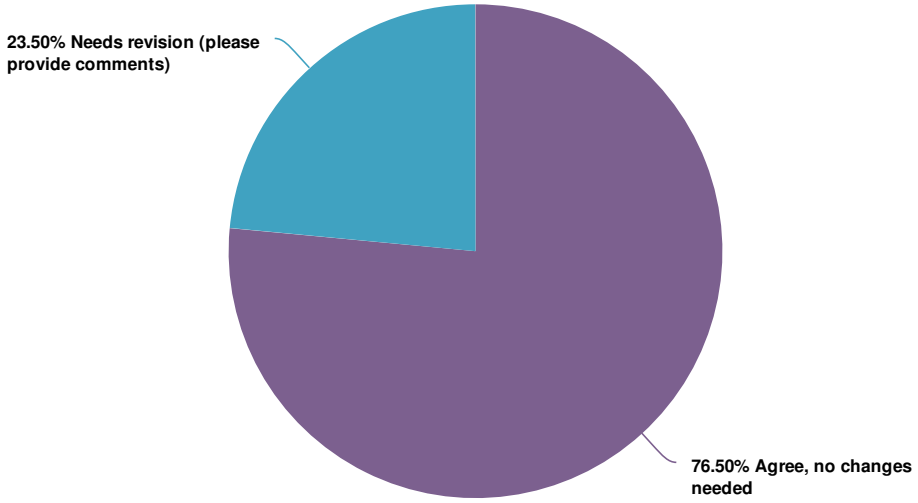
Value	Percent	Responses
Agree, no changes needed	82.4%	14
Needs revision (please provide comments)	17.6%	3

Total: 17

93. To what extent do you agree with the following recommendation? Refer adults with slowly (within weeks to months) progressive limb weakness for neurological assessment. - comments

Count	Response
1	As discussed above, progression over weeks would justify an urgent referral (for either imaging or neurological opinion, depending on the circumstances)
1	for 'Routine' referral
1	useful that the guidance separates acute/sudden onset and progressive to help referral to correct service
1	“Appropriate haematological investigations for causes of myopathy should be conducted before referral.” Perhaps better worded as “Appropriate blood tests for causes of myopathy should be conducted before referral” (rather than 'haematological investigations'): depending on interpretation, ‘haematological’ might exclude ‘biochemical’ etc.

94. To what extent do you agree with the following recommendation? For adults with symptoms of compression neuropathy of the radial nerve, common peroneal nerve or ulnar nerve: refer for a splint and review the symptoms after 6 weeks, and refer for neurological assessment if there is no evidence of improvement.



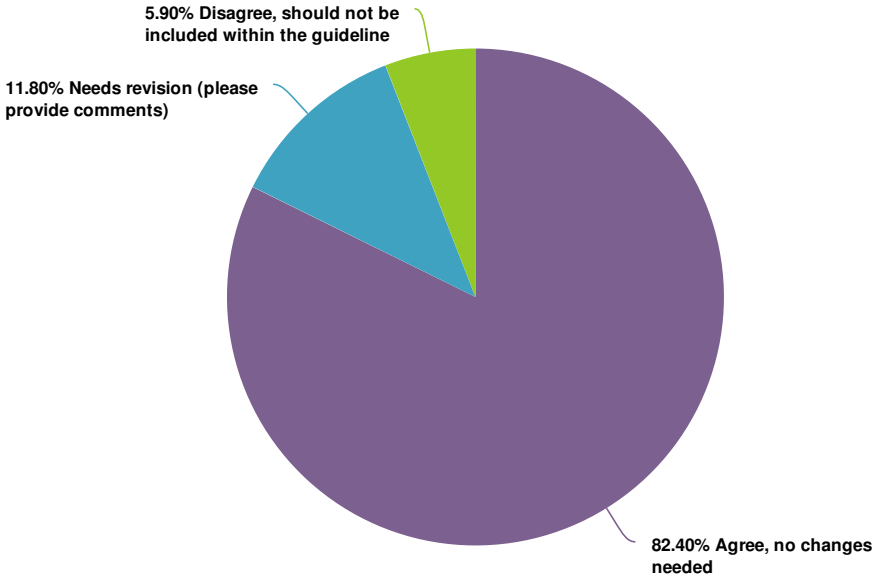
Value	Percent	Responses
Agree, no changes needed	76.5%	13
Needs revision (please provide comments)	23.5%	4

Total: 17

95. To what extent do you agree with the following recommendation? For adults with symptoms of compression neuropathy of the radial nerve, common peroneal nerve or ulnar nerve: refer for a splint and review the symptoms after 6 weeks, and refer for neurological assessment if there is no evidence of improvement. - comments

Count	Response
1	Advice must include not sleep in armchair (radial), not sit with legs crossed (CPN) lean on elbow (ulnar) . Splints of little if any value other than to palliate tripping in CPN
1	In practice referring for orthotics or even physio to fit the splint will fall outside of the 6 weeks. I appreciate this is when to refer neurology but the alternative options needs be realistic and available.
1	May need additional explanation of what symptom patterns are for each of above
1	muscle wasting is an indication for early referral
1	would there be any instance where surgical decompression would be warranted sooner e.g. if the patient presents already with muscle wasting or significantly affecting QOL, would a trial of 6 week splint delay surgery and affect outcome?

96. To what extent do you agree with the following recommendation? Advise adults with limb or facial weakness to avoid activities that predispose them to trauma to the affected nerve. For example, where linked to over-sedation due to excessive alcohol use.



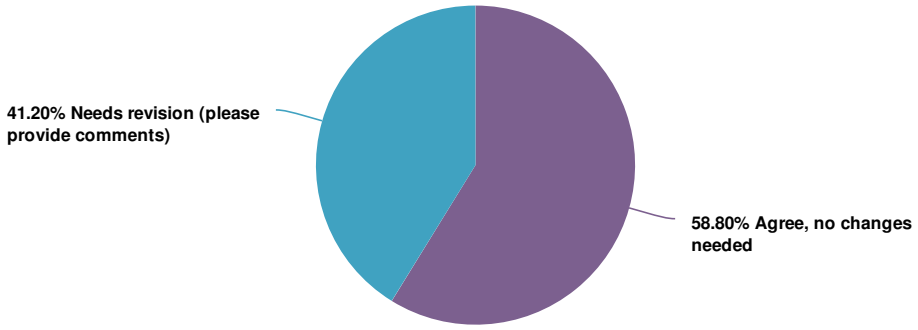
Value	Percent	Responses
Agree, no changes needed	82.4%	14
Needs revision (please provide comments)	11.8%	2
Disagree, should not be included within the guideline	5.9%	1

Total: 17

97. To what extent do you agree with the following recommendation? Advise adults with limb or facial weakness to avoid activities that predispose them to trauma to the affected nerve. For example, where linked to over-sedation due to excessive alcohol use. - comments

Count	Response
1	Not sure about the example given
1	Not sure what this is addressing? Don't think that it will be a helpful recommendation. Maybe ulnar nerve irritation might be relevant
1	Surely excessive EtOH use should be addressed even in the absence of these symptoms? And does it really cause facial weakness

98. To what extent do you agree with the following recommendation? Be aware that recurrent limb weakness in adults may be part of a functional neurological disorder and may not need referral, particularly in people with a previous diagnosis of functional disorder, no neurological signs and normal neuroimaging within the past 6 months.



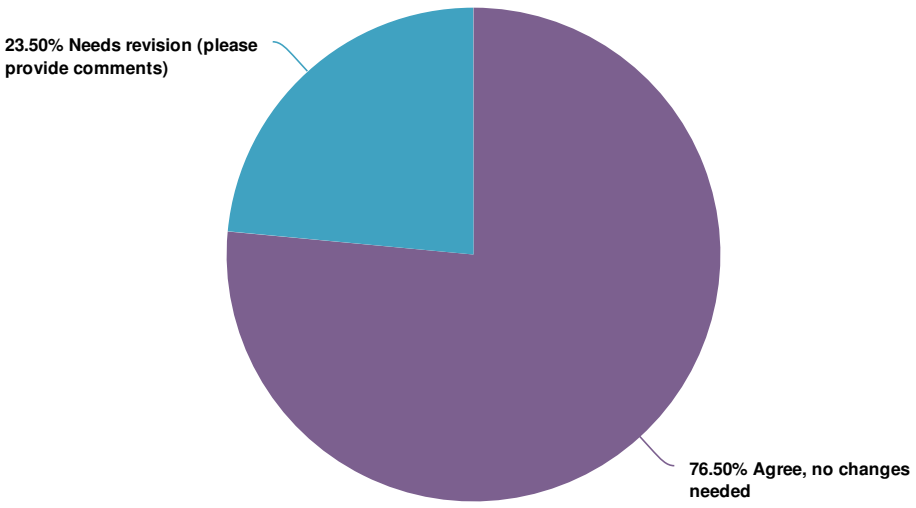
Value	Percent	Responses
Agree, no changes needed	58.8%	10
Needs revision (please provide comments)	41.2%	7

Total: 17

99. To what extent do you agree with the following recommendation? Be aware that recurrent limb weakness in adults may be part of a functional neurological disorder and may not need referral, particularly in people with a previous diagnosis of functional disorder, no neurological signs and normal neuroimaging within the past 6 months. - comments

Count	Response
1	Consider referral if the presentation changes.
1	Difficult - I would remove part of people with previous diagnosis of functional disorder and emphasise that weakness patient describes may not be explainable anatomically
1	Emphasise importance of neuro exam particularly Hoover's sign
1	Fully support guidance on functional symptoms. Primary care may be aided by advice on use of www.neurosymptoms.org web site or other web tool for patient information
1	consider additional link to web resource eg www.neurosymptoms.org
1	typo in rationale - "me" = "be"? Although symptoms of corticobasal degeneration are not those described above, it is difficult for generalists to diagnose. Most patients have had a difficult course over several years of being given various diagnoses (often functional) before being seen in a movement disorder clinic. Pain can be a prominent feature. Should any reference be made to features that might raise concern?
1	"....psychological support would often me more appropriate than a neurological services re-investigation": shoud be 'be' rather than 'me'

100. To what extent do you agree with the following recommendation? Advise adults with limb or facial weakness and a suspected functional neurological disorder that the limb or facial weakness will fluctuate and evolve over time and may increase at times of stress. Reassure them that this should not cause concern.



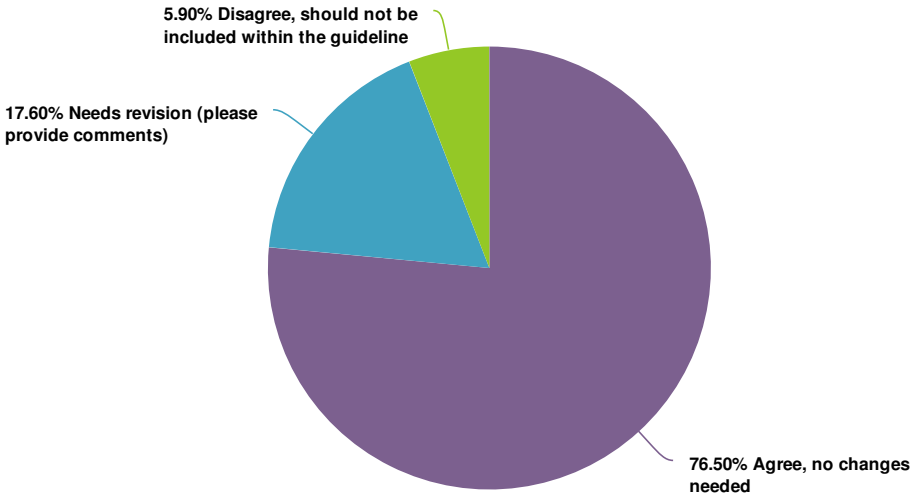
Value	Percent	Responses
Agree, no changes needed	76.5%	13
Needs revision (please provide comments)	23.5%	4

Total: 17

101. To what extent do you agree with the following recommendation? Advise adults with limb or facial weakness and a suspected functional neurological disorder that the limb or facial weakness will fluctuate and evolve over time and may increase at times of stress. Reassure them that this should not cause concern. - comments

Count	Response
1	As above, important to have guidance on functional neurological symptoms and ths may be further helped by guidance from web tool such as www.neurosymptoms.org
1	I think this is bland and patronising. Better to acknowledge that this really does cause concern, but does not increase risk of serious cause. All symptoms whether functional or organic tend to be worsened by stress.
1	The rationale doesnt make sense: The committee felt it was important for non-specialists to advise people with suspected functional disorders about the nature of their condition, as this might cause them unnecessary concern.- surely you mean the opposite?!
1	consider additional link to web resource eg www.neurosymptoms.org
1	“The committee felt it was important for non-specialists to advise people with suspected functional disorders about the nature of their condition, as this might cause them unnecessary concern.” The wording of this sentence needs clarifying; currently the wording could be taken to mean that the advice about the nature of their condition might cause them unnecessary concern; I think the intended meaning is that nature of their condition might cause them unnecessary concern

102. To what extent do you agree with the following recommendation? Refer adults who have bilateral leg weakness for urgent specialist review and imaging to exclude cauda equina syndrome if they also have severe low back pain, bilateral sciatica, sphincter disturbance or saddle anaesthesia.



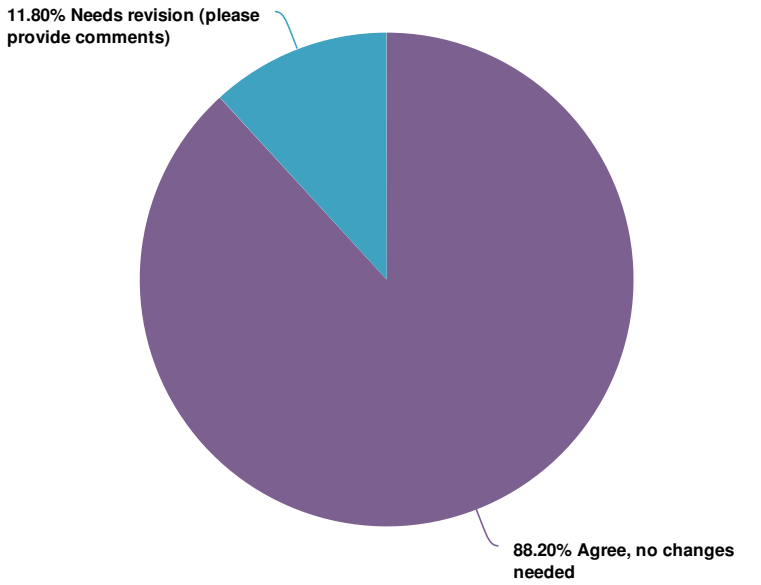
Value	Percent	Responses
Agree, no changes needed	76.5%	13
Needs revision (please provide comments)	17.6%	3
Disagree, should not be included within the guideline	5.9%	1

Total: 17

103. To what extent do you agree with the following recommendation? Refer adults who have bilateral leg weakness for urgent specialist review and imaging to exclude cauda equina syndrome if they also have severe low back pain, bilateral sciatica, sphincter disturbance or saddle anaesthesia. - comments

Count	Response
1	Cauda equina syndrome is an emergency requiring immediate attention. It is a condition that may require surgical decompression. In this scenario, an urgent MRI needs arranging, usually from an acute hospital setting. "urgent specialist review" might be misleading. If this means 2 weeks to see a neurologist or a neurosurgeon, it is inappropriate (sphincter disturbance probably will not be reversible at that point!).
1	Perhaps an additional comment is needed here regarding urgency/timelines - ie that imaging for suspected cauda equina syndrome should be 'same day' to ensure surgical decompression, where appropriate, is undertaken on an emergency basis
1	Saddle anaesthesia requires explanation. Neuro exam needs at least a mention!
1	suggest immediate review if there is sphincter disturbance particularly

104. To what extent do you agree with the following recommendation? Be aware that lower limb claudicating symptoms in adults with adequate peripheral circulation may be caused by lumbar canal stenosis and may need specialist assessment and imaging.



Value	Percent	Responses
Agree, no changes needed	88.2%	15
Needs revision (please provide comments)	11.8%	2

Total: 17

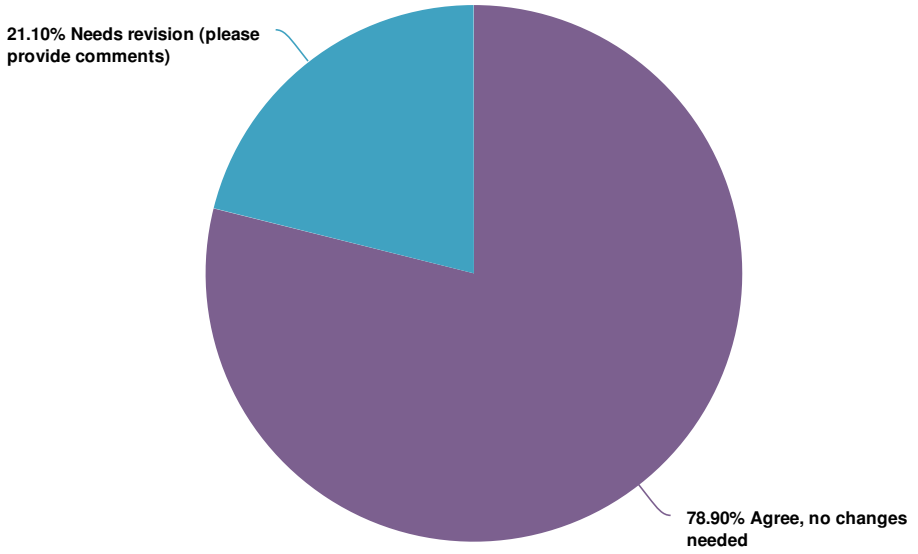
105. To what extent do you agree with the following recommendation? Be aware that lower limb claudicating symptoms in adults with adequate peripheral circulation may be caused by lumbar canal stenosis and may need specialist assessment and imaging. - comments

Count	Response
1	non-urgent
1	set a standardised method of assessing 'adequate peripheral circulation' e.g. ABPI in primary care + peripheral pulse examination

106. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Emphasise critical importance of neuro exam. Key point: in symptomatic patient, normal examination diminishes urgency or need for referral

107. To what extent do you agree with the following recommendation?Refer children immediately for neurological assessment if they present with sudden-onset facial or limb weakness.



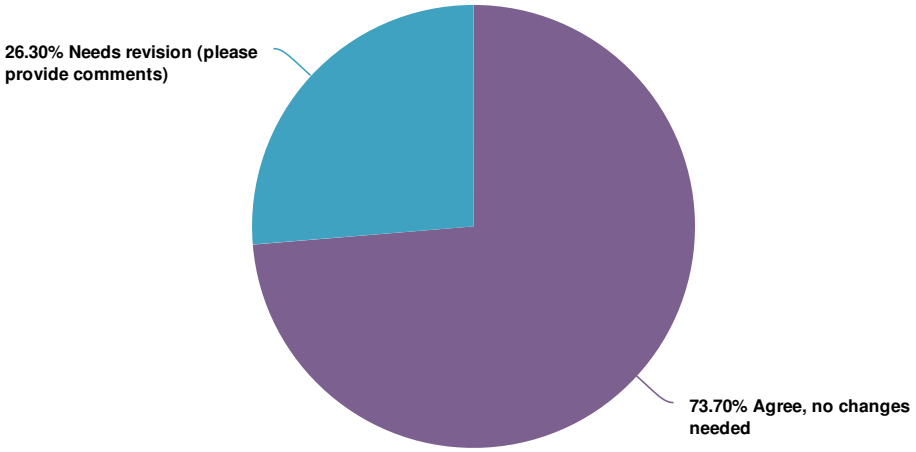
Value	Percent	Responses
Agree, no changes needed	78.9%	15
Needs revision (please provide comments)	21.1%	4

Total: 19

108. To what extent do you agree with the following recommendation?Refer children immediately for neurological assessment if they present with sudden-onset facial or limb weakness. - comments

Count	Response
1	'May or may not need steroids'- clarify if GP OK to prescribe or only after specialist referral?
1	Caveat needed regarding history or suspicion of injury/trauma- and referral for "neurological assessment", not neccesarily to neurologist
1	should we say paediatric as might not neccesarily go straight to paed neurology
1	unless in the context of known epilepsy and transient post ictal paresis?

109. To what extent do you agree with the following recommendation?Refer children with progressive limb weakness immediately for neurological assessment, including tests for neuromuscular disorders.

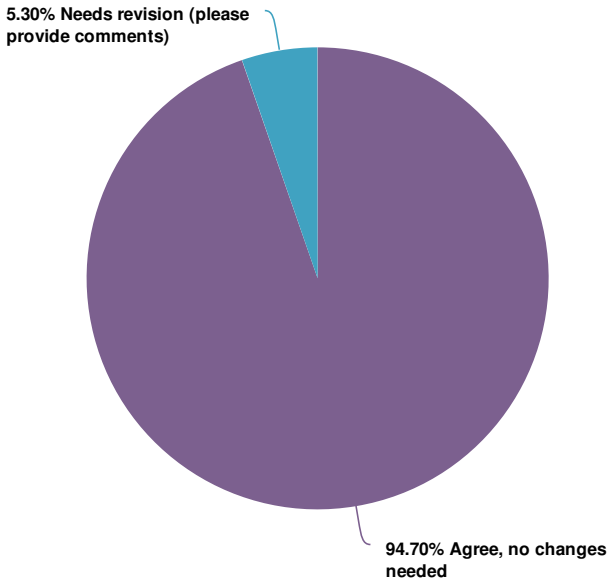


Value	Percent	Responses
Agree, no changes needed	73.7%	14
Needs revision (please provide comments)	26.3%	5
	Total: 19	

110. To what extent do you agree with the following recommendation?Refer children with progressive limb weakness immediately for neurological assessment, including tests for neuromuscular disorders. - comments

Count	Response
1	As per point 31 above
1	Depends on rate of progression. Immediately not required for a problem that has happened over weeks; probably immediately for a problem progressing over days
1	If symptoms are progressive rather than sudden "urgent" referral may be appropriate .
1	The Committee could consider a recommendation to consider a tandem referral into physiotherapy/occupational therapy services depending on presentation. This can avoid delays in accessing therapy and equipment in the presence of motor delay.
1	Thinking in terms of Guillain Barre, a good general paediatric set up should be able to consider this and do early necessary Ix given delay otherwise in being seen

111. To what extent do you agree with the following recommendation?For boys with limb weakness, see the recommendations on global and motor developmental delay in boys.* * these will be displayed in the Motor developmental delay section of this survey.



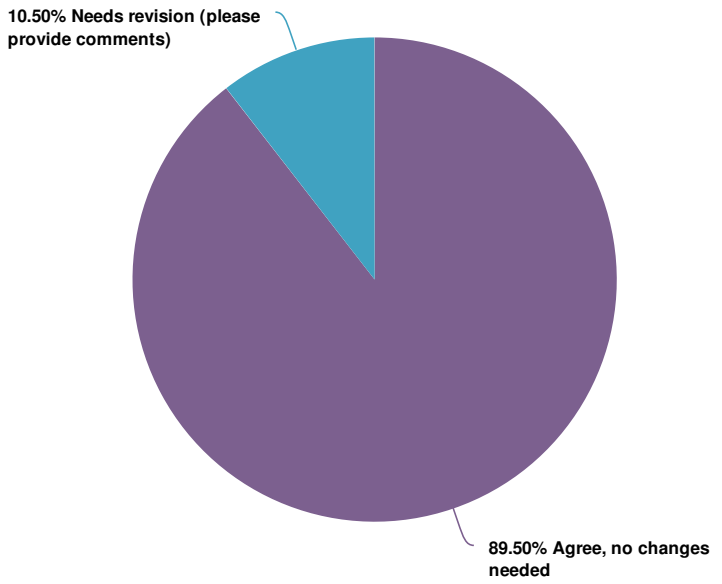
Value	Percent	Responses
Agree, no changes needed	94.7%	18
Needs revision (please provide comments)	5.3%	1

Total: 19

112. To what extent do you agree with the following recommendation?For boys with limb weakness, see the recommendations on global and motor developmental delay in boys.* * these will be displayed in the Motor developmental delay section of this survey. - comments

Count	Response
1	Should read "boys with generalised limb weakness"

113. To what extent do you agree with the following recommendation? Refer children who present with limb weakness as part of a developmental disorder to paediatric services, in line with the NICE guideline on cerebral palsy in under 25s.



Value	Percent	Responses
Agree, no changes needed	89.5%	17
Needs revision (please provide comments)	10.5%	2

Total: 19

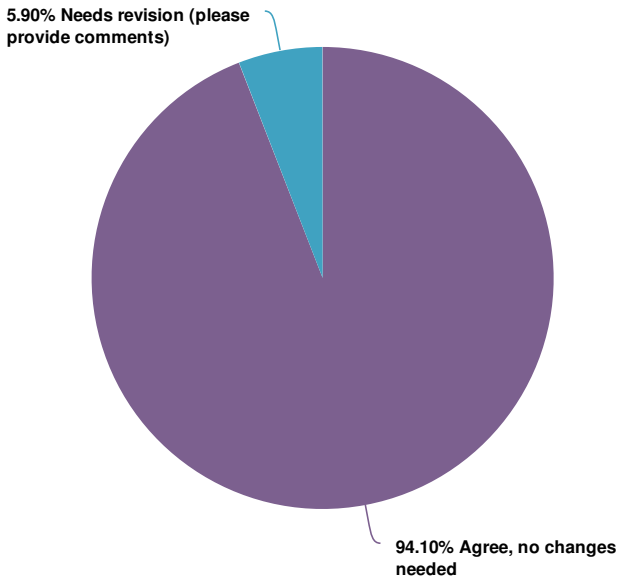
114. To what extent do you agree with the following recommendation? Refer children who present with limb weakness as part of a developmental disorder to paediatric services, in line with the NICE guideline on cerebral palsy in under 25s. - comments

Count	Response
1	? would it be helpful to include 'abnormalities of tone' in place of 'limb weakness'
1	Reword "Refer children who present with limb weakness as part of a developmental disorder to Community paediatric services and consider NICE guideline on cerebral palsy in under 25s"

115. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Early intervention from therapists (speech and language, occupational therapy and physiotherapy) is considered best practice therefore early referral to supporting community services should also be considered
1	Health visitor could complete an Ages and Stages Questionnaire, providing further information regarding the child's development. A global or specific motor delay becomes more obvious.
1	No
1	Some of the above services will vary depending on local services
1	might need to consider if this includes guillain barre and myasthenic etc

116. To what extent do you agree with the following recommendation?Be aware that isolated loss of sense of smell or taste in adults is likely to have a rhinological cause.



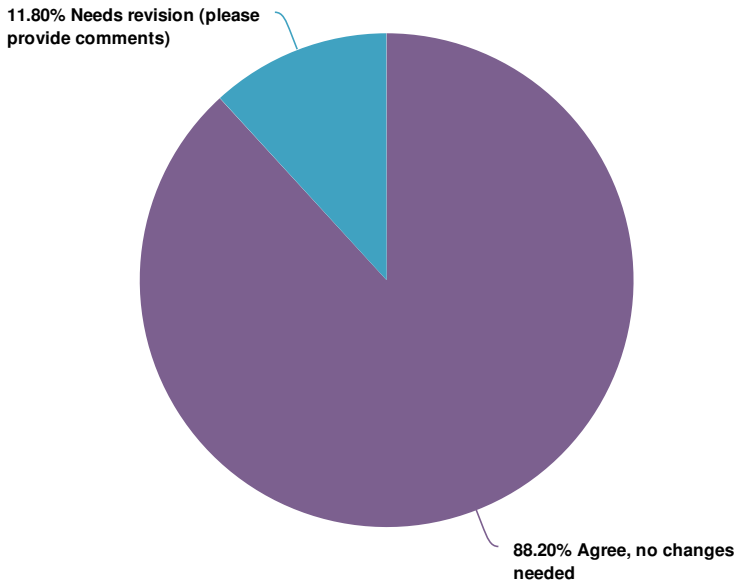
Value	Percent	Responses
Agree, no changes needed	94.1%	16
Needs revision (please provide comments)	5.9%	1

Total: 17

117. To what extent do you agree with the following recommendation?Be aware that isolated loss of sense of smell or taste in adults is likely to have a rhinological cause. - comments

Count	Response
1	Consider ... Be aware that isolated loss of sense of smell or taste in adults is likely to have a rhinological cause (although a central cause may exist).

118. To what extent do you agree with the following recommendation?Be aware that sudden-onset distortion of sense of smell or taste in adults is rarely associated with structural neurological abnormality and usually resolves within a few months.



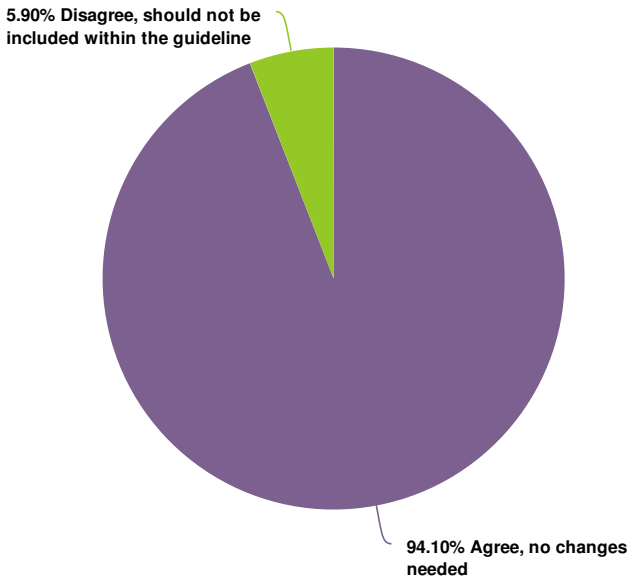
Value	Percent	Responses
Agree, no changes needed	88.2%	15
Needs revision (please provide comments)	11.8%	2

Total: 17

119. To what extent do you agree with the following recommendation?Be aware that sudden-onset distortion of sense of smell or taste in adults is rarely associated with structural neurological abnormality and usually resolves within a few months. - comments

Count	Response
1	In 30 years of practice (>28,000 recorded cases in 22 years) I have encountered only 2 cases of anosmia caused by structural lesion (meningioma) of which the population risk is about 1%
1	May still need imaging/ENT review
1	Specify in the absence of other focal neurology

120. To what extent do you agree with the following recommendation?Do not refer adults who have lost their sense of smell or taste immediately after a head injury.



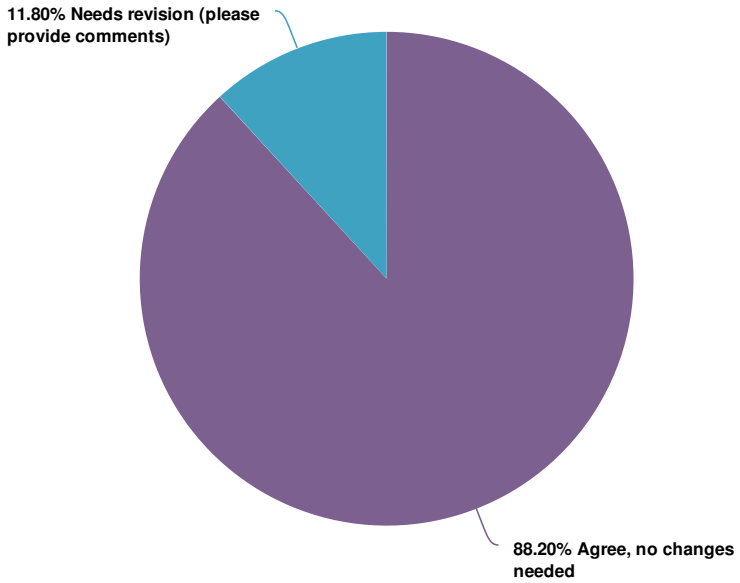
Value	Percent	Responses
Agree, no changes needed	94.1%	16
Disagree, should not be included within the guideline	5.9%	1

Total: 17

121. To what extent do you agree with the following recommendation?Do not refer adults who have lost their sense of smell or taste immediately after a head injury. - comments

Count	Response
1	This could reflect an otherwise unidentified frontal fracture

122. To what extent do you agree with the following recommendation?Refer adults with transient, repetitive taste or smell hallucinations for neurological assessment.



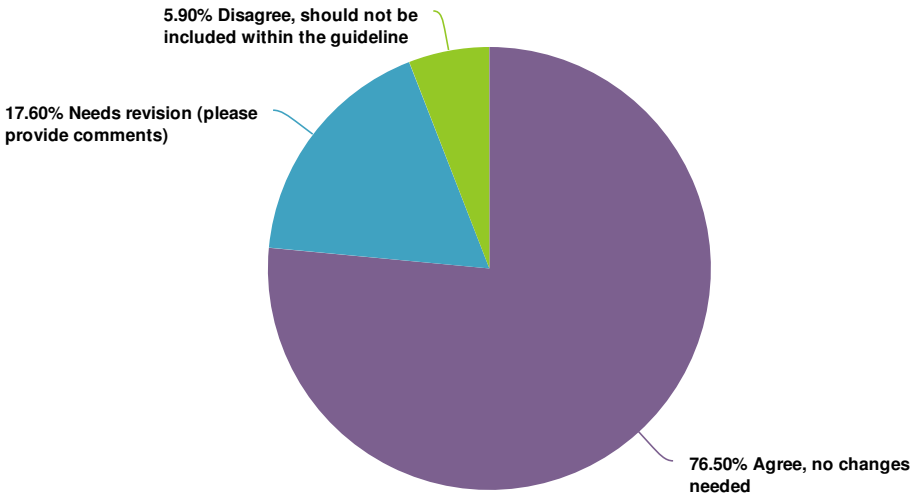
Value	Percent	Responses
Agree, no changes needed	88.2%	15
Needs revision (please provide comments)	11.8%	2

Total: 17

123. To what extent do you agree with the following recommendation?Refer adults with transient, repetitive taste or smell hallucinations for neurological assessment. - comments

Count	Response
1	If new onset then needs to be urgent referral
1	It is exceptional to find a serious cause. The key agenda is partial seizure for which the diagnosis requires a witness account

124. To what extent do you agree with the following recommendation?Consider neuroimaging for adults with persistent unexplained loss of sense of smell or taste, in line with the recommendation on brain and central nervous system cancers in adults in the NICE guideline on suspected cancer.



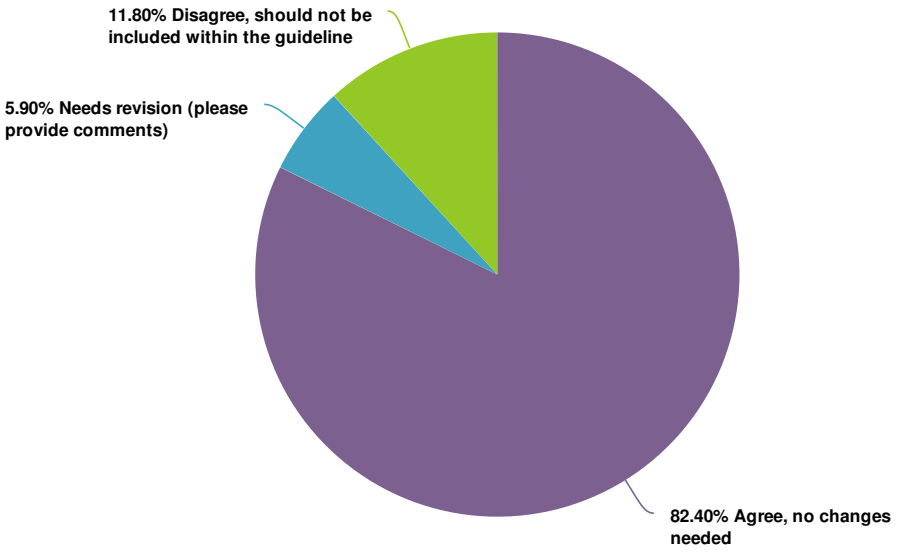
Value	Percent	Responses
Agree, no changes needed	76.5%	13
Needs revision (please provide comments)	17.6%	3
Disagree, should not be included within the guideline	5.9%	1

Total: 17

125. To what extent do you agree with the following recommendation?Consider neuroimaging for adults with persistent unexplained loss of sense of smell or taste, in line with the recommendation on brain and central nervous system cancers in adults in the NICE guideline on suspected cancer. - comments

Count	Response
1	A brain tumour would not normally present this way, unless it is an olfactory groove meningioma, which typically grow very slowly. My opinion is that a routine (not urgent) scan may be indicated (though they are usually normal in this scenario).
1	Depends on definition of "unexplained". I fear this recommendation will trigger much unnecessary imaging (as per 69 above)
1	Should the wording include progressive as well as persistent?
1	This contradicts item 69 above and could be rather confusing

126. To what extent do you agree with the following recommendation?Do not refer adults with loss of sense of smell or taste and normal neuroimaging.



Value	Percent	Responses
Agree, no changes needed	82.4%	14
Needs revision (please provide comments)	5.9%	1
Disagree, should not be included within the guideline	11.8%	2

Total: 17

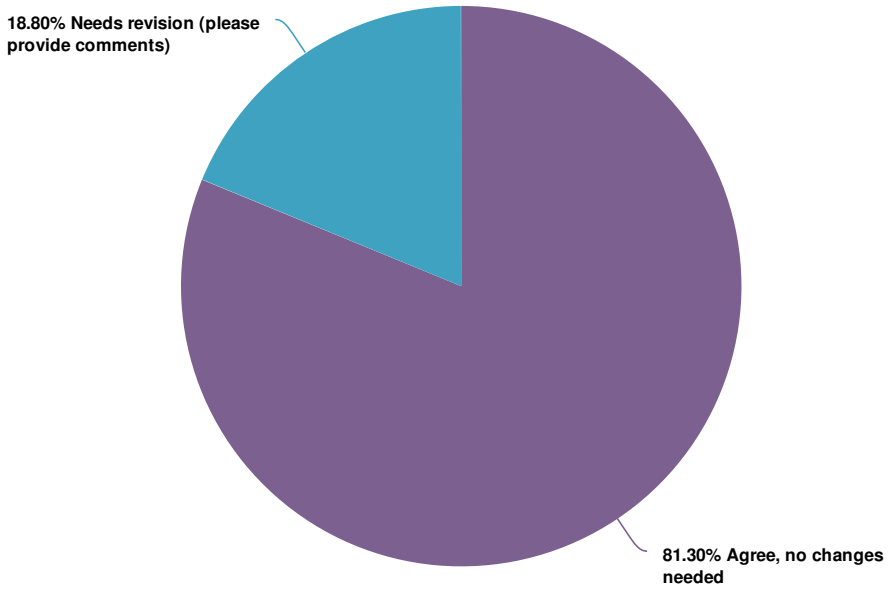
127. To what extent do you agree with the following recommendation?Do not refer adults with loss of sense of smell or taste and normal neuroimaging. - comments

Count	Response
1	Again we have suggestion of need for imaging
1	Not sure about this one. This symptom can reflect a neurodegenerative disorder

128. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Note idiopathis anosmia is very common. Also note that anosmia may be an early manifestation of neurodegenerative conditions such as parkinson's disease (a referral to neurology is not warranted on this basis, but GPs should be aware of this).
1	There is some confusion. On the one hand, this does not require referral. On the other hand, it can be caused by brain tumours. This could cause apprehension and confusion. Further detailed clarification is required here please
1	This is ENT not neuro matter

129. To what extent do you agree with the following recommendation?In adults with memory or concentration difficulties, look for anxiety or depression as an underlying cause.



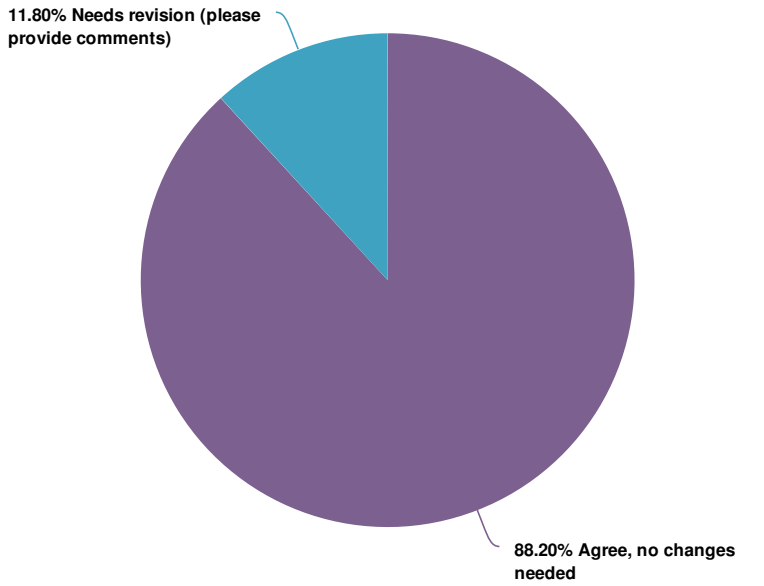
Value	Percent	Responses
Agree, no changes needed	81.3%	13
Needs revision (please provide comments)	18.8%	3

Total: 16

130. To what extent do you agree with the following recommendation?In adults with memory or concentration difficulties, look for anxiety or depression as an underlying cause. - comments

Count	Response
1	Consider the possibility of carbon monoxide poisoning in the preceding 12 months as a cause. Such patients will have missed the window of opportunity to receive hyperbaric oxygen therapy and will require prolonged psycho-social support.
1	Look for anx/dep means perform objective test (HADS etc) NOT ask pt if anx/dep!
1	anxiety, depression, stress or burnout
1	consider rather than look

131. To what extent do you agree with the following recommendation?Do not refer adults who have concentration difficulties associated with chronic fatigue syndrome or fibromyalgia.



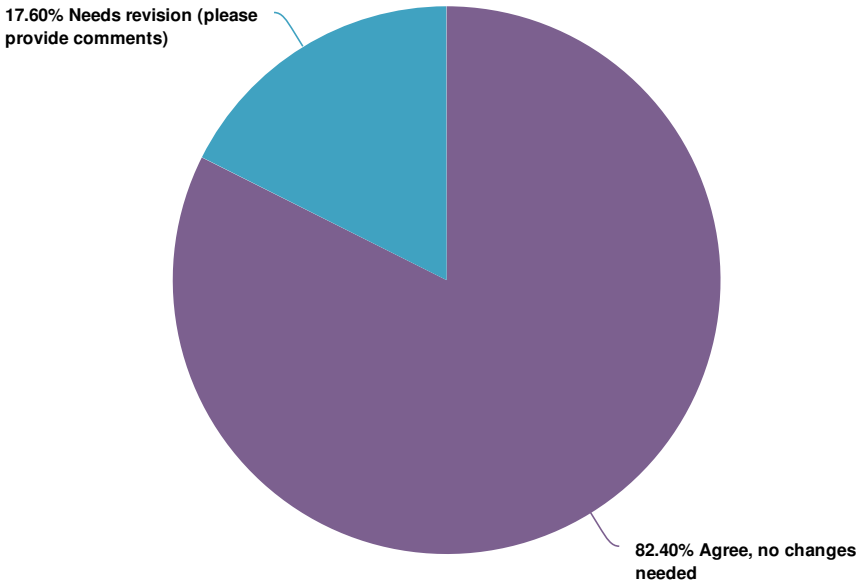
Value	Percent	Responses
Agree, no changes needed	88.2%	15
Needs revision (please provide comments)	11.8%	2

Total: 17

132. To what extent do you agree with the following recommendation?Do not refer adults who have concentration difficulties associated with chronic fatigue syndrome or fibromyalgia. - comments

Count	Response
1	Needs clarification. Sometimes people with other neurological illnesses (for example multiple sclerosis) maybe erroneously labelled as Chronic Fatigue syndrome. CFS should be a diagnosis of exclusion
1	No sure about this, could be a common underlying cause for both. Such patients might warrant assessment

133. To what extent do you agree with the following recommendation? Do not refer adults aged under 50 with memory problems if brief testing shows memory function to be normal and symptoms are consistent with concentration difficulties.



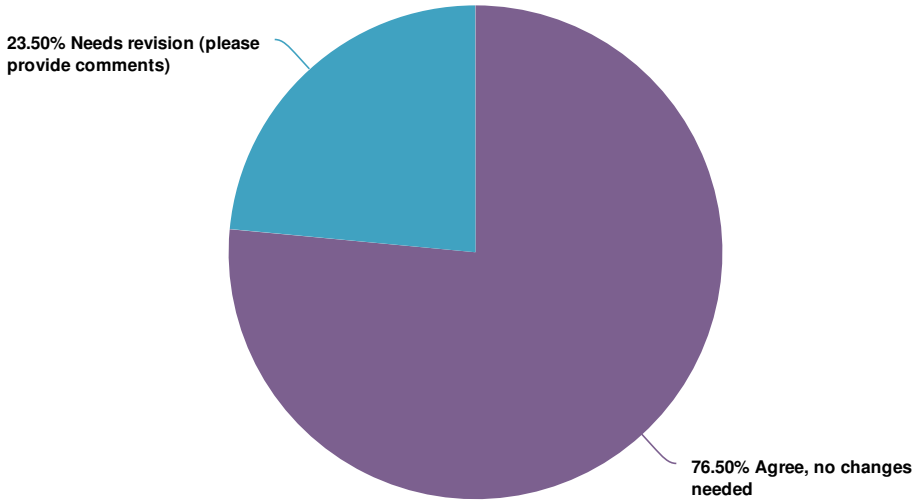
Value	Percent	Responses
Agree, no changes needed	82.4%	14
Needs revision (please provide comments)	17.6%	3

Total: 17

134. To what extent do you agree with the following recommendation? Do not refer adults aged under 50 with memory problems if brief testing shows memory function to be normal and symptoms are consistent with concentration difficulties. - comments

Count	Response
1	Be careful re atypical younger onset AD eg posterior atrophy and also frontotemporal dementias which will not show on testing memory function in primary care
1	With the increasing prevalence of veganism, I think certain blood tests like Vit B12, TFT needs to be considered even if the scales don't pick up deficits in any particular cognitive domains.
1	consider referral if concerns about significant behaviour change and memory from an independent observer voiced about the patient (as may reflect bvFTD and memory testing can be normal.

135. To what extent do you agree with the following recommendation?Do not refer adults with a single episode of dense amnesia (inability to recall the recent past or form new memories) if: the episode lasts less than 8 hours and there is complete recovery and there are no features suggestive of an epileptic seizure (see seizure markers for suspected epilepsy in the NICE guideline on transient loss of consciousness [‘blackouts’] in over 16s). Reassure the person that they have probably had an episode of transient global amnesia and the recurrence rate is low.



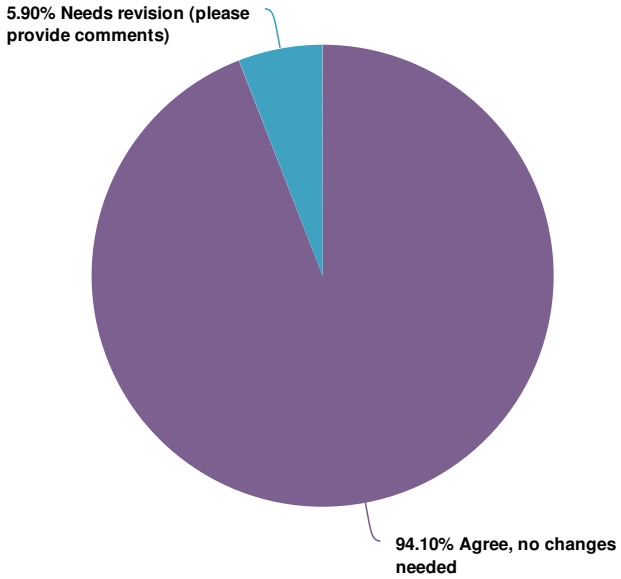
Value	Percent	Responses
Agree, no changes needed	76.5%	13
Needs revision (please provide comments)	23.5%	4

Total: 17

136. To what extent do you agree with the following recommendation?Do not refer adults with a single episode of dense amnesia (inability to recall the recent past or form new memories) if: the episode lasts less than 8 hours and there is complete recovery and there are no features suggestive of an epileptic seizure (see seizure markers for suspected epilepsy in the NICE guideline on transient loss of consciousness [‘blackouts’] in over 16s). Reassure the person that they have probably had an episode of transient global amnesia and the recurrence rate is low. - comments

Count	Response
1	I suspect this will be difficult to implement, requires confidence on the part of the GP, and many patients will require reassurance
1	In think this is very difficult in primary care and would not criticise referral of such cases
1	needs structural imaging and EEG
1	specify in the absence of focal neurology

137. To what extent do you agree with the following recommendation?Refer adults with recurrent episodes of dense amnesia to have an assessment for epileptic amnesia.



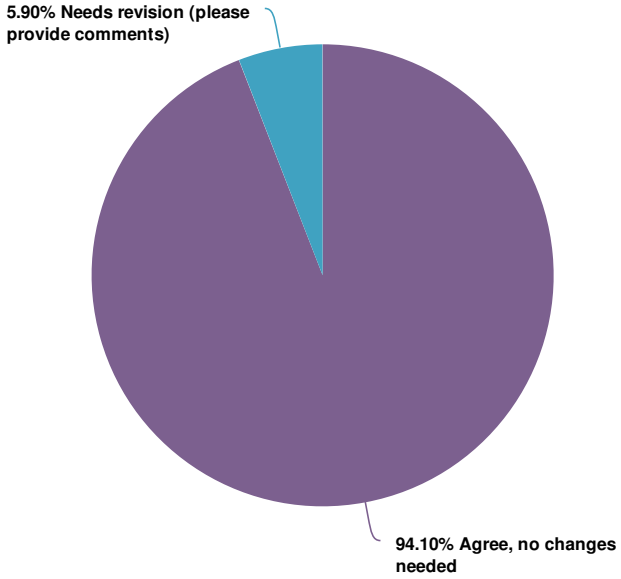
Value	Percent	Responses
Agree, no changes needed	94.1%	16
Needs revision (please provide comments)	5.9%	1

Total: 17

138. To what extent do you agree with the following recommendation?Refer adults with recurrent episodes of dense amnesia to have an assessment for epileptic amnesia. - comments

Count	Response
1	To non specialists this implies EEG & MRI whereas in fact a witness description is usually the key matter

139. To what extent do you agree with the following recommendation?Refer adults for specialist (neurological or memory clinic) assessment if they have progressive memory problems or progressive cognitive difficulties that affect several domains, such as language, numerical skills or sequencing of movements.



Value	Percent	Responses
Agree, no changes needed	94.1%	16
Needs revision (please provide comments)	5.9%	1

Total: 17

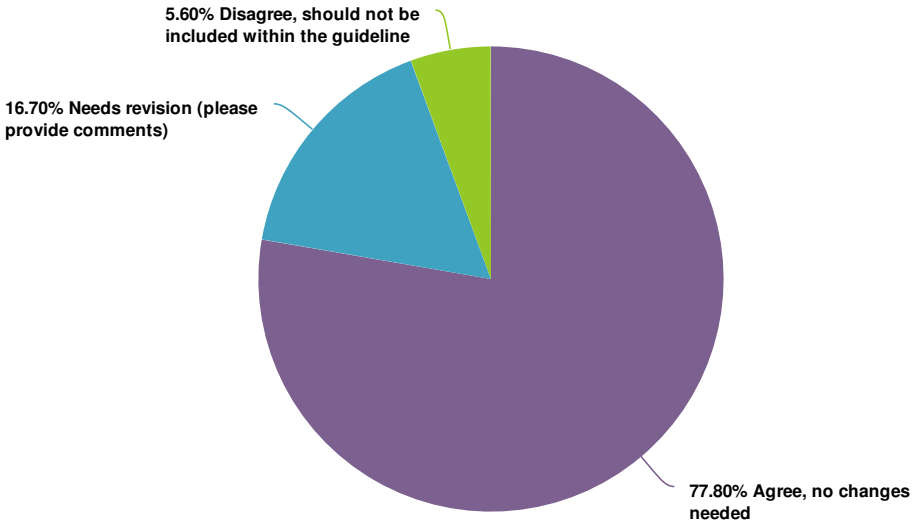
140. To what extent do you agree with the following recommendation?Refer adults for specialist (neurological or memory clinic) assessment if they have progressive memory problems or progressive cognitive difficulties that affect several domains, such as language, numerical skills or sequencing of movements. - comments

Count	Response
1	And ensure they attend the consultation with someone who knows them well and is ready to give a history
1	“Refer adults for specialist (neurological or memory clinic) assessment if they have progressive memory problems or progressive cognitive difficulties that affect several domains, such as language, numerical skills or sequencing of movements.” Need to be very careful here about the wording: it is unrealistic to suggest that neurology services can accommodate all such adults with this presentation. Perhaps ‘memory clinic’ should be the default, with the facility for younger onset cases to be considered for neurology referral?

141. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Independent reporter of symptoms of concern regarding cognition friend/family/ employer should consider referral
1	Q80. Is there any role for basic blood tests, and allowing time for correction (eg fixed low B12/folate or treating infection) before referral?
1	The main problem with memory referrals is the patient who attends alone. Essential to emphasise that if a person truly has memory difficulties then their history cannot be relied upon. So obvious, but so often overlooked.
1	This is more a general comment - I expect most generalists won't have encountered TGA and might feel under-confident. This might then make it hard to reassure the patient. In this situation, a phone call to a Neurology colleague can be really helpful.
1	no

142. To what extent do you agree with the following recommendation?Be aware that frequent unrecognised epileptic absence seizures may present as memory and concentration difficulties in children.



Value	Percent	Responses
Agree, no changes needed	77.8%	14
Needs revision (please provide comments)	16.7%	3
Disagree, should not be included within the guideline	5.6%	1

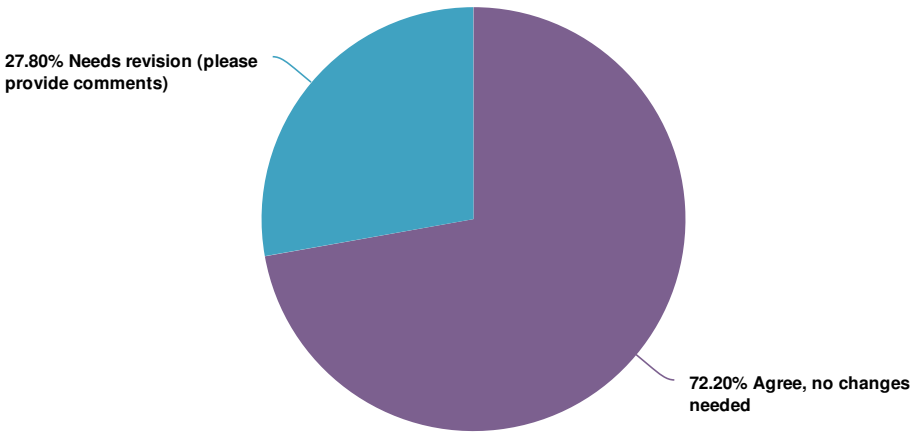
Total: 18

143. To what extent do you agree with the following recommendation?Be aware that frequent unrecognised epileptic absence seizures may present as memory and concentration difficulties in children. - comments

Count	Response
1	I don't like the wording - doesn't seem to me to recognised between cinical absence seizures (not recognised for what they are) and subclinical seizures
1	Note that it is more commonly not caused by absence epilepsy!
1	absence seizures does not need to be preceded by 'epileptic'
1	never seen or heard of absence epilepsies presenting like that, sorry

144. To what extent do you agree with the following recommendation?Refer children with concentration difficulties or memory failure for neurological assessment if epilepsy is

suspected.



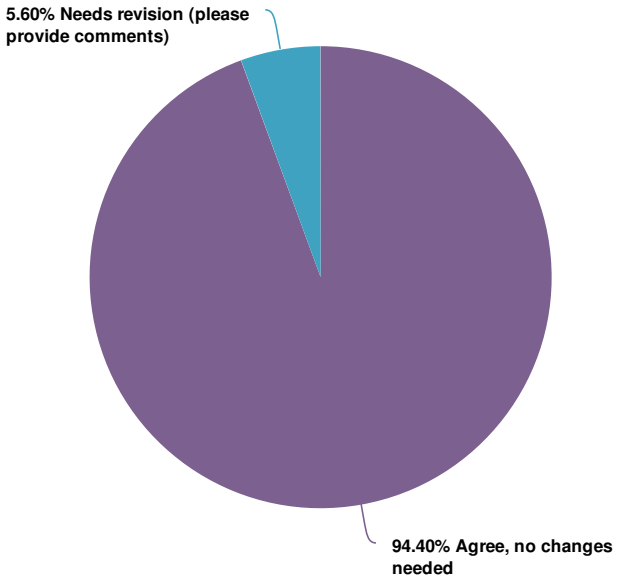
Value	Percent	Responses
Agree, no changes needed	72.2%	13
Needs revision (please provide comments)	27.8%	5

Total: 18

145. To what extent do you agree with the following recommendation?Refer children with concentration difficulties or memory failure for neurological assessment if epilepsy is suspected. - comments

Count	Response
1	Firstly the local team is better placed in clarifying what parents call 'memory failure' ie getting info from school, SENCO etc as often this is not substantiated and masks a child with learning difficulties who is struggling at school (one of the most common reasons for above)
1	Most general paediatricians do this well. In the NHS adult neurologists do not usually see children and paediatric neurologists are thin in the ground. SO referral should usually be to a paediatrician.
1	need to be a little more specific "such as mid activity vacant spells"
1	should the last bit be omitted - not clear what criteria are being recommended as suggestive of epilepsy
1	specific such as mid activity vacant spells

146. To what extent do you agree with the following recommendation?Refer children with concentration and memory difficulties that interfere with learning, school progress or behaviour to community paediatric or paediatric neurodevelopmental services for assessment.



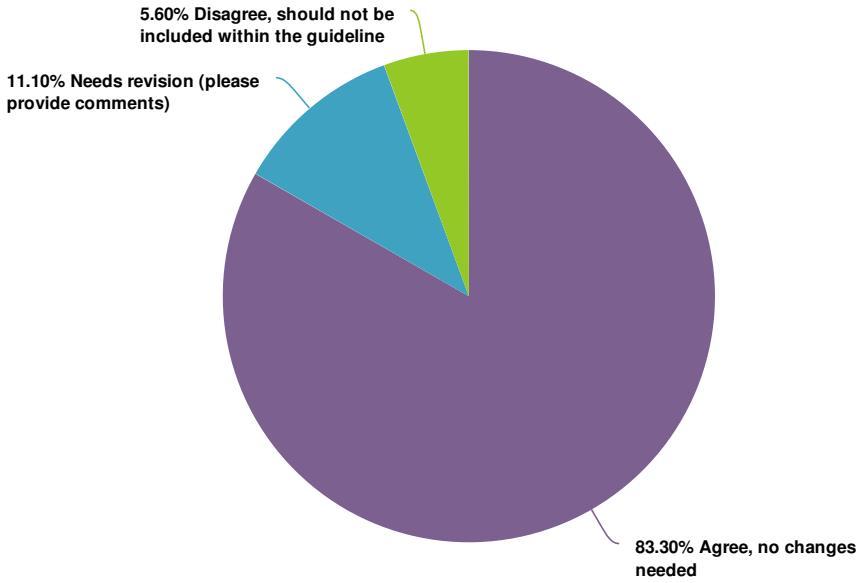
Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

147. To what extent do you agree with the following recommendation?Refer children with concentration and memory difficulties that interfere with learning, school progress or behaviour to community paediatric or paediatric neurodevelopmental services for assessment. - comments

Count	Response
1	Before referral, gather as much evidence as possible, eg, information from parents and teachers
1	need to stress evaluate other possible factors emotional, domestic, bullying etc

148. To what extent do you agree with the following recommendation?Be aware that some children with attention and concentration difficulties do not have hyperactivity.



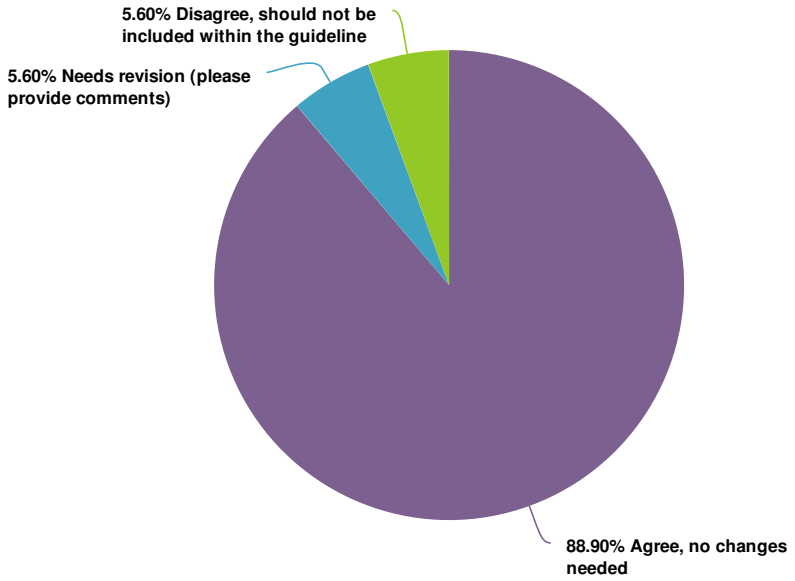
Value	Percent	Responses
Agree, no changes needed	83.3%	15
Needs revision (please provide comments)	11.1%	2
Disagree, should not be included within the guideline	5.6%	1

Total: 18

149. To what extent do you agree with the following recommendation?Be aware that some children with attention and concentration difficulties do not have hyperactivity. - comments

Count	Response
1	Rephrasing: not all children with attention and concentration difficulties have a diagnosis of ADHD or ADD - to consider other differential diagnoses
1	if attention deficit strongly suspeted the refere to nice adhd guidance?

150. To what extent do you agree with the following recommendation?Be aware that medicines commonly used to treat epilepsy in children can adversely affect concentration and memory.



Value	Percent	Responses
Agree, no changes needed	88.9%	16
Needs revision (please provide comments)	5.6%	1
Disagree, should not be included within the guideline	5.6%	1

Total: 18

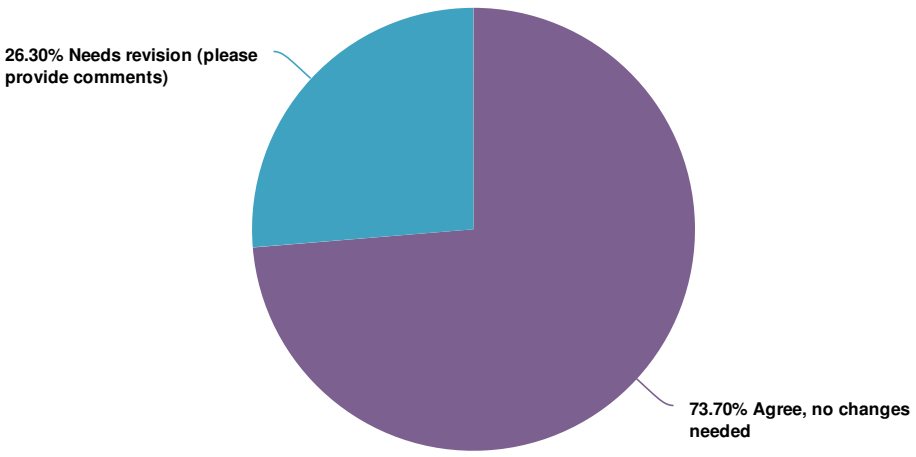
151. To what extent do you agree with the following recommendation?Be aware that medicines commonly used to treat epilepsy in children can adversely affect concentration and memory. - comments

Count	Response
1	?not sure about this statement or who it is aimed at.
1	Is this covered in nice epilepsy guidance - should include evaluation of effectivenes of medication, side effects as well as behavior, learning and education

152. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	All of above highly pertinent BUT access to CAMHS/psychology and neuropsychology services is a big limiting factor and needs to be acknowledged
1	I am dubious about the term memory failure - I think what is being described is some more global cognitive dysfunction/failure not just confined to memory; this stroke me as terminology more applicable to dementia
1	I welcome the advice that children should be referred for an assessment - because whatever the cause, early intervention is important. This is in keeping with Future in Mind and Facing the Future. However, in reality, many generalists from Health and Education find it hard to know whether to refer children to Neurology, Community Paeds or Psychiatry. Different areas have different policies around this too.
1	Out of scope
1	mental health, anxiety, depression, social/abuse needs to be referred to. can refer to nice guidance on suspected abuse?? if concerns.
1	need to add the impact of emotional, behavioural and social factors/adversity on this as can oftern be in context of domestic difficulties, abuse, bullying, anxiety, depression, etc

153. To what extent do you agree with the following recommendation?Refer children to a neurodevelopmental paediatric service if they: are not sitting by 8 months or are not walking by 18 months or show early asymmetry of hand function (hand preference) before 1 year.



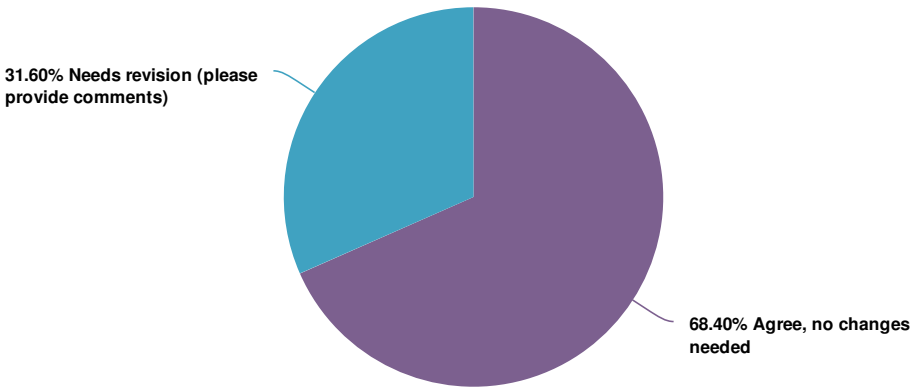
Value	Percent	Responses
Agree, no changes needed	73.7%	14
Needs revision (please provide comments)	26.3%	5

Total: 19

154. To what extent do you agree with the following recommendation?Refer children to a neurodevelopmental paediatric service if they: are not sitting by 8 months or are not walking by 18 months or show early asymmetry of hand function (hand preference) before 1 year. - comments

Count	Response
1	Amend: Refer if not sitting unsupported by 8 mths or walking independently by 18 mths
1	Concerns regarding the neurodevelopment might be obvious prior to the above stated milestones. Suggest revision to allow for clinical judgement for a timely referral.
1	Early intervention from therapists (speech and language, occupational therapy and physiotherapy) is considered best practice therefore early referral to supporting community services should also be considered
1	The Committee could consider including a recommendation to refer into Physiotherapy concurrently to allow early intervention if necessary. I would also recommend including a bullet point regarding signs of developmental regression or loss of skills.
1	sitting independently, walking independently

155. To what extent do you agree with the following recommendation?Refer boys with global or motor developmental delay to a paediatric neurodevelopmental service to exclude Duchenne muscular dystrophy.



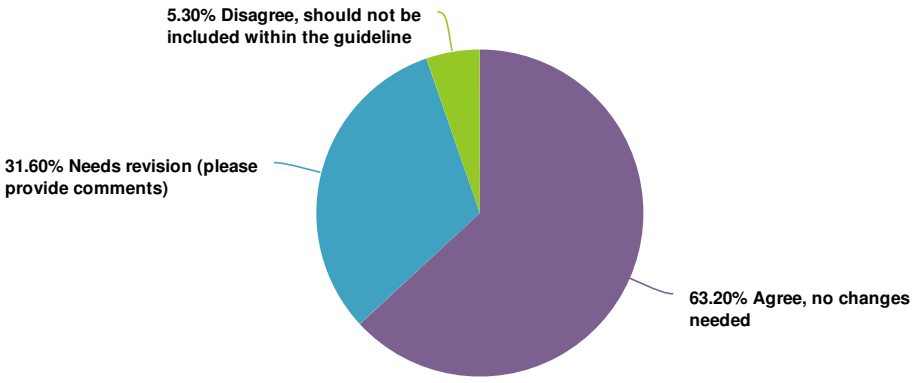
Value	Percent	Responses
Agree, no changes needed	68.4%	13
Needs revision (please provide comments)	31.6%	6

Total: 19

156. To what extent do you agree with the following recommendation?Refer boys with global or motor developmental delay to a paediatric neurodevelopmental service to exclude Duchenne muscular dystrophy. - comments

Count	Response
1	Although most boys may walk before 18 months and present with later climbing or gait abnormalities, speech delay
1	I would recommend including the wording 'Refer boys with global or motor developmental delay/REGRESSION'.
1	Most children with Duchennes or Beckers walk before 18 months but presnt later with motor/gait difficulties and frequently have speech delay. Investigation of global and developmental delay is a topic with number of papers Horrdge et al with array genetics being a high on aetiology. C.k important but shouldn't overlook other causes. Could say genetic, muscular dystrophy or other causes.
1	Suggest referral " to consider " Duchenne dystrophy .
1	The local team needs to consider doing a simple CK blood test PRIOR to referral of all these cases- I've just seen statement below
1	rather too specific a reason?

157. To what extent do you agree with the following recommendation?If investigating the possible cause of motor developmental delay in boys before referral, include creatine kinase testing to exclude Duchenne muscular dystrophy.



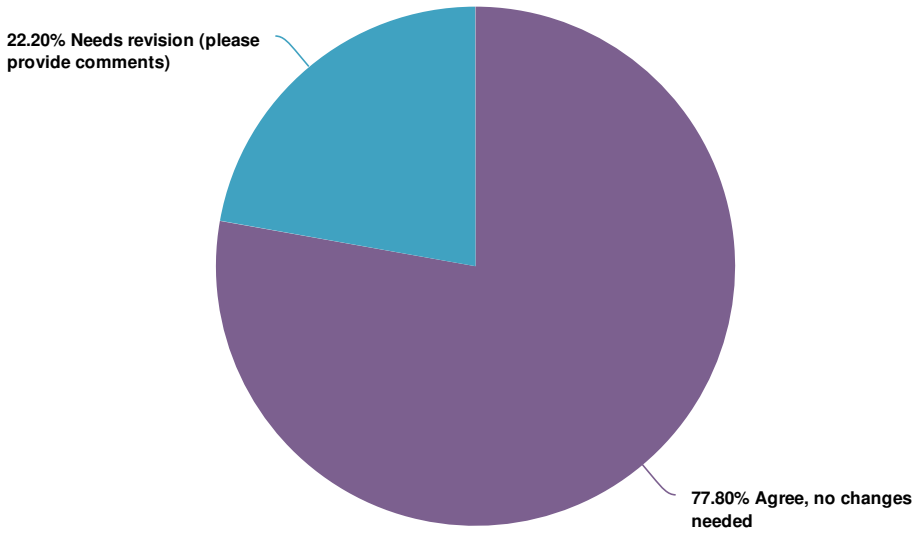
Value	Percent	Responses
Agree, no changes needed	63.2%	12
Needs revision (please provide comments)	31.6%	6
Disagree, should not be included within the guideline	5.3%	1

Total: 19

158. To what extent do you agree with the following recommendation?If investigating the possible cause of motor developmental delay in boys before referral, include creatine kinase testing to exclude Duchenne muscular dystrophy. - comments

Count	Response
1	CK should form part of the investigations undertaken at secondary care, for children with delayed development rather than being organized at primary care level. Disadvantage is the boy/ child may need two needle pricks for another set of investigations.
1	I am unsure regarding this recommendation. It is not clear from the guideline if the committee expects a non-specialist to conduct a CK test and discuss an abnormal result with the family before onward referral. I do not think it is role of a non-specialist to be suggesting a possible diagnosis of such significance when the family cannot access immediate support of specialists. The guideline needs to be more specific as to what should happen in the event a high CK is detected before referral to specialists.
1	I don't like "...to exclude..." when it is really to work towards a diagnosis. But I don't feel strongly about it.
1	Referral usually required even if CK normal
1	There should be consideration of timeframe for referral so that Duchenne can be identified before parents consider another pregnancy. eg Child should be investigated within 4 wks of referral .
1	To combine 43-44 as per comment above
1	i think if supicions are high a paediatrician may do a genetic save and so minimise the need for a repeat so this would be covered in 43.
1	i think test should be done by secondary care but clarified in point 43. There might be other tests to be considered and this approach might put the child through additional blood tests plus resource and family impact in term of two phlebotomy visits

159. To what extent do you agree with the following recommendation?Refer children with new-onset gait abnormality to acute paediatric services immediately.



Value	Percent	Responses
Agree, no changes needed	77.8%	14
Needs revision (please provide comments)	22.2%	4

Total: 18

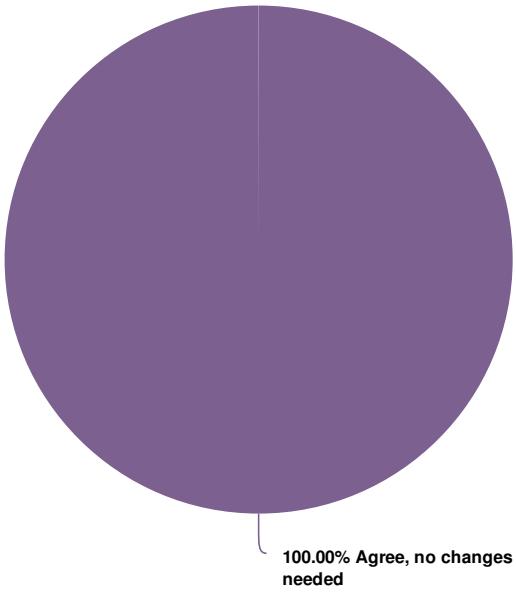
160. To what extent do you agree with the following recommendation?Refer children with new-onset gait abnormality to acute paediatric services immediately. - comments

Count	Response
1	Although some functional, tip toeing in context of autism may need to be considered
1	How about if the gait abnormality is secondary to trauma or infection?
1	What is the time frame of "new onset" gait abnormality? If not sudden then an urgent referrral may be appropriate
1	perhaps greater emphasis to clarify gait abnormality.gait abnormality typically this is limping child with trauma/ transient synovitis/ etc in most children.

161. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Are we going to talk about physio or wider mdt support?
1	Consider that parents and carers may benefit from advice on positioning infants to promote motor development - particularly if they are not engaging with Health Visitor.
1	Early intervention from therapists (speech and language, occupational therapy and physiotherapy) is considered best practice therefore early referral to supporting community services should also be considered

162. To what extent do you agree with the following recommendation?Offer advice on sleep hygiene to adults with insomnia.

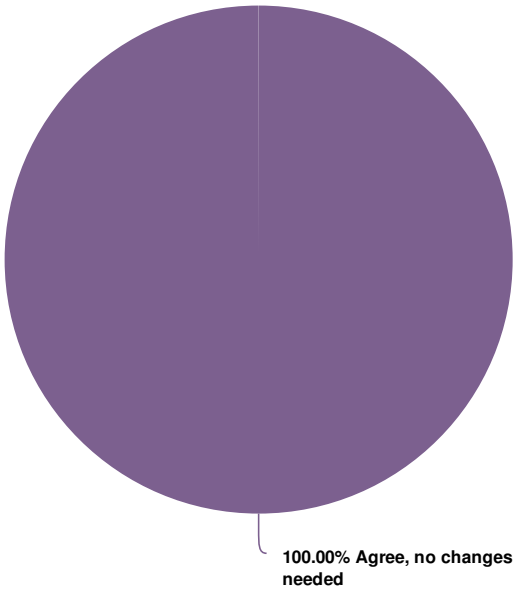


Value	Percent	Responses
Agree, no changes needed	100.0%	16
		Total: 16

163. To what extent do you agree with the following recommendation?Offer advice on sleep hygiene to adults with insomnia. - comments

Count	Response
1	strongly support comments to Not refer insomnia to sleep clinic

164. To what extent do you agree with the following recommendation?Do not refer adults with insomnia, jerks on falling asleep or isolated brief episodes of sleep paralysis.

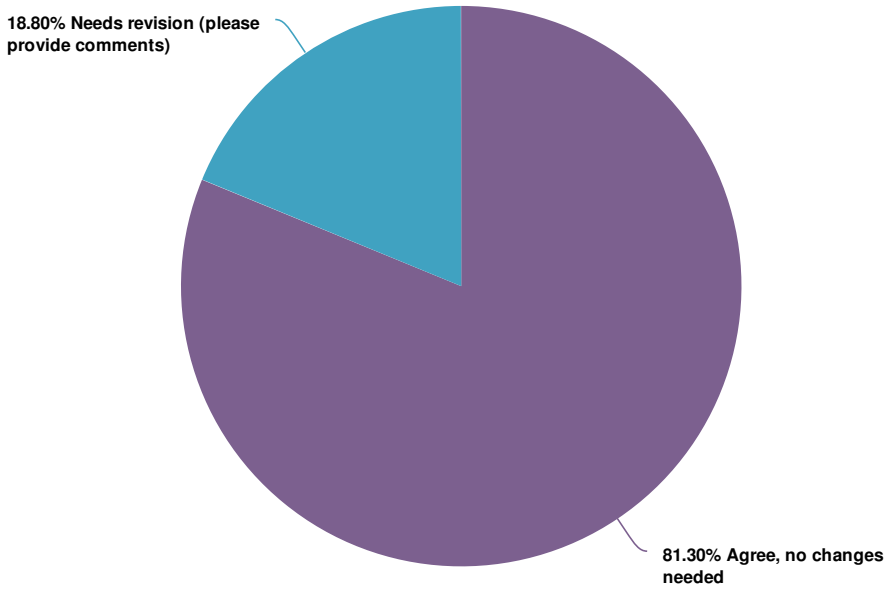


Value	Percent	Responses
Agree, no changes needed	100.0%	16
	Total:	**16**

165. To what extent do you agree with the following recommendation?Do not refer adults with insomnia, jerks on falling asleep or isolated brief episodes of sleep paralysis. - comments

Count	Response

166. To what extent do you agree with the following recommendation?For adults with excessive sleepiness: use the Epworth score together with history of obstructive symptoms in sleep to assess the likelihood of sleep apnoea and refer in accordance with local policy and if appropriate, offer advice on weight reduction, alcohol consumption and smoking cessation.



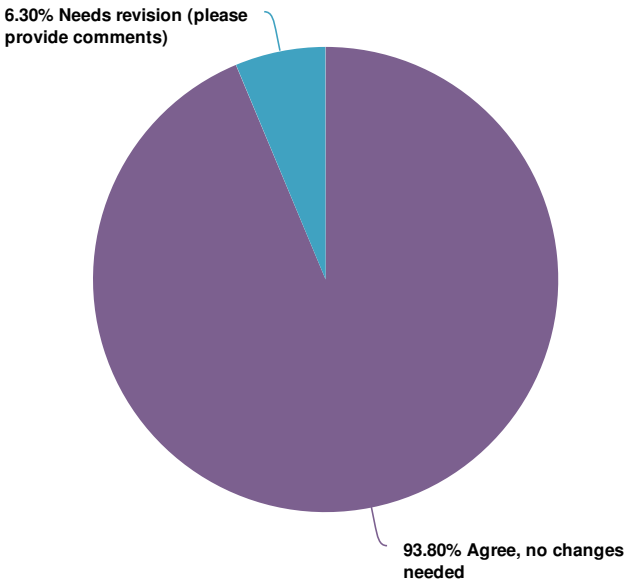
Value	Percent	Responses
Agree, no changes needed	81.3%	13
Needs revision (please provide comments)	18.8%	3

Total: 16

167. To what extent do you agree with the following recommendation?For adults with excessive sleepiness: use the Epworth score together with history of obstructive symptoms in sleep to assess the likelihood of sleep apnoea and refer in accordance with local policy and if appropriate, offer advice on weight reduction, alcohol consumption and smoking cessation. - comments

Count	Response
1	Epworth score must not be the sole criteria nor the BMI. If there is suggestion of recent increase in weight, short neck and a typical history of OSAS, even without significant increase in BMI or Epworth scores, OSAS must still be considered.
1	Need advice on driving to be added. Epworth not that reliable. I think that there is not good evidence that weight reduction actually helps
1	Remove "if appropriate" as it is always appropriate!
1	guidance to help differentiate who should be referred to respiratory OSA clinic/ not neurology is very useful

168. To what extent do you agree with the following recommendation?Consider referring adults with persistent symptoms suggestive of sleep behaviour disorders (such as kicking and agitated or violent movement) for neurological assessment.



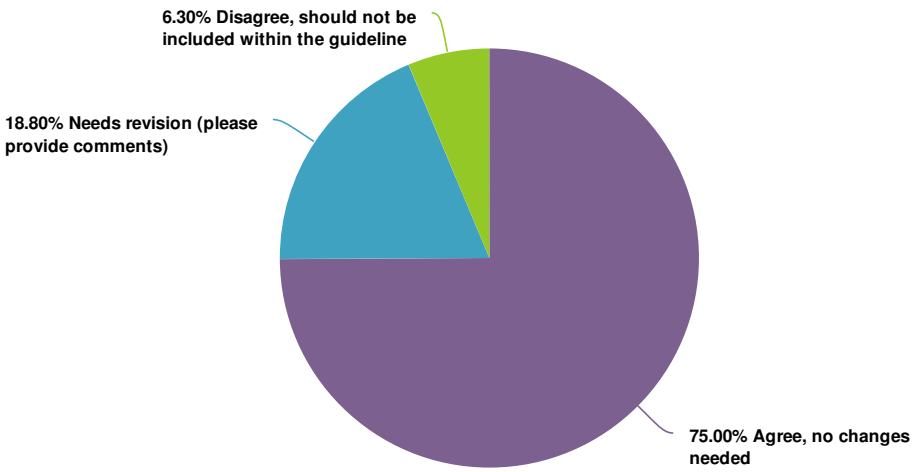
Value	Percent	Responses
Agree, no changes needed	93.8%	15
Needs revision (please provide comments)	6.3%	1

Total: 16

169. To what extent do you agree with the following recommendation?Consider referring adults with persistent symptoms suggestive of sleep behaviour disorders (such as kicking and agitated or violent movement) for neurological assessment. - comments

Count	Response
1	There is hardly ever a neurological cause unless there is other neuro impairment. OK this can be presentation of neurodegen but can't address that unless symptomatic so why fill the clinic with this common symptom?

170. To what extent do you agree with the following recommendation?Refer adults with symptoms suggestive of nocturnal epilepsy for neurological assessment.



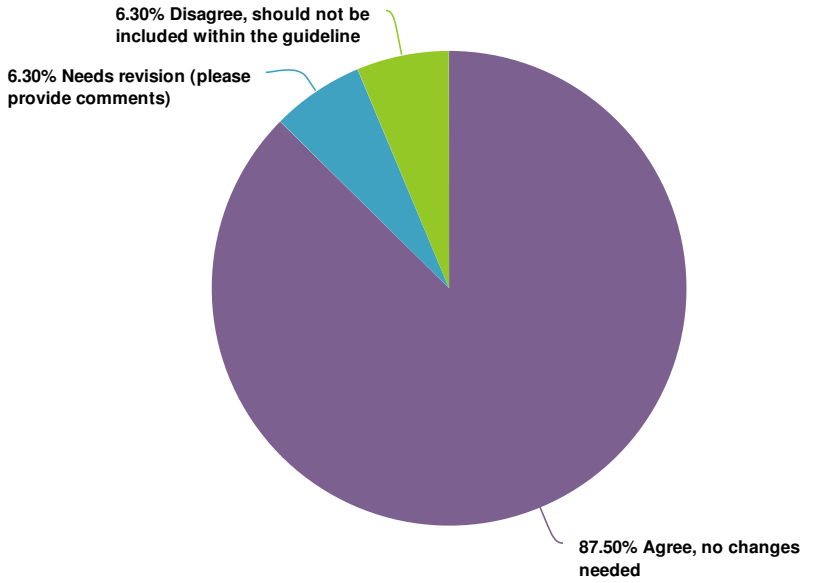
Value	Percent	Responses
Agree, no changes needed	75.0%	12
Needs revision (please provide comments)	18.8%	3
Disagree, should not be included within the guideline	6.3%	1

Total: 16

171. To what extent do you agree with the following recommendation?Refer adults with symptoms suggestive of nocturnal epilepsy for neurological assessment. - comments

Count	Response
1	Add comment that they need to be seen urgently. High risk of SUDEP, and possibility of structural abnormality
1	If new onset then needs to be urgent in line with NICE epilepsy guidelines
1	Nocturnal epilepsy an unhelpful term that does not belong in evidence based practice: seizures can occur in sleep or wakefulness. Both require neur assessment (does not matter if sun or moon shining!)
1	Specify in recommendation what criteria needs to be fulfilled for suspected nocturnal epilepsy to aid GP's in taking a focused history.

172. To what extent do you agree with the following recommendation?Refer adults with narcolepsy with or without cataplexy for neurological assessment.



Value	Percent	Responses
Agree, no changes needed	87.5%	14
Needs revision (please provide comments)	6.3%	1
Disagree, should not be included within the guideline	6.3%	1

Total: 16

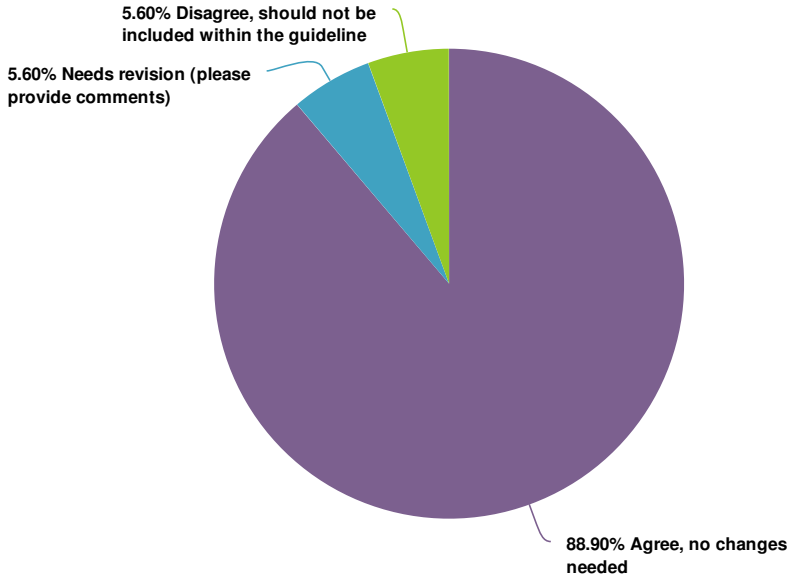
173. To what extent do you agree with the following recommendation?Refer adults with narcolepsy with or without cataplexy for neurological assessment. - comments

Count	Response
1	In some areas this would be managed by sleep physicians belonging to a respiratory team, rather than neurology.
1	Really these patents belong with sleep specialist - but NHS does not provide so default to neurology

174. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Again the importance of a witness is paramount but overlooked. Suggest also note morbidity/mortality of sleepwalking
1	Would it be possible to add comments on whether patients should be told not to drive, and if so for how long, to save cross-referencing with the DVLA at a glance document?
1	no

175. To what extent do you agree with the following recommendation?Reassure parents and carers of children with sleep disturbances that these are common in healthy children and rarely indicate a neurological condition.

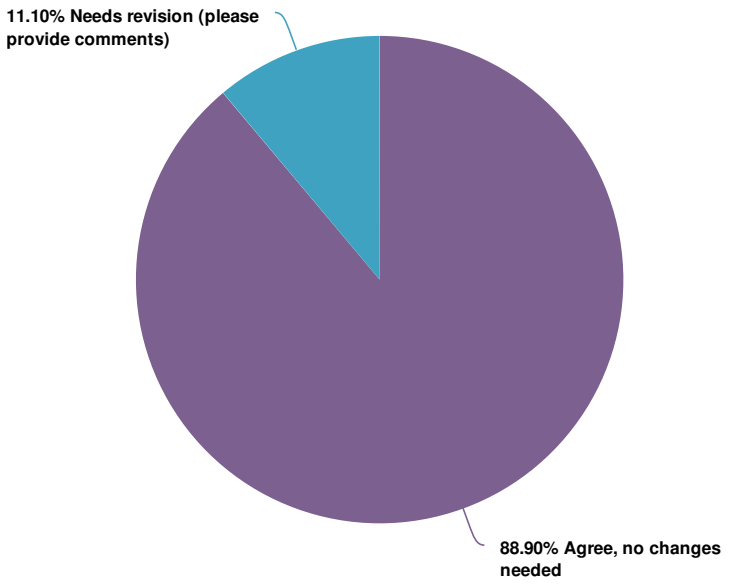


Value	Percent	Responses
Agree, no changes needed	88.9%	16
Needs revision (please provide comments)	5.6%	1
Disagree, should not be included within the guideline	5.6%	1
	Total: 18	

176. To what extent do you agree with the following recommendation?Reassure parents and carers of children with sleep disturbances that these are common in healthy children and rarely indicate a neurological condition. - comments

Count	Response
1	Depends inevitably on the nature of the 'sleep disturbances' hence too broad sweeping
1	surely this depends on nature of the sleep disturbance - this sounds very vague

177. To what extent do you agree with the following recommendation?Offer advice on sleep hygiene to parents of children with insomnia.

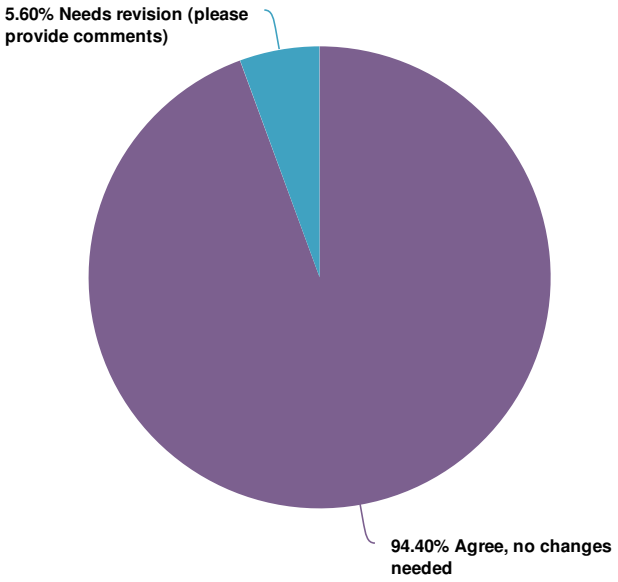


Value	Percent	Responses
Agree, no changes needed	88.9%	16
Needs revision (please provide comments)	11.1%	2
	Total: 18	

178. To what extent do you agree with the following recommendation?Offer advice on sleep hygiene to parents of children with insomnia. - comments

Count	Response
1	After trying to find out what is driving the insomnia (lay person term)
1	Suggest to specify- ' Behavioural insomnia'

179. To what extent do you agree with the following recommendation?Consider referring children aged under 5 years with sleep disturbances to a health visitor for advice.



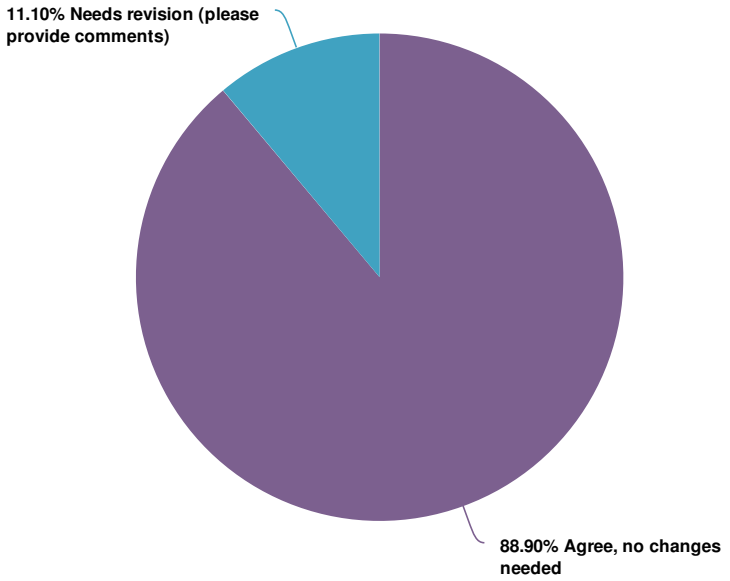
Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

180. To what extent do you agree with the following recommendation?Consider referring children aged under 5 years with sleep disturbances to a health visitor for advice. - comments

Count	Response
1	"Or other specialist sleep services if Health visitors do not have the specific expertise", as in many regions they are not able to help.
1	Very hard to access health visitors nowadays
1	or other sleep practitioner

181. To what extent do you agree with the following recommendation?Be aware that sleep disorders in children may be a symptom of gastro-oesophageal reflux or constipation. See the recommendations on diagnosing and investigating gastro-oesophageal reflux disease in the NICE guideline on gastro-oesophageal reflux disease in children and young people.



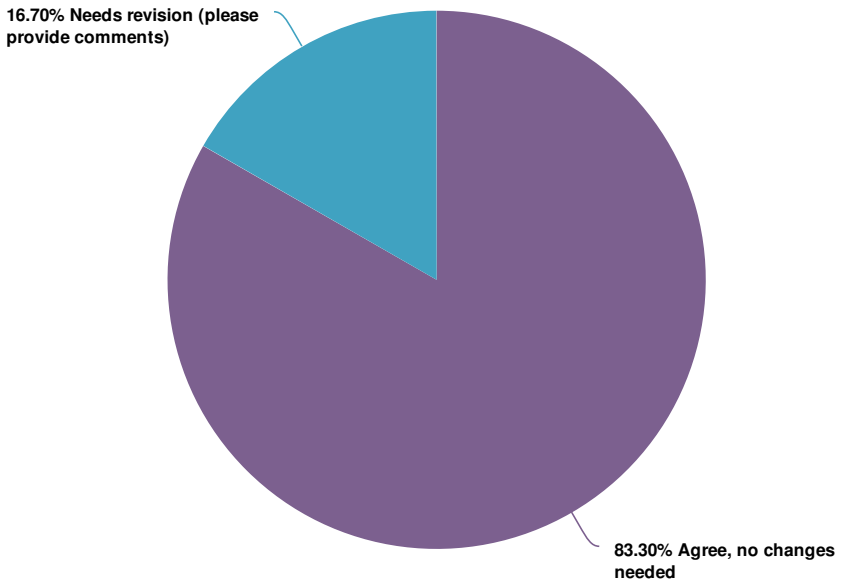
Value	Percent	Responses
Agree, no changes needed	88.9%	16
Needs revision (please provide comments)	11.1%	2

Total: 18

182. To what extent do you agree with the following recommendation?Be aware that sleep disorders in children may be a symptom of gastro-oesophageal reflux or constipation. See the recommendations on diagnosing and investigating gastro-oesophageal reflux disease in the NICE guideline on gastro-oesophageal reflux disease in children and young people. - comments

Count	Response
1	GI amongst other causes- not sure of this particular statement
1	I did not know this was important, but seems reasonable if there is evidence for it
1	Reword that gastro- oesophageal reflux disease may be associated with sleep distrubance as may other disorders which can cause discomfort at night eg refer to NICE guideline on reflux disease
1	should this be before poiint 47?

183. To what extent do you agree with the following recommendation?Consider referring children with sleep disorders associated with neurodevelopmental disorders and intellectual disabilities (learning disabilities) to community paediatric services.



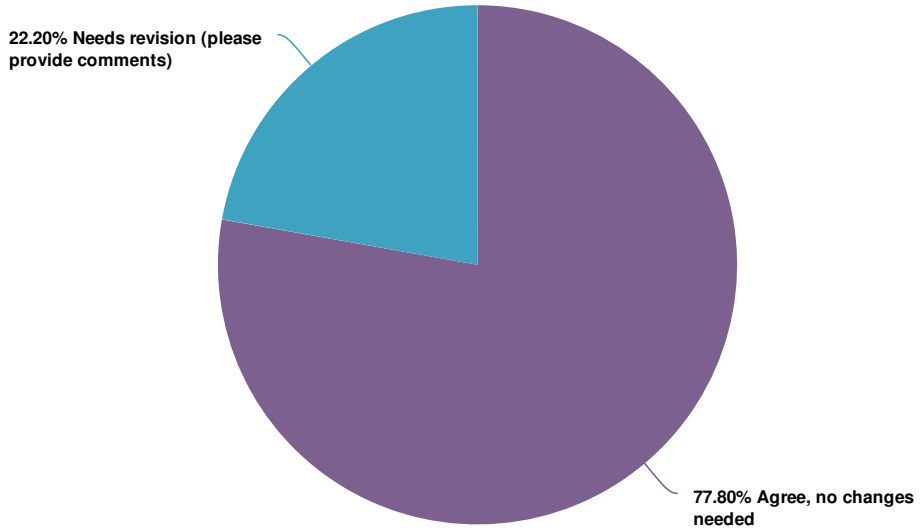
Value	Percent	Responses
Agree, no changes needed	83.3%	15
Needs revision (please provide comments)	16.7%	3

Total: 18

184. To what extent do you agree with the following recommendation?Consider referring children with sleep disorders associated with neurodevelopmental disorders and intellectual disabilities (learning disabilities) to community paediatric services. - comments

Count	Response
1	After initial advice and simple measures have failed
1	Many Community Paediatric teams now offer specialist sleep services.
1	Surely the presence of neurodevelopmental disorders and intellectual disabilities is sufficient for referral, whether or not associated with sleep disorders

185. To what extent do you agree with the following recommendation?Refer children with symptoms suggestive of nocturnal epilepsy for neurological assessment.



Value	Percent	Responses
Agree, no changes needed	77.8%	14
Needs revision (please provide comments)	22.2%	4

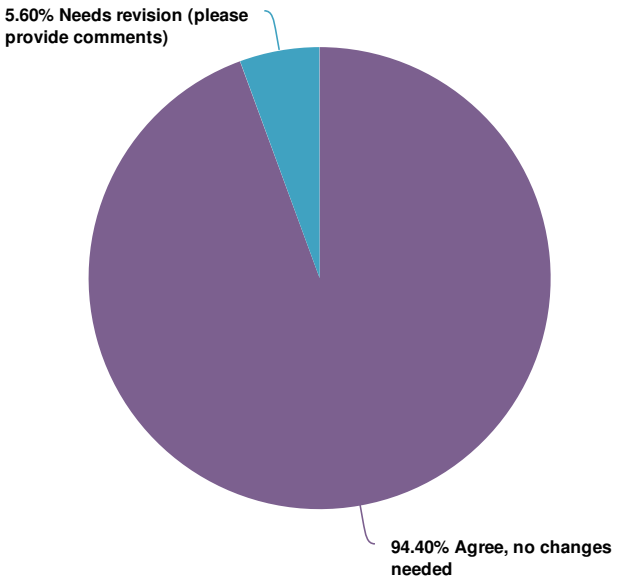
Total: 18

186. To what extent do you agree with the following recommendation?Refer children with symptoms suggestive of nocturnal epilepsy for neurological assessment. - comments

Count	Response
1	Explain symptoms suggestive of nocturnal epilepsy. Red flag symptoms should be described in this guideline
1	Main problem is there are no 'symptoms suggestive of nocturnal epilepsy' given significant delays in identifying these children because of that reason (misdiagnosed as parasomnias /night terrors etc) - Rephrase: if concerned or videos of sleep events look atypical to consider referral ....
1	Oh dear "nocturnal epilepsy" again. Sleep or wake epilepsy please.
1	does this need to specify what such symptoms are

187. To what extent do you agree with the following recommendation?Refer children with

narcolepsy with or without cataplexy for neurological assessment.



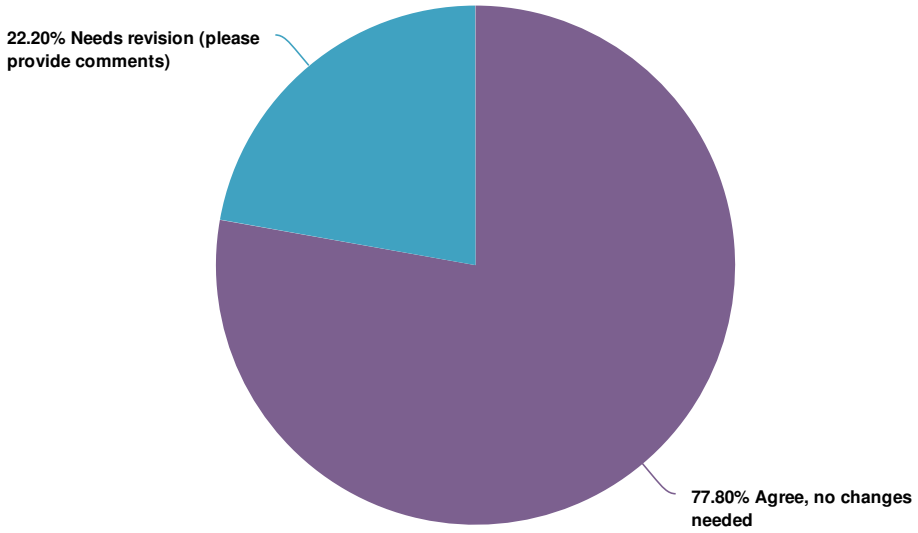
Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

188. To what extent do you agree with the following recommendation?Refer children with narcolepsy with or without cataplexy for neurological assessment. - comments

Count	Response
1	Not many centres have access to sleep studies as long waiting lists
1	Paediatric not neurological assessment please
1	or to a paediatric sleep service

189. To what extent do you agree with the following recommendation?Refer children with symptoms of sleep apnoea to paediatric respiratory services. If the child is obese, offer advice on weight reduction.



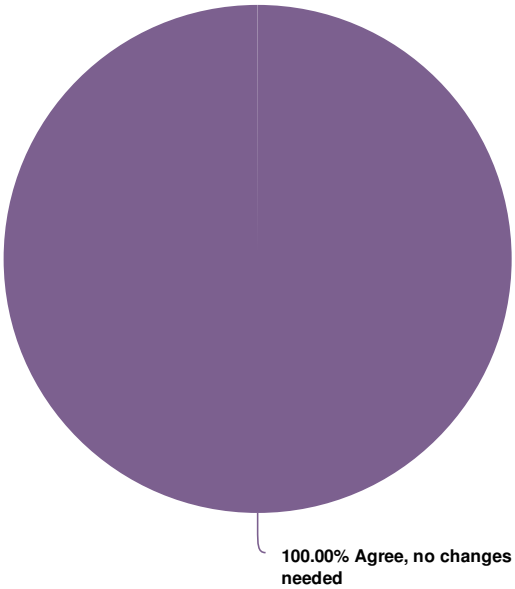
Value	Percent	Responses
Agree, no changes needed	77.8%	14
Needs revision (please provide comments)	22.2%	4

Total: 18

190. To what extent do you agree with the following recommendation?Refer children with symptoms of sleep apnoea to paediatric respiratory services. If the child is obese, offer advice on weight reduction. - comments

Count	Response
1	Child with large tonsils and/or Down syndrome may be referred to paediatric ENT services and local neurodevelopmental service can consider overnight oxygen saturation study
1	Ent probably more useful - most osa tonsils and addenoids in normal children
1	Somewhat unsure of the referral pathway- as the statement implies a direct referral to tertiary paediatric respiratory services.
1	or to a paediatric sleep service
1	possible ENT referral if the child also has large adenoids
1	probably ent services as usually tonsils and adenoids or rhinitis rather than requiring paed respiratory as such

191. To what extent do you agree with the following recommendation?Be aware that children with neuromuscular disorders have an increased risk of sleep apnoea and breathing disorders during sleep.



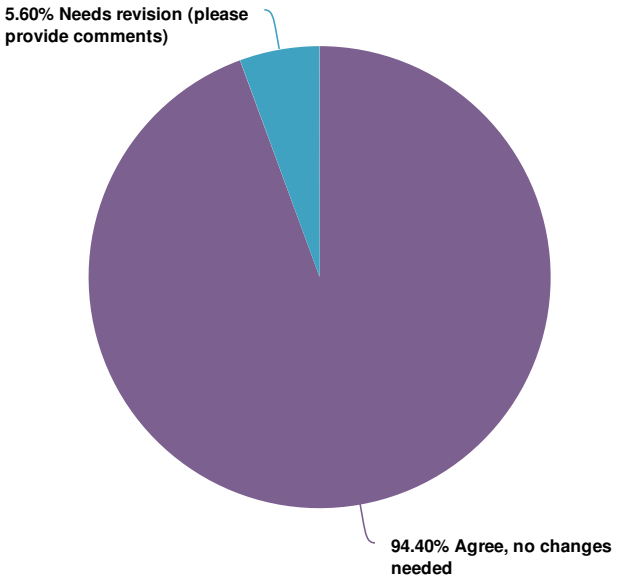
Value	Percent	Responses
Agree, no changes needed	100.0%	18

Total: 18

192. To what extent do you agree with the following recommendation?Be aware that children with neuromuscular disorders have an increased risk of sleep apnoea and breathing disorders during sleep. - comments

Count	Response

193. To what extent do you agree with the following recommendation?Refer children with neuromuscular disorders urgently for a breathing assessment if they present with early morning headaches and new-onset sleep disturbance.



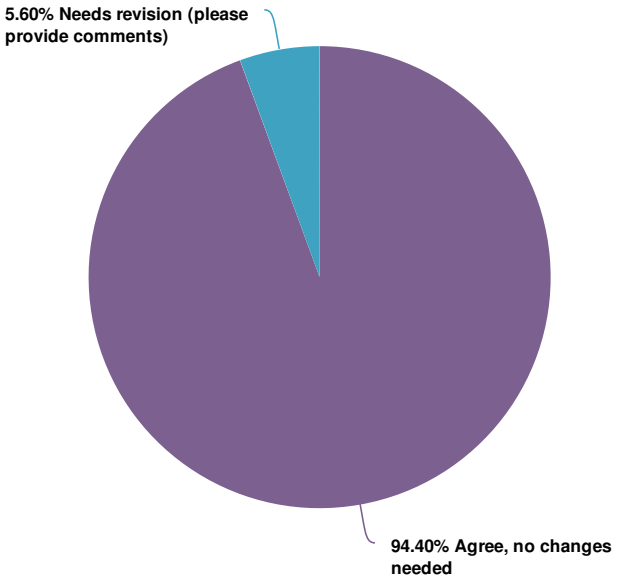
Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

194. To what extent do you agree with the following recommendation?Refer children with neuromuscular disorders urgently for a breathing assessment if they present with early morning headaches and new-onset sleep disturbance. - comments

Count	Response
1	but better to use "or" in place of "and"
1	put respiratory rather than breathing

195. To what extent do you agree with the following recommendation?Refer children with headaches that wake them from sleep urgently for neurological assessment and neuroimaging.



Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

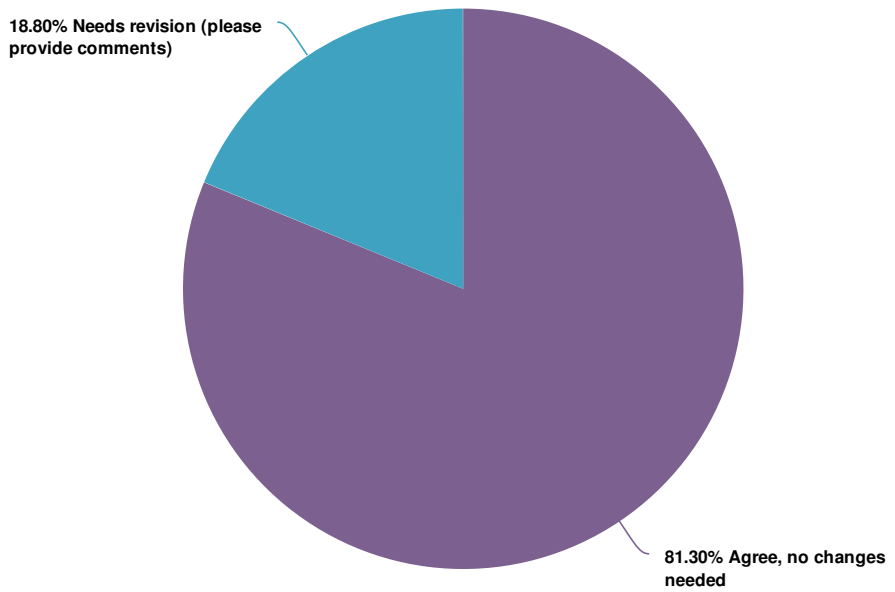
196. To what extent do you agree with the following recommendation?Refer children with headaches that wake them from sleep urgently for neurological assessment and neuroimaging. - comments

Count	Response
1	Migraine often wakes from sleep. Key symptom is headache present every or most days on waking or after lying down. Always look for papilloedema which if present requires same day neuroimaging.
1	Refer to Headsmart guideline
1	This is what is classically taught; but in clinical practice almost all of these children have a primary headache disorder and will wake up with migraines

197. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	All of these recommendations are great but will the lack & limitation of resources (access to videoEGs during sleep/ sleep studies/ access to specialist services etc) be addressed?
1	Anxiety or depression and sleep?
1	Out of scope
1	See above re ENT assessment if the child presents with large adenoids

198. To what extent do you agree with the following recommendation?Refer adults with sudden-onset speech disturbance urgently for assessment of a possible vascular event, in line with local stroke pathways and following the recommendations on prompt recognition of symptoms of stroke and TIA in the NICE guideline on stroke and transient ischaemic attack in over 16s (section 1.1.1).



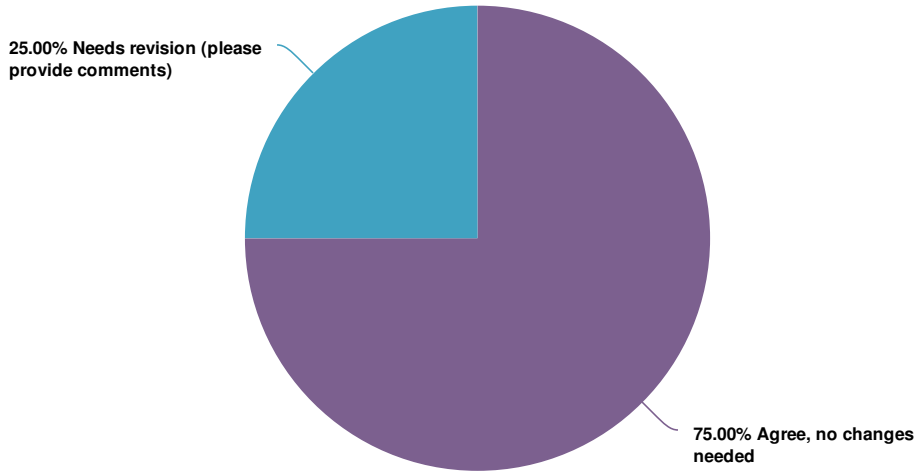
Value	Percent	Responses
Agree, no changes needed	81.3%	13
Needs revision (please provide comments)	18.8%	3

Total: 16

199. To what extent do you agree with the following recommendation?Refer adults with sudden-onset speech disturbance urgently for assessment of a possible vascular event, in line with local stroke pathways and following the recommendations on prompt recognition of symptoms of stroke and TIA in the NICE guideline on stroke and transient ischaemic attack in over 16s (section 1.1.1). - comments

Count	Response
1	Point is maximal-at-onset not sudden onset (as it is a binary symptom) and not specific to speech but applies to all max-at-onset motor impairment
1	Should the referral be an urgent one or an immediate one? In primary care 'urgent' usually means more rapidly than routine (which could be many months the way the NHS is currently).
1	consider additional comments that recurrent stereotyped dysphasia unlikely to be TIA and more likely to represent focal seizure disorder and recommend referral to neurology

200. To what extent do you agree with the following recommendation?Refer adults with progressive slurred or disrupted speech for assessment of possible motor neurone disease in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease.



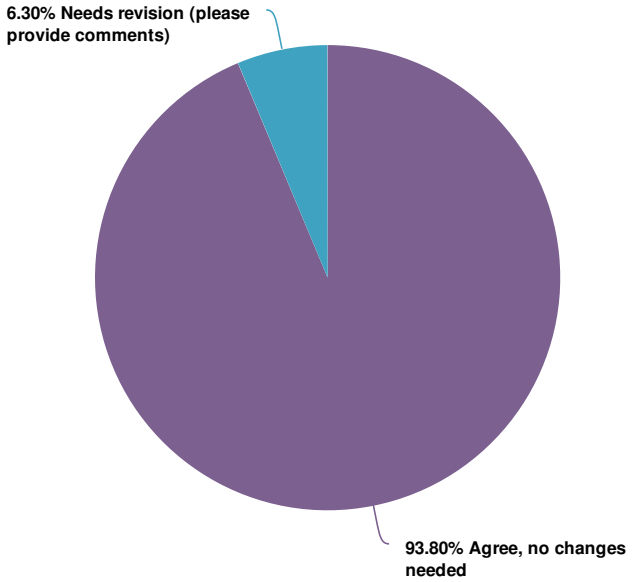
Value	Percent	Responses
Agree, no changes needed	75.0%	12
Needs revision (please provide comments)	25.0%	4

Total: 16

201. To what extent do you agree with the following recommendation?Refer adults with progressive slurred or disrupted speech for assessment of possible motor neurone disease in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease. - comments

Count	Response
1	A circular argument "adults with symptoms of disease X should be referred in line with the disease X recommendations". Consider also the myasthenia or ill-fitting dentures recommendations! Again it is the clinical examination not the symptom that guides referral.
1	Add in look for swallowing issues
1	MND is only one of many possible causes of slurred speech- may be inappropriate to only mention MND and not other (treatable) casues such as myasthenia gravis?
1	motor neurone disease or myasthenia gravis

202. To what extent do you agree with the following recommendation?Be aware that functional neurological disorder is the most common cause of minor word-finding difficulties in adults.



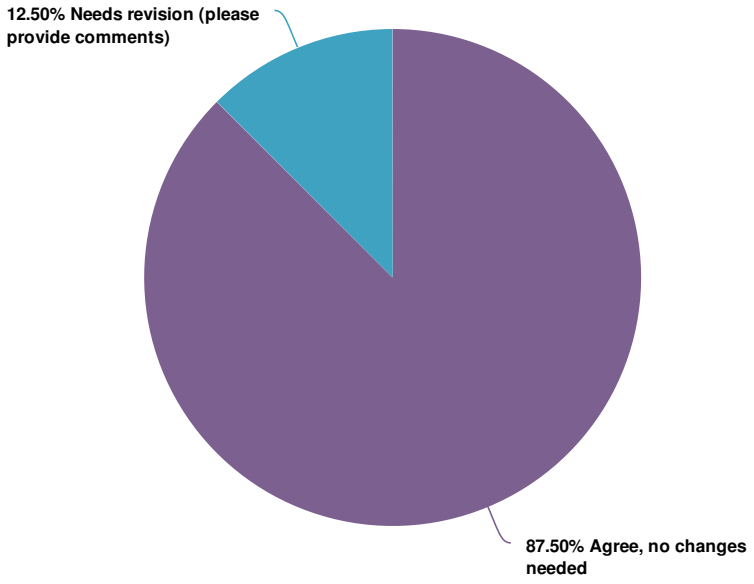
Value	Percent	Responses
Agree, no changes needed	93.8%	15
Needs revision (please provide comments)	6.3%	1

Total: 16

203. To what extent do you agree with the following recommendation?Be aware that functional neurological disorder is the most common cause of minor word-finding difficulties in adults. - comments

Count	Response
1	What is meant by "minor"? Patient or doctor defined? Again the examination and the witness account are key.

204. To what extent do you agree with the following recommendation?Be aware that persistent dysphonia (a quiet, hoarse or wobbly voice) in adults may be a presenting symptom of a neurological condition such as Parkinson's disease. For recommendations on the diagnosis and management of Parkinson's disease see the NICE guideline on Parkinson's disease in over 20s.



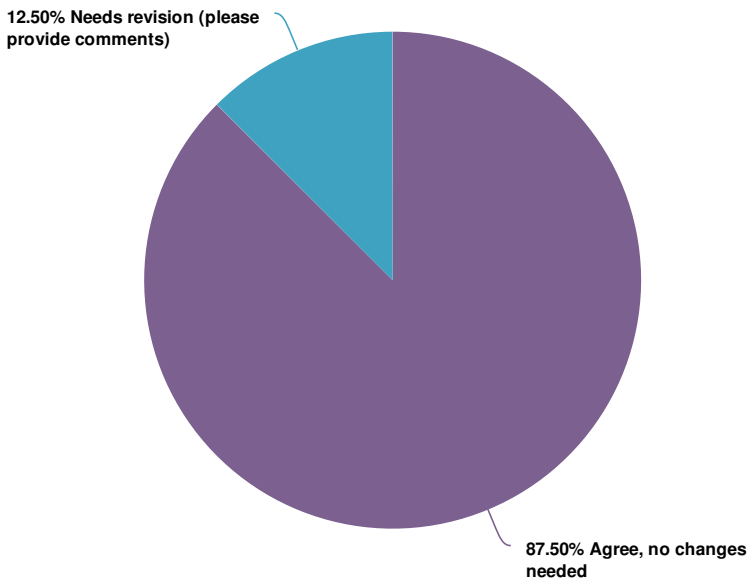
Value	Percent	Responses
Agree, no changes needed	87.5%	14
Needs revision (please provide comments)	12.5%	2

Total: 16

205. To what extent do you agree with the following recommendation?Be aware that persistent dysphonia (a quiet, hoarse or wobbly voice) in adults may be a presenting symptom of a neurological condition such as Parkinson's disease. For recommendations on the diagnosis and management of Parkinson's disease see the NICE guideline on Parkinson's disease in over 20s. - comments

Count	Response
1	Exclusion of vocal cord disease is however the priority. A moment ago this symptom was on the MND pathway.
1	Specify in the absence of other red flags e.g. new onset hoarse voice and smoker should be referred urgently to ENT

206. To what extent do you agree with the following recommendation?Consider referring adults with isolated and unexplained persistent dysphonia for consideration of a diagnosis of laryngeal dystonia (involuntary contractions of the vocal cords).



Value	Percent	Responses
Agree, no changes needed	87.5%	14
Needs revision (please provide comments)	12.5%	2

Total: 16

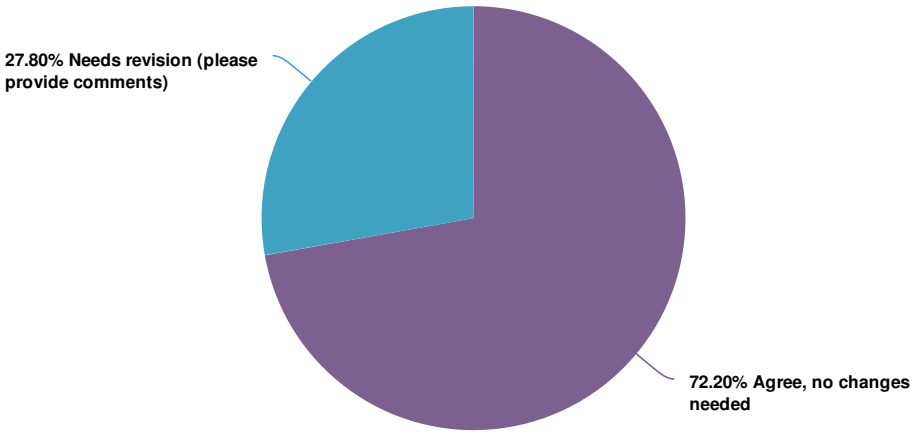
207. To what extent do you agree with the following recommendation?Consider referring adults with isolated and unexplained persistent dysphonia for consideration of a diagnosis of laryngeal dystonia (involuntary contractions of the vocal cords). - comments

Count	Response
1	Consider also myasthenia; consideration of laryngeal dystonia belongs in the ENT not the neurology clinic.
1	It may be worth it to mention that the ENT team would normally assess this in the first instance?
1	May also need ENT assessment

208. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	ENT might be the correct place to refer Laryngeal Dystonia in some service areas, and Neurology in others?
1	Recurring theme - 2 key point omitted 1. If patient complains of speech difficulty and their partner or workmates notice nothing then there is unlikely to be a neurological cause 2. Neurological examination (dysphasia, dysarthria, lower cranial nerves) is critically important
1	no

209. To what extent do you agree with the following recommendation?Consider referring children aged over 2 years with abnormal speech development to speech and language services.



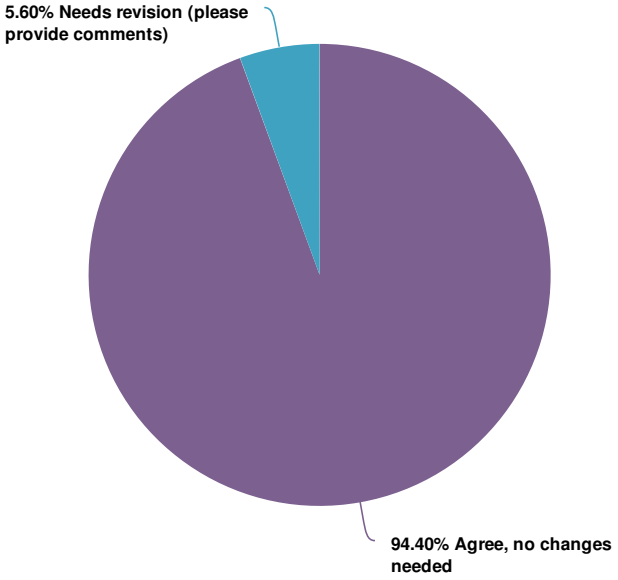
Value	Percent	Responses
Agree, no changes needed	72.2%	13
Needs revision (please provide comments)	27.8%	5

Total: 18

210. To what extent do you agree with the following recommendation?Consider referring children aged over 2 years with abnormal speech development to speech and language services. - comments

Count	Response
1	Does the panel consider that the norms of speech development should be included as guidance?
1	Earlier referral if there are other concerns, and delayed or regression of milestones in other areas.
1	Should we take out consider
1	isolated abnormal speech
1	over 18 months as some are severe and can already be identified as aberrant speech development earlier than 2

211. To what extent do you agree with the following recommendation?Be aware that delay or regression in speech and language in children can be a presenting symptom of autism. Follow the recommendations on recognising children and young people with possible autism and referring children and young people to the autism team in the NICE guideline on autism spectrum disorder in under 19s.



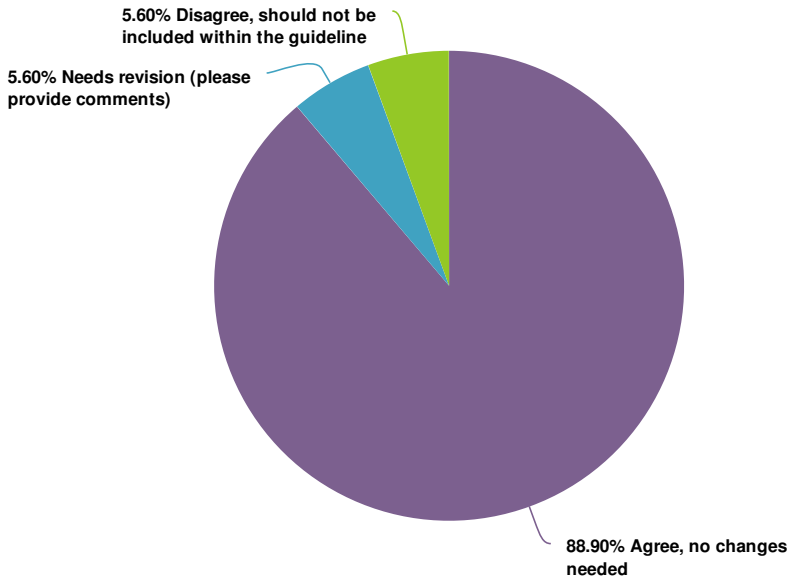
Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

212. To what extent do you agree with the following recommendation?Be aware that delay or regression in speech and language in children can be a presenting symptom of autism. Follow the recommendations on recognising children and young people with possible autism and referring children and young people to the autism team in the NICE guideline on autism spectrum disorder in under 19s. - comments

Count	Response
1	A thought - Should the comment about waiting times of 2-3 years be in the rationale? Whilst this is undoubtably the case - often as a result of internal waits - it is also anecdotal.

213. To what extent do you agree with the following recommendation?Refer children with new-onset slurred or disrupted speech urgently for neurological assessment.



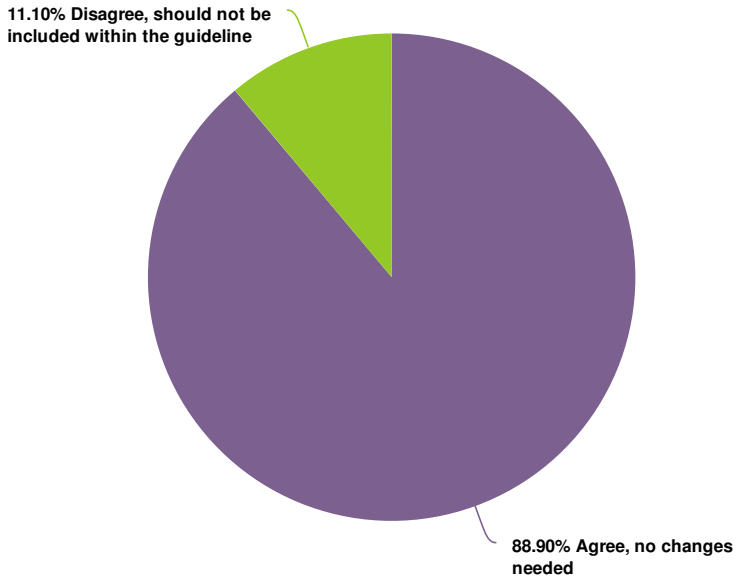
Value	Percent	Responses
Agree, no changes needed	88.9%	16
Needs revision (please provide comments)	5.6%	1
Disagree, should not be included within the guideline	5.6%	1

Total: 18

214. To what extent do you agree with the following recommendation?Refer children with new-onset slurred or disrupted speech urgently for neurological assessment. - comments

Count	Response
1	Vague - risks having children with new onset stammer/stutter referred - detailed history and examination required which needs to be done by local paediatric team as either this is a speech/language deficit or symptomatic of something else - if the latter there are usually pointers in the history
1	is this including stutters and stammers

215. To what extent do you agree with the following recommendation?Check whether slurred or disrupted speech in a child is a side effect of prescribed medicines, recreational drugs or alcohol.



Value	Percent	Responses
Agree, no changes needed	88.9%	16
Disagree, should not be included within the guideline	11.1%	2

Total: 18

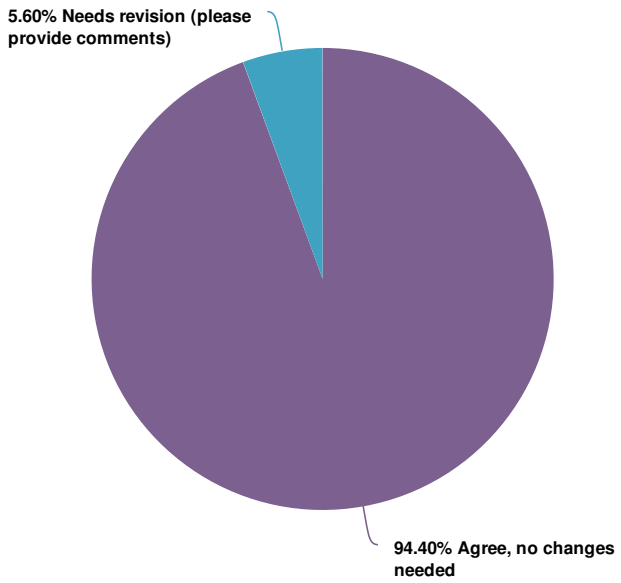
216. To what extent do you agree with the following recommendation?Check whether slurred or disrupted speech in a child is a side effect of prescribed medicines, recreational drugs or alcohol. - comments

Count	Response
1	i'm not sure this is useful clinically.
1	most CYP will not disclose taking any recreational drugs and parents often not aware

217. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Out of scope

218. To what extent do you agree with the following recommendation?Refer children with squint to ophthalmology services.



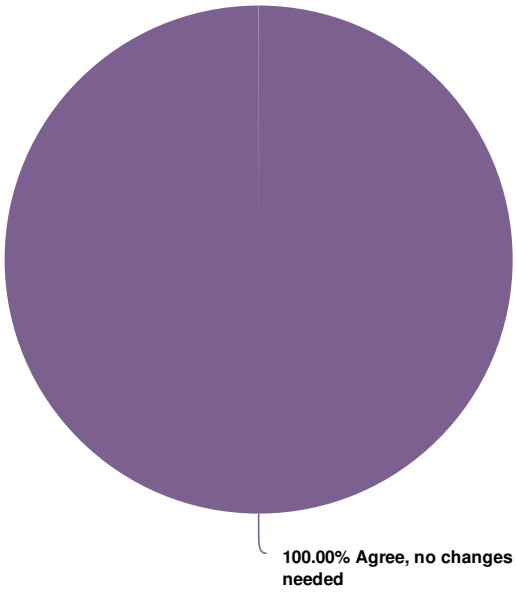
Value	Percent	Responses
Agree, no changes needed	94.4%	17
Needs revision (please provide comments)	5.6%	1

Total: 18

219. To what extent do you agree with the following recommendation?Refer children with squint to ophthalmology services. - comments

Count	Response
1	Some Providers have orthoptic services for initial assessment and management with local arrangements for referral to Ophthalmology

220. To what extent do you agree with the following recommendation?Refer children immediately to ophthalmology services if new-onset squint occurs together with loss of red reflex in one or both eyes.

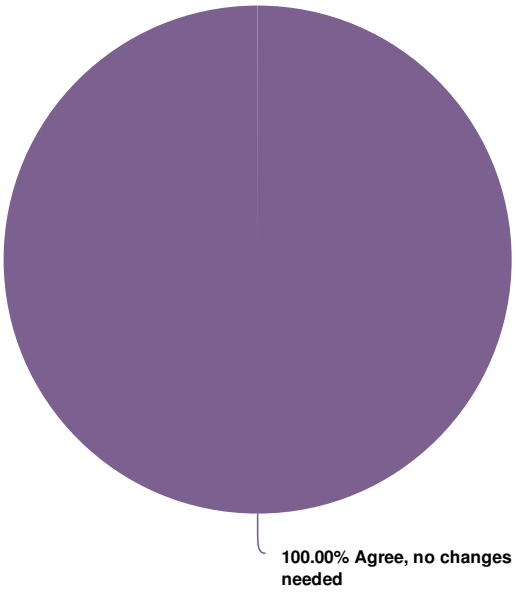


Value	Percent	Responses
Agree, no changes needed	100.0%	18
	Total: 18	

221. To what extent do you agree with the following recommendation?Refer children immediately to ophthalmology services if new-onset squint occurs together with loss of red reflex in one or both eyes. - comments

Count	Response

222. To what extent do you agree with the following recommendation?Refer children immediately to acute paediatric services if new-onset squint occurs together with ataxia, vomiting or headache in line with the recommendation on brain and central nervous system cancers in children and young people in the NICE guideline on suspected cancer.



Value	Percent	Responses
Agree, no changes needed	100.0%	18
	Total: 18	

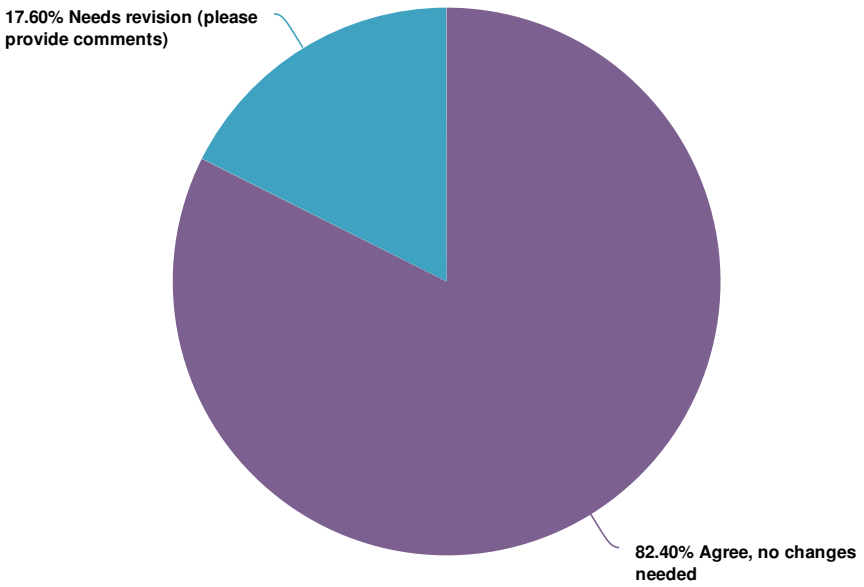
223. To what extent do you agree with the following recommendation?Refer children immediately to acute paediatric services if new-onset squint occurs together with ataxia, vomiting or headache in line with the recommendation on brain and central nervous system cancers in children and young people in the NICE guideline on suspected cancer. - comments

Count	Response

224. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	New onset squint in an older child - consider referral
1	Out of scope

225. To what extent do you agree with the following recommendation?Refer children presenting with tremor for neurological assessment if: they have additional neurological signs and symptoms such as unsteadiness or the onset of the tremor was sudden.



Value	Percent	Responses
Agree, no changes needed	82.4%	14
Needs revision (please provide comments)	17.6%	3

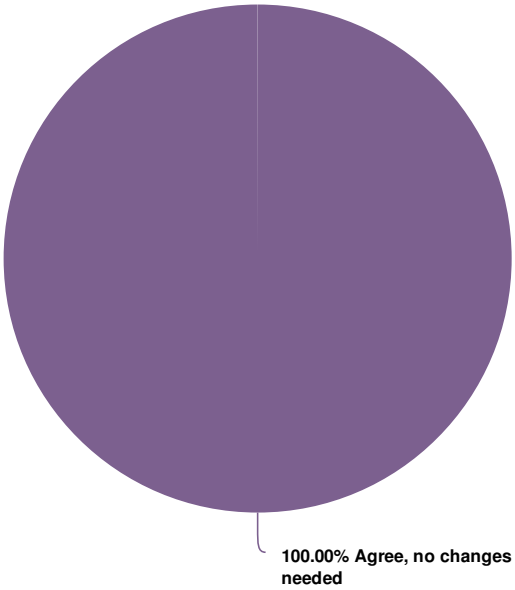
Total: 17

226. To what extent do you agree with the following recommendation?Refer children presenting with tremor for neurological assessment if: they have additional neurological signs and symptoms such as unsteadiness or the onset of the tremor was sudden. - comments

Count	Response
1	consider referral if tremor is asymmetrical
1	for URGENT neurological assessment
1	paediatric not neurological assessment

227. To what extent do you agree with the following recommendation?Be aware that isolated postural tremor in children may be a side effect of sodium valproate or a beta-adrenergic

agonist.

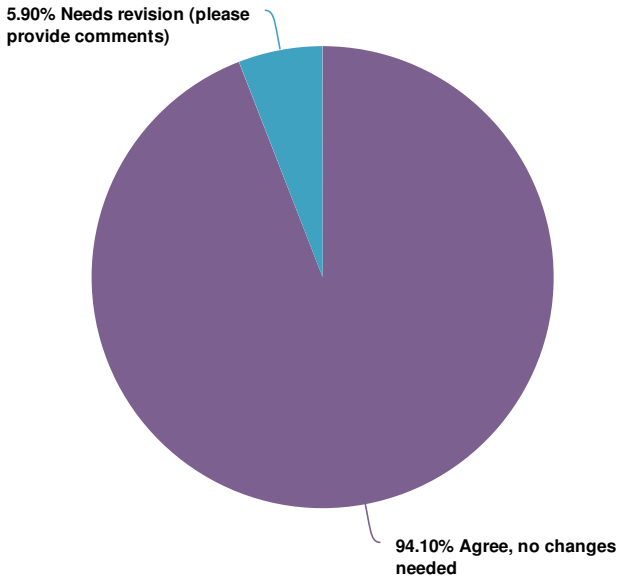


Value	Percent	Responses
Agree, no changes needed	100.0%	17
		Total: 17

228. To what extent do you agree with the following recommendation?Be aware that isolated postural tremor in children may be a side effect of sodium valproate or a beta-adrenergic agonist. - comments

Count	Response
1	A good point

229. To what extent do you agree with the following recommendation?Offer thyroid function tests for children with isolated postural tremor.



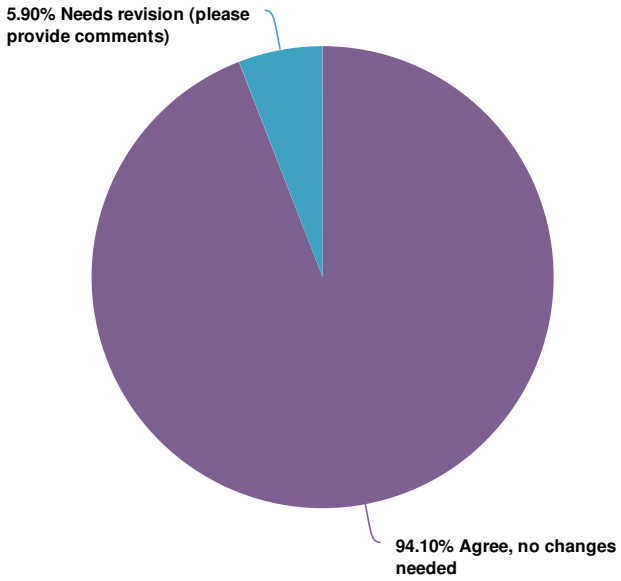
Value	Percent	Responses
Agree, no changes needed	94.1%	16
Needs revision (please provide comments)	5.9%	1

Total: 17

230. To what extent do you agree with the following recommendation?Offer thyroid function tests for children with isolated postural tremor. - comments

Count	Response
1	Suggest " Examine for signs of thyroid disease and consider thyroid testing"

231. To what extent do you agree with the following recommendation?Refer children with postural tremor for occupational therapy only if the tremor is affecting activities of daily living such as writing, eating and dressing.



Value	Percent	Responses
Agree, no changes needed	94.1%	16
Needs revision (please provide comments)	5.9%	1

Total: 17

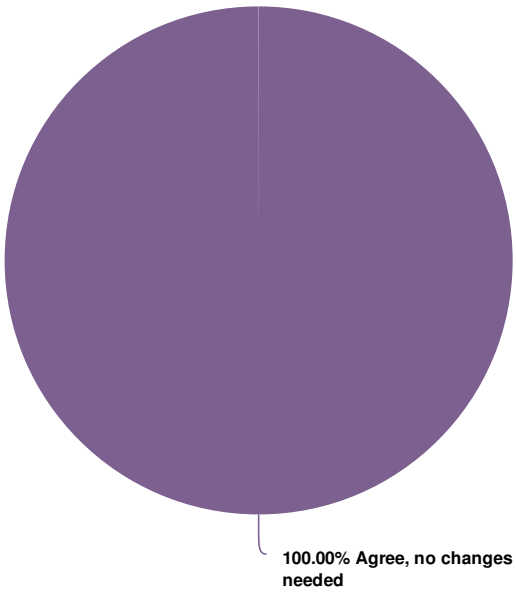
232. To what extent do you agree with the following recommendation?Refer children with postural tremor for occupational therapy only if the tremor is affecting activities of daily living such as writing, eating and dressing. - comments

Count	Response
1	Severe limitation in access to OT for older children hence in practice these referrals will often be rejected
1	take out "only"

233. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	A family history may be elicited in children with benign essential tremors.
1	General comments - some people get tremor on even low doses inhaled salbutamol and similar medications and it isn't always appropriate to withdraw. Also, tremor in children will be a rare presentation to individual GP's. This is another situation where phone advice to GP might be useful. Facing the Future described how children's health services might configure to provide advice and support and offer more care in the community. However, most areas have't had the resources to do this.
1	Out of scope

234. To what extent do you agree with the following recommendation?For recommendations on assessing sudden-onset unsteady gait in adults, see the NICE guideline on stroke and transient ischaemic attack in over 16s.

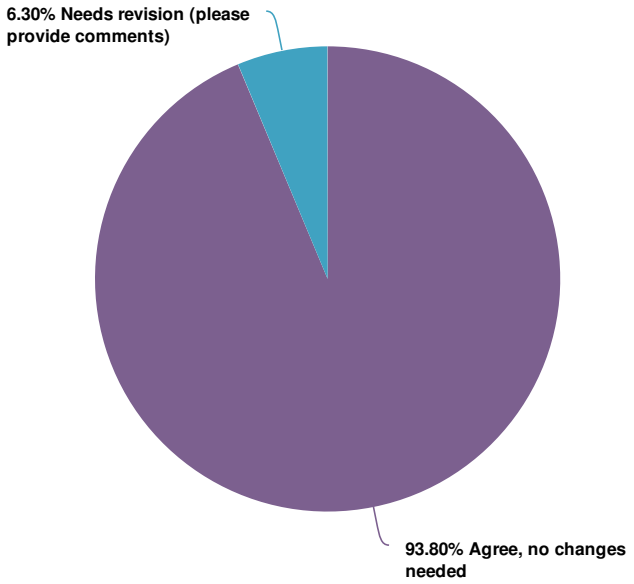


Value	Percent	Responses
Agree, no changes needed	100.0%	16
	Total:	**16**

235. To what extent do you agree with the following recommendation?For recommendations on assessing sudden-onset unsteady gait in adults, see the NICE guideline on stroke and transient ischaemic attack in over 16s. - comments

Count	Response

236. To what extent do you agree with the following recommendation?Refer adults with rapidly (within days to weeks) progressive gait ataxia for urgent (within 2 weeks) neurological assessment.



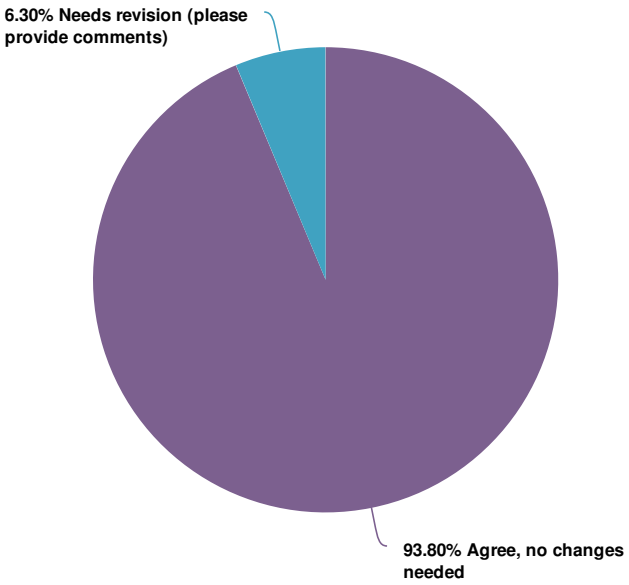
Value	Percent	Responses
Agree, no changes needed	93.8%	15
Needs revision (please provide comments)	6.3%	1

Total: 16

237. To what extent do you agree with the following recommendation?Refer adults with rapidly (within days to weeks) progressive gait ataxia for urgent (within 2 weeks) neurological assessment. - comments

Count	Response
1	Correct, but note this is often caused by metabolic conditions such as hyponatremia rather than a primary neurological disorder. It would be appropriate for GP to do a metabolic screen and medication review in the first instance.

238. To what extent do you agree with the following recommendation?Refer adults with unexplained gradually progressive unsteady gait for neurological assessment.



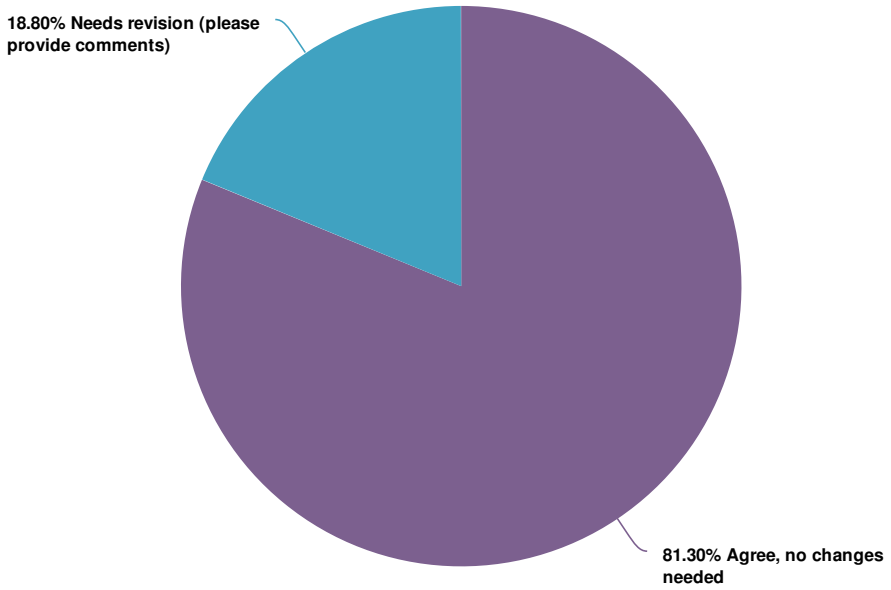
Value	Percent	Responses
Agree, no changes needed	93.8%	15
Needs revision (please provide comments)	6.3%	1

Total: 16

239. To what extent do you agree with the following recommendation?Refer adults with unexplained gradually progressive unsteady gait for neurological assessment. - comments

Count	Response
1	Unsteady gait is common in older arteriopaths so does not always need referral.

240. To what extent do you agree with the following recommendation?For adults with a gradually progressive unsteady gait, take an alcohol history and consider serological testing for gluten sensitivity.



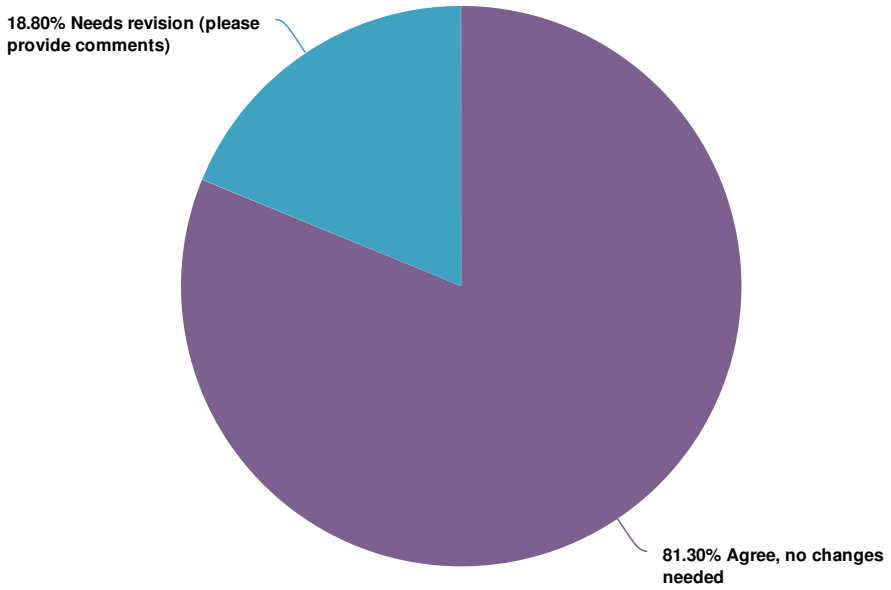
Value	Percent	Responses
Agree, no changes needed	81.3%	13
Needs revision (please provide comments)	18.8%	3

Total: 16

241. To what extent do you agree with the following recommendation?For adults with a gradually progressive unsteady gait, take an alcohol history and consider serological testing for gluten sensitivity. - comments

Count	Response
1	In consistent with #67. Agree take alcohol history. Then refer.
1	Omit testing for gluten sensitivity
1	Remove gluten sensitivity

242. To what extent do you agree with the following recommendation?Refer adults who have difficulty initiating and coordinating walking (gait apraxia) and for whom surgery is suitable to neurology or an elderly care clinic to exclude normal pressure hydrocephalus.



Value	Percent	Responses
Agree, no changes needed	81.3%	13
Needs revision (please provide comments)	18.8%	3

Total: 16

243. To what extent do you agree with the following recommendation?Refer adults who have difficulty initiating and coordinating walking (gait apraxia) and for whom surgery is suitable to neurology or an elderly care clinic to exclude normal pressure hydrocephalus. - comments

Count	Response
1	Is up to surgeon to determine if surgery suitable. i would remove the comment about "if surgery is suitable"
1	NPH is a diagnosis commonly considered and rarely substantiated. Most have diffuse cerebrovascular disease. NPH cannot be diagnosed from neuroimaging.
1	“Gluten sensitivity is one of the most common treatable causes of sporadic gait ataxia. Often, non-specialists do not consider it as a possible diagnosis. Gluten sensitivity may result in malabsorption and hence malnutrition. Frequently, low B12 levels can lead to peripheral neuropathy and sensory ataxia. Gluten sensitivity can present at any age. If it is identified, primary care can treat it independently of gait ataxia. There is no advantage in waiting for a neurological assessment. The NICE coeliac guideline recommends considering tests for coeliac disease in people with unexplained neurological symptoms, particularly peripheral neuropathy or ataxia.” Perhaps this text would be better in the preceding row (covering ataxia) rather than in this row (covering gait apraxia)? The text can also probably be reduced as there is some duplication/redundancy with the existing text in the preceding row.

244. Are there any additional recommendations that you would include regarding the recognition and referral of this sign/symptom?

Count	Response
1	Emphasise importance of Falls Prevention Team particularly for older people
1	no

245. Do you have any other comments regarding this guideline?

Count	Response
1	Consider pain (neuralgias), sensory disturbances, spinal cord symptomatology, functional disorders in children, loss of vision (very important), dysphagia
1	I found it useful and I have learned a lot from taking part.
1	I have some concerns that this is a rather mixed bag of various symptoms, and i am a little unclear as to the target audience, (presumably GPs) and how this is going to be implemented?
1	I suggest more explicit explanation of terms such as "acute onset" , "new onset" and time frame for referrals which are not considered immediate or urgent. Explanation of "neurological assessment". Does this just mean "examination of the neurological system " which should be included in all paediatric medical examinations
1	NO thank you. A pleasant and useful experience
1	No
1	No, I think the guideline is comprehensive and gives clear guidance to the correct management of many clinical presentations.
1	Referral speed isn't clear from my reading of these notes. Does urgent mean within a few weeks, or immediately (eg via 999 ambulance)? In one place the text says 'Urgent (within two weeks)' as if there is another degree of urgency elsewhere in the document. For a doctor working in primary care it would be useful to know whether a condition requires 999 to A&E, medical referral to the local hospital, a medical referral to a nearby specialist centre (to cut out the middle man), an 'urgent' referral (via letter that might take a day or two to be typed from dictation) or a routine referral. I did not see any advice on adults with dizziness - I commented on a section for dizziness in children I seem to remember. In the USA anyone with dizziness is encouraged to attend their ED departments in case it is stroke. Would there be room to mention this anywhere? It's a sore point for me having failed a CSA station during the MRCGP (and subsequently the exam by 2 marks) after the station I wa
1	Thanks for the opportunity to comment on this draft guidance. I am a very strong supporter and advocate of NICE. I think that NICE's evidence-based approach to clinical practice is extremely powerful for GPs who need to rapidly access the best quality clinical information. In the absence of evidence, a rigorous expert and consensus-based approach to guideline development provides pragmatic advice for generalists despite the inevitable uncertainty when evidence is lacking. In keeping with the above, this draft guidance is well structured and easy to read and overall I think it is excellent. 'Neurological Conditions' is a very diverse and complex topic and the draft guidance provides a nice structure and is relatively easy to read. However, I would like to raise a few issues: Accessibility of the Guidance GPs typically have 10 minute appointments and very little non-contact time to reflect and read about specific conditions seen earlier in the day/week (although we obvious l

Count	Response
1	Thorough and has certainly been thought through; my concerns are the 'bottlenecks' already present regarding access and referral to various specialist services and how this could be worsened with current recommendations and how to raise this as a matter that needs addressing (ie resources)
1	Too much emphasis on rarities e.g. neuro presentation of gluten sensitivity. Questionnaire should have "no comment/no opinion" option.
1	Very comprehensive and easy to understand.
1	Yes. There is scope to include advice pertaining to other common presentations. Headache For example, there is no guidance for headache and the importance of recognising medication overuse headache. There is opportunity to cross-refer to existing NICE guidance, or local headache guidance (eg http://www.lancsmmg.nhs.uk/download/guidelines/NW%20Headache%20Management%20Guideline%20(Version%2010).pdf). Neurology referral is most often not necessary for headache. We have some local guidance on GP referral forms: "Is this referral for migraine or medication overuse headache?" "Is yes, has standard symptomatic and/or preventative medication been tried?" "Has any previous specialist advice been followed?" "Have the British Association for the Study of Headache (BASH) guidelines been consulted?" (or local / NICE guidance) Suspected CNS cancer On a related theme, there is opportunity to give further guidance about suspected CNS cancer referrals (with cross reference to appropriate
1	a comprehensive guideline. well done.
1	no
1	should clarify eliciting history of possible causes of symptoms such as medications as well as other factors such as emotional, school or domestic that may be a possible factor for the symptoms.
1	think its really important to include definitions and also to qualify statements like "when epilepsy is suspected" - to guide the non-specialist
1	well done