

Appendix A: Stakeholder consultation comments table

2019 surveillance of Child maltreatment: when to suspect maltreatment in under 18s (2009)

Consultation dates: 29 November 2018 to 4 January 2019

Do you agree with the proposal not to update the guideline?			
Stakeholder	Overall response	Comments	NICE response
Parent Advocacy Network on Child Protection	No	No The guideline has serious errors in its analysis and interpretation of the research evidence often overstating the need for 'suspicion' of abuse. This is exemplified by recent research which has criticised the guideline's recommendations regarding bruising in premobile infants (Bilson, 2018). This paper concluded that:	Thank you for your response. Thank you for highlighting these concerns. This guidance provides a summary of the clinical features associated with child maltreatment that may be observed when a child presents to healthcare professionals.
		'The NICE pathway has shortcomings in respect of bruising in premobile infants. It lacks a definition of "not independently mobile" despite using this as a category for suspicion. It does not provide an assessment of the "epidemiology, incidence, prevalence and natural history"	In the development of the recommendation for bruising and petechiae in this guideline, one systematic review was identified by the guideline committee that included 23 studies. Drawing on the evidence and clinical practice, there was consensus within the guideline committee about the recommendations made for this area.

(Public Health England, 2015) of physical child abuse in premobile children. Among other things, this means that the evidence of the association between a bruise and the likelihood of physical abuse is not robust. The small number of research papers on bruises in premobile children, their limitations, and the inconsistency of their results is not sufficiently acknowledged in the guidance, and it is particularly concerning that the guidance has not been updated to take account of Kemp et al.'s (2015) research.'

This latter research, led by Kemp the Clinical Advisor to the Guideline Development Group, is cited by herself and colleagues to indicate that bruising in pre-mobile infants is 'very uncommon' despite it showing that 1 in 15 pre-mobile infants had an accidental bruise on any day and 27% had one over an average of 7 to 8 weekly observations – a finding that Clifford (2015), a consultant paediatrician, responding in a letter to Kemp et al.'s article pointed out was "[I]ost in the text of the results section" and was not reported in the abstract or summary of results. This research thus shows that bruises caused by accidents are common, affecting a large proportion of all premobile babies at some time during this stage of development. In contrast, non-accidental physical injuries amounting to significant harm are thankfully rare - out of just under a million individuals who were aged under six months at some time during the 2016-17 financial year, 410 were found to be physically abused and placed on a child protection plan, including some who did not suffer bruises (Source: Freedom of Information request response by the Department for Education and annual birth rate statistics for England). The very high probability that bruises in

Recommendation 1.1.2 states to 'suspect child maltreatment if there is bruising or petechiae (tiny red or purple spots) that are not caused by a medical condition (for example, a causative coagulation disorder) and if the explanation for the bruising is unsuitable.' Examples are given, including bruising in a child who is not independently mobile. The term 'not independently mobile' is considered suitably clear for healthcare professionals using the guideline. Evidence on bruising was identified through this surveillance review but was not considered to have an impact on current recommendations.

Thank you for highlighting the research by Kemp et al (2015). Kemp et al (2015) was one of the papers identified during the surveillance review. Its results found that more bruises were recorded in data collections in mobile children (45.6% in early mobile and 78.8% in walking children) compared to premobile children (6.7%). It also provides findings on distribution of bruises. It is not a comparative study of bruising in non-abused children compared with bruising in abused children. It also relied on data collection on bruises being performed by parents over a prolonged time period and it is not certain whether all recording of bruises was accurate and there was possible selection bias depending on parents' willingness to participate.

A systematic review by the RCPCH on bruising conducted in 2017 was also identified in this surveillance review and referred to bruising in children who are not independently mobile. Kemp at al (2015) was included in the systematic review. Its key findings state that 'Bruising was the most common injury in children who have been abused and a common injury in non-abused children, the exception to this being in non-mobile infants where accidental

children who are not independently mobile are likely to be accidental thus shows the error in the evidence statement that they are "suggestive of physical child abuse" (Guidance page 26) and thus form a basis for 'suspicion'. This is a very important flaw in the guidance because promoting the view that accidental bruises are rare misleads professionals, including paediatricians, who have to make the difficult assessment of whether a bruised child is one of the genuinely rare group who are seriously physically harmed by a parent.

Similar issues can be seen in other criteria where the false logic that an indicator is more common in maltreated children is taken to mean that it provides an indication of a need for concern. For example, the evidence base for including the presence of petechiae seems sparse and worthy of further consideration. The cited evidence in the paper by Nayak et al. (2005) is very weak as the paper used assessments by paediatricians to determine whether a child was abused in a study designed to measure whether unexplained petechiae can be used as a diagnostic instrument. This is despite the paper acknowledging that "clinical anecdote suggests that petechiae with or without other bruising may indicate an increased likelihood of nonaccidental injury" and there was no attempt made to ensure that petechiae were not being used as an indication that the child was abused thus negating the methods used. In addition, two studies of the presence of petechiae in the general population of children aged under one-year-old are not cited in the evidence for the guidelines and these found

bruising is rare. The number of bruises a child sustains increases as they get older and their level of independent mobility increases.' This is consistent with this guideline's recommendations which includes the consideration of medical conditions and other explanations for the bruising.

We acknowledge that not all bruising in children, including children who are not independently mobile, will be due to maltreatment and appreciate your concerns. Under 'Using this guidance', it is expected that if a healthcare professional encounters a potential alerting feature of child maltreatment that they follow a detailed process before arriving at any suspicion of maltreatment. This includes piecing together information from different sources and seeking an explanation for any injury or presentation from both the parent or carer and the child or young person in an open and non-judgmental manner. The guideline committee noted that it is important to exclude bruises from everyday activity, accidental injury, meningococcal septicaemia and other blood disorders.

The NICE guideline on child abuse and neglect (NG76) includes recommendations on assessing risk and need and the multi-agency response to child abuse and neglect, which are areas which are out of the scope of CG89. NICE guidelines NG76 and CG89 share a common pathway which brings together the recommendations from both guidelines in an interactive flowchart.

that it was common for all babies to have a small number of petechiae (10% of all children under-one-year-old Soheilifar et al., 2012; and 25% Downes, et al., 2002). This again exemplifies the lack of a critical appraisal of the quality of research evidence.

The guidance does not conform to the high standards that are expected of NICE Guidelines including those concerning conflicts of interest. It is concerning that the Clinical Advisor to the Guideline Development Group did not declare any interests despite receiving funding from the National Society for Prevention of Cruelty to Children a charity committed to "influencing legislation, policy, practice, attitudes and behaviours ... through a combination of service provision, lobbying, campaigning and public education." Some of her research, which formed a major part of the evidence for the guidelines, was directly supported by the NSPCC. It is not suggested that Professor Kemp was attempting to hide this involvement which is well known, but not seeing this as an interest needing to be declared demonstrates a potential bias concerning an organisation that campaigns on child protection issues and has been criticised for exaggerating the level of child abuse (e.g. https://www.independent.co.uk/news/uk/homenews/nspcc-accused-of-risking-its-reputation-andwhipping-up-moral-panic-with-child-porn-addiction-study-10171195.html and https://www.thirdsector.co.uk/charities-exaggerate-raise-

Thank you for highlighting additional papers. Bilson et al (2018) is out of scope based on its abstract describing it as a review of the policies of children's services departments rather than evidence on the features associated with child maltreatment that may present to healthcare professionals. The publication by Clifford (2015) is a letter and therefore the study type would not meet the criteria to be included in this review. Downes et al (2002), Nayak et al (2006) and Soheilifar et al (2010) are out of the date range used for this review as they would have been available at the time of the last <u>surveillance review</u> in 2012.

Finally, in relation to your point concerning conflicts of interest, the guideline was developed in line with the 2004 version of the guidelines manual and all conflicts of interest should be managed according to the relevant NICE policy on declaring and managing interests for NICE advisory committees. Although we acknowledge that the guidelines manual has subsequently been updated since CG89 was developed, it was still produced using robust systematic methods and processes. The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. The evidence used in the development of this guideline is available in the 'Evidence table' published on the NICE website, which includes relevant information where known on the source of funding of the research included.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

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		Bilson, A. (2018). Policies on bruises in premobile children: W hy we need improved standards for policymaking. Child & Family Social Work.	
		Clifford, R.G. (2015). Cross-sectional presentation of longitudinal data. Archives of Disease in Childhood	
		Downes, A. J., Crossland, D. S., & Mellon, A. F. (2002). Prevalence and distribution of petechiae in well babies. Archives of disease in childhood, 86(4), 291-292.	
		Kemp, A. M., Dunstan, F., Nuttall, D., Hamilton, M., Collins, P., & Maguire, S. (2015). Patterns of bruising in preschool children—a longitudinal study. Archives of disease in childhood, archdischild-2014.	
		Nayak, K., Spencer, N., Shenoy, M., Rubithon, J., Coad, N., & Logan, S. (2006). How useful is the presence of petechiae in distinguishing non-accidental from accidental injury?. Child abuse & neglect, 30(5), 549-555.	
		Soheilifar, J., Ahmadi, M., Ahmadi, M., & Mobaien, A. R. (2010). Prevalence and location of petechial spots in well infants. Archives of disease in childhood, 95(7), 518-520.	
BASPCAN	No	BASPCAN does not agree with the proposal not to update the guidelines. Evidence has expanded significantly since 2012 as pointed out by the expert reviewers. It is our position that there is applicable research that will enhance the guideline. It appears that the methodology and inclusion criteria for research does not necessarily capture all relevant data on the subject areas. It would be useful to	Thank you for your response. The remit of NICE is to develop evidence-based guidance, based on a systematic and transparent review of the evidence. Our methodology and inclusion criteria are to ensure high quality outputs. Further details about the process can be found in the manual for developing NICE guidelines.
		have criteria that recognise a broader range of research	

		evidence, particularly as the evidence base is rapidly emerging. The example of Fabricated and Induced Illness (FII) is instructive here. This is an area of abuse where known numbers are small and it is often categorised as emotional, physical abuse and/or neglect. This leads to underrecognition of the specific nature of this abuse and its exclusion from research which does not assist practitioners in recognising and understanding this specific form of abuse. The guidance should not just reflect existing limited research but help practitioners to consider FII as a possibility. This will then help to develop the evidence base and mitigate against current under-recognition.	No evidence that met our review criteria was identified in the surveillance review process that would impact on the guideline recommendations. Research recommendations are developed to increase the evidence base in poorly researched areas. Fabricated or induced illness is an area included under 2.3 in the guideline's research recommendations.
Royal College of Paediatrics and Child Health	Yes	Yes, there isn't any significant new evidence since 2009 however, it is felt that having separate guidance on Maltreatment and Abuse and Neglect is confusing. It could easily be thought that the 2017 Child Abuse and Neglect Guidance superseded the Maltreatment 2009 guidance and thus no longer look at the Maltreatment guidance due to not realising the different emphasis on each of the guidelines.	Thank you for your response. The NICE guideline Child Abuse and Neglect cross-references to the NICE guideline on Child maltreatment: when to suspect maltreatment in under 18s and there is a single NICE pathway on child abuse and neglect covering these areas. We acknowledge the overlap between the guidelines and will endeavour to conduct surveillance of the two guidelines together in future.
Parents Protecting Children UK	No	No. I do not agree with the decision not to update the guideline. The reason that I disageee is that the guideline is so frequently misinterpreted, that it must be inadequate or unfit for purpose. Since the guideline was published we have changed from Statements of Special Educational Need to Education, Health and Care Plans, with a much greater emphasis on 'working together'. Sadly this new system (which had the potential to have been good) has	Thank you for your response. We appreciate the impact that investigations for child maltreatment can have on families. NICE guideline CG89 provides a summary of the clinical features associated with child maltreatment that may be observed when a child presents to healthcare professionals with the aim of raising awareness among people who are not child protection specialists. Under 'Using this guidance', it is expected that if a

been under resourced and many of the additional professional or ancillary staff involved have been working beyond their area of expertise or experience. This has led to a vastly increased number of 'risk assessments' based on Local Authority or Voluntary Organisations guidelines (which are designed to be compliant with the NICE guideline on child maltreatment). These risk assessments are made in situations where nobody has a sufficiently clear view of the whole picture to make a common sense judgement; and / or with the fear of professional careers stalling if things go wrong and a family's problems escalate. Nobody considers the fact that these investigations are not benign - they cause severe educational, medical and social disruption, leaving children stigmatised and often bullied, leaving innocent parents suffering from PTSD in the wake of official intrusion into their families. Investigations frequently precipitate job loss for parents and the costs of legal defence may cause families to lose their homes. The investigations waste scarce and precious resources, (which could have been used to help and support the child and family) to investigate the family in an adversarial manner which makes innocent parents feel as if they are regarded as criminals. Very many children have been temporarily or permanently removed from their families on the basis of these flawed, hyperactive risk assessments. If this is happening as a result of these NICE guidelines, then something must be very wrong with the guidelines. What is needed is not a line by line tweaking of individual points in the guidance, but a fundamental review of the way in which the guidance is being used and what is going wrong to cause the sharp and still escalating rise in the number of

healthcare professional encounters a potential alerting feature of child maltreatment that they follow a detailed process before arriving at any suspicion of maltreatment. This includes piecing together information from different sources and seeking an explanation for any injury or presentation from both the parent or carer and the child or young person in an open and non-judgmental manner.

We appreciate your concerns about the current system. Resourcing of the system; professionals' competency, training and behaviour; and how professionals proceed once they suspect child maltreatment, including risk assessments, investigations and child protection policies, are out of the scope of this guideline.

This guideline refers to the 'Working Together to Safeguard Children' document that provides statutory guidance on interagency working to safeguard and promote the welfare of children. The NICE guideline on child abuse and neglect (NG76) includes recommendations on assessing risk and need in relation to child abuse and neglect; early help for families showing possible signs of child abuse and neglect; multi-agency response to child abuse and neglect; therapeutic interventions; and planning and delivering services. NICE guidelines NG76 and CG89 share a common pathway which brings together the recommendations from both guidelines in an interactive flowchart.

Thank you for highlighting the report by Oxley (2017). This is a blog and therefore does not meet the evidence type for this surveillance review.

		child protection investigations and reception of children into care since the change to EHCPs. http://janloxley.blogspot.com/2017/02/for-conference-report.html	
Department of Health and Social Care	Yes	Yes. DHSC's Children, Families & Communities branch has no objection to CG89 not being updated, as long as there is a reference in it to the latest DfE `Working Together to safeguard children' guidance https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/729914/Working_Together_to_Safeguard_Children-2018.pdf	Thank you for your response. The reference in the guideline to the DfE 'Working Together to safeguard children' guidance has been amended to the latest version.
The Ehlers-Danlos Support UK	No	No. The Ehlers-Danlos Support UK believes the guidance should be updated in light of a recent review showing many local safeguarding boards' policies for when to initiate an S47 investigation are based on flawed interpretation of evidence (Bilson, A., (2018) Policies on bruises in premobile children: Why we need improved standards for policymaking. Child & Family Social Work 23:676–683 https://doi.org/10.1111/cfs.12463). The guidance makes several assumptions about potential indicators of maltreatment which seem flawed given the cited review and we feel it is overly biased towards initiating investigations rather than working in partnership with parents/care-givers, especially where there is a history of specific medical conditions within the family.	Thank you for your response. This guidance provides a summary of the clinical features associated with child maltreatment that may be observed when a child presents to healthcare professionals. The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. Child protection policies and how healthcare professionals should proceed once they suspect maltreatment and child protection policies are out of the scope of this guideline. The NICE guideline on child abuse and neglect (NG76) includes recommendations on assessing risk and need in relation to child abuse and neglect; therapeutic interventions; and multi-agency response to child abuse and neglect. NICE guidelines NG76 and CG89 share a common NICE pathway which brings together the recommendations from both guidelines in an interactive flowchart.
		Our organisation is contacted by approximately 20 families per year where Ehlers-Danlos syndromes coincide with	It is not possible for the guideline to cover every scenario a healthcare professional may encounter. Under 'Using this guidance'

		investigations of suspected maltreatment of children. The majority of these cases have not resulted in a child protection plan (the term 'majority' is used here only as we do not know the outcome of every case we are contacted about). We recommend adding more information to the guidance about the need to be especially aware of medical conditions which have symptoms which could also indicate potential maltreatment (e.g. inherited connective tissue disorders).	in the guideline it is expected that if a healthcare professional encounters a potential alerting feature of child maltreatment that they follow a detailed process before arriving at any suspicion of maltreatment. This includes piecing together information from different sources and seeking an explanation for any injury or presentation from both the parent or carer and the child or young person in an open and non-judgmental manner. Thank you for highlighting that some medical conditions could have symptoms which could also indicate potential maltreatment (e.g. inherited connective tissue disorders). The definition of unsuitable explanation is accounted for in the guideline and includes an injury or presentation that is implausible, inadequate or inconsistent with existing medical conditions. Some recommendations under sections 1.1 (physical features), 1.2 (clinical presentations) and 1.4 (emotional, behavioural, interpersonal and social functioning) refer specifically to suspecting or considering maltreatment if there is no obvious medical explanation or an absence of a relevant medical condition. No evidence on this area was identified in this review to indicate these recommendations should be updated.
Royal College of Nursing	Not answered	No comments to submit.	Thank you for your response.
Royal College of Psychiatrists	Not answered	If the below comments can be added without updating the guideline, in the form of amendments, that should be done. Otherwise would recommend updating CG89.	Thank you for your response.

Fiightback No

We at Fiightback feel the new update proposed regarding the guidelines has serious errors, which we have addressed below. As parents who have been affected by The system, and the errors within it we are greatly concerned. We are living proof that this system does not work, and that support within this system is flawed. When parents are too afraid to ask for help or to state concerns regarding their children,the system obviously is broken. Parents lose children often, there same children placed into a perpetuating system.

The terminology "the need for 'suspicion' of abuse", clearly shows this. After reading leading research from well respected individuals shows that a similar of false logic in other criteria can be seen. The definition of "not being independently mobile "is unclear, despite this being used as a main category of suspicion. Leading to potential to misuse this criteria. There is not an assesment of the "epimiology, incidence, and natural history" (public health England 2015). Thus meaning that amongst other things the evidence of association between a bruise in pre mobile children and the likelihood of abuse. The small number of research papers available in this arena do not give enough guideline to correlate and provide professional guidance.

Baring in mind 1 in 15 pre mobile children have an accidental bruise on any given day in a 7/8 weekly observation (how many carers can list where this came from?) Of these surveyed 28% had more than one. The

Thank you for your response.

Thank you for raising your concerns. This guidance provides a summary of the clinical features associated with child maltreatment that may be observed when a child presents to healthcare professionals. Under 'Using this guidance', it is expected that if a healthcare professional encounters a potential alerting feature that they follow a detailed process before arriving at any suspicion of maltreatment. This includes piecing together information from different sources and seeking an explanation for any injury or presentation from both the parent or carer and the child or young person in an open and non-judgmental manner.

Early support for families; child protection policies; the impact of false allegations; and the treatment and care of the child if maltreatment is suspected are out of the scope of this guideline but recommendations may be found in other guidance. This guideline refers to the 'Working Together to Safeguard Children' document that provides statutory guidance on inter-agency working to safeguard and promote the welfare of children. The NICE guideline on child abuse and neglect (NG76) includes recommendations on assessing risk and need in relation to child abuse and neglect; early help for families showing possible signs of child abuse and neglect; multi-agency response to child abuse and neglect; principles for working with children, young people, parents and carers; factors that increase vulnerability; therapeutic interventions; and planning and delivering services. NICE guidelines NG76 and CG89 share a common pathway which brings together the recommendations from both guidelines in an interactive flowchart.

document drafted does not adhere to the standards of previously published NICE guidelines. There has been sparce considerations to other mitigating factors (undiagnosed health issues etc) The guidelines do not consider the impact of false allegations on both parents and children, the post traumatic issues that the nhs will surely be expected to address. The trauma caused is long lasting and intergenerational, leading to parent mistrust in the very professionals whom are supposed to provide assistance. Fiightback and others have seen such a great increase already in those falsely accused. The guideline provides no measures of sensitivity of those accused, false suspicion rarely leads to help when needed by these families. Merely a label, a 'black Mark' on their records.

Early intervention programs have drastically reduced in the last few years, leading to a break down of support for families. If the investigative responses used in the UK are found to be effective in the protection and early intervention, preventing further harm we wound surely have seen a decline in cases and referrals? Shockingly data shows that 1 in 5 under 5s are known to services, and a 30% increase in section 47 enquiries. This is truly shocking.

To carry out a screening program across the populous of UK minors would need strong evidence that there is a treatment for the condition diagnosed. At present fii/munchausen by proxy is still disputed and no known treatment options are available. That is un conceivable. We feel that the NICE guidelines should be further

In the development of the guideline, one systematic review (n=23) studies) relating to bruising was identified by the guideline committee. Recommendation 1.1.2 states to 'suspect child maltreatment if there is bruising or petechiae (tiny red or purple spots) that are not caused by a medical condition (for example, a causative coagulation disorder) and if the explanation for the bruising is unsuitable.' Examples are given, including bruising in a child who is not independently mobile. The term 'not independently mobile' is considered suitably clear for healthcare professionals using the guideline. Evidence on bruising related to children who are not independently mobile was identified in this surveillance review: Kemp et al (2015) and a systematic review by the RCPCH on Bruising (2017). These both found that bruising is more common in children who are independently mobile compared to children who are premobile. It is acknowledged that not all bruising in premobile children will be due to maltreatment and the guideline advises that they follow a detailed process before arriving at any suspicion of maltreatment. The guideline committee noted that it is important to exclude bruises from everyday activity, accidental injury, meningococcal septicaemia and other blood disorders.

Thank you for highlighting that some medical conditions could have symptoms which could also indicate potential maltreatment (e.g. inherited connective tissue disorders). The definition of unsuitable explanation is accounted for in the guideline and includes an injury or presentation that is implausible, inadequate or inconsistent with existing medical conditions. Some recommendations under sections 1.1 (physical features), 1.2 (clinical presentations) and 1.4 (emotional, behavioural, interpersonal and social functioning) refer specifically to suspecting or considering maltreatment if there is no

		reviewed in regards the proposed changes, both for the safety of the children effected and for a more tangible way to assess these cases to be provided. Thus saving lives and finances in duality.	obvious medical explanation or an absence of a relevant medical condition. No evidence on this area was identified in this review to indicate these recommendations should be updated. In developing the recommendations about considering or suspecting maltreatment, the guideline committee carefully considered any available evidence, they also used formal consensus processes and their own knowledge and experience. With individual cases there are many variables to be considered, context will vary, and there will be confounding factors. This would make calculations of sensitivity, specificity, and the effect of false positives or negatives, difficult and imprecise. The variability with each case would not lend this guideline to a classification as a screening programme. No new evidence has been identified of that would confidently allow sensitivity and specificity of the features of child maltreatment to be given. The treatment and care of a child once maltreatment is suspected is out of the scope of this guideline.
Faculty of Dental Surgery	Not answered	General comment - there is no reference to concerns that might be raised when parent/carers fail to bring children to healthcare appointments. This is an important issue, and all healthcare professionals should appreciate the potential link with child maltreatment and missed appointments p15, 1.1.14 There is no current reference to dental caries and potential neglect. Healthcare professionals should be	Thank you for your response. In the development of the guideline, the guideline committee found the available evidence showed no certainty about the relationship between poor oral health and child maltreatment. Delphi methods related to failure to access appropriate medical care or treatment were conducted. This led to a number of recommendations related to access to appropriate medical care and treatment and neglect, including:

		made more aware of the potential link between high caries experience, dental infection and overall neglect	- Recommendation 1.3.10 'Consider neglect if parents or carers repeatedly fail to bring their child to follow-up appointments that are essential for their child's health and wellbeing.' - Recommendation 1.3.12 'Consider neglect if parents or carers have access to but persistently fail to obtain treatment for their child's dental caries (tooth decay).' No new evidence on oral health was identified in this surveillance review to indicate these recommendations should be updated.
Do you have any com	ments on areas ex	xcluded from the scope of the guideline?	
Stakeholder	Overall response	Comments	NICE response
Parent Advocacy Network on Child Protection		Yes. The guideline has no measures of sensitivity or specificity of the proposed criteria for suspecting abuse; does not consider the impact of false positives or negatives; and does not consider whether the proposed intervention will reduce harm, or whether it is the best approach to reduce maltreatment. The guideline aims to cover "the signs of possible child maltreatment in children and young people aged under 18 years." It thus conforms to the UK National Screening Committee's defintion of screening: "The systematic application of a test, or inquiry, to identify individuals at sufficient risk of a specific disorder to warrant further investigation or direct preventive action, amongst persons who have not sought medical attention on account of symptoms of that disorder." Unlike decisions to implement screening, the guideline	Thank you for your response. For the recommendations about considering or suspecting maltreatment, the guideline committee carefully considered any available evidence, they also used formal consensus processes and their own knowledge and experience. With individual cases there are many variables to be considered, context will vary, and there will be confounding factors. This would make calculations of sensitivity, specificity, and the effect of false positives or negatives, difficult and imprecise. The variability with each case would not lend this guideline to a classification as a screening programme. We acknowledge your concerns about prevention, interventions and a rising number of investigations. The prevention of child

provides no measures of sensitivity or specificity of the criteria being proposed and thus there is no consideration of the level of false positives and false negatives that may occur due to the proposed criteria or of the harm that may be done by over diagnosis or false reassurance. Being suspected of abusing your child significantly harms families and children (Davies, 2011) causing shame and stigma (Gibson, 2016; Smithson & Gibson, 2017) and, where this is false suspicion, it rarely leads to help being offered or accepted even where a child is in need (Thorpe, Denman, & Regan, 2011).

To ethically justify a screening programme, especially one being carried out across the population of all children, it is essential that there is strong evidence that there is a treatment for the condition being screened for and that all appropriate preventive measures are in place. However, preventive programmes have been decimated in recent years (Clements, Ellison, Hutchinson, Moss, & Renton, 2017). There is also little evidence to show that, at the population level, child protection activity of the type used in England either reduces harm to children or promotes well-being. Gilbert et al. (2012 p.758) in a study across six countries including England considering neglect and physical maltreatment in children younger than eleven found "no clear evidence for an overall decrease in child maltreatment despite decades of policies designed to achieve such reductions". If the investigative responses used in the UK are effective in protecting children or preventing future harm we would expect to have seen a reduction in investigations and findings of abuse over time but there has been an increasing rate of both for the last fifteen years in England. It is sad to note that despite the considerable rise in investigations, the number of child deaths recorded by the Child Death Overview Panels as being due to deliberately inflicted injury, abuse or neglect have changed little since 2010, fluctuating between a low of 30 in 2010 and a high of 62 in 2014 (DfE, 2017). This is

maltreatment and interventions are out of the scope of this guideline. The impact of false suspicions; child protection policies; and the treatment and care of the child if maltreatment is suspected are also out of the scope of this guideline. This guideline refers to the 'Working Together to Safeguard Children' document that provides statutory guidance on inter-agency working to safeguard and promote the welfare of children. The NICE guideline on child abuse and neglect (NG76) includes recommendations on assessing risk and need in relation to child abuse and neglect; early help for families showing possible signs of child abuse and neglect; multiagency response to child abuse and neglect; principles for working with children, young people, parents and carers; factors that increase vulnerability therapeutic interventions; and planning and delivering services. NICE guidelines NG76 and CG89 share a common pathway which brings together the recommendations from both guidelines in an interactive flowchart.

Thank you for highlighting studies in this area.

Bilson et al (2019), Gilbert et al (2012) and the Department for Education (2017) describe epidemiological trends. These are out of scope as they do not provide new evidence on when to suspect child maltreatment. Clements et al (2017), an inquiry into children's social care services, is also out of scope as this guideline does not include recommendations on interventions, child protection procedures or service organisation. These areas are covered under the NICE guideline on child abuse and neglect (NG76).

Davies et al (2011), a personal reflective account, does not meet the criteria for inclusion in this surveillance review because of study type and is out of the date ranges used in this review. Gibson et al (2016) and Smithson et al (2017), which examine the experiences of

despite one in every five children being referred to children's services before their fifth birthday in 2016-17 and an increase of 30% in the rate of children being investigated in five years to one in every 16 children being investigated under section 47 of the 1989 Children and Young Persons Act before their fifth birthday in 2016-17 (Bilson and Munro, 2019).

Bilson, A., & Munro, E. H. (2019). Adoption and child protection trends for children aged under five in England: Increasing investigations and hidden separation of children from their parents. Children and Youth Services Review, 96, 204-211.

Clements, K., Ellison, R., Hutchinson, D., Moss, D., & Renton, Z. (2017). No Good Options: Report of the Inquiry into Children's Social Care in England.

Davies, P. (2011). The impact of a child protection investigation: A personal reflective account. Child & Family Social Work, 16(2), 201-209.

Department for Education (2017). Statistics: child death reviews. available from

https://www.gov.uk/government/collections/statistics-child-death-reviews.

Gibson, M. (2016). Constructing pride, shame, and humiliation as a mechanism of control: A case study of an English local authority child protection service. Children and youth services review, 70, 120-128.

Gilbert, R., Fluke, J., O'Donnell, M., Gonzalez-Izquierdo, A., Brownell, M., Gulliver, P., ... & Sidebotham, P. (2012). Child maltreatment: variation in trends and policies in six developed countries. The Lancet, 379(9817), 758-772. Smithson, R., & Gibson, M. (2017). Less than human: A qualitative study into the experience of parents involved in the child protection system. Child & Family Social Work, 22(2), 565-574.

Thorpe, D., Denman, G., & Regan, S. (2011). RIEP and

social workers and parents respectively, do not meet the criteria for inclusion in this review as they are out of scope. Thorpe et al (2011) does not meet the date range for this review as it would have been available at the time of the last surveillance review in 2012.

	ACDS Funded Safeguarding and Promoting Welfare Research Project. Yorkshire: Yorkshire and Humber DCS.	
BASPCAN	BASPCAN is of the opinion that a number of very significant areas are not covered in the review and agrees with the list provided by the topic experts. We suggest that a review group should be convened to determine the parameters of inclusion. BASPCAN would be willing to participate in this review group.	Thank you for your response. We acknowledge that areas were raised by topic experts that are not covered in this guideline, including risk factors for child maltreatment, factors that make disclosure of abuse difficult, child exploitation, female genital mutilation, and distinguishing more between younger people and children. There was either no or insufficient evidence on when to suspect maltreatment identified to indicate that the guideline should be updated, or the areas were out of the scope of this guideline. NICE has produced a guideline on child abuse and neglect (NG76) that addresses some of these topics and has a broader scope, including recommendations on factors that increase vulnerability to child abuse, factors that may make disclosure of maltreatment difficult and how to respond to suspected maltreatment. It also refers to recognising that children and young people may be trafficked for sexual exploitation and other reasons, and provides a recommendation on the action to take if this is suspected. There is also a recommendation on the action that should be taken if female genital mutilation is identified. NICE guidelines NG76 and CG89 share a common pathway which brings together the recommendations from both guidelines in an interactive flowchart.
Royal College of Paediatrics and Child Health	Attachment and emotional trauma (outside LAC) seem to lack clarity based on evidence and generate difficulties, challenges and barriers for children in practice – are these validated descriptions or defined conditions? If so what is	Thank you for your response. In the development of the guideline, the guideline committee reviewed evidence on disturbances of attachment. Two systematic

the evidence? There is a problem as certain tertiary centres do not accept these dimensions and seem to over emphasise other medical diagnoses in complex situations – sometimes missing safeguarding alongside or without primary neurodevelopmental conditions.

reviews were identified. The guideline committee noted that the literature used hypothetical scenarios to measure attachment and that it can be inferred that disorganised attachment in young children is associated with maltreatment, and 'aggression and difficulties in interpersonal relationships, compulsive caregiving and coercive controlling towards the parent are associated with disorganised attachment'. Whilst attachment is not specifically mentioned in the recommendations, the consequences of attachment issues are included under recommendations on emotional and behavioural states.

We did not identify any further evidence on attachment and emotional trauma through this surveillance review that would change recommendations.

Parents Protecting Children UK

Yes. Over the past two to three decades there have been massive developments in the awareness and diagnosis of invisible and often heritable disabilities and medical conditions. Research and knowledge has increased exponentially during the seven or eight years since the guidance was drafted and published. Much more is now known about conditions such as Ehlers Danlos Syndrome, Postural Orthostatic Tachycardia Syndrome . Mast Cell Activation Disorders and other immunological issues as well as changes and improvements to the understanding of previously known conditions such as Osteogenesis Imperfecta, ME / CFS and Autism Spectrum Differences & Difficulties. The statistical prevalence of genetic disorders is now thought to be much higher than it was when the NICE guidance was first published so the guidance is out of date. The guideline needs urgently to be updated to be abreast of these changes in medical understanding. Currently many children with these familial conditions, where siblings and / or parents may also be affected, are assumed to be 'faking it' or their parents are wrongly assumed to be over anxious, attention seeking or having

Thank you for your response.

We acknowledge the developments in the understanding of invisible and often heritable disabilities and medical conditions and your concerns around maltreatment. Under 'Using this guidance', it is expected that if a healthcare professional encounters a potential alerting feature of child maltreatment that they follow a detailed process before arriving at any suspicion of maltreatment. This includes piecing together information from different sources and seeking an explanation for any injury or presentation from both the parent or carer and the child or young person in an open and non-judgmental manner.

The definition of unsuitable explanation in the guideline includes an injury or presentation that is implausible, inadequate or inconsistent with existing medical conditions. Some recommendations under sections 1.1 (physical features), 1.2 (clinical presentations) and 1.4 (emotional, behavioural, interpersonal and social functioning) refer

	vivid imaginations. This misunderstanding by education, health and social care practitioners and the inadequacy or misinterpretation of current guidelines, means that far too many of these families find themselves under child protection surveillance, rather than receiving the help and support to which they should be entitled. Some children are wrongly removed from these families and placed for adoption, without the adoptive families awareness or understanding the child's heritable medical difficulties and with the child's new medical practitioners having no contact with, or ability to access, birth family genetic information to help with diagnosis and treatment. Unsurprisingly some of these adoptions are breaking down with devastating consequences for all concerned.	specifically to suspecting or considering maltreatment if there is no obvious medical explanation or an absence of a relevant medical condition. No new evidence was identified on medical conditions and heritable disabilities in this surveillance review to indicate that the recommendations should be updated. This guidance provides a summary of the clinical features associated with child maltreatment that may be observed when a child presents to healthcare professionals. It does not give recommendations on how to diagnose, confirm or disprove child maltreatment. Professionals' competency, training and behaviour; child protection policies; interventions; and the treatment and care of a child if maltreatment is suspected are out of the scope of this guideline. NICE's guideline on child abuse and neglect (NG76) that has recommendations on assessing risk and need; early help for families; principles for working with children, young people and carers; multiagency response; therapeutic interventions' and planning and delivering services.
Department of Health and Social Care	No (see above)	Thank you for your response.
The Ehlers-Danlos Support UK	Where neurodevelopmental disorders are mentioned as an example of something to consider when making assessments and talking to children, young people, parents/carers, we feel connective tissue disorders should also be listed as another example requiring special consideration due to symptoms of the various conditions and patterns which can cross over with signs of abuse and fabricated and induced illness.	Thank you for your response. This surveillance review did not find any evidence on connective tissue disorders as an example requiring special consideration in the guideline. We will add this comment to our issue log for the guideline for consideration at the next surveillance review.

Royal College of Nursing	No comments to submit.	Thank you for your response.
Royal College of Psychiatrists	We suggest that the following issues need to be made more explicit and clearly identified in NICE Guidance CG89 - The issues of young carers (to ensure they are recognised as such, assessed and get the right support) - Children and young people living in families where there is domestic abuse whether witnessed by them or not (living in a household where there is domestic abuse would constitute exposure to emotional abuse with/without physical abuse and neglect - Children and young people who are exploited and groomed could present as being in possession of money or material goods like jewellery, clothing and electronic gadgets which would be unlikely in their situation, frequent disappearances/absences without explanation.	with child maltreatment that may be observed when a child or young person presents to healthcare professionals. We found no evidence in this surveillance review on young carers in relation to child maltreatment. The assessment and support of young carers falls outside the remit of this guideline. Recommendation 1.5.1 in the guideline states to 'consider emotional abuse if there is concern that parent- or carer-child interactions may be harmful' and gives examples. In the full guidance one example is 'exposure to frightening or traumatic experiences, including domestic abuse'. The reference to domestic abuse does not appear in the website version of CG89 recommendations and we believe this omission is an error so will correct this as an editorial

		suspected. To note, recommendation 1.5.1 in the guideline refers to considering child abuse if there is a failure to promote the child's appropriate socialisation (for example, involving children in unlawful activities). Recommendation 1.2.13 refers to considering child maltreatment if a child has poor school attendance that the parents or carers know about that has no justification on health.
Fiightback	No comments submitted	Thank you.
Faculty of Dental Surgery	No comments submitted	Thank you.

Do you have any comments on equalities issues?

Stakeholder Overall response	Comments	NICE response
Network on Child Protection	Despite evidence of a strong relationship between deprivation and intervention rates and large inequalities between ethnic categories (e.g. Bywaters et al 2017) these issues are not addressed in the guideline. Bywaters, P., Brady, G., Bunting, L., Daniel, B., Featherstone, B., Jones, C., & Webb, C. (2018). Inequalities in English child protection practice under austerity: A universal challenge?. Child & Family Social Work, 23(1), 53-61.	Thank you for your response. In accordance with NICE's Equality Scheme, ethnic and cultural considerations and factors relating to disabilities were considered by the guideline committee throughout the development process and were specifically addressed in individual recommendations where relevant. No new evidence has been identified during this review on the association of deprivation or ethnicity with clinical features associated with child maltreatment to indicate the guideline should be updated. NICE's guideline on child abuse and neglect (NG76) provides recommendations on factors that increase vulnerability to child abuse and neglect. Recommendation 1.2.2 refers to socioeconomic vulnerability factors for child abuse and neglect.

		Thank you for highlighting the study by Bywaters et al (2018), which focuses on the relationship between economic inequality and out-of-home care and child protection interventions. Interventions and how healthcare professionals should proceed once they suspect maltreatment are out of the scope of this guideline.
BASPCAN	Gender is an important issue here. For example CSE and FGM primarily impact girls and young women as victims; Criminal Exploitation primarily impacts boys and young men; perpetrators of FII are primarily women and perpetrators of CSE and Criminal Exploitation are primarily men. Consideration should also be given to the relevance of ethnicity and physical or learning disabilities and how these intersect with broader categories of abuse as outlined by the topic experts. This applies to both victims and perpetrators of abuse.	Thank you for your response. In accordance with NICE's Equality Scheme, ethnic and cultural considerations and factors relating to disabilities were considered by the guideline committee throughout the development process and were specifically addressed in individual recommendations where relevant Under the section 'Using this Guideline, 2. Seek an explanation' it states that 'alerting features of maltreatment in children with disabilities may also be features of disability, making identification of maltreatment more difficult. Healthcare professionals may need to seek appropriate expertise if they are concerned about a child or young person with a disability.' No new evidence has been identified during this review on the association of disability, gender or ethnicity with clinical features associated with child maltreatment to indicate the guideline should be updated. NICE's guideline on child abuse and neglect (NG76) provides recommendations on factors that increase vulnerability to child abuse and neglect. Recommendation 1.2.6 refers to gender and recommendation 1.2.7 refers to disability.

Royal College of	(Apologies I am not sure which category to place these	Thank you for your response
Paediatrics and Child Health	comments under, I hope this is ok.) 1. Page 7 second paragraph line 6, page 11, 4. Third bullet point; it talks about health gathering information from other agencies not just other health agencies, care needs to be taken to not stray into investigation as that is not health's role. 2. The references on page 8 are neither comprehensive nor up to date. 3. It is likely that the consider, expect and exclude terminology was debated at length but the reality is that you can't absolutely exclude, in the same way as you can't absolutely identify, this should at least be discussed in the guidance. 4. Page 11 4, second bullet point; it should read a consultant paediatrician not a community paediatrician 5. The sexual abuse terminology has changed a little with the latest "physical signs of child sexual abuse" book so at 1.1.18 a fissure is now a laceration and at 1.1.19 a gaping anus would now be an anus exhibiting dynamic anal dilatation. 6. Ideas about fabricated or induced illness have evolved from the positions described. 7. On page 28 the references re the Sexual Offences Act are misleading and wrong in part. All sexual intercourse with a person under 16 is illegal. If the person is 13 to 15 years old and deemed to be consenting, the CPS advises a sensible approach but only if the person having sexual intercourse with them is young and there are no aggravating factors (need to clarify whether must be under 18). A child under 13 years old cannot consent to sexual intercourse whatever the age of their "partner". It is also an offence to have sexual intercourse with a 16 or 17-year-old if you are in a position of trust. Proper legal advice is	 Thank you for your response. The scope of NICE guideline CG89 excludes how healthcare professionals should proceed if they suspect maltreatment and child protection policies. Thank you for highlighting this. We will remove the references on p.8 (footnote 1 of the introduction) except the 'Working together' link. We will make editorial amendments to change the footnote to say: 'Working together to safeguard children, which also includes an appendix of further guidance from the Department for Education, other government departments and agencies, and external organisations.' As you note, the guideline committee considered the terminology at length. The full guideline states 'The guidance-specific definitions and associated actions have been derived from the collective clinical experience of guideline committee members informed by evidence identified in systematic searches and the views expressed in the Delphi consensus survey.' Thank you for highlighting this. We consulted with topic experts on this amendment and received mixed responses We will therefore not be changing the wording. Thank you for highlighting this. We have reviewed this document and will update this terminology under editoria amendments. No new evidence was identified during this review on fabricated or induced illness.

	needed for this section. Laws also differ slightly between nations.	7. Thank you for highlighting this. To ensure the Crown Prosecution service guidance is accurately reflected we will make editorial amendments to the relevant footnotes.
Parents Protecting Children UK	Yes. Equality in the area of disability and chronic ill health is as legally and socially important as racial, sexual and gender equality. Currently families with disabilities and ill health are receiving unequal treatment. Many families with neurological difference, physical disability, chronic or serious illness, mental health issues, learning difficulties etc are afraid to seek help for fear of losing their children to state care or adoption. The situation is escalating and getting out of hand - an urgent review of the whole question of undertaking risk assessments rather than providing support to keep families together is long overdue. Families with disabling conditions should be entitled to 'Reasonable Adjustments' in interpretation of any guidance but this is not happening. Many voluntary organisations, groups and networks such as Parents Protecting Children UK, False Allegations Support Organisation, Educational Equality, Fiightback, SOS!SEN, IPSEA, and the support organisations for conditions such as Ehlers Danlos Syndrome and Autism could supply numerous examples of discrimination against families with neurological difference, physical disability, chronic or serious illness, mental health issues, learning difficulties etc. The Autism Act is regularly breached by child protection investigations, as is Article 8 of the Human Rights Act with lack of 'respect for private and family life'.	In accordance with NICE's Equality Scheme, ethnic and cultural considerations and factors relating to disabilities were considered by the guideline committee throughout the development process and were specifically addressed in individual recommendations where relevant. Under the section 'Using this Guideline' it states that 'alerting features of maltreatment in children with disabilities may also be features of disability, making identification of maltreatment more difficult. Healthcare professionals may need to seek appropriate expertise if they are concerned about a child or young person with a disability.' Under 'Using this guidance', it is also expected that if a healthcare professional encounters a potential alerting feature of child maltreatment that they follow a detailed process before arriving at any suspicion of maltreatment. This includes piecing together information from different sources and seeking an explanation for any injury or presentation from both the parent or carer and the child or young person in an open and non-judgmental

		obvious medical explanation or an absence of a relevant medical condition.
		No new evidence has been identified during this surveillance review on the association of disability, gender or ethnicity with clinical features associated with child maltreatment to indicate the guidelines should be updated.
		NICE's guideline on child abuse and neglect (NG76) provides recommendations on factors that increase vulnerability to child abuse and neglect. Recommendation 1.2.6 refers to gender and recommendation 1.2.7 refers to disability.
		We acknowledge your concerns about situations escalating and the potential impact on families. This guidance provides a summary of the clinical features associated with child maltreatment but how professionals should proceed once they suspect maltreatment, the treatment and care of a child if maltreatment is suspected and child protection policies are out of the scope of this guideline. NICE's guideline on child abuse and neglect (NG76) has recommendations on assessing risk and need; early help for families; and principles for working with children, young people, parents and carers. NICE guidelines NG76 and CG89 share a common pathway which brings together the recommendations from both guidelines in an interactive flowchart.
Department of Health and Social Care	No	Thank you for your response.

The Ehlers-Danlos Support UK	No	Thank you for your response.
Royal College of Nursing	No comments to submit.	Thank you for your response.
Royal College of Psychiatrists	No comments submitted	Thank you.
Fiightback	No comments submitted.	Thank you.
Faculty of Dental Surgery	No comments submitted	Thank you.

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