Appendix B: Stakeholder consultation comments table

2021 surveillance of CG128 Autism spectrum disorder in under 19s: recognition, referral and diagnosis (2017)

Consultation dates: 26th October to 6th November 2020

1. Do you agree with the proposal to not to update the guideline?

Stakeholder	Overall response	Comments	NICE response
Evelina Children's Hospital, London	Update needed – I don't agree with proposal not to update		Thank you for your response.
False Allegations Support Organisation	No		Thank you for your response.
Child Oriented Mental Health intervention Centre (COMIC) – a collaborative research team between	Yes		Thank you for your response.

University of York and Leeds and York Partnership NHS Foundation Trust			
Autistic UK	No, we do not agree.	Recommendation regarding updating the learning disability prevalence percentage: Context (p.31) – The statement that IQ<70 occurs in approx. 50% of young Autistic people is inaccurate. Particularly as current research suggests that intelligence tests underestimate IQ in Autistic individuals. The current statistic is often used as a gatekeeping tool to prevent referral onto the diagnostic pathway, and therefore it is important it is updated to reflect current understanding. Ostrolenk, Alexia & Bertone, Armando. (2016). Gender-Specific Differences in Autism Spectrum Cognitive Profiles: WIS vs. Raven. 401.on Research Gate [Online] https://www.researchgate.net/publication/318470420 (Accessed 04/11/20) Kinnear D, Rydzewska E, Dunn K, et al (2019) Relative influence of intellectual disabilities and autism on mental and general health in Scotland: a cross-sectional study of a whole country of 5.3 million children and adults in BMJ Open 9:e029040. [Online] doi: 10.1136/bmjopen-2019-029040 (Accessed 04/11/20)	Thank you for your comments about learning disability prevalence. The statistic you refer to is on p.3 of the full guideline of CG128. The full guideline describes the context, evidence and methods underpinning the recommendations, they are not the recommendations themselves. IQ is not referred to in the recommendations themselves. We only assess the need to update recommendations within a guideline, not the other sections such as the context. Thank you for sharing the paper by Ostrolenk et al. This is a conference poster describing differences in presentation of autism by gender. This is out of scope as we can only consider published peer-reviewed research. Thank you for sharing the paper by Kinnear et al. This is a large cross-sectional study of 1,548,819 children/youth aged 0-24 years, and 3,746,584 adults aged over 25 years that investigates the extent that autism and intellectual disabilities are independently associated with poor mental and general health. It reports that both predict poor mental and general health, but that autism predicts more so for mental health particularly in children and youth, where an odds ratio for increased risk of 25.04 is reported for this group.

		Recommendation to update prevalence figures: Context (p. 31) suggests there's a 1% prevalence of autism. This has increased in recent studies, and this figure is used as a gatekeeping mechanism to refuse referral to autism diagnostic pathways. Updating the percentage could help reduce the incidence of missed/misdiagnosis. Recommendation to update table 1 regarding imagination and pretend play: Table 1 (p. 37) – states 'reduced or absent imagination and variety of pretend play.' This is a misrepresentation of Autistic play, which is often imaginative, but looks different to non-Autistic play. This statement is also used to refuse diagnosis when the evidence shows that Autistics can be incredibly imaginative (Sir Anthony Hopkins, Chris Bonnello, and Dan Akroyd are all relevant examples). Recommendation to update language regarding emotional reactivity: Table 2 (p. 41) – Stating that Autistic people have 'extremes of emotional reactivity that are excessive for the circumstances' doesn't account for the reason for the reaction, which may in fact be entirely measured and reasonable for how Autistic people experience the world (trauma, sensory differences, etc.). Using the word 'excessive' deems the emotions felt by the Autistic person to be an overreaction – something not to be believed and/or to be ignored. It is dismissive of Autistic experience,	We are aware of these associations and autism diagnosis in children (CG128) recommendation 1.5.15 recommends to consider whether the child or young person may have mental and behaviour problems and disorders as a coexisting condition, and if suspected to carry out appropriate assessments and referrals. This paper therefore supports this recommendation. Thank you for your comments about autism prevalence. The statistic you refer to is on p.3 of the full guideline of CG128. The full guideline describes the context, evidence and methods underpinning the recommendations, they are not the recommendations themselves. The recommendations can be found here and none put a number on prevalence. Prevalence is only mentioned with respect to factors that may increase it (see box 1 recommendation 1.3.3). We did find new evidence ('Service capacity effects on implementing the guidelines' section of surveillance proposal) from a Scottish study that put the prevalence of childhood autism at 1.6% (Rydzweska et al.) . We concluded that although this is higher than the 1% prevalence quoted in the guideline, an update to the guideline is not necessary at this time because commissioners can determine local needs based on referrals in their population, and it is not within the remit of the surveillance proposal to do this. Thank you for your comments about imagination and pretend play in CG128 appendix table 1. This is a table of signs and symptoms of possible autism in pre-school children and is based on the experience of the guideline committee and a review of evidence of potential indicators. It is noted before the tables that 'they are not intended to be used alone to make a diagnosis, but to help professionals recognise a pattern' That may alert them to the possibility of autism. We did not find any evidence during the latest surveillance review to suggest the table needs updating but if you

		and leaves Autistic people open to abuse (planned ignoring, refusal to accommodate sensory needs, gaslighting, etc.). Recommendation regarding amendment to single point of referral: 1.1.8 – Single point of referral needs to include self and/or parent/carer referral. Many primary health providers are unable to identify more complex presentations, and yet they use such presentations as a reason to refuse a referral to the autism pathways. This need not increase workload as requests can be qualified prior to acceptance, but this will be done by someone who specialises in autism rather than by GP/schools etc. Recommendation to update information on masking to include its consideration before considering FII: 1.2.5 – It needs to be made clear that a child who's masking can make the parent appear to have FII. Many parents are accused of this, and children are refused diagnosis based on this assumption. Adding that masking needs to be considered and investigated prior to any consideration of FII/similar is essential. Recommendation to include that masking is not to be a barrier to assessment: 1.2.5 – Displaying characteristics only at home should not be a barrier to accessing assessment. Alongside masking, it needs to be made clear that as a direct result of masking, it is possible for someone	have any evidence you can share with us that would be helpful. It is worth also noting that recommendation 1.2.7 in CG128 says do not rule out autism because of pretend play. Thank you for your comments about emotional reactivity in table 2 of the CG128 appendix. This is a table on signs and symptoms of possible autism in children aged 5-11 years based on the experience of the guideline committee and a review of evidence of potential indicators (see page 62 of full guideline). It is noted before the tables that 'they are not intended to be used alone, but to help professionals recognise a pattern.' We did not find any evidence during the latest surveillance review to suggest the table needs updating but if you have any evidence you can share with us that would be helpful. Thank you for your comments about a single point of referral and recommendation 1.1.8. This is based largely on guideline committee expertise and a single point of referral is recommended to simplify the process and ensure equity of access to NHS services (see section 3.4 of the full guideline). The committee emphasised that carers play a huge role in referral and that referral must include them. Recommendation 1.2.2 in CG128 recommends always take parents' or carers' concerns about behaviour or development seriously and recommendation 1.1.8 should be considered alongside this and other recommendations in the guideline, including recommendation 1.3.11. This recommends If a concern about possible autism has been raised but there are no signs, symptoms or other reasons to suspect autism, use professional judgment to decide what to do next.

		to be Autistic but hide this (at a great mental cost) in settings such as schools and extracurricular activities. Recommendation to add a glossary definition for masking: Glossary – we note there is no glossary. It would be worth adding a definition of masking so all those who read the document are aware of what this term means. It is not the same as adaptation, and the ability to mask doesn't deem diagnosis and support unnecessary. It can result in the loss of identity, and comes as a great mental and physical cost to the person who is masking.	Thank you for your comments about FII (fabricated and induced illness) and recommendation 1.2.5. We did not find any evidence during this surveillance review that indicated 1.2.5 needs to be updated with information about FII. Recommendation 1.2.2 in CG128 recommends always take parents' or carers' concerns about behaviour or development seriously even if these concerns are not shared by others. Thank you for your comment about recommendation 1.2.5. This recommendation does not suggest that displaying characteristics only at home is a barrier to accessing assessment, it provides a list of issues that may confound recognition of autism for professionals in contact with children with possible autism to be aware of. It also cautions that older children may mask their signs. Thank you for your comment about a glossary definition of masking. During guideline development decisions about which concepts require a glossary definition are made. We have not received any feedback querying its meaning. The guideline is aimed at health and social care professionals and children and young people who have or may have autism, and their families and carers. We think it is reasonable to assume these groups would know what masking is in the context of autism.

In Fair Treatment for the Women of Wales (FTWW)	No	Terminology used in the guideline needs amending to avoid perpetuating existing gender biases and stereotypes. For example, on page 41, the reference to ‘emotional reactivity’ is problematic for a few different reasons, such as its potential applicability to any number of mental health conditions (including in neurotypical people), extreme stress, anxiety, and trauma. Further, ‘emotional reactivity’ is a highly subjective concept, often underpinned by unconscious bias where women are more likely to be perceived as ‘over-emotional’, ‘highly-strung’, and ‘over-reacting’. The potential result of this is either to dismiss an autism diagnosis or to over-medicate. As per page 45 of the surveillance document, the guideline needs updating to include references to long-term health conditions which mainly affect girls and women, and which have been shown to have a correlation with autism. Ehlers Danlos Syndrome and Auto-Immune conditions are two-such and for which diagnosis is often delayed, much like autism itself. One study looking at prevalence and diagnosis of EDS found that, despite the condition affecting more girls, boys were diagnosed more quickly, and that gender stereotyping played a role in this: https://bmjopen.bmj.com/content/9/11/e031365 Contrary to page 47 of the surveillance document, rates of anorexia and self-harm are higher in girls / young women and have well-reported associations with being on the autistic spectrum. In fact, in younger women, these may be	Thank you for your comment about emotional reactivity. We think this is referring to its use in the tables of signs and symptoms in the guideline appendix. These tables are based on the experience of the guideline committee and a review of evidence of potential indicators (see page 62 of full guideline). The committee noted that these could vary from one person to another and that consideration should always be given to the child or young person as a whole, looking for combinations of signs and symptoms to identify patterns of behaviour and development. While we note your comments about unconscious bias, the tables are not intended to be used alone, but are there to help professionals. They should be applied to both boys and girls equally where appropriate and the guideline equality impact assessment did not assess them as acting to entrench bias. Thank you for your comment about long-term health conditions that affect girls and women. As you highlighted the surveillance proposal (p.44-45) found no evidence that autoimmune disorders, EDS or other connective tissue disorders are more prevalent in autistic people. Box 1 in diagnosis in children (CG128) factors associated with an increased prevalence of autism lists comorbidities that may be associated with autism. Risk factors included in the list were mostly associated with at least double the risk of autism, with reasonable precision (i.e., narrow variation around an average estimate). We did not find any evidence during this surveillance review that indicated that EDS was a risk factor for autism. Thank you for sharing the article by Demmler et al. that investigates the prevalence of EDS and hypermobility spectrum disorder (HSD). It reports a prevalence of 194.2 per 100 000 in 2016/2017 for EDS or HSD and that women are diagnosed at a later age than men.

		indicators which improve rates of diagnosis and the types of intervention / support offered. This urgently needs incorporating into an updated guideline. Looking at signs like these contrasts quite markedly with page 78 of the surveillance document, where the tools designed to spot repetitive and restrictive behaviour mention 'cars, numberplates and trains' – very 'male-centric' examples, potentially perpetuating diagnostic delay for females. It may be that the repetitive / restrictive behaviour exhibited by females is simply not of a type that is considered by observers. In fact, this section of the surveillance document goes on to state that an observational study found, 'girls with autism…are more likely to have emotional and behavioural problems'. An observational study is more likely to be beset with issues arising from unconscious bias. This will likely have a bearing on the findings: what may be deemed unacceptable behaviour in girls is more likely to be considered 'normal' in boys, whilst the reference to 'emotional…problems' is both subjective and gendered.	However, the article does not relate EDS to autism and is therefore not in scope for this surveillance review. Thank you for your comments about anorexia and self-harm in girls. The surveillance review reports that when developing the NICE guideline on diagnosing autism in children (see the full guideline, page 157), the committee suggested anorexia as a possible coexisting condition, but no evidence was identified, and anorexia was not included in the list We did not identify suitable evidence on possible links with anorexia and autism during this surveillance review. Thank you for your comments about the tools designed to spot repetitive and restrictive behaviours and potential bias in the observational study identified during the surveillance review (page 78). We are aware that potential underdiagnosis in girls is an issue and CG128 research recommendation 1 Training professionals to recognise signs and symptoms of autism acknowledges this. We did not find any evidence of tools that can adequately address this issue during this surveillance review. We will highlight this issue to the National Institute for Health Research (NIHR) as an area of potential health inequality where research is needed.
Nottinghamshire Healthcare NHS Foundation Trust (Theresa Foster, Clinical Lead, CAMHS ID Team)	No	More guidance needed for supporting parents following diagnosis	Thank you for your comments. Recommendation 1.9.1 recommends provide individual information on support available locally for parents, carers, autistic children and young people, according to the family's needs. We did not find any evidence during this surveillance review that would impact recommendations about supporting parents.

University Hospitals Dorset NHS Foundation Trust		Please see below regarding changes as a result of COVID	Thank you for your comments on COVID-19, we have responded to them below.
Royal College of Nursing	No	Updates are required due to new evidence and to promote best practice considering the most recent research results	Thank you for your comments. However, in the absence of references, we are not able to consider the evidence you refer to. If you are aware of new evidence that meets the inclusion criteria for the surveillance review which are published systematic reviews, randomised controlled trials or diagnostic studies that have not already been considered, we would be grateful if you could share these with us. We can also consider information about ongoing research and updated or new national policy that is directly relevant to the topic.
British Association of Social Workers (BASW) – England	Not sure	50% of BASW England member respondents stated 'yes', 50% responded no. One member said: 'There is little mention in this of a child's environmental context. Autism impacts a child's social communication and relationships as does trauma. Social workers have key role in understanding a child's relational and environmental context. There is a risk that children will receive a diagnosis when therapeutic support could prevent this need for labelling with lifelong consequences. They should be part of group. They may have valuable insight into patterns of diagnosis'.	Thank you for your comments concerning the response of BASW members. In relation to the comment about environmental context, Recommendation 1.2.5 highlights a number of issues that comprise a child's social context for a health and social care professional to take account of, for example, the presence of a supportive environment, a child's overall development, and disruptive home experiences. Additionally recommendation 1.5.6 recommends a physical examination to look for signs of injury, self-harm or maltreatment and cross-refers to child maltreatment: when to suspect maltreatment in under 18s (NICE guideline CG89).
The Challenging Behaviour Foundation	No	All the guidelines were published before Building the Right Support (NHSE et al 2015) set out new approaches including dynamic risk registers, CTRs/CETRs and other	Thank you for your comments. Although the guidelines were published before 2015 all have undergone subsequent surveillance reviews to check they remain up-to-date, the latest in 2016 This

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		processes and structures which have changed the landscape to some extent. Recent years have also seen much more work added to the evidence base (see details here of 2018 Transforming Care evidence seminar re children https://www.challengingbehaviour.org.uk/driving-change/evidenceseminar.html) and other national reviews (e.g. Lenehan review, Children's Commissioners reviews, CQC reviews) which should all be incorporated into a review of the guideline.	resulted in a partial update to CG170 (please see summary of 2016 surveillance for CG128 and CG170 and CG142). CTRs and CETRs with children help to improve care for people whose behaviour is seen as challenging and/or improve care for people with mental health conditions. Management of autism in under 19s contains recommendations 1.4.5 and 1.4.6 about reviewing support for behaviour that challenges. Section 1.3 in autism in adults Identifying the correct interventions and monitoring their use contains recommendations about monitoring and reviewing interventions. Recommendation 1.3.5 in section 1.3 recommends that there should be regular reviews of interventions to ensure their appropriateness. Thank you for sharing the Transforming Care evidence seminar: Children and young people with learning disabilities whose behaviours challenge. We are aware of transforming care and that it aims to reduce hospitalisations and enable autistic people and those with learning disabilities to live in the community closer to family and friends. The seminar aimed to identify evidence from key decision makers of use to those commissioning, designing and delivering services to children and young people with learning disabilities or autism whose behaviours challenge. The document provides an overview of what was discussed but does not provide links to evidence that we can consider in relation to the recommendations. We note the comment 'NICE need to think about their criteria for what is considered as robust evidence and the implications of gaps in NICE guidelines for prioritisation of interventions and treatments by NHS England.' The 3 guidelines considered for this review all include research recommendations

			that acknowledge gaps in the evidence and they are an attempt to stimulate research. With the exception of new evidence for melatonin we did not find any evidence that suggests any of the research recommendations should be stood down because they have been answered. As part of the 2020 surveillance review, in addition to published evidence from the literature we also considered the latest national level policy, for example the UK government's Autism self-assessment framework which reviews progress in implementing the autism strategy in England. We also considered the views of topic experts and patient groups (see page 16 of surveillance review for an overview). None of this evidence indicated that recommendations were out of step with current policy.
National Autistic Society	No	- Throughout, to better align with ICD-11 and DSM-V in the language it uses around neuro-developmental conditions, rather than to conflate them with mental health disorders. This would help clinical practice and tackle persisting confusion among medical professionals. - Diagnosis waiting times in England are still far in excess of NICE guidelines, between referral and first appointment. NHS data released in 2019 found that people are still facing long gaps between assessments. Whilst the data was limited, we know that there is also a significant variation in waits following first referral, as found by research undertaken by the All Party Parliamentary Group on Autism. In order to ensure that clinical practice does not incentivise pathways that leave long gaps between assessments, we believe that an overall	Thank you for your comments about ICD-11 and DSM-V. Topic experts suggested that the terminology in the NICE guideline should also be updated to align with ICD-11. We will track ICD-11 and assess its impact post-adoption, January 2022. In December 2017 we updated the guideline recommendations to refer to DSM-V. Thank you for your comments about diagnosis and wating times and for sharing the research from the All Part Parliamentary Group on Autism which reports 'A Freedom of Information request last year uncovered a similarly concerning waiting times postcode lottery for children' (p.21) . Thank you for also sharing the NHS experimental data for autism waiting times. We have been alerted to issues about wating times by patient groups and stakeholders. We also identified

		benchmark should be established for the period between referral to final diagnosis. As mentioned in our 2019 surveillance questionnaire, we would recommend a starting point being the 30 weeks recommended by the National Autism Plan for Children, as developed by NIASA in 2003. - We also think there needs to be a greater focus on mental health and mental well-being in the guideline. - It is important that the guideline refers to the most recent work being undertaken by NHS England, NHS Wales and NHS Improvement, including the *Transforming Care* programme. This will ensure that the guideline aligns with NHS messaging and advice.	the autism self-assessment framework which also highlights these issues. The issues stem from problems with implementing the recommendations due to lack of capacity, staff training and service organisation. We did not find evidence to suggest the current NICE guidelines, particularly recommendations 1.5.1 and 1.5.2 in autism diagnosis in under 19s (NICE guideline CG128) act to exacerbate these issues, nor did we find evidence that may alleviate these issues. Therefore, we assessed current recommendations as being consistent with policy. You state that referral to diagnosis timescale should not exceed 30 weeks. Currently recommendation 1.5.1 recommends that diagnostic assessment should be within 12 weeks of referral to the autism team. This is also included in the autism quality standard (QS51) which enables benchmarking of good services. Thank you for your comments on mental health. Management in children and young people (CG170) makes cross referrals to guidelines that will help manage coexisting mental health conditions in children and young people: see section 1.7. Thank you for your comments about transforming care. We are aware of the transforming care programme and that it aims to reduce hospitalisations and enable autistic people and those with learning disabilities to live in the community closer to family and friends. We would need to see evidence from transforming care projects before we could refer to them or assess their impact, if you can share evidence from these projects with us that would be helpful.

Royal College of Psychiatrists	No	The existing guidance was a great gold standard, however many services have not been able to be fully NICE compliant, nor is the full NICE assessment necessary in all cases. Particularly when paediatric and CAMHS services take the lead separately without overlap. The pressures on the system (capacity vs demand) make it unworkable, resulting in either NICE compliant very long pathways and waiting lists causing significant delays in assessment and care (which defeats the object of a gold standard to offer better care), vs short cut processes that aren't NICE compliant which may be poorer in quality owing to no guidance. There is a bit of a why bother effect, if you can't be NICE compliant. The role of research tools such as the aDOS-2 and ADI-R should be discussed in more detail re: their role within clinical assessments (when needed, when not, limitations since they identify caseness for research and still miss cases clinically). The original guidance only includes the research on the original ADOS, not the updated ADOS-2 with additional module and new algorithms (both in the manual and an extra module 4 algorithm in the literature) There is some repetition in the guidance e.g., visual and hearing impairment appear in both the psychiatric and paediatric differential diagnosis sections, irregularities with OCD being separated from anxiety disorders, sensory	Thank you for your comments I have responded to these below. **Involvement of paediatric and CAMHS services in assessment.** The organisation of services is not within the scope of the autism guidelines; however, the guideline does accommodate collaboration with CAMHS and recommends multidisciplinary autism teams. For example, recommendation 1.1.3 recommends In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a paediatrician and/or child and adolescent psychiatrist. Recommendation 1.1.4 also says this team should include or have access to a child and adolescent psychiatrist. CG128 section 1.5:'autism diagnostic assessment for children and young people makes recommendations for best practice based on a consideration of the best available evidence and the opinions of topic experts and patient groups. We have been alerted to issues with implementing the recommendations as a result of service capacity and service organisation issues and there are government initiatives in place to try and remedy these issues. For example, the NHS Long-term plan which includes initiatives about testing and implementing ways to reduce waiting times for specialist autism diagnostic services (NHS Long Term Plan page 52, 3.33). It is worth noting that it is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual and do so in the context of local and national priorities for funding and developing services (as stated in the overview section of all NICE guidelines). However, you allude to situations when a 'full NICE assessment is not necessary' and we would be

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		differences are not in the comorbidity section, but rather in the history. We would recommend that the guidance is re-written with a clearer section on screening whether an ASD assessment should proceed or not, a core ASD assessment pathway for simpler/clearer cases and specified add-ons to the assessment when there is additional complexity (differential diagnoses, co-morbidity, uncertainty)- with flow charts for how to make those decisions. The research base would remain mainly unchanged]d for assessment (apart from some new screening questionnaires), however the expert clinical recommendations would change though and new clinical views/approaches could be inserted. NICE guidance needs to be evidence based (research and expert), but also needs to be workable to actually offer improved assessment and then care. The guidance also needs to move with the times and incorporate newer clinical developments/practices and a discussion of these (some are local initiatives that are being used clinically but without the research evidence base e.g., online assessments, local shorter developmental history schedules, a variety of screening tools being used particularly for females). Screening for differential diagnoses and comorbidity is not just being done by trained medical Drs now, this section may require more detail on a screening schedule for the	interested in seeing any evidence- guidelines, policies or studies - that describe these situations, in order for us to assess the validity of current recommendations against them. **ADI-R and ADOS-2 tools** The guideline on diagnosing autism in children (CG128) suggests that tools can be useful for structuring assessments, but other information should also be taken into consideration when making a diagnosis of autism. Although we identified recent evidence about ADOS and ADI-R in this surveillance review (see surveillance proposal p.66) it did not clearly show that any autism diagnostic tool had sufficient diagnostic accuracy to specifically recommend it and change current recommendations for diagnosis in children, young people, or adults. **Repetition in the guidance** Thank you for your comments about repetition. Reference to visual and hearing impairment appear in recommendation 1.1.9, 1.5.7 and 1.5.12 of CG128. These recommendations are based mainly on expert consensus. Recommendation 1.1.9 recommends that the autism team should have the skills to deal with coexisting conditions such as hearing and visual impairments; 1.5.7 recommends that an awareness of frequently coexisiting conditions (e.g. hearing and visual impairments) will help inform whether specific investigations are needed; and 1.5.12 refers to diagnostic certainty when coexisiting conditions are present. We feel that this is not unnecessary repetition but required wording to ensure the completeness of the recommendations. Although OCD is separated out from anxiety disorders the recommendation 1.5.7 does not preclude people having more than one of the conditions in the list.

		mental health/physical health differential diagnoses/co-occurring conditions with guidance on if identified, then refer to a psychiatrist/paediatrician/OT/S&LT/Psychologist as indicated for further assessment. It may also need consideration of eating disorders and gender identity adding. From a digital data perspective the guidance should also reference meaningful data collection e.g. waiting times, time in assessment, diagnosis registers in electronic patient records, SNOMED coding, MHSDS/CQiNNs. It would be better if NICE guidance did not just specify the time between referral and starting and assessment and the time between diagnosis and follow-up. There should also be a recommended time for the duration of an assessment- some are being done too quickly (one stop shops), others are stuck on waiting lists for years. Perhaps a recommendation of assessment should be completed within a 6-month period after commencement to ensure information gathered is from a comparable time frame. The differences between ICD10- and DSM5 and ICD11 should be covered, since which system you use may alter the diagnostic outcome. (DSM includes sensory issues, has lost Asperger's, PDDUS/PDDNOS and atypical autism, added social communication disorder)- so ICD-10 is easier	Recommendation 1.5.8 says, consider which assessments are needed to construct a profile for each child or young person, for example sensory sensitivities. The guideline development committee considered that the diagnostic assessment should include assessments to develop a profile of individuals' strengths, needs, skills and impairments, by a member of the autism team in order to construct a profile for each child or young person. The list of coexisting conditions is based on guideline committee expertise and a review of studies of their prevalence. The committee chose to develop a more clinically relevant list of conditions based both on the evidence and members' knowledge and experience. **Screening section in CG128** Thank you for your comments about the screening section in CG128 and the proposal for 2 assessment pathways: one for more clear-cut cases and one where there is more uncertainty due to complexity arising from differential diagnoses. You may find the NICE pathway Identifying possible autism spectrum disorder in under 19s which is a visual representation of the guideline useful. During this surveillance we did not find any evidence about new screening tools or approaches that indicated recommendations need to be changed. You suggest an approach for 2 pathways following a decision to refer: a core ASD assessment pathway for simpler/clearer cases and specified add-ons to the assessment when there is additional complexity. We did not identify any evidence for this 'dual pathway' approach, but we would be interested in any published evidence you could share with us about this. We note your comments about NICE guidance needing to be workable as well as evidence-based, 'move with the times' and that it should incorporate the latest clinical practices. However, without

		to get a diagnosis. – this impacts upon who gets services after assessment if they are ASD specific. There are also differences in the definition of Intellectual disability between ICD10 and DSM5, which is relevant in DSM5 since it is ASD with or without an intellectual disability. The section on genetics and test may need updating to reflect the many advancements in knowledge of genetic conditions that are now known to link to ASD. And specifying what genetic tests should be arranged. Recommendations for how to assess co-occurring neurodevelopmental conditions simultaneously- ASD, ADHD and ID in particular would be helpful and how they resemble each other and how to tell the difference clinically during assessment and how to identify combinations of them- this will improve the identification of co-occurring diagnoses (reducing diagnostic overshadowing) and also drive diagnostic decisions when there is uncertainty. A whole section on attachment/trauma/adverse childhood experiences vs ASD would be valuable. There is wide variation in practice regarding how to assess the difference and different professional groups erring towards ASD or attachment dependent upon their theoretical leanings. This affects diagnostic outcomes and care offered. When both	the evidence to support the effectiveness of these practices we cannot make recommendations about them, because we do not know if they improve care. **Comorbid conditions** Thank you for your comments about screening for comorbid and coexisiting conditions, establishing a differential diagnosis and the involvement of a number of different medical and healthcare professionals in these steps. Recommendation 1.1.9 recommends the autism team should either have the skills needed to carry out an autism diagnostic assessment or have access to professionals that have the skills, including assessments where coexisting conditions are suspected. During this surveillance review we did not identify any evidence that suggested gender identity or eating disorders should be added to the list of coexisting conditions. **Digital data collection** Thank you for your comments about data collection. Recommendation 1.1.2 accommodates these sources in its recommendation that the autism strategy group should ensure meaningful data collection and audit of the local care pathway takes place. **ICD and DSM** Thank you for your comments about ICD-10 and ICD-11 and DSM-5. Recommendation 1.5.5 recommends focussing on developmental and behavioural features consistent with DSM-5 or ICD-10. It also recommends using autism-specific tools to gather this information. Evidence for the use of these for diagnosis was assessed as very low quality by the guidelines committee but generally where evidence was found it suggested diagnosis was reliable when made using ICD

		occur is also important to cover, since they are not mutually exclusive. NICE could create an exemplar pathway with all standard documentation to use for history taking, assessment of differential diagnoses/comorbidity, observation forms, evidence gathering tool for final diagnostic/formulation meeting, final report formats and an exemplar resource pack for parent etc Also, it is confusing that this guidance goes up to 19, but the adult guidance starts at 18 so two different standards for 18-19-year olds (the over 18 guidance is shorter/simpler than the under 19 guidance) by them being the same for 18-19, it would allow assessment cases to be transitioned between child and adult assessment teams without their assessment needing to change. Commentary could be made on recommended size and makeup of assessment teams per numbers of expected referrals per 100,000 population. Training required. The original audit was helpful in getting services commissioned, but needed to have the recommendations split down into smaller parts to encourage passing more	and DSM criteria across different age groups. The committee suggested the most effective approach is to use the ICD-10/DSM-IV-TR criteria with expert clinical judgement. During current surveillance we found no studies that suggested recommendations about use of DSM and ICD should be amended. Additionally, we updated the guideline in 2017 with references to DSM-V and we plan to assess the impact of ICD-11 in January 2022 when it comes into effect. **Co-occurring neurodevelopmental conditions** The scope of the guideline is to develop recommendations about the features of autistic spectrum disorder that should prompt professionals working with children and/or parents or carers to consider it in a child or young person. The recommendations about co-occurring conditions are provided to make health and social care professionals aware of potential differential diagnosis. The guideline lists in tables 1-3 in the appendix potential signs and symptoms that autistic people may present with and it also acknowledges that these may be presentations of other conditions (see for example recommendation 1.2.10). NICE has produced guidance on attention deficit hyperactivity disorder: diagnosis and management (NG87) and on other neurological and behavioural conditions that make recommendations about how these conditions present and their common comorbidities. We plan to look at all the mental health guidelines in NICE's portfolio together in order to explore the implications of system drivers including the NHS Long Term Plan and the impact of COVID-19 on service delivery on our recommendations. **Attachment, trauma and adverse childhood conditions**

		parts of the audit (items were bunched together). The audit could be updated.	Thank you for your comments on attachment/trauma/adverse childhood experiences. Recommendation 1.5.5 recommends that every autism diagnostic assessment includes a medical history, including prenatal, perinatal and family history, and past and current health conditions. This accommodates a consideration of traumatic events and attachment. Recommendation 1.5.6 also recommends looking for signs on maltreatment and cross-refers to child maltreatment: when to suspect maltreatment in under 18s (NICE guideline CG89). Thank you for your comments about exemplar pathways and standard documentations, however it is not within NICE's remit to produce and maintain these sets of information. **Overlap in age groups covered by the autism guidelines** Thank you for your comments about the overlap in age groups between the autism guidelines. CG128 covers people from birth up to their 19th birthday and autism in adults (CG142) covers 18 years onwards. This overlap was decided at scoping stage and is appropriate as CG128 covers transition to adult services – see recommendations 1.1.2, 1.1.10 and 1.9.1. **Assessment teams** Thank you for your comments about the size and makeup of assessment teams. The guideline development committee did not identify any evidence about optimal numbers and composition, nor did we identify any during this surveillance review. In relation to your final comments on an audit, we are not sure what is being referred to, but assume that this refers to the baseline assessment tool in the tools and resources section of the guideline.

			This is not covered as part of the surveillance review, but we will share your comments with the relevant team within NICE. If you are referring to a different audit, please do let us know..
Help for Psychology		The research base has not changed sufficiently and Jan 2022 would be a better time for a thorough review.	Thank you for your comments. Guidelines are generally reviewed every 5 years unless an event (for example, an ongoing study directly relevant to a guideline, a drug safety update or a substantial change in policy or legislation) is brought to our attention that may impact the guidance (further details can be seen in the NICE methods manual chapter 13 Ensuring that published guidelines are current and accurate). We then track these events and asses their impact on recommendations as soon as we can after the evidence is published. For example, we plan to review the impact of ICD-11 when it is published in January 2022. This will not be a full surveillance review. We are also aware from contacts in NHS England that the Re-ASCed (A Realist Evaluation of Autism ServiCe Delivery) study which is investigating what factors speed up autism diagnosis and what factors slow it down, is due to complete in 2022. We will monitor this study and asses its impact on the NICE autism guidelines on publication.
Cheshire and Wirral Partnership NHS FT	No. A small number of changes could make a very significant impact on services	• In section 1.1.5- there is no specific mention of speech and language therapy and we feel there should be. • Some language is not current or neuro-diverse eg “symptoms” • There needs to be greater focus and joint working for young people who were waiting for diagnosis who are then passed to adult services if they have not reached the top of the waiting list in children’s	Thank you for your comments. Recommendation 1.1.3 recommends that in each area a multidisciplinary group (the autism team) should be set up. The core membership should include a speech and language therapist. Thank you for your comments about language. ‘Symptoms’ is always used with the word ‘signs’. However, it is used to describe the

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

	delivered to families.	services to ensure they are prioritised and their needs are not overlooked.	presentation of other conditions that could co-occur with autism and do present medical symptoms, for example anxiety. However, we will consider whether it is appropriate to remove the word ‘symptoms’ from the appendix and from recommendations that refer to the appendix as the appendix does not include medical conditions but rather descriptions of common traits that some autistic people may present with. Thank you for your comments about joint working. Recommendation 1.1.10 recommends that if young people present at the time of transition to adult services, the autism team should consider carrying out the autism diagnostic assessment jointly with the adult autism team, regardless of the young person's intellectual ability. Also NICE has produced transition from children’s to adults’ services for young people using health or social care services (NICE guideline NG43) This contains recommendation 1.3.1 which recommends children's and adults' service managers should ensure that a practitioner from the relevant adult services meets the young person before they transfer from children's services, by, for example, arranging joint appointments.
PDA Society	Yes	Specifically on the question of PDA. We would hope that this remains under review as further evidence is published.	Thank you for your comments. The guidelines are reviewed approximately every 5 years unless we identify or are alerted to new events that may trigger an exceptional review. If this happens, we will undertake a review as soon as we can. An ‘event’ may be a large study, significant policy change, new guidelines or a safety alert (see

		We agree that the PDA profile is identifiable in an assessment that follows the current Guidance It wouldn't be appropriate for NICE to be referring to PDA as a 'diagnosis' currently. There is increasing evidence pointing to the need for differentiation of management strategies according to the group of characteristics seen in the ASD assessment which may be termed a 'PDA profile'. These implications for management should be fully reported. It is hoped that additional clarity can be provided following the review in January 2022	the NICE methods manual Chapter 13 Ensuring that published guidelines are current and accurate for more details). The January 2022 review you refer to in your comments is referred to on p.68 of the surveillance report and it says: "we will consider how to update the references to ICD-11 and consider the effects on the wording of recommendations in line with its planned adoption in January 2022." We will consider the impact of ICD-11 on pathological demand avoidance (PDA) during this review. During preparation of the guideline, the developers acknowledged that PDA is not a recognised disorder in the sense that is not included in the ICD or DSM, and developed specific advice on how to differentiate between alternative diagnoses with similar features, available in appendix K of the full guideline. The appendix describes PDA as a particular subgroup of autism that it is characterised by a refusal to comply (demand avoidance) and such oppositional behaviour can be described as ODD. Recommendation 1.5.7 in 'Autism spectrum disorder in under 19s: recognition, referral and diagnosis' recommends considering ODD as a potential differential diagnosis and whether specific assessments are needed to interpret the autism history and observations.
Royal College of Paediatrics and Child Health	Yes	Regarding the first page of this proposal, should it read 'existing' rather than 'exiting'.	Thank you for your comments about the typo, this will be corrected. Thank you for your suggestion concerning recommendation 1.4.5. This recommendation was based on guideline development group

		A thorough review appears to have been conducted and areas for further consultation identified. Section 1.4.5: As input from certain health professionals does not immediately come to mind for gathering further information, it may be helpful to give examples of health professionals such as audiologists or those professionals who work in the hearing clinics. Behavioural concerns of many of these children is first spotted in an audiology clinic and these professionals would be able to provide invaluable information.	consensus that a coordinated system for collecting information would speed up decision-making. There was no evidence found that highlighted specific healthcare professionals as being more key than others, with respect to gathering information.
Autistica, the UK's autism research charity	No. The decision not to update this guidance is an understandable but serious mistake.	We can understand why NICE has come to the conclusion not to update the guidance. In many areas, the applicable evidence base on how to effectively deliver healthcare for autistic people is limited. To those unfamiliar with the field, the progress of good-quality, relevant evidence will appear underwhelming. However, we are <u>not</u> confident that the surveillance proposal's conclusions accurately reflect the evidence base and policy context. We strongly recommend that NICE urgently discusses this surveillance proposal in detail with NHS England's Autism Team. Our reading of the surveillance proposal suggests that NICE were missing vital information about recent developments when drawing their conclusion.	Thank you for your comments. The surveillance review's conclusions were based on an assessment of evidence identified via contact with topic experts and patient groups including yourselves, Autistica and detailed systematic searches. We disagree the conclusions do not accurately reflect the evidence base and policy context. We greatly appreciate your ongoing engagement with this surveillance process, and during the initial stages of the surveillance review you responded to our questionnaire and submitted a large number of reports produced by Autistica. We considered these reports fully and none impacted recommendations. Many of the reports confirmed information we had seen elsewhere, for example in the NHS long term plan and some were out of scope for this surveillance process, because for example, they were news items which are not eligible as an evidence type. For this surveillance review the following types of evidence are eligible for inclusion: published systematic reviews of experimental, observational and qualitative research; randomised controlled trials, diagnostic studies; new and updated national policy, guidelines and ongoing studies.

		Consultation issues The surprisingly short timeframes for this consultation have made it practically impossible to review NICE's surveillance report proposals in detail. The surveillance report itself is 172 pages long, cover 3 separate clinical guidelines, cites 201 academic publications and relies on considerable understanding of NICE's processes. We have had sight of this material for just over a week, in the middle of a pandemic – when our resources are stretched and we need to focus on informing other time-sensitive policy decisions – and while key parts of our policy and research teams are seconded to support NHS England. Unfortunately, this means our feedback cannot be comprehensive. The points we make below focus on some the more obvious anomalies that we could see while scanning through the surveillance report. It also means that we will be provided a single response, rather than separate responses concerning each guideline. *We would welcome clarification from NICE on why two weeks was considered adequate time to properly review and feedback on work that has taken well over a year to compile.* Concerns with the surveillance review Without replicating the surveillance review or having considerably more time and resource to examine the review's methodology, we cannot conclusively know how comprehensively NICE has accounted for the available	We had contact with representatives of NHS England and NHS Improvement (NHSE&I) early in the process, prior to and during this consultation. Their comments have informed the surveillance decision to use a living surveillance model to monitor the progress of relevant work and assess the impact of findings on the autism guidelines on an ongoing basis. Thank you for your comments about the consultation timescale. The timescale for consultation was 2 weeks as per the standard NICE surveillance process (please see with 'Developing NICE guidelines: the manual', section 13 on Ensuring that published guidelines are current and accurate'). In addition to this we sent an email to all stakeholders 5 days before the consultation opened in order to give advanced notice of the consultation. You are able to contact us if you feel you are unable to respond within the specified timescale. We understand current circumstances with the COVID-19 pandemic can cause issues and we will feed your comments back to colleagues in the NICE programme management team. The work has taken longer than normal to complete due to delays caused by staff redeployment to Covid-19 rapid guidelines projects from March to October 2020 when non-COVID-19 work was suspended. With regards to your concerns with the surveillance review, the methodology for this review, including search sources, inclusion criteria, and details of topic experts and patient groups consulted is described on pages 4-11 of the surveillance proposal document and at the start of appendix A in the same document. Information about how evidence was interpreted, and conclusions drawn from it is

		evidence; let alone the validity of its decisions over which evidence to utilise or dismiss. However, as a scientific funder that continually follows, assesses, and strategically intervenes to improve this evidence base there are pieces of research that we would have expected to see in the surveillance report. Their apparent absence is a cause of serious concern. In particular: ▪ Realist review of child diagnostic pathways – This is a large NHS England commissioned research study exploring what diagnostic pathways work well in particularly contexts. The study protocol was registered in July 2020 and so was understandably not captured by NICE's surveillance review. It's findings are, however, very likely to impact on the relevance of CG128. pubmed.ncbi.nlm.nih.gov/32636288/ There are other relevant ongoing studies that we are aware of not cited in the surveillance review that we could list. We have focused on the three above because we understand they are of considerable relevance to the work NHS England are leading to improve (and clarify) diagnostic and post-diagnostic support pathways for autistic people. Misunderstanding of the policy context	provided in a 'surveillance proposal' that summarises findings at the end of each section in the surveillance proposal document. Further information about the surveillance process is contained in ensuring that published guidelines are current and accurate, Chapter 13 of the NICE guidelines manual. Thank you for sharing Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD). This is a protocol for a study and does not yet have results or conclusions therefore we cannot assess its impact on recommendations at this time. However, as you state the results may well have an impact on the guidelines, so we will monitor the progress of this study and assess its impact on NICE's autism guidelines when it published results and conclusions. Thank you for comments about the policy context. We disagree that the surveillance review authors have misunderstood the policy context. We identified the autism self-assessment framework which highlighted in chapter 5 of its executive summary that although all local authorities reported having an autism pathway, only 17% rated themselves as meeting requirements for the 3-month waiting time limit recommended in the NICE guideline on diagnosis of autism in children and young people (recommendation 1.5.1). Topic experts and patient expert groups highlighted implementation issues around diagnosis, joined up services and the competencies of healthcare staff in dealing with autistic people. We also met with representatives of NHSE&I who also highlighted that there are issues around implementing some of the recommendations.

		"Overall, the government reports and policies do not contradict any recommendations in NICE's autism guidelines. They do not suggest a need to update the guidelines." This statement contradicts our understanding, as close stakeholders, of NHS England's workstream to improve the diagnosis and post-diagnostic support pathways for autistic people, as specified in the NHS Long Term Plan. Unless, NICE has directly and recently engaged with the NHS England Autism Team about that workstream, this assumption is flawed and unjustified. In fact, we suspect that NICE's expertise could be invaluable for realising goals set out in paragraph 3.33 (page 52) of the Long Term Plan. We note that the surveillance report does not mention the Long Term Plan commitment to: *"jointly develop packages to support children with autism or other neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD) and their families, throughout the diagnostic process."* Delivering this commitment is likely to involve considerably more work in guiding intervention decisions that it may first appear. NICE should play an active role in this work. To be clear: we strongly recommend that NICE urgently discusses the risks of not updating CG142, CG170 and CG128 with NHS England's Autism Team. We are concerned that critical context was missing for the surveillance proposal.	We also identified initiatives about diagnosis and testing and about management of autism in the NHS long-term plan, including section 3.33 which the surveillance review quotes and references on p. 19. Additionally, we identified the review of the 2014 Autism Strategy the outcomes of which will inform the aims of the NHS Long-term plan. The issues we identified are problems with implementing the recommendations due to lack of capacity, staff training and service organisation. We did not find evidence to suggest the current NICE guidelines, Therefore, we assessed current recommendations as being consistent with policy. We have recently engaged with the autism team at NHSE&I. Their comments have informed the surveillance decision to use a living surveillance model to monitor the progress of relevant work and assess the impact of findings on the autism guidelines on an ongoing basis. You note in the Long term plan section 3.33's commitment to *"jointly develop packages to support children with autism…throughout the diagnostic process"* may require considerable work to guide intervention choice and that NICE has a role to play in this. NICE can make recommendations about choice of diagnostic tools and interventions only if the evidence is available on which to base them. If there is published evidence about screening tools or approaches that enable more effective and efficient intervention choices, from systematic reviews, randomised controlled trials or diagnostic studies, we would be grateful if you could share this with us.

			With respect to section 3.33 in the NHS long term plan it also says: "Over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to test and implement the most effective ways to reduce waiting times for specialist services. This will be a step towards achieving timely diagnostic assessments in line with best practice guidelines." It also recommends that each child with autism, learning disability or both with the most complex care needs "will have a keyworker." Recommendations 1.5.1 and 1.5.2 which respectively recommend a maximum wating time of 3 months for an autism diagnostic assessment and recommend a case coordinator for every child having an autism assessment, are consistent with these aims. These recommendations are based on guideline development committee consensus and are informed by their experience and knowledge of examples of good practice in the UK.
Takeda UK Ltd	No		Thank you for your response.
Healthwatch Calderdale	Agree		Thank you for your response.
Autism Rights Group Highland	No. The guideline should be changed.	Some conceptual issues which contribute to negative views of autism, for example: • Concept of 'severity' is problematic • 1.4.4 'Symptoms' is not the right idea – autism is not a disease • 1.4.2 Social skills – compare and describe using a map of autistic norms, not NT norms. Then plans	Thank you for your comments and for highlighting the Independent Guide to Quality Care for Autistic People by the National Autistic taskforce. This document was identified during our searches for policy and reports. It was noted that recommendations in the guidelines under review did not contradict the conclusions and recommendations in the report but that the report covered wider aspects of daily living that are out of the scope of the guidelines

	To inform those changes we recommend using the Independent Guide to Quality Care for Autistic People 2019 by the *National Autistic Taskforce*: https://nationalautistictaskforce.org.uk/wp-content/uploads/RC791_NAT_Guide_to_Quality_Online.pdf	for development can be adapted, be positive and realistic. - 1.5.15 mental, behavioural, neurodevelopmental, genetic and medical *problems* and *disorders* – unnecessarily negative way to think about and characterise people - 1.9.1 Add contact details for autistic-led orgs and autistic Disabled Person's Organsiations. - Pg 25 and throughout: Misconception of social difficulties. See Milton, D. (2012). On the ontological status of autism: The 'double empathy problem'. Disability & Society, 27(6) https://kar.kent.ac.uk/62639/ - Pg 25-26 and throughout: Concept of autism is professional-centred and very medical. It does not reflect how autistic people characterise their own condition. This is essential for offering relevant care and support consistent with autistic priorities.	which are predominantly about diagnosis and management of autism. Thank you for your comments about choice of words in specific recommendations these are addressed as bullets that mirror your comments: - the concept of 'severity' in relation to identifying possible autism was used by the CG128 guidelines committee to reflect the fact that autism spectrum disorder can encompass a range of behaviours that manifest in various combinations, levels and intensity of presentation. The committee recognised that consideration should always be given to the child or young person as a whole, (see full guideline p.32) - Recommendation 1.4.4 recommends when deciding whether to carry out an autism diagnostic assessment take account of the severity and duration of the signs and/or symptoms. This recommendation is based largely on expert consensus. The full guideline acknowledges the debate and complexity around definitions of autism (see introduction section 1.1.). and the recommendations do not describe autism as a disease or suggest that it is one. . 'Symptoms' is always used with the word 'signs' and it is used to describe the presentation of other conditions that could co-occur with autism and do present as medical symptoms. However, we will consider whether it is appropriate to remove the word 'symptoms' from the appendix and from recommendations that refer to the appendix as the appendix does not include medical conditions but rather descriptions of common traits that some autistic people may present with.

			- Recommendation 1.4.2 Social skills and neurotypical (NT) norms. This recommendation is based on guideline committee consensus, in the absence of evidence, about information, other than the risk factors identified in box 1 recommendation 1.3.3, that may indicate the presence of autism. The committee agreed that regression of language or social skills in a child of under 3 years is strongly associated with a diagnosis of autism, unless there are other clinical signs suggesting an alternative medical disorder, which may require a different assessment pathway. - 1.5.15 recommends considering whether the child or young person may have any of the following as a coexisting condition, mental problems or disorders etc. The guideline development group identified these coexisiting conditions based on evidence of prevalence, evidence of benefit from specific treatment and impact on the quality of life of children. Evidence suggested that the presence of these conditions can extend the diagnostic assessment timescales for autism. Therefore, they are listed to make clinicians aware their coexistence with autism is possible so they can provide appropriate care. The headings used (mental problems or disorders, Neurodevelopmental problems and disorders etc) are those commonly used in diagnostic manuals like ICD-10 and DSM-V to classify these conditions to enable diagnosis. - 1.9.1 thank you for your comment about linking out to further info. The information for the public page of the guideline provides links to national organisations who can provide expert advice and support.

			Thank you for your comments about misconception of autism and for sharing the paper by Milton et al. This was published in 2012 and predates the timescales for the searches for this review which cover the period 27 January 2016 to 1 November 2019. With respect to your comments about how people characterise their own autism; the guideline committee did include lay members who contributed to the writing of the guidelines. The list of committee members can be seen here
Nottinghamshire Healthcare NHS Foundation Trust	No	More guidance needed for supporting parents following diagnosis	Thank you for your comment; however without further details about what support you think is needed, we cannot consider making further changes to the recommendations within NICE guideline CG128, which do highlight that autism team members should offer information to parents and carers about appropriate services and support (recommendation 1.1.7) and has a section on information and support for families and carers (recommendation 1.9.1).
Lead of NHSE funded study: Realist evaluation of autism diagnostic service delivery for children with possible autism	Fine	From study above so far we need to move thinking from autism only approach to neurodevelopmental pathway. Whilst this is described in the guideline and quality statement in reality most teams do an autism yes/no then discharge approach but claim NICE comliant co multidisc assessment-the guideline needs to be more explicit about broader neurodevelopmental/mental health assessment and ideally combine with ADHD guidline so conditions seen as part of same continuum warranting and integrated CAMHS/CDC approach/single pathway to diagnosis	Thank you for your comments. Thank you for highlighting the study you are leading called 'Realist evaluation of autism diagnostic service delivery for children with possible autism, the RE-ASCeD study that is due to complete in 2022. We were alerted to this by contacts at NHSE and we will assess the impact of its results on recommendations when it publishes. Thank you also for sharing with us the case study by Male et al. (2020) which contrasts and costs an integrated child development team/CAMHS pathway with non-integrated pathways for a hypothetical patient. The study is out of scope for this surveillance review which considered systematic reviews, randomised controlled trials and diagnostic studies published between 27 January 2016 to 1 November 2019.

			We cannot comment on the practices of individual teams. The guideline does make reference to mental health services and neurodevelopmental conditions and recommends the autism team should either include or have regular access to those and other professionals (see recommendation 1.1.4). As you highlight NICE has produced attention deficit hyperactivity disorder: diagnosis and management (NICE guideline NG87). It would not be possible to combine the autism guidelines with the ADHD guideline as they have very different scopes and different evidence bases. We think it is reasonable to expect that an autism practitioner would be aware of NICE guidelines on ADHD and refer to them if needed.

4. Do you have any comments on areas excluded from the scope of the guideline?

Stakeholder	Overall response	Comments	NICE response
False Allegations Support Organisation		Answer 4. - Our helpline manages many people referring themselves to us for support, especially on mental health. They tell us they get no support from local NHS mental health/organisations units. As well as the Ministry of justice for both them and their families. Over the initial period of allegation and defendant on the route to go down– prison/ case dropped or from local Dr's / mental health - support is not there. Our voluntary group, again takes up the slack and are making ourselves available to anyone in this position.	Thank you for your comments. NICE is unable to comment on the level of support provided by individual local NHS mental health trusts or GPs. During surveillance we identified the Parliamentary Joint Select Committee report on the detention of young people with learning disabilities and/or autism. This report highlights severe failings in mental health services. We consider that the select committee's report describes care that is inconsistent with recommended practice described in a range of NICE guidelines, including service user experience in adult mental health (NICE guideline CG136), and

		However, FASO are limited in what their volunteers from all walks of life can do. Professional should be available and neds to be in place.	the guidelines on autism. The select committee made several recommendations including: • the creation of legal duties on Clinical Commissioning Groups and local authorities to ensure the right services are available in the community narrowing of the Mental Health Act criteria to avoid inappropriate detention • substantive reform of the Care Quality Commission's approach and processes. These should act to improve the situation and we will continue to monitor the impact of NICE recommendations on these recommendations. It might also be helpful to know that NICE have produced quality standards that provide metrics against which service performance can be benchmarked. There is an autism quality standard (QS51) based on the guidelines which includes, for example, quality statement 4, which says: 'People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.' Information about how to use quality statements can be found at this link.
Autistic UK		Recommendation regarding the addition of inpatient guidance: P. 22 You currently have no specific inpatient guidance in your documents. This should be added in line with the Oliver McGowan Mandatory Training information to ensure a consistent approach across all care/medical settings. It should also be included to ensure that Autistics who become hospital inpatients (for example, for a physical health issue) are cared for appropriately. In these cases, NHS Trusts would refer to guidelines written by NICE, not	Thank you for your comments about inpatient care of autistic people. NICE have produced patient experience in adult NHS services: improving the experience of care for people using adult NHS services (NICE guideline CG138) This covers the components of a good patient experience and aims to make sure that all adults using NHS services have the best possible experience of care. Several topic experts and patient organisations noted that autistic people are frequently admitted for inpatient psychiatric care. However, we did not identify any new studies reporting on this

		the CQC. This point also stands for the under 19s support and management document. Recommendation regarding the addition of EDS and Autoimmune conditions as co-occurring conditions in the guidance: P. 45 Surveillance – Your current guidance makes no reference to Ehlers Danlos Syndrome or other connective tissue disorders (hereby referred to solely as EDS) or autoimmune conditions, however there is increasing evidence to demonstrate that Autistics are more predisposed to having EDS or an autoimmune condition as a co-occurring condition. These should be added to your list of co-occurring conditions within guidelines. This is particularly important with regard to children. Parents (typically mothers) of Autistics who mask are at risk of being accused of FII. The presence of EDS further puts parents at risk of this accusation. The addition of EDS as a co-occurring condition in your guidelines will not only aid timely diagnosis and support, but will also prevent false FII accusations. Baeza-Velasco, C., Cohen, D., Hamonet, C., Vlamynck, E., Diaz, L., Cravero, C., Cappe, E., & Guinchat, V. (2018). Autism, Joint Hypermobility-Related Disorders and Pain. In *Frontiers in psychiatry, Vol. 9, 656*. [Online] https://doi.org/10.3389/fpsyt.2018.00656 (Accessed 04/11/20)	outcome and therefore we do not propose to any specific recommendations about inpatient care at the current time. We did identify two initiatives from the NHS long-term plan (see surveillance proposal document p. 22) that were relevant to inpatient care, but they did not indicate that NICE recommendations no longer represent best practice, but rather that services have not been able to achieve recommended best practice. It should be noted that the recommendations in the autism guidelines apply to secondary settings, including inpatient settings and should be applied to them. For example, in the guideline on management in children (CG170) recommendation 1.1.9 recommends practitioners consider the physical environment in which autistic children and young people are supported and cared for and minimise any negative impact by making adjustments. The guidelines also include recommendations about training of health and social care professionals, for example, recommendation 1.1.2 in diagnosis in children (CG128) recommends an autism strategy group should be appointed which has responsibility for raising awareness of the signs and symptoms of autism through multi-agency training. Similarly recommendation 1.1.6 in management of autism in children (CG170) recommends that autism teams provide training and support for other health and social care professionals and staff who may be involved in the care of autistic children. Thank you for your comments about Ehlers Danlos Syndrome (EDS) and for sharing the 3 articles about EDS and joint hypermobility syndrome, the latter of which can be indicative of EDS.As you highlighted the surveillance proposal (p.44-45) found no evidence that autoimmune disorders, EDS or other connective tissue disorders are more prevalent in autistic people.

		Cederlöf, M., Larsson, H., Lichtenstein, P., Almqvist, C., Serlachius, E., & Ludvigsson, J. F. (2016). Nationwide population-based cohort study of psychiatric disorders in individuals with Ehlers-Danlos syndrome or hypermobility syndrome and their siblings. In *BMC psychiatry*, *Vol. 16*, *207*. [Online] https://doi.org/10.1186/s12888-016-0922-6 (Accessed 04/11/20) Casanova, E. L., Sharp, J. L., Edelson, S. M., Kelly, D. P., & Casanova, M. F. (2018). A Cohort Study Comparing Women with Autism Spectrum Disorder with and without Generalized Joint Hypermobility. *In Behavioral sciences (Basel, Switzerland)*, *Vol. 8(3)*, *35*. https://doi.org/10.3390/bs8030035 (Accessed 04/11/20) Recommendation regarding the addition of eating disorders – namely anorexia and ARFID – into co-occurring conditions in the guidance: P. 47 & 133 Surveillance - In addition to anorexia, there needs to be the addition of Avoidant Restrictive Food Intake Disorder (ARFID) which, in both with our engagement with the community and our review of the few research studies, have demonstrated is an eating disorder with a strong overlap with autism. Zimmerman, J., & Fisher, M. (2017) Avoidant/Restrictive Food Intake Disorder (ARFID) in Science Direct Vol. 47 No. 4 [Online] https://doi.org/10.1016/j.cppeds.2017.02.005 (Accessed 04/11/20)	The Baeza-Velasco paper is a review article which describes the results of studies selected by the authors that suggest EDS is associated with autism. However, this is a not systematic review and is therefore outside the scope of this surveillance review which can only consider systematic reviews, randomised controlled trials or diagnostic studies. The Cederlöf paper is a large Swedish matched-cohort study which is also out of scope. The Casanova paper is a survey of women 25 years and older with a diagnosis of autistic spectrum disorder and women 25 years or older with dual ASD and EDS, generalised hypermobility spectrum disorder (G-HSD), or Joint Hypermobility Syndrome (JHS) – referred to collectively as the ASD-generalised joint hypermobility (GJH) group - diagnoses (*N* = 20). It reports that there was no difference in the presence of immune-mediated symptoms and proportions of specific immune phenotypes between these groups. It does not compare prevalence of ASD in women with and without EDS or G-HSD. Taken as a group these papers are not enough to include EDS as a co-occurring condition and more evidence from a UK setting is needed. However, we will add EDS as a potential co-occurring condition to the autism issues log to ensure we look for evidence from a UK setting about EDS the next time we review this guidance. Box 1 in diagnosis in children (CG128) 'Factors associated with an increased prevalence of autism' lists comorbidities that may be associated with autism. Risk factors included in the list were mostly associated with at least double the risk of autism, with reasonable precision (narrow confidence intervals); as this has not been shown to be the case with EDS, it is not currently being considered as a co-occurring condition that should be added to the guideline.

		As typical therapies are not appropriate for use with patients with ARFID, we suggest the guidance is updated to state that Autistic patients with these needs are referred for a dietitian review in a timely manner. Comment regarding diagnostic stability findings: P. 79 Surveillance – Diagnosis stability cannot use an Autistic child's development as a sign they are no longer Autistic. Many Autistics (despite it often being painful) learn to mimic or give eye contact. Some Autistic people are comfortable with eye contact anyway (it should not be exclusion criteria). Furthermore, most Autistic children will learn how to speak, though this is often delayed. Development in those areas does not equal misdiagnosis.	A surveillance review in 2017 identified evidence that indicated small for gestational age, pre-natal use of selective serotonin reuptake inhibitors (SSRIs) and fertility treatments may be risk factors. It found a 'vast amount of evidence' for various risk factors most reporting odds rations of 1.25 or more. After a guidelines update committee reviewed the available evidence, only ADHD was added to the list of risk factors listed in the NICE guideline, which based on around 20-times higher increase risk of ADHD in autistic people. For the other potential risk factors, the committee considered the evidence to be 'insufficient'. Thank you for your comments about anorexia and avoidant Restrictive Food Intake Disorder (ARFID) and for sharing the article by Zimmerman and Fisher. The surveillance review did not identify any new evidence that reported statistical data on the difference in rates of anorexia in autistic people and those without autism. The Zimmerman paper is an overview of ARFID identification and management and reports that "higher rates of autism spectrum disorder…have been reported by one source." This source is a retrospective chart review by Nicely et al. from 2014 which reports that there was a statistically significant correlation between autism and ARFID. This is based on findings that 13 out of 39 7-17 year olds were found to have both autism and ARFID. Recommendation 1.5.15 in diagnosis in children does recommend considering whether the child or young person may have feeding problems, including restricted diets, as a coexisting condition. This recommendation accommodates ARFID but the Nicely paper alone is not enough to justify specifically mentioning ARFID. Additionally, recommendation 1.1.5 recommends including in the autism team (or arranging access

			for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment. This accommodates referral to a dietician. Thank you for your comments about diagnostic stability and p.79 of the surveillance proposal. On p.79 the surveillance review describes a study by Barbaro and Dissanayake in toddlers aged 24 to 48 months which describes behavioural markers associated with a change in autism diagnosis, which included, among other markers, "better eye contact" and "integrated gaze". No changes to current recommendations have been made on the basis of this evidence. The guideline on diagnosis in children (CG128) recognises that a child's overall development should be taken into consideration when carrying out an autism assessment – see recommendation 1.2.5 and recommendation 1.2.7 specifically says 'Do not rule out autism because of: good eye contact, smiling and showing affection to family members; reported pretend play or normal language milestones; difficulties appearing to resolve after a needs-based intervention (such as a supportive structured learning environment); a previous assessment that concluded that there was no autism, if new information becomes available'.
Fair Treatment for the Women of Wales (FTWW)	The guidelines should be updated to include more detail around sex and gender considerations including	The experiences and needs of autistic females and other marginalised communities are not adequately represented in the existing guideline. The surveillance document refers to the under-diagnosis of females and the importance of reducing associated suicide rates. However, the proposal to not update the existing guideline does not address these issues and may in fact perpetuate the gender gap in diagnosis and management of autistic individuals.	Thank you for your comments about the experiences and needs of autistic females, sex and gender considerations and the needs of other marginalised groups. We identified new evidence that does indicate an underdiagnosis in girls and women. However, no evidence for gender-specific diagnostic criteria were identified, and new evidence suggests that high-quality diagnostic assessment may reduce this disparity. CG128 research recommendation 1 Training professionals to recognise

	differentiated presentation; rates of suicide; long-term health conditions more prevalent in females.		signs and symptoms of autism includes addressing underdiagnosis in girls acknowledges this issue and we will highlight this to the National Institute for Health Research (NIHR) as an area where research is needed (see surveillance proposal p. 11). Without evidence of effectiveness of gender specific diagnostic and management interventions we are unable to amend recommendations. However the guidance does address this issue: for example, diagnosis of autism in children (CG128) recommendation 1.2.5 recommends 'clinicians should be aware that autism may be underdiagnosed in girls'. Autism in adults (CG142) recommendation 1.8.3 recommends that local autism strategy groups should develop pathways specifically for women. It might be helpful to note that NICE has produced guidance on preventing suicide in community and custodial settings (NG105) aimed at commissioners in the NHS and local authorities and others working in health and social care and organisations in the public, private, voluntary and community sectors. With respect to your comments about marginalised groups, each of the guidelines has to undergo an equalities impact assessment to ensure they do not act to exclude particular groups; for example, looked-after children, people who are homeless, people who misuse drugs and people in prison. Identifying such groups is an aspect of NICE's compliance with both general public law requirements to act fairly and reasonably, and human rights obligations. The equality impact assessments can be seen for each of the guidelines can be reached from the following links Diagnosis and management of autism in under 19s

			Autism spectrum disorder in adults Autism spectrum disorder in under 19s: support and management
University Hospitals Dorset NHS Foundation Trust	In agreement with the overall scope of guidance	In Box One reference is made to Down's Syndrome. The term Down Syndrome is increasingly preferred given the recognition that the apostrophe denotes ownership over the syndrome.	Thank you for your comments. Use of Down's syndrome reflects that it is named after the clinician who first described the syndrome John Langdon Down. It is also the phrase used by the Downs' Syndrome Association.
Royal College of Nursing	Yes	Young children who are deaf are slipping through the system and going undiagnosed. Communication barriers sometimes prevent them from even being referred for a screening for autistic spectrum disorder (ASD).	Thank you for your comments.. Children with sensory impairments were included in the scope of this guidance and several recommendations are made about children with hearing impairments. For example, recommendation 1.4.7 recommends once it has been decided to carry out an autism diagnostic assessment gather any additional health or social care information, including results from hearing and vision assessments.
The Challenging Behaviour Foundation		More detail needed around the clinical presentation of girls with autism: Currently, the number of autistic women and girls in Assessment and Treatment units is increasing. https://chrishatton.blogspot.com/2019/03/children-and-young-people-with-learning.html. Ensuring women receive timely diagnosis of autism is very important so that they can receive access to appropriate support and services early on. When diagnosing autism, professionals need to be very aware of the different presentation of autism in girls than boys.	Thank you for sharing the blog which presents and describes data, mostly taken from the 'Assuring Transformation' dataset maintained by NHS Digital, about the number of autistic children and young people in mental health inpatient units. This reports that the number of children and young people in inpatient units increased from 170 in March 2016 to 260 in December 2018. It also reports that in March 2018 62% of these children were female. During this surveillance we did not identify evidence for gender-specific diagnostic criteria, and new evidence suggests that high-quality diagnostic assessment may reduce this disparity. CG128 research recommendation 1 Training professionals to recognise signs and symptoms of autism includes addressing underdiagnosis in

		The guidance currently states that “autism may be under-diagnosed in girls” (section 1.2.5). We recommend that the guidance includes a description of the clinical presentation of autism in girls and how that differs from boys. The guidance currently does not include any reference to or guidance on diagnosis removal: This is a serious issue. Removal of an autism diagnosis can have a significant impact on an individual’s access to appropriate care and support. When a diagnosis is removed inappropriately, this can have very serious and long-lasting consequences. Families supported by the CBF have shared their experiences. A Safeguarding Adults Review of one individual’s care found that removal of their autism diagnosis was inappropriate and the decision only made by one clinician. The review states “This flawed diagnosis removal is particularly troubling given that it appears that TT was not alone in having his diagnosis of autism removed by Danshell.” https://www.safeguardingworcestershire.org.uk/documents/worcestershire-safeguarding-adults-board-serious-case-review-the-care-and-treatment-of-adult_tt/ This highlights that the removal of the diagnosis was not a one-off incident. In this case, the impact of the removal of the individual’s diagnosis meant they no longer had access to appropriate	girls and we will highlight this to the NIHR as an area where research is needed. Thank you for your comments on presentation of autism in girls compared with boys. We did not identify evidence describing these differences and techniques for addressing them. If you have any published evidence from systematic reviews, randomised controlled trials or diagnostic studies you can share with us about this that we can assess that would be helpful. Thank you for your comments about autism diagnosis removal and highlighting the serious case review (SCR). NICE were contacted about this issue and we did consider this during this surveillance review. We did not identify any evidence that this is a system-wide issue or that the guidelines act to worsen this issue. However, this is on our issues log and we will continue to monitor this issue and flag it for checking at the next surveillance timepoint. It should be noted also that diagnosis of autism in children (CG128) does not make any recommendations about removal of diagnosis. It does recommend that autism teams are multidisciplinary (recommendation 1.1.3) so that decisions about diagnosis are not made by individuals in isolation and include child and carer input.

		care and support. The individual and their family have been left traumatized. Two of the SCR recommendations were for NICE, I.e: Recommendation 7: (National) That Worcestershire Safeguarding Adults Board should write to the National Institute for Clinical Excellence to draw their attention to this SCR and seek advice on whether a protocol for the removal of a diagnosis of Autism Spectrum Disorder should be developed. Recommendation 8: (National) That Worcestershire Safeguarding Board should write to the National Institute for Clinical Excellence to draw their attention to this SCR and seek their views on the proposal that a responsible clinician considering the removal of a diagnosis of autism spectrum disorder should be obliged to submit their decision to peer review by another clinician unconnected with the case, the responsible clinician or the establishment which employs the responsible clinician. This guidance needs to address removal of diagnosis, ensuring that at least two professionals have to come to a joint decision before a diagnosis can be removed	
National Autistic Society	The guideline should explicitly reflect the work	We believe that the guideline would benefit from reflecting the work of NHS England and NHS Wales. Currently, there is ongoing work around diagnosis, post-diagnosis and	Thank you for your comments about NHS England and NHS Wales. We have been in touch with NHS England who have highlighted ongoing work, for example, the Realist Evaluation of Autism ServiCe

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	being done by NHS England and NHS Wales.	mental health. NICE should link up with teams in NHS England and NHS Wales to ensure that all guidelines and practice reflect each other.	Delivery (RE-ASCeD) that we plan to monitor and assess for impact when it publishes. NHS England and Wales also highlighted the SHAPE project, which was also highlighted by patient groups during initial surveillance. This study published post-stakeholder consultation. SHAPE is a 2-stage exploratory mixed methods study that investigated the experiences of service users and staff and the outcomes associated with implementing specialist autism teams (SATs). The study directly addresses CG142 research recommendation 2.2 which asks 'What structure and organisation of specialist autism teams are associated with improvements in care for people with autism?.' The study reports that only 16% of Local Authorities have SATs for autistic adults without learning disabilities. There is evidence that SATS combining diagnosis and post-diagnostic care improve mental health outcomes and there was a strong association with improved mental health with increasing multidisciplinary skills mix, which was also associated with increasing costs. The authors recommend that further robust comparative research comparing SATs with diagnosis-only centres is needed, therefore research recommendation 2.2 remains valid. The authors note that while some senior practitioners involved in SATs thought NICE's vision for SATs needed modifying, the modifications highlighted were more applicable to SAT service specifications than the NICE guideline recommendations themselves. It was also reported that sustainability may be improved by focussing SAT services on low intensity interventions and mainstream staff skilling. The findings of the SHAPE study therefore support recommendations 1.1.13 and 1.1.14 which recommend that SATs are established in each area, describe the professional composition of SATs, and recommend that SATs provide both diagnostic and

			care services. As the study findings do not have an impact on current recommendations and was published after the date for included studies considered in this surveillance review, we will ensure that the study and the impact of any further published research on SATs is considered in future surveillance reviews of the NICE autism guidelines. NHS England also responded as stakeholders to this consultation and we have considered their responses fully.
Royal College of Psychiatrists	Yes	Needs cross reference to other nice guidance e.g., challenging behaviour and assessment of other conditions e.g., ADHD.	Thank you for your comments. We will include a cross referral to attention deficit hyperactivity disorder: diagnosis and management (NICE guideline NG87) in the NICE pathway Identifying possible autism spectrum disorder in under 19s
Cheshire and Wirral Partnership NHS FT	1. Specified timeframes for the *completion* of diagnostic assessments is needed. 2. Clarity on the case co-ordinator role (1.5.3) 3. Clarity on the physical examination (1.5.5)	There has been a national focus on the '12 week wait' for initial assessment. In many regions and services described in research papers, this focus has resulted in inequities and internal waits and bottlenecks. Consider replacing the term 'case co-ordinator' with 'case administration'. Further clarity and research evidence on the function of the physical examinations would be helpful to demonstrate to commissioners the need to build the necessary capacity for this aspect of the pathway.	Thank you for your comments on specified timeframes for the completion of diagnostic assessments. Recommendation 1.5.1 recommends diagnostic assessment should start within 3 months of the referral to the autism team. During this surveillance we did not identify any research that suggested this timescale acts to produce health inequalities. If you could share these research papers with us that would be helpful, and we can assess their impact. We can consider systematic reviews, randomised controlled trials and diagnostic studies. Thank you for your comments about case co-ordinator. This reflects the language used by the guideline expert committee to interpret

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	4. Screening for additional co-existing neuro-developmental differences The need for data collection	Given the prevalence of co-existing neuro-developmental conditions such as dyslexia, dysgraphia, dyscalculia and executive functioning (as well as ADHD, ID, mood, and motor coordination, etc), screening is often needed to understand the presence or absence of autism within the context of other needs. There is a need for commissioners, leaders and policy makers to have accurate data on the true prevalence of autism and the specific needs associated with the condition (e.g. sleep, co-morbid mental health conditions, school refusal, vulnerabilities and risks, etc)	the concept of 'key worker' that was identified by the qualitative review on which the recommendations that contain this term are based. Thank you for your comment on physical examinations. Recommendation 1.5.5 is based on guideline committee consensus about what should be included in an autism diagnostic assessment. The committee said that the findings from the physical examination may be useful to consider coexisting conditions or whether there are physical signs suggestive of a causative condition (a condition strongly associated with autism which could help determine a diagnosis of autism) (see full guideline page 112-113) Thank you for your comments on coexisting neurodevelopmental conditions. Recommendation 1.5.7 recommends considering differential diagnoses for autism and whether specific assessments are needed for neurodevelopmental conditions. NICE have produced guidance on a number of neurodevelopmental conditions, including ADHD . Thank you for your comments on prevalence. Diagnosis of autism in children recommendation 1.1.2 recommends that the autism strategy team take the lead in gathering data.
PDA Society		Overall response: Given that there is a significant problem with **implementation** of existing guidance, can additional and updated 'tools and resources' be provided? Information on good implementation of the needs and strengths assessment process in relation to issues such as 'demand avoidance', co-morbid 'eating disorders',	Thank you for your comments about implementation of the existing guidance. As you say, implementation issues have been identified with implementing some of the recommendations in the autism guidelines. If you have any implementation resources you can recommend we would be really grateful for your suggestions, NICE have a process for endorsing these tools and further information about how you can submit resources for consideration can be found on the NICE endorsement page. Further we will share your

		‘assessment in inpatient units’ and ‘masking’ should help to improve practice. Overall response: The report describes an inadequate Government response to issues of capacity and highlighting of ‘lack of training and competency by healthcare staff and specialists’ The report refers to the provisions in the NHS Long-term Plan …‘*over the next three years, autism diagnosis will be included alongside work with children and young people’s mental health services to test and implement the most effective ways to reduce waiting times for specialist services’* With existing waiting lists of >1000 this appears insufficient. NICE will need to consider whether tiered guidance should be proposed in the January 2022 review, thinking about new ways to provide ‘diagnostic opinions’ rather than current use of gate-keeping and inaccurate triaging. Specific consideration should be given to evidence for harm done by not fast-tracking in cases where children may be taken into care / parents are accused of ‘Fabricated or induced illness’ and where individuals are at risk of entry into / have entered and inpatient unit	comments that the ‘tools and resources’ section requires updating with the NICE endorsement team. If you have any examples of resources you use to implement NICE guidance you may be interested in submitting to the NICE Shared Learning case studies collection. These case studies show how NICE guidance and standards have been put into practice by a range of health, local government and social care organisations. Thank you for your comment about the government response to issues of capacity and waiting time. We are unable to comment on the appropriateness or otherwise of national policies from the UK government. We will assess the impact of the review of the 2014 autism strategy on autism recommendations, which will feed into the NHS Long term plan, on NICE recommendations when it is published. The January 2022 review you refer to in your comments is referred to on p.68 of the surveillance report which says: “we will consider how to update the references to ICD-11 and consider the effects on the wording of recommendations in line with its planned adoption in January 2022.” This review will consider the impact of ICD-11 on recommendations and may or may not result in updates to the guidance. Thank you for your comments about fast tracking. We did not identify any evidence about the use or otherwise of fast-tracking in specific situations. NICE has produced Child maltreatment: when to suspect maltreatment in under 18s (NICE guideline CG89) which

		There is a crisis in the sector, even more so in adult care, where need is outpacing the education and training of specialists, but also nature of understanding of existing specialists. An overhaul is needed. If an adult psychiatrist is used to 'seeing' borderline personality disorder rather than autism, re-jigging of systems won't help. Overall response: Need for assessments to be integrated Pathways often do not meet the needs of individuals or other services. You looked for evidence of effectiveness of implementation of ASD diagnostic pathways, but we need movement towards integrated or holistic assessments – both evidence of effectiveness and perhaps greater integration of Guidance too? Overall response: Need for research It is very disappointing that so many issues are raised only for the report to say 'there was no evidence found'. Autistica do amazing work to increase research in areas of importance to the community and there are fantastic research institutions working on key questions, but funding is very limited and less often focused on clinical practice.	helps practitioners recognise situations where presentations of potential neglect may be due to other reasons. Recommendations 1.2.11 and 1.2.12 make recommendations about recognising fabricated or induced illness and the guideline is cross-referred to from CG128 recommendation 1.5.6. Thank you for your comments about demand for services outpacing the speed with which specialists can be trained. NICE is unable to comment on training of staff. Thank you for your comments about borderline personality disorder. We did not find any evidence that indicated psychiatrists routinely conflate borderline personality disorder with autism. All of the guidelines advocate the involvement of multidisciplinary teams with appropriate training to ensure a correct diagnosis. Thank you for your comments about integrated pathways. It may be helpful to look at the NICE Pathway on autism spectrum disorder which brings together everything NICE recommends about autism in a single graphical flowchart The referrals from the Department of health and Social Care we received for the guidelines were specifically about autism and the guidelines therefore necessarily focus on recommendations for autism diagnosis and treatment. This in turn informed the content of the surveillance review. However, the guidelines take account of the fact that people may be in another pathway when they are identified as possibly autistic. For example diagnosis in children recommendation 1.1.2 recommends having a lead autism professional who can make sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access

		Can NICE highlight the areas where there are particular issues concerning Guidance, increasing awareness and putting in effort to ensure they are filled? Without sufficient research the Guidance will become increasingly out-dated.	diagnostic services. Autism in adults recommendation 1.1.14 recommends that a multidisciplinary team should deliver advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for autistic adults (as not all may be in the care of a specialist team). Recommendation 1.1.16 in management of autism in children recommends that the autism team offer advice, training and support for other health and social care professionals and staff (including in residential and community settings) who may be involved in the care of autistic children and young people. Thank you for your comments about the need for research. Proposals on the need to update a guideline or not are based on an assessment of the relevant evidence published since guideline publication (abstracts of primary or secondary evidence), information obtained through intelligence gathering and feedback from stakeholder consultation that meet the following inclusion criteria: are published systematic reviews, randomised controlled trials, diagnostic studies, new or updated national policy and guidelines or information about ongoing studies . We consider the cumulation of evidence from all previous surveillance timepoints as well as the latest one and we need a clear signal that the evidence contradicts guideline recommendations before we recommend a full or partial update. More information about the surveillance process can be found in the NICE guidelines manual. Thank you for your comments about highlighting gaps in guidance. NICE do highlight areas where there are gaps in the evidence base. We make research recommendations in order to address these gaps. The research recommendations for each of the autism guidelines are

			linked to below. If we identify research that addresses a research recommendation we will recommend an update of the guideline if appropriate and stand the relevant research recommendation down. Autism research recommendations Diagnosis in children (CG128) Management in children (CG170) Diagnosis and management in adults (CG142)
Autistica, the UK's autism research charity	We cannot develop a substantive response to this question in the time available.		Thank you for your comments. We allowed 2 weeks for the consultation and sent out notification that the consultation would begin 1 week before the start date. This is the standard amount of time given for consultation on a surveillance review proposal (please see with 'Developing NICE guidelines: the manual', section 13 on Ensuring that published guidelines are current and accurate'); however if you had contacted us to say this was an issue we could have allowed more time for you to respond.
Takeda UK Ltd	Yes		Thank you for your response.
Nottinghamshire Healthcare NHS Foundation Trust	More guidance required.	Similar but not identical comment in CG170 When young people are referred to us, some parents can have little insight into how their child's Autism affects them and therefore have developed unhealthy patterns of behaviour. As a team we discuss if there could have been preventative early intervention support as part of post	Thank you for sharing this information about your provision of early support for parents, post-diagnosis to give them more insight into how they may be affected by their child's autism. The approach you have outlined sounds like it is consistent with several recommendations in the autism guidelines for children. For example, autism diagnosis in children (CG128) contains recommendation 1.8.3 in the 'Communicating the results from the autism diagnostic assessment' section, which recommends for

		diagnosis to provide guidance on what to expect, what can help and discussion around areas that can be affected, such as sensory processing, to better equip the parent. This may help with preparing the child for daily experiences, hopefully reducing the need to enter into a CAMHS service.	children and young people with a diagnosis of autism, discuss and share information with parents or carers and, if appropriate, the child or young person, to explain: • what autism is • how autism is likely to affect the child or young person's development and function. Also managing autism in children (CG170) section 1.2 Families and carers includes recommendations specifically aimed at the needs of families. It includes recommendation 1.2.2 which recommends offering families an assessment of their own needs including practical caring needs.

5. Do you have any comments on equalities issues?

Stakeholder	**Overall response**	**Comments**	**NICE response**
False Allegations Support Organisation		Those accused of rape/ sex offences/child protection issue are treated differently and assumed to be guilty -therefore robust checks on identifying those who are Autistic is paramount. (as for all mental health patients arising from false allegations.	Thank you for your comments. The intended audience for the NICE autism guidelines recommendations are healthcare professionals autistic children and adults, their families. This will include healthcare professionals who work with people who come into contact with the criminal justice system. It might also be helpful to know that NICE have also published Mental health of adults in contact with the criminal justice system (NICE guideline NG66) which covers assessing, diagnosing and managing mental health problems in adults who are in contact with the criminal justice system.

Child Oriented Mental Health intervention Centre (COMIC) – a collaborative research team between University of York and Leeds and York Partnership NHS Foundation Trust	Yes	We have just completed a Medical Research Council funded study adapting and validating the SRS-2 (screening instrument), the ADOS-2 (play/interaction based assessment) and the ADI-R (parent semi-structured interview) for use with Deaf children. There are now validated versions: SRS-2- Deaf adaptation ADOS-2-Deaf adaptation ADI-R Deaf adaptation with good sensitivities and specificities. An MRC report has been submitted and all three papers have been submitted for publication in peer reviewed journals. We recommend this be included in any updates and are happy to supply the papers.	Thank you for sharing this information with us. We would be grateful if you could supply citations for these papers once they have been accepted and published and we will consider them at the next surveillance timepoint.
Autistic UK		Comment relating to gender equality issue within the guidelines: GENDER: p. 78 Surveillance – The most commonly used diagnostic tools are not designed to spot repetitive and restrictive behaviour in girls. These issues also extend to the trans community and a-typically presenting boys. The guidance needs to be updated to reflect the differences between stereotypical repetitive behaviours (lining up cars) and repetitive and restrictive behaviour in girls (repeatedly brushing a doll's hair, for example, which is seen as 'more socially acceptable' and therefore often dismissed).	Thank you for your comments about tools for spotting restrictive behaviour. We did not identify any evidence during this surveillance review that describes gendered differences in restrictive behaviours or specific tools that are effective at identifying this behaviour in boys, girls or transgender people. Therefore, we have not proposed amending existing recommendations about restrictive behaviour to make them more nuanced. If you have any published evidence from systematic reviews, randomised controlled trials or diagnostic studies about this we would be grateful if you could share it with us. Diagnosis of autism in children (CG128) recognises the importance of individual presentation of autism signs; recommendation 1.2.4 recommends to help identify the signs and symptoms of possible

			autism, use tables 1 to 3 (see the appendix). Do not rule out autism if the exact features described in the tables are not evident; they should be used for guidance, but do not include all possible manifestations of autism.
Fair Treatment for the Women of Wales (FTWW)		The guideline needs updating to take much more account of protected characteristics listed in the Equality Act 2010, most particularly: sex, gender reassignment, race, and disability (which would include the sensory and mental health issues which are often associated with autism). It is worth noting that the Equality Act enshrines protected characteristics as 'aspects of a person's identity that make them who they are'. This has significant implications for NICE's recommendations for treatment which include social and behavioural skills. Further, under Equality Law and the Public Services Equality Duty, there is a requirement that reasonable adjustments are made to accommodate the needs of those in possession of protected characteristics. Some aspects of the NICE recommendations suggest the opposite: that neurodiverse people should learn skills that make them more 'socially acceptable'. Geographical considerations need to be factored into an updated guideline, including the limited access to specialist services and personnel in Wales, both those directly dealing with autism, and those providing support for health issues associated with it, such as eating disorder clinics.	Thank you for your comments about protected characteristics and the Equality Act 2010. The recommendations in all 3 autism guidelines underwent equality impact assessments. NICE uses this approach to consider not just equality in relation to groups sharing the characteristics protected by the Equality Act (2010) but also health inequalities arising from socioeconomic factors or associated with the shared circumstances, behaviours or conditions of particular groups (for example, looked-after children, people who are homeless, people who misuse drugs and people in prison). Identifying such groups is an aspect of NICE's compliance with both general public law requirements to act fairly and reasonably, and human rights obligations. The equality impact assessments for each of the guidelines can be reached from the following links Diagnosis and management of autism in under 19s Autism spectrum disorder in adults Autism spectrum disorder in under 19s: support and management Thank you for your comments about the Equality Act and highlighting that it enshrines the 'aspects of a person's identity that makes them who they are.' We disagree that recommendations about social and behavioural skills act to try and make neurodiverse people more socially acceptable. The recommendations are clear that an autistic person's preferences and wishes must be taken into

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			account: the guideline recommendations about management of autism in adults and children (CG142 and CG170) both include sections on person-centred care and the recommendations should be applied in the context set out in these sections. Specifically CG142 (adults) person-centred care section says: ‘Support and care should take into account peoples' needs and preferences. People with autism should have the opportunity to make informed decisions about their care, in partnership with their healthcare professionals.’ CG170 (management in children) patient-centred care section says:’ Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If the patient is under 16, their family or carers should also be given information and support to help the child or young person to make decisions about their treatment.’ Additionally all of NICE’s autism guidelines contain a ‘my responsibility’ section which says ‘when exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service.’ Thank you for your comments about geographical issues. We identified evidence from government policy and from topic experts that included lack of service capacity that applied to both Wales and England. We also identified sections of the NHS Long-term plan designed to address these issues and we plan to monitor them and assess their impact (see surveillance report p.18). These plans apply to Wales and England.

			NICE has a remit to produce national recommendations for the NHS in Wales and England in order to reduce health inequalities. These are designed to reduce regional inequalities in both countries.
Royal College of Nursing	Yes	Consider communication barriers for people with both hearing impairments and learning disabilities.	Thank you for your comments. The 3 guidelines include recommendations about communicating with people with learning disabilities and hearing impairments. Diagnosis in children (CG128) makes several recommendations about coexisting conditions including recommendation 1.1.19 which recommends that 'the autism team should either have the skills (or have access to professionals that have the skills) needed to carry out an autism diagnostic assessment, for children and young people with special circumstances including…'– the list includes learning (intellectual) disability and hearing or vision impairment. Autism in adults (CG142) recommendation 1.1.15 recommends 'all health and social care professionals providing care and support for adults with autism and their families, partners and carers should… take into account communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters.' Management of autism in under 19s (CG170) recommendation 1.1.5 recommends 'Local autism teams should provide (or organise) the interventions and care recommended in this guideline for children and young people with autism who have particular needs, including… severe visual and hearing impairments (and) intellectual disability.'

British Association of Social Workers (BASW) – England	Yes	The BASW England capabilities statement and CPD pathway resources contain resources to support autistic people, social workers, social work organisations and educators. The full reference is below: BASW. (2020). *BASW Capabilities Statement and CPD Pathway Resources*. Accessed 04.11.2020. Available from: https://www.basw.co.uk/capabilities/autistic-adults/resources. In particular, this addresses issues around people from Black and Minoritized communities commonly being excluded from timely diagnosis and intervention due to racial discrimination. This issue closely links to the gender-bias and inherent sexism which exists in the autistic diagnostic process – another area of discrimination which ought to be addressed. Furthermore, one BASW England member said: 'I could not find any discussion of equalities issues which is an omission. In particular I would have expected to see a recommendation that universal health services IAPT (Improved Access to Psychological Therapies) must make reasonable adjustments as per the Equality Act 2020 to ensure they are accessible to autistic people.	Thank you for your comments and for sharing *BASW Capabilities Statement and CPD Pathway Resources*. The document describes what social workers need to know and be able to do to make positive changes in the lives of adults with learning disability. We would recommend that you submit this as a potential implementation tool for endorsement. Further details can be found on the NICE endorsement page. Thank you for your comments about gender-bias and sexism. Diagnosis of autism in children (CG128) recommendation 1.2.5 recommends 'clinicians should be aware that autism may be underdiagnosed in girls' and autism in adults (CG142) recommendation 1.8.3 that local autism strategy groups should develop pathways specifically for women. We identified new evidence that does indicate an underdiagnosis in girls and women. However, no evidence for gender-specific diagnostic criteria were identified, and new evidence suggests that high-quality diagnostic assessment may reduce this disparity. CG128 research recommendation 1 Training professionals to recognise signs and symptoms of autism includes addressing underdiagnosis in girls acknowledges this issue and we will highlight this to the National Institute for Health Research (NIHR) as an area where research is needed. (see surveillance proposal p. 11). The recommendations in all 3 autism guidelines underwent equality impact assessments. NICE uses this approach to consider not just equality in relation to groups sharing the characteristics protected

			by the Equality Act (2010) but also health inequalities arising from socioeconomic factors or associated with the shared circumstances, behaviours or conditions of particular groups (for example, looked-after children, people who are homeless, people who misuse drugs and people in prison). Identifying such groups is an aspect of NICE's compliance with both general public law requirements to act fairly and reasonably, and human rights obligations. The equality impact assessments can be seen for each of the guidelines can be reached from the following links: Diagnosis and management of autism in under 19s Autism spectrum disorder in adults Autism spectrum disorder in under 19s: support and management In relation to IAPT services, it is expected that those managing IAPT services who may implement recommendations from the autism guidelines would adhere to the Equality Act 2010 and make reasonable adjustments. This is described in the 'My responsibility' section of all NICE guidelines which says that when applying guidelines local providers should 'have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.'
National Autistic Society	Autistic people face an unacceptable and well-documented health inequality – evidence suggests that this results in an	This health inequality is now enshrined in the Government's Mandate to NHS England and the NHS England Long Term Plan. The All Party Parliamentary Group on Autism last year published its Autism Act: 10 Years On report, which highlights the additional barriers that autistic people with other protected characteristics	Thank you for your comments about increased premature mortality and for sharing The Autism Act, 10 Years On: A report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England. This document concludes that whilst the Autism Act has led to welcome improvements in some areas of support, for example there has been an increasing recognition of autism among commissioners and the public, there is significant unmet need. These unmet needs stem

	increased risk of premature mortality.	may face. We would be happy to discuss these further with you. 1.5.5. When assessing for autism there is also a need to consider the variation in profiles of autism as a result of the intersectionality with gender and ethnicity. This needs to include the assessment of ethnicity, cultural and gender factors and how these need to be considered within the context of assessment and feedback.	from a low awareness of the duties that are included in the Autism Act. The report also highlights that allocation of funding has affected the ability to provide services. We are aware from topic experts, and this is also highlighted in the provided report, that there are service capacity issues and these are having an impact on implementing recommendations in NICE guidelines particularly around diagnosis and assessment. Topic experts also highlighted lack of staff training which is also described on p.23 of your report. The autism topics were referred to NICE by the Department of Health and Social Care in order to help reduce health inequalities in autistic people. We believe the implementation of NICE recommendations and also the NICE autism quality standard (QS51) will help to reduce these inequalities. We understand that the guidelines can only be implemented in the context of local and national priorities for funding and developing services. We have not identified any evidence that suggests the recommendations may be contributing to these issues. The findings of the government's Autism self-assessment framework which reviews progress in implementing the 2014 autism strategy in England are consistent with the issues highlighted by topic experts and patient groups. The government has started a review of the 2014 Autism Strategy to address these issues and we will monitor its progress and assess its impact on the guidelines covered by this surveillance review on publication.

			Thank you for your comment about recommendation 1.5.5 which makes recommendations about the components of a diagnostic assessment. This recommendation should be applied taking into consideration the other recommendations. This includes recommendation 1.2.5 which recommends signs and symptoms should be seen in the context of the child's or young person's overall development, taking account of cultural variation and bearing in mind autism may be under-diagnosed in girls.
Royal College of Psychiatrists	Yes	References to cultural differences e.g., use of eye contact with adults, initiating conversations with adults, cultural sensitivities re: gender of the clinician vs the child, history taking/assessing when the parent is not present e.g., use of nannies/hired help. Assessment of females. Access to assessments within assessment for gender identity disorders as differential diagnosis/co-occurring condition.	Thank you for your comment about cultural differences. Diagnosis of autism in children (CG128) makes recommendation 1.2.5 which recommends when considering the possibility of autism, be aware that it is necessary to take account of cultural variation. We did not find any evidence about the impact of clinician gender on a child's response to the clinician. If you have any published evidence from systematic reviews, randomised controlled trials or diagnostic studies about this it would helpful if you could share it with us. Both autism guidelines covering children (CG128 and CG170) use the phrase 'parent or carer' throughout the recommendations. This accommodates the presence of nannies or hired help in the absence of a parent. We identified new evidence that does indicate an underdiagnosis in girls and women. However, no evidence for gender-specific diagnostic criteria were identified, and new evidence suggests that high-quality diagnostic assessment may reduce this disparity. CG128 research recommendation 1 Training professionals to recognise signs and symptoms of autism includes addressing underdiagnosis in girls acknowledges this issue and we will highlight this to the National Institute for Health Research (NIHR) as an area where research is needed. (see surveillance proposal p. 11). However,

			without evidence of effectiveness of gender specific diagnostic and management interventions we are unable to amend recommendations. However the guidance does address this issue: for example, diagnosis of autism in children (CG128) recommendation 1.2.5 recommends 'clinicians should be aware that autism may be underdiagnosed in girls'. We did not find any evidence specifically about gender dysphoria and autism during this surveillance or the 2016 surveillance of diagnosis of autism, in children (CG128). However, people undergoing assessment for gender identity disorders would not be precluded from accessing autism diagnostic services if autism was suspected.
Cheshire and Wirral Partnership NHS FT	1. Every individual assessed has the right to understand the assessment findings to support their self-understanding (regardless of co-existing conditions and regardless of the complexity of the	Caution is needed when developing services to ensure that abbreviated pathways (or alternative pathways for different subpopulations) do not inadvertently introduce inequities. In some areas referral procedures focus heavily on school information and this could disadvantage those young people with less visible needs in school/out of school. Caution is also needed to avoid 'gatekeeping' (e.g. families asked to attend a course prior to accessing the diagnostic assessment) which can delay a diagnostic assessment that is indicated. Additional clarity also has potential to reduce national geographical inequities as well as local inequities – i.e. better alignment of services across teams working everywhere (whilst accepting that there will be a level of inevitable and acceptable variation).	Thank you for your comments about assessed individuals' rights to understand assessment findings. We agree with this and recommendation 1.8.1 recommends that after the autism diagnostic assessment discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person. Explain the basis of conclusions even if the diagnosis of autism was not reached. Thank you for your comments about which parts of the guidance are essential and which less so. The recommendations should be applied along with clinical judgement. The overview page in the 'Your responsibility' section says: 'It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.'

	diagnostic decision). It can be especially important for those who do not reach the criteria for a diagnosis to access this aspect of the pathway. This is already covered in the current guidelines, but see number 2 below). 2. Additional clarity would be helpful to indicate aspects of the guidance that are essential (because they impact on equity) versus those that are less pivotal. Different people		Thank you for your comments about developing services. The guideline should act to reduce health inequalities across England and Wales and it has undergone a full equalities impact assessment to ensure the recommendations do not act to exclude or marginalise specific groups.

	interpret guidelines in different ways. To ensure that diagnostic information is provided in an accessible format to parents, carers and young people.		
PDA Society		There remains a very stereo-typical view of what 'autism looks like' and so being more specific about (or greater acknowledgment of) less typical autism, autism in girls / women, greater heterogeneity in gender and sexuality and the failure to even consider ASD in certain groups is essential. Evolution of more holistic or integrated assessments should help. In addition, the move by clinicians to less of a deficit model in terms of language used is also important (reflective of the neurodiversity movement	Thank you for your comments about greater acknowledgement of how autism may present in different ways in different groups of people, particularly in girls and women. Diagnosis of autism in children (CG128) recommendation 1.2.5 recommends 'clinicians should be aware that autism may be underdiagnosed in girls' and autism in adults (CG142) recommendation 1.8.3 that local autism strategy groups should develop pathways specifically for women. Although recommendation 1.2.8 (in CG128) does link to an appendix of possible signs and symptoms of autism, it does caution to 'not rule out autism if the exact features described in the tables are not evident; they should be used for guidance, but do not include all possible manifestations of autism.' We identified new evidence that does indicate an underdiagnosis in girls and women. However, no evidence for gender-specific

			diagnostic criteria were identified, and new evidence suggests that high-quality diagnostic assessment may reduce this disparity. CG128 research recommendation 1 Training professionals to recognise signs and symptoms of autism includes addressing underdiagnosis in girls and we will highlight this to the National Institute for Health Research (NIHR) as an area where research is needed. (see surveillance proposal p. 11). Thank you for your comments about a 'deficit model.' We found no evidence that suggested clinicians view autistic people as being 'deficient' or used a 'deficit model' when supporting autistic people.
Autistica, the UK's autism research charity	We cannot develop a substantive response to this question in the time available.		Thank you for your comments. In line with 'Developing NICE guidelines: the manual', section 13 on Ensuring that published guidelines are current and accurate' we provided the standard timescale of 2 weeks for the consultation. We also sent advanced notification of the consultation 5 days before the start. In future, please contact us when you have received notification of a consultation if you do not think you will be able to respond by the deadline and we can discuss extending the deadline for a response.

6. NICE acknowledges that services may be impacted by the current COVID-19 situation.

Please tell us if there are any particular issues we should be considering in relation to the Autism guidelines?

Stakeholder	**Overall response**	**Comments**	**NICE response**
Evelina Children's Hospital, London	Yes – assessment of children with ASD has needed	Services will simply not manage to address the volume of children required unless new online assessments are used. This is challenging and only a few services have been able	Thank you for your comments. We are aware of the issues around the use of digital resources and telemedicine, particularly in relation to mental health and learning disability services. We did not identify

	to radically change to cope with COVID-19	to show an agile approach. Nevertheless some of the assumptions about diagnosis without face- to – face contact have not been tested and need careful consideration.	evidence about this issue but we fully expect it to emerge in the near future and we will assess its impact on recommendations when it publishes.
False Allegations Support Organisation	Issues	Answer 6 - The availability of the local NHS mental health groups is not working and reject requests for support od autistic persons and are often signed off unnecessarily. Thy are easily rejecting requests – for mental health support and leaving persons to take their life. The Autistic person and their families need to have in place and recognise a competent, robust and ethical support system to support their needs, whilst being traumatised. NICE guidelines should make these requirements stricter and accountable for the MoJ The guidelines should encompass that the MoJ system be fit for purpose and identify individuals with Autism FASO are the ones picking up the individuals and families to support them going through the justice system.	Thank you for your comments. We appreciate that this is a difficult time for service delivery. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio. Diagnosis of autism in children (CG128) recommendations will apply to health and social care professionals who work with people who come into contact with the justice system. The guideline scope says: 'This is an NHS guideline. It will comment on the interface with other services, such as social services and the voluntary sector. But it will not include recommendations relating to services provided exclusively by these agencies, except relating to care provided in those settings by healthcare professionals funded by the NHS.' Therefore, we are unable make recommendations about Ministry of Justice services.
Autistic UK		Recommend adding information regarding the misuse of DNARs: Guidelines should be updated to state that encouraging Autistics to agree to a DNAR being added to their medical file during a global pandemic is unacceptable. Recommend adding sections regarding the difficulties Autistics have in accessing healthcare: Difficulties in accessing healthcare, particularly without support, affects	Thank you for your comments about 'do not attempt resuscitation' instructions. This is outside the scope of these guidelines which are about the diagnosis and management of autism not about the management of COVID-19. We have not identified any evidence on the misuse of DNARs, but we will share you're your comments with colleagues in NICE's COVID-19 team. NICE have also produced making decisions about your care a guide for the public about using NICE guidelines to inform their care, which includes advice about shared decision making that says:' It is your right to be involved in

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		many people in the Autistic community, regardless of whether or not they have a learning disability. We have been informed of some of our Autistic stakeholders being refused accompaniment and/or someone to advocate for them in medical settings during the pandemic due to it being deemed unnecessary due to the lack of a co-occurring learning disability. Guidance should be updated to add that all Autistics are entitled to receive support and/or advocacy from someone during appointments should they wish to have one. Consider the rise in excess deaths within the community and the reasons for this including co-occurring conditions: The rise in excess deaths within our community during the pandemic is of concern. Some of these pertain to co-occurring conditions such as asthma, heart defects/disease, and mental health conditions. The lack of an updated co-occurring conditions list is concerning as it is repeatedly mentioned in literature that excess deaths pertain to co-occurring conditions rather than solely being because a person is Autistic, yet guidelines do not reflect this. As Autistics often present with pain/discomfort differently to non-Autistics, both due to communication and interoception differences, they also tend to seek medical advice later than non-Autistics. Therefore, some of our stakeholders who work in medical professions have reported that Autistics have worse prognoses than non-Autistic counterparts. However, our Autistic stakeholders also state that they are often dismissed without	making choices about your care'. NICE is currently producing guidelines on shared decision making due for publication in June 2021. Thank you for your comments about issues with accessing healthcare for autistic people and the importance of autistic people having the choice of being accompanied to healthcare appointments. While we appreciate that services have to mitigate risk by minimising numbers during the pandemic this should not act to exclude carers or advocates being refused access to healthcare facilities if that results in an autistic person attending a healthcare service unaccompanied when they do not feel comfortable doing so, or they are vulnerable. Diagnosis and management of autism in adults (CG142) recommendation 1.1.1 still applies. This recommends that all staff working with autistic adults should work in partnership with autistic adults and, where appropriate, with their families, partners and carers. Thank you for your comments about the rise in excess deaths within the autistic community and for sharing references about this. We are aware of this issue and reducing this inequality is the reason that the Department for Health and Social Care referred these topics to NICE. The study overview by the NHS Behind the headlines service you have shared entitled 'People with autism are 'dying younger,' warns study', highlights these issues. It draws on a Swedish study which reports the average age of death for people with autistic spectrum disorder is 53.87 years, compared with 70.2 years for people without. It notes suicide and epilepsy 'stand out' as causes.

		investigation for medical concerns because they don't 'look' as sick/in pain as non-Autistic counterparts. We recommend that medical co-occurring conditions such as CHD and asthma are added to the list of co-occurring conditions which, in turn, will assist in the earlier referral for diagnosis and treatment of said conditions. Bazian (2016). People with autism are 'dying younger,' warns study on NHS [Online] https://www.nhs.uk/news/neurology/people-with-autism-are-dying-younger-warns-study/ (Accessed 04/11/20) Calderon, J., Henson, B., & Ware, J. (2020). Congenital heart disease and autism: A possible link? In Harvard Health Publishing [Online] https://www.health.harvard.edu/blog/congenital-heart-disease-and-autism-a-possible-link-2020010218552 (Accessed 04/11/20) Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. In Autism : the international journal of research and practice, 19(7), 814–823. [Online] https://doi.org/10.1177/1362361315577517 (Accessed 04/11/20)	Autism in adults recommendation 1.2.10 recommends that during a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as mental health disorders like depression and anxiety, and neurological conditions including epilepsy. This study was conducted in a Swedish setting and its applicability to a UK setting in questionable, although it does seem to support the current recommendations about considering specific co-occurring conditions. The Croen et al. study you highlighted describes the frequency of several psychiatric and 'medical conditions' among a large, diverse, insured population of autistic adults in the United States. It reports that depression, anxiety, bipolar disorder, obsessive–compulsive disorder, schizophrenia, and suicide attempts are higher in autistic people than non-autistic people. The study published in April 2015 predates the search period for this surveillance review, which is from January 2016, It also reports results from a sample of people (n=15.070) living in California and its applicability to a UK setting is open to question. However, the guidelines accommodate the co-occurring conditions highlighted by this study and it is supportive of recommendations about coexisting conditions. Thank you for your comments about co-occurring conditions. The list of co-occurring conditions in diagnosis of autism in children (CG128) is based on guideline committee expertise and a review of studies of the prevalence of co-occurring conditions. The list of co-occurring conditions in autism in adults (CG142) is based mainly on guideline development committee expertise. The committee considered that attention should also be paid to coexisting physical

			health problems but noted that a number of co-occurring conditions will be outside the expertise of a specialist autism team. Given this, the guidelines committee highlighted the important role of the specialist team io seek advice from other healthcare professionals on the management of coexisting physical health problems. To that end CG142 recommendation 1.2.5 recommends a comprehensive assessment should be team-based and draw on a range of professions and skills. Most of the evidence identified in this surveillance review was consistent with the lists of coexisting conditions in current recommendations. Evidence for conditions not currently on the list (obesity, asthma, persistent crying as infants, and hypocholesterolaemia) tended to be from studies with methodological limitations and did not sufficiently establish links between autism and other coexisting conditions. It might be helpful to know that NICE has produced rapid covid-19 guidelines on managing acute myocardial injury (NICE rapid guideline NG171) and severe asthma (NG166) that place people at greater risk during the pandemic. The full list of COVID-19 guidelines can be reached at this link and they apply to autistic and non-autistic people. The Calderon et al paper you have shared with us is a blog that gives an overview of a possible link between congenital heart disease and autism, but it is outside the inclusion criteria for this surveillance review, which only considered randomised controlled trials, systematic reviews and diagnostic studies. We did identify 7 systematic reviews and 2 observational studies that reported on risk factors related to cardiovascular and metabolic conditions during pregnancy (see surveillance proposal p.24). None of these studies reported odd ratios greater than 2.0 for increased risk, which was

			the threshold for inclusion in diagnosis of autism in children (CG128).
Fair Treatment for the Women of Wales (FTWW)		Covid-related pauses on health services have restricted access to mental health support and psychological therapy for those underlying / co-existing conditions experienced by autistic individuals. Stress emanating from the uncertainty of the situation may have a pronounced impact on autistic individuals. Further, government guidance regarding handwashing, social distancing, masks etc will be exacerbating repetitive and restrictive behaviours and worsening some of the more distressing aspects of autistic people's lives and the lives of those close to them. For autistic females, the restrictions around maternity services, such as partners not being allowed into pregnancy scans, will be having a particularly detrimental impact on mental health. Current guidance includes only allowing birth partners to be present in the latter stages of labour. For those women whose autism includes selective mutism when under extreme stress may find this impacting negatively on their ability to communicate their needs at this time, potentially resulting in trauma and a higher chance of post-natal mental health issues.	Thank you for your comments about mental health services. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio. Thank you for your comments about stress and uncertainty for autistic individuals and the effect of government guidance. We appreciate the situation may be difficult for some autistic people, but we are unable to comment on the effects of government guidance. Thank you for your comments about maternity services. NHS staff have a duty to mitigate risk during COVID-19. Diagnosis and management of autism in adults (CG142) recommendation 1.1.1 still applies. This recommends that all staff working with autistic adults should work in partnership with them and, where appropriate, with their families, partners and carers. This partnership working still applies during COVID-19. NICE has also produced COVID-19 rapid guideline: arranging planned care in hospitals and diagnostic services (NG179) which applied to all adults and children and contains recommendations on shared decision making.

University Hospitals Dorset NHS Foundation Trust	Please note that there are difficulties with some assessments such as ADOS, which do not have current authorisation to be administered virtually. This is leading to disparity across the country where some teams are using the ADOS via video, some are doing it face to face but adapting some parts which are not Covid-Safe and others have stopped doing them. There needs to be consideration of the evidence base for using or adapting	Please consider the evidence base for adapting formalised assessment tools.	Thank you for your comments about adapting assessment tools and issues with using ADOS during COVID-19. If you have any published evidence, you can share with us about adapting assessment tools for use during COVID-19 we would be grateful if you could share them with us. We are aware of the issues around the use of digital resources and telemedicine, particularly in relation to mental health and learning disability services. We plan to look at the mental health guidelines in NICE's portfolio together in order to explore the implications of system drivers including the NHS Long Term Plan and the impact of COVID-19 on service delivery on our recommendations. In addition NHS England have produced Managing capacity and demand within inpatient and community mental health, learning disability and autism services for all ages which says: 'providers will need to prioritise face-to-face contacts (in line with existing guidance on use of personal protective equipment (PPE) and social distancing) for those patients for whom remote or virtual contacts are not possible or viable, and for those deemed at higher risk, such as people with complex and severe mental health problems and co-existing needs who do not have access to technology and those living alone as well as some people who have a learning disability or who are autistic. Decisions regarding the type of contact offered should be risk assessed and considered in terms of reasonable adjustments, documented and regularly reviewed.' Current NHS England Legal guidance for mental health, learning disability and autism, and specialised commissioning services supporting people of all ages during the coronavirus pandemic dated May 2020, chapter 13 Specific considerations for mental health, learning disability and autism and the criminal justice system,

	assessment materials.		recommends that where appropriate, digital technology should be used across relevant services in respect of undertaking assessments and clinical discussions.
Royal College of Nursing	Yes	- Assessment and diagnosis appointment delayed. - Lack of appropriate community support due to not having a formal diagnosis. - Families struggling to cope with family members who lack input from specialised community services. - Impact on family members' mental health due to not being able to cope without support.	Thank you for your comments. NICE has produced COVID-19 rapid guideline: arranging planned care in hospitals and diagnostic services which aims to help patients make decisions about their planned care and healthcare providers minimise risk. NHS England has also produced Managing capacity and demand within inpatient and community mental health, learning disability and autism services for all ages which provides advice on when it is appropriate to deliver remote diagnosis. Thank you for your comments. We are aware of the impact that the pandemic has had on mental health services from a number of sources including stakeholders. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio.
British Association of Social Workers (BASW) – England	Yes	Same comment as per CG142. These comments are: One England member said: 'Guidance on Personal Protective Equipment (PPE) and supporting people to desensitize to using PPE and seeing people in PPE Guidance of Covid-19 test for autistic people: e.g	Thank you for your comments about PPE, swab tests and social distancing. NHS England have produced Managing capacity and demand within inpatient and community mental health, learning disability and autism services for all ages. This says: 'Providers should consider whether it is possible to reconfigure the inpatient estate to create 'cohorted' wards to reduce the risk of contagion.

		desensitisation through the rather unpleasant swab test, as well as support to adjust and accept social distancing'. Another member said: 'In terms of Autism services- need to be far more then diagnostic- What is needed is a locus to call people in to work in it otherwise people end up going to the wrong place and they either don't get seen, an assessment or a service. Having a central point is key to enabling people to get access to the right support. The Autism Act doesn't cut it which is why areas can get away with having a diagnostic service only. The Autism strategy is delayed and unlikely to be published until December 2020'.	This will need to be considered in line with the specialist nature of service provision and the considerations for all services needs of each patient group and the requirement to make reasonable adjustments for people with a learning disability and those who are autistic.' It also makes recommendations about service planning within community settings. Thank you for your comments about autism services and having a central point of contact. Autism in adults (CG142) makes research recommendation 2.2 about the future structure of specialist teams. This acknowledges that the Department of Health's autism strategy (2010) proposes the introduction of a range of specialist services for autistic people built around specialist autism teams, However, there is little evidence to guide the establishment and development of these teams. It proposes a large-scale observational study, which should provide important information on the characteristics of teams associated with positive outcomes for autistic people in terms of access to services and effective coordination of care. We note your comment about the autism strategy. We plan to monitor the 2014 review of the autism strategy and we will assess its impact on the 3 autism guidelines when it publishes.
The Challenging Behaviour Foundation	As restrictions continue, the guidance should emphasise the need for reasonable	Emerging research into the impact of Covid 19 on autistic children, young people and adults and those with learning disabilities and their families shows there have been negative and some positive impacts of lockdown restrictions.	Thank you for your comments. NHS England has produced Managing capacity and demand within inpatient and community mental health, learning disability and autism services for all ages which provides advice on when it is appropriate to deliver remote diagnosis and assessment. Section 11 Specific considerations for

	adjustments to ensure any barriers to diagnosis are removed.	Increased flexibility around meeting virtually rather than face to face has been beneficial to some individuals and the opportunity for flexibility at diagnosis and support should be carried forward.	learning disability and autism services of this document recommends: To have equality of access to care and treatment, people with a learning disability and autistic people may require individuals and systems to make reasonable adjustments to their practice, policy and procedures. Thank you for your comments around meeting virtually. We are aware of the issues around the use of digital resources and telemedicine particularly in relation to mental health and learning disability services. We will discuss these issues and your comments related to autism services with NICE's COVID-19 team as an area of potential guideline development.
National Autistic Society		Our Left Stranded report highlights the devastating impact on the mental health and wellbeing prospects on hundreds of thousands of autistic people and their families. 9 in 10 autistic people worried about their mental health during lockdown and 85% said their anxiety levels got worse. Autistic people were also 7 times more likely to be chronically lonely than the general population and 6 times more likely to have low life satisfaction (comparisons using ONS data).	Thank you for sharing this information about the report. The report is called Left stranded: The impact of coronavirus on autistic people and their families in the UK and describes the findings of a survey (n=4,232) of autistic people and their families. It reports that compared to the general public, autistic people were seven times more likely to be chronically lonely during June and July 2020 and six times more likely to have low life satisfaction. We are aware of the impact that the pandemic has had on people's mental health and on mental health services from a number of sources including stakeholders. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio.

Royal College of Psychiatrists		How to assess online, many tests not validated. Limitations. Options- modification, alternative tests e.g., BOSA, NODA. (both short, so may need to wait if not conclusive) Use of PPE in assessment- use of clear face masks/visors, PPE might alter the assessment outcomes. Managing waiting lists to cherry pick out clearer cases that might be concludable without the face to face assessments- to maintain flow in a diagnostic clinic, rather than all wait and extra delays for everyone. Some teams have created their own online assessment due to COVID (non-validated but still helpful e.g., ROSSCO by TEWV NHS FT)	Thank you for your comments about online assessments. We are aware of the issues around the use of digital resources and telemedicine, particularly in relation to mental health and learning disability services. We plan to look at all the mental health guidelines in NICE's portfolio together in order to explore the implications of system drivers including the NHS Long Term Plan and the impact of COVID-19 on service delivery on our recommendations. Thank you for your comments about PPE. We have noted your comments and will share them with NICE's COVID-19 team. Thank you for your comments about identifying clearer cases for potential non-face-to-face assessments. Thank you for your comments about autism teams creating their own online assessments. Colleagues at Tees, Esk and Wear foundation may want to consider submitting ROSSCO as a potential implementation tool. NICE have a process for endorsing these tools and further information about how you can submit resources for consideration can be found on the NICE endorsement page. Further if you have published evidence from systematic reviews, randomised controlled trials or diagnostic studies on the effectiveness of these tools we would be grateful if you could share it with us or ask colleagues at Tees, Esk and Wear Foundation Trust to share any relevant published research they may have.
Cheshire and Wirral Partnership NHS FT		1. How services are offer assessment and intervention, eg via video or technology can disadvantage certain autistic adults who may struggle with these formats or not have the means to have technology or the internet.	Thank you for your comments. We are aware of the issues around the use of digital resources and telemedicine, particularly in relation to mental health and learning disability services. We plan to look at all the mental health guidelines in NICE's portfolio together in order to explore the implications of system drivers including the NHS Long

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		2. Consider including recommendations on standardised procedures for video / socially distanced observations as research evidence emerges (e.g. BOSA, ASD-PEDS). Continue to offer choices / alternatives to families who cannot attend clinic appointments in person (e.g. home/school visits, video call, phone call, email exchange).	Term Plan and the impact of COVID-19 on service delivery on our recommendations. Thank you for your comments about offering choice and alternative methods of assessment. NHS England Legal guidance for mental health, learning disability and autism, and specialised commissioning services supporting people of all ages during the coronavirus pandemic dated May 2020 in chapter 13 Specific considerations for mental health, learning disability and autism and the criminal justice system, recommends that: • Where appropriate, digital technology should be used for clinical assessments.
PDA Society		We were pleased that there was consideration of adaptations needed for those with ASD / LD as new laws were put in place. As Guidance isn't being correctly implemented in many areas anyhow, trying to identify the possibility of flexibility that could be adopted in times of crisis is probably meaningless.	Thank you for your comments. We are aware that the pandemic has been difficult for services and that there are unfortunately issues with implementing guidance recommendations.
Royal College of Paediatrics and Child Health		Many children with autism are first referred to the audiology clinics as they 'appear not to hear well' but are found to have no hearing difficulties. In these clinics their behavioural difficulties are sometimes seen more easily because of the expectations from them in performing a hearing test. A fast-track referral system from these clinics may help in earlier referral and diagnosis of autism in such	Thank you for your comments about audiology clinics. Autism diagnosis in children (CG128) recommendation 1.1.2 recommends that the local autism strategy group should aim to: • improve early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training

		children and less stress in the parents with long waiting times. A key difficulty is implementation and service delivery, but this has been acknowledged and the review of the 2014 autism strategy is awaited.	• make sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services This accommodates working with professionals working in audiology clinics. Thank you for your comments about the review of the 2014 autism strategy. We plan to assess the impact of the review on recommendations in the NICE autism guidelines when it is published.
Takeda UK Ltd	Yes	There needs to be an evaluation on appropriate use and effectiveness of telepsychiatry in this patient cohort	Thank you for your comments. We are aware of the issues around the use of digital resources and telemedicine, particularly in relation to mental health and learning disability services. We plan to look at all the mental health guidelines in NICE's portfolio together in order to explore the implications of system drivers including the NHS Long Term Plan and the impact of COVID-19 on service delivery on our recommendations.
Lead of NHSE funded study: Realist evaluation of autism diagnostic service delivery for children with possible autism		Impact on mental health and waiting times for diagnosis- accepting diagnostic tools being used outside original guidance eg ADOS in PPE including face mask invalidates recording it as ADOS but many teams using it and writing up results recognising less than ideal	Thank you for your comments. We are aware of the impact that the pandemic has had on people's mental health and on mental health services from a number of sources including stakeholders. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio. We are also aware of the issues around the use of digital resources and telemedicine, particularly in relation to mental health and learning disability services. We plan to look at all the mental health guidelines in NICE's portfolio together in order to explore the

			implications of system drivers including the NHS Long Term Plan and the impact of COVID-19 on service delivery on our recommendations.