Appendix B: Stakeholder consultation comments table

2020 surveillance of CG142 Autism spectrum disorder in adults: diagnosis and management (2016)

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
False Allegations Support Organisation	No	Answer 1 - The comments at para 3, of the guidelines previously known as - : Autism: recognition, referral, diagnosis and management of adults on the autistic spectrum. And now the updated version does not suggest the justice system be pro active in giving instructions to all police/CPS, forces and prisons in England and Wales to ensure and have in place checks and balances to deal with individuals that fall into the autistic category. In an appropriate manner.' Answer 2 - Many of this cohort, along with mental health issues of other kinds are not identified immediately at the start of the justice system, either pre/on arrest/in imprisonment and not using the individuals family and	Thank you for your comment. The guideline identified that some autistic people may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised. Recommendation 1.8.3 suggests that the autism strategy group should develop local care pathways that promote access to services for all autistic adults , including people in the criminal justice system. Recommendation 1.1.12 advises that in order to effectively provide care and support for autistic adults, the local autism multi-agency strategy group should include representation from the criminal justice system.. We have existing relevant NICE guidance: Mental health of adults in contact with the criminal justice system (NG66) which covers assessing, diagnosing and managing mental health problems in adults who are in contact with the criminal justice

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		friends comments on confirmation of Autism and are treated inappropriately at arrest time and not often medically supported on the long wait until the investigations are completed (can be up to 2 years) there is no support put in place by the criminal justice system, or in your instructions, identifying the need of support of individuals in this category. A comprehensive assessment if appropriate following triage whilst at the police station, or interceded by the solicitor/individual's Dr to be triaged at home	system. NICE guideline NG66 recommends: Commissioners and providers of criminal justice services and healthcare services should support the development of liaison and diversion functions for police custody and the courts that provide prompt access to the following: • the effective identification and recognition of mental health problems • a comprehensive mental health assessment • advice on immediate care and management • appropriate treatment and care (including medication).(recommendation 1.8.1) There is also NICE's guideline on physical health of people in prison which covers mental health assessment for the prison population as part of the first-stage health assessment for people going into prison, and continuity of mental health care for people leaving prison.
University of York (Social Policy Research Unit)	In the comments section (right) I briefly summarise key findings from a national study responded directly to a research recommendation set out in this Guideline (ref. para 2.1). The	Surveillance work may not have identified a study (NIHR-HS&DR) which evaluated the 'Specialist Autism Team' model. This model was a core recommendation of the guideline (ref: para 1.1.13) and research on this model of provision was one of the key research recommendations (ref: para 2.2 of guideline). We anticipate NIHR will publish this the report of this research next month. The study provides mixed-method evidence on: the implementation of this type of model of service organisation and delivery, lessons learnt in implementation,	Thank you for your comment and for making us aware of the SHAPE project at the University of York. This study published post-stakeholder consultation. As you highlight, 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

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	report of this research will, we anticipate, be published by NIHR next month.	views about sustainable service models going forward, user experiences and outcomes, and the features of both the delivery model and individual characteristics associated with outcomes @ 12months. Questions of cost-effectiveness are also addressed. These were the core questions which, in their research recommendations, the GDG said needed to be addressed. Findings from this study have been shared and extensively discussed with NHS EI's Autism & LD Programme. A link to a first look summary can be found here: https://fundingawards.nihr.ac.uk/award/13/10/86 We'd be very pleased to share pre-publication version with you. The above study also offers initial comparative evidence on experiences and outcomes of two groups of individuals: • those who received a multi-session post-diagnosis psychoeducation intervention (delivered via group or 1:1) (i.e. those accessing a 'Specialist Autism Team') • those diagnosed by a service which only provided diagnostic assessment and a single follow-up appointment (as recommended in the current guidance (ref. Para 1.2.18)	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.

		Our findings suggest that a single follow-up appointment is, for at least some, inadequate and has long-term adverse consequences. A further finding was that only a minority of autistic adults (<25%) engage with autism-specific groups/communities. In addition, sign-posting to such provision appears to be 'ineffective' (Ref. para 1.1.7 of guidance) and, for some, experienced as a rejection and served to heighten the sense of isolation.	
2gether NHS Foundation Trust (now Gloucestershire Health and Care NHS Foundation Trust)	No	See below	Thank you for your response.
Surrey and Borders Partnership NHS Foundation Trust	Agree	A date for a planned review would be helpful although understand this to be dependent on changes in evidence.	Thank you for your comment. The guidelines are reviewed approximately every 5 years unless we identify or are alerted to new event (large study, significant policy change, new guidelines or a safety alert) that may trigger an exceptional review. If this happens, we will undertake a review as soon as we can. Please see the NICE methods manual Chapter 13 Ensuring that published guidelines are current and accurate for more details. We also plan to track several pieces of evidence and policy to assess their impact on recommendations on publication, these are listed below: • The review of the 2014 autism strategy on autism which will feed into the NHS Long term plan

			• ICD-11 when it is implemented fully in January 2022 • Sixteen ongoing trials identified during surveillance which are listed in the surveillance report 'ongoing research' section • Work in progress by NHS England and NHS Innovation (NHSE&I) to help deliver the objectives for autism services in the NHS Long-term plan. This includes 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; due to complete in 2022. NHSE&I also alerted us to the SHAPE project at the University of York. This study published post-stakeholder consultation. As you highlight, 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.
Autistic UK	No, we do not agree.	Recommendation to update the introduction to remove functioning labels and allusion to a linear scale: The introduction (p. 5) states that 'the features of autism may range from mild to severe.' Though this is qualified by the addition of fluctuation and responses to changes in circumstance, it doesn't account for a 'spiky' profile; autism isn't linear. Comments regarding our concern over the use of the term 'challenging behaviour' and recommendation to remove: 1.2.19 – We are concerned with the use of the term 'challenging behaviour' and this point which states that assessment of challenging behaviour should be integrated into autism assessment. There is no legal single definition for the term 'challenging behaviour' (or indeed, 'behaviours	Thank you for your comments. We do not believe that recommendations leave the impression that autism spectrum is a linear scale. The term 'function' is used within the recommendations in relation to assessment and adaptive skills, but we disagree that this acts to label people or is in any way used pejoratively. The 'spectrum' consists of many traits and a person with autism may have set of traits all in different areas of the spectrum which the combination can range from mild or severe. Please note, we only assess the need to update recommendations within a guideline, not the other sections such as the Introduction as this describes the context when the original guideline was developed.

		which challenge') and its application is subjective. The individual shouldn't be assessed based solely on behaviourism, rather the environment should be assessed to ensure it's conducive to a good quality of life for the Autistic. I.e. there should be less focus on the Autistic's behaviour, and more on those around them. There is also no consistency with the language which surrounds 'challenging behaviour' and the term has different meanings in different settings. Someone in a care home stating that someone has 'challenging behaviour' because they get upset while going to the park could result in someone else assuming the term equates to violence and lead to inappropriate medical intervention or denial of access to services leading to further health inequalities. It also leads to issues within the justice system if someone has been noted as having 'challenging behaviour'. Why are NICE assuming Autistics will display 'challenging behaviour'? What will the outcomes of these subjective terms and assessments achieve? More useful would be recording strengths and weaknesses, likes and dislikes etc. Comment regarding qualifying autism 'severity' and how this doesn't fit Autistic experience: 1.3.1 – 'the nature and severity of their autism' is a statement with no qualification. Based on whose judgement? Is this how the Autistic person experiences being Autistic, or relating to outward behaviours which often don't match internal experience? Again, environment plays a big part in the Autistic experience and so-called 'severity' is not static i.e.	The intention of the term 'challenging behaviour' is to prevent the phrase being used as a diagnosis and to stop people feeling that they needed to 'fix' the person, so that they would instead concentrate on 'fixing' the environment. Users of NICE guidelines are expected to use the definition provided in a guideline's glossary, which in NICE guideline CG142 makes it clear that it is important to recognise that 'challenging behaviour' is the result of an interaction between the person and their environment, and as such is largely socially constructed. Challenging behaviour is defined in the glossary as 'a term used to describe behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour. Such behaviour is seen as challenging when it affects the person's or other people's quality of life and or jeopardises their safety'. The guideline committee agreed that the impact of the physical and social environment would need to be considered in the assessment of challenging behaviour (p139 full guideline). This is reflected in recommendation 1.5.1 which recommends interventions aimed at changing the physical or social environment including advice to the family, partner or carer(s) and changes or accommodations to the physical environment. However, we note an inconsistency in language between CG142 and CG170 and that CG170 uses 'behaviour that challenges' which was considered to be appropriately person-centred language. Therefore, we will make editorial amendments to CG142 to change the use of 'challenging behaviour' in recommendations to 'behaviour that challenges' in line with the NICE style guide and CG170. Please note that NICE has also produced a guideline on Challenging behaviour and learning disabilities (NG11) that highlights the kinds of behaviour referred to include: aggressive behaviour (such as

		Dr Beardon's golden equation autism + environment = outcome. Recommendation regarding updating psychosocial group guidance: 1.4.1 – This recommendation is only warranted if the groups are peer led and focus on safety and wellbeing rather than teaching an Autistic person to mask their differences. These groups need to focus on what matters to Autistic people. Recommendation to update guidance pertaining to the acquisition of life skills: 1.4.4 – Suggesting behaviourism for life skills issues is inappropriate due to the artificial nature of the learned response and reduced ability to adapt. It also implies that the delayed acquisition of a life skill is behavioural rather than due to physical and/or cognitive delays and/or disabilities. Comment regarding informed consent and how this isn't possible within ABA/PBS frameworks: 1.5.5 – There needs to be informed consent by the Autistic participant, which is missing from behaviourist approaches. What are the interventions? PBS/ABA are not appropriate. These words imply that you endorse ABA. Recommendation regarding determining efficacy of psychosocial interventions: 1.5.7 – Who decides whether psychosocial interventions are working? Who decides if 'behaviour is challenging'? If an Autistic person is still in	verbal abuse, threats and physical violence), destructive behaviour (such as breaking or destroying furniture and other objects and setting fires), disruptive behaviour (such as repetitive screaming, smearing faeces, setting off fire alarms when there is no fire, calling the emergency services when there is no emergency), self-injurious behaviour (including self-biting, head banging), sexually harmful behaviour (including sexual assaults, rape and stalking). The guideline (NG11) highlights that some of these behaviours may fall under the purview of the criminal justice system, but by no means all those with a learning disability who engage in illegal behaviour are arrested, as the criminal justice system requires not just proof that the act was done but also proof that it was intended, so most people with a severe disability who engage in potentially illegal behaviour are not involved in the criminal justice system. NICE did not assume that autistic people display behaviour that challenges. As a part of the comprehensive assessment, the need for assessment of challenging behaviour, where appropriate, was considered (see p 139 full guideline). The emphasis was on the impact of the physical and social environment in the assessment of challenging behaviour. Thank you for your comment about severity in recommendation 1.3.1. The recommendation suggests, when deciding whether to carry out an autism diagnostic assessment take account of the severity. The concept is used 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 impact of social and physical environment was highlighted throughout the guideline (please see recommendations in following sections 1.1 general principles of care; 1.2 Identification and assessment; 1.3

		distress other interventions cannot have been exhausted. There is a real risk of the overmedication of our community due to a lack of understanding of the Autistic experience. We suggest that the information contained within the Oliver McGowan Mandatory Training is consulted prior to the end of your consultation. Recommendation to include Autistic people, and further marginalised groups, in the autism strategy group: 1.8 – There is nothing to indicate that Autistic people should be consulted with regarding the pathway as part of the autism strategy group. Nor does point 1.8.3 indicate that those further marginalised groups should be consulted. Co-production is key when manging pathways, and should be written into your guidelines. Recommendation to update definition of 'challenging behaviour' (or to remove its use): Glossary - p. 40 your definition of 'challenging behaviour' includes harmless stims which are in no way challenging. This is entirely inappropriate as it gives harmful ABA/PBS practices validity. Recommendation to remove items suggestive of ABA: Glossary – p. 40 you claim that you do not recommend ABA, yet your guidelines and glossary definition of 'behavioural techniques' indicates that you do. This is inappropriate considering recent research which both	Identifying the correct interventions and monitoring their use; 1.5 Interventions for challenging behaviour). We have not received any feedback indicating any confusion caused by the use of the term 'severity'. The guideline is aimed at health and social care professionals and people who have or may have autism, and their families and carers. Thank you for your comment about recommendation 1.4.1. The recommendation is about interventions that can address problems with social interaction, not about safety and wellbeing *per se*: 'For autistic adults without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, consider: • a group-based social learning programme focused on improving social interaction • an individually delivered social learning programme for people who find group-based activities difficult.' This recommendation was drafted based on evidence (observational studies) evidence on peer-led programmes and expert knowledge. The guideline committee judged that social skills group interventions may help to address significant issues for autistic adults, including social isolation, which may in turn impact on other outcomes such as employment (see p231 full guideline). We found no evidence suggesting that this recommendation needs updating. Thank you for your comment about recommendation 1.4.4. The recommendation was based on expert knowledge and expertise suggesting that adaptive skills training based on behavioural principles could be beneficial for autistic people who need help with

		debunks the efficacy of ABA and implicates it as a cause of PTSD within the Autistic community. Refs: Sandoval-Norton, A., Shkedy, G., & Rushby, J. (Reviewing editor) (2019) How much compliance is too much compliance: Is long-term ABA therapy abuse?, in Cogent Psychology, Vol. 6:1, [Online] DOI: 10.1080/23311908.2019.1641258 (Accessed 04/11/20) Department of Defence. (2020) Comprehensive Autism Care Demonstration Annual Report 2020 [Online] https://altteaching.org/wp-content/uploads/2020/10/Annual-Report-on-Autism-Care-June-2020.pdf (Accessed 04/11/20)	developing daily living skills. It was identified that such programmes should be structured and predictable, in line with both the knowledge of effectiveness of behavioural therapies beyond autism and the particular importance of structure and consistency for people with autism (see p208 full guideline). We found no evidence suggesting that this recommendation needs updating. Thank you for your comment about recommendation 1.5.5. The recommendation was drafted based on the expert knowledge and expertise as there was no evidence on effectiveness of behavioural therapies for challenging behaviour in autistic people. Based on the expert knowledge and judgement, the committee decided that behavioural therapies should be considered for managing challenging behaviour in the context of a comprehensive behaviour management and treatment approach (see p284 full guideline). PBS/ABA are not mentioned. With regards to your comment about informed consent, the guideline has a specific section on person-centred care which clearly states that 'people with autism should have the opportunity to make informed decisions about their care, in partnership with their healthcare professionals. If autistic adults do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act. In Wales, healthcare professionals should follow advice on consent from the Welsh Government.' Thank you for your comment about recommendation 1.5.7. The recommendation says to 'consider' antipsychotic medication in conjunction with a psychosocial intervention for challenging behaviour when there has been no or limited response to

			psychosocial or other interventions (such as environmental adaptations). Please note we use 'consider' to reflect a recommendation for which the evidence of benefit is less certain (see Developing NICE guidelines: the manual). The guidelines also include recommendations about training of health and social care professionals, for example, recommendation1.1.4 recommends that the specialist autism team should have a key role in the delivery and coordination of training, support and consultation for staff who care for autistic people in residential and community settings. Similarly, recommendation 1.8.3 suggests that autism strategy groups should be responsible for developing, managing and evaluating local care pathways. Ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway for relevant health professional. Please note NICE no longer make recommendations on training of staff and professional bodies should be developing and endorsing a training package for its members. Thank you for your comment about section 1.8. The recommendations in this section of the guidelines were adopted from NICE guideline Common mental health problems: identification and pathways to care and partly revised to address specific needs of autistic people. The recommendations in CG142 clearly indicate that local pathways should be accessible and acceptable to all people in need of the services served by the pathway (recommendation 1.8.1). Recommendation 1.8.3 suggests that the autism strategy group should develop local care pathways that promote access to services for ALL autistic people therefore should not be specific only to the

			groups that are listed. Co-ordination and co-operation was encouraged throughout the guideline recommendations. Thank you for your comments about the glossary definition of ‘challenging behaviour’ and ‘ABA/ABS’. Decisions about which concepts require a glossary definition are made during guideline development. ABA is not mentioned anywhere in the recommendations or glossary. We have not received any other feedback querying these definitions or concerns that the guideline promotes ABA, which it does not. With regards to the reference by Sandoval-Norton et al., 2019, the article is a discussion paper and not eligible for inclusion. For this surveillance review the following types of evidence are eligible for inclusion: published systematic reviews, randomised controlled trials, diagnostic studies, new and updated national policy and guidelines. Thank you for sharing the Department of Defence publication (Report to the Committees on Armed Services of the Senate and House of Representatives). This is an annual report on efforts being conducted by department of defence (USA) on applied behaviour analysis services. This is out of scope as we can only consider published peer-reviewed research or UK policy. Given we are not aware of any evidence meeting the inclusion criteria which shows ABA is harmful, and that NICE guideline CG142 does not recommend ABA, we will not be proposing any changes to the guideline in relation to this.
Fair Treatment for the Women of Wales (FTWW)	No	We don’t feel that the existing guideline considers the different ways in which autistic female adults present and the associated diagnostic delay. Partly as a consequence of this, management of, and support for, autistic females needs to be considered in a lot more detail. This would	Thank you for your comments. The guideline identified that particular groups, including people with coexisting conditions, women, older people, people from black and minority ethnic groups and transgender people, were less likely to be identified by standard case identification tools (p113 full

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		include reference to chronic health conditions which are more prevalent in females and which would appear to have a correlation with autism, such as Ehlers Danlos Syndrome and auto-immune conditions, and a clearer appreciation of the high(er) rate of suicide and self-harm in females on the autistic spectrum. We have concerns over some of the diagnostic criteria and its potential to be unscientific. For example, page 23 of the guideline refers to the assessment of 'challenging behaviour' which is a highly subjective determination and one likely to be influenced by unconscious biases underpinned by societal norms and gender stereotypes. Perceptions of 'challenging behaviour' may well differ substantially when assessing a female individual compared to a male one, with a far lower threshold for what is deemed acceptable in women compared to men. There is much sociological research examining this phenomenon which needs to be considered when positing diagnostic criteria which lack objectivity. Pages 25 and 26 of the guideline require updating, particularly in light of the female experience, because the references to 'social skills' and 'behaviourism for life skills' do not adequately reflect the coping strategies already employed by autistic females, namely 'masking', or 'disguising' their autism and discomfort by 'copying' neurotypical behaviours or skills. These two approaches would tend to embed further 'masking' as an appropriate mechanism for self-management, whilst not appreciating its potential for triggering or exacerbating mental health	guideline) and women may be under diagnosed. Recommendation 1.8.3 recommends that the autism strategy group should develop local care pathways that promote access to services for all autistic adults, including women. 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. 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. Recommendations in NICE guideline CG142 underwent an equality impact assessment (EIA) to ensure compliance with the Act. Please see the link to the EIA form: Autism in Adults. The co-existing conditions in autism were fully assessed (please see surveillance review Appendix A: Assessing coexisting conditions in the autism diagnostic assessment (p.42). Evidence on Ehlers Danlos Syndrome or auto-immune conditions was not identified, nor highlighted by topic experts as co-existing and more prevalent conditions in autism. NICE has produced a guideline on Preventing suicide in community and custodial settings (NG105) that identifies autistic people as a group at high risk of suicide. However, we did not identify any new evidence linking the risk of suicide to gender in autistic people. With regards to your comments on recommendations 1.2.19 and 1.2.20 on the 'assessment of challenging behaviour', the intention of the term 'challenging behaviour' is to prevent the phrase being used as a diagnosis and to stop people feeling that they needed to 'fix'

		problems. This is of significant concern, given the higher rate of suicide in autistic females. The surveillance document itself makes reference to the need to reduce suicide (page 20), yet the guidelines in their current incarnation do not encompass this. This alone should warrant their updating. Existing guidance on suicide is not sufficient to deal with the exceptional and untypical data around high suicide rates in autistic females. We are also concerned that a guideline which seems focused on making neurodiverse people 'fit in' could have implications for Equality Law, where employers, public services etc are required to make 'reasonable adjustments' to accommodate the needs of marginalised communities / individuals rather than expect them to change their identities to be more 'acceptable'. We are concerned that the Surveillance Proposal document itself merely suggests research as a solution to the disenfranchisement of autistic female / trans / BAME communities (page 11). Whilst research is welcomed, in the absence of it, there is continued suffering and lack of tailored support. On page 17, there is an implicit suggestion that the testimony of autistic people's organisations / communities is not sufficiently robust to be considered within the scope	the person, so that they would instead concentrate on 'fixing' the environment. It is important to recognise that 'challenging behaviour' is rather the result of an interaction between the person and their environment, and as such is largely socially constructed. Challenging behaviour is defined in the glossary of the NICE guideline CG142 as 'a term used to describe behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour. Such behaviour is seen as challenging when it affects the person's or other people's quality of life and or jeopardises their safety. The guideline committee agreed that the impact of the physical and social environment would need to be considered in the assessment of challenging behaviour (p139 full guideline). We found no evidence showing that challenging behaviour assessment was biased against women. Please note NICE has also produced a guideline on Challenging behaviour and learning disabilities (NG11) that highlights the kinds of behaviour referred to include: aggressive behaviour (such as verbal abuse, threats and physical violence), destructive behaviour (such as breaking or destroying furniture and other objects and setting fires), disruptive behaviour (such as repetitive screaming, smearing faeces, setting off fire alarms when there is no fire, calling the emergency services when there is no emergency), self-injurious behaviour (including self-biting, head banging), sexually harmful behaviour (including sexual assaults, rape and stalking). The guideline recommends that any risk assessment of autistic adults should consider the risk of self-harm, in particular, in people who are also depressed or who have a moderate or severe learning

		of the guideline(s). However, in the absence of academic research, evidence presented by these sources should be considered and the guideline updated to encompass those people excluded from it in its current form.	disability (recommendation 1.2.12). The guideline identified that it was important to be aware of the sensitivity of some autistic people to changes in their physical or social environment and the possibility of very rapid escalation of problems including risk-related problems. We did not find evidence reporting on gender-specific suicide rate in autistic adults. NICE has published a guideline on Preventing suicide in community and custodial settings (NICE guideline NG105) which recognises that autistic people are a group at high risk of suicide. Therefore, an update to the autism guidelines is not considered necessary because NICE already has guidance on preventing suicide that includes autistic people. NICE guideline CG142 has broad recommendations about the organisation and delivery of services for diagnosing and managing autism spectrum disorder. See recommendations on: General principles of care – structures for the organisation and delivery of care and interventions and organisation and delivery of care in CG142. We disagree that recommendations about social and behavioural skills serves 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 account. CG142 person-centred care section says: 'Support and care should take into account peoples' needs and preferences. Autistic people should have the opportunity to make informed decisions about their care, in partnership with their healthcare professionals.' The recommendations should be applied in the context set out in this section. In addition, NICE has produced autism quality standard (QS51) based on the autism guidelines to enable commissioners and clinicians to benchmark and recognise good service performance. Please note that NICE guideline CG142 recommendations

			underwent an equality impact assessment (EIA) to ensure compliance with the Act. Please see the link to the EIA form: Autism in Adults. Thank you for your comments about disenfranchisement of autistic female/trans/BAME communities. Findings from the surveillance review about the issue is outlined in the surveillance report (equalities section). Topic experts raised the issue that take up of specialist services among black and minority ethnic groups was low, but we found no evidence about pathways or interventions to address this which indicated that the recommendations should or could be changed at this time. All of the recommendations in CG142 where the subject of an equality impact assessment which included consideration of black and minority ethnic groups and other groups with protected characteristics. We will log take up of services by female, transgender and BAME communities as an area to look for evidence at the next surveillance timepoint. Thank you for your comment about patient group organisation. Lay members and patient representatives contributed to the development of the original guideline and inform how we undertake the surveillance review, highlighting areas which are considered of importance and for which we do seek published evidence meeting specific inclusion criteria. Feedback from 3 autistic people's organisations was considered in drafting the current surveillance report and we did consider evidence from a broad range of sources, including UK policy and views of patient groups and topic experts, as reported in the surveillance review. These groups highlighted a number of ongoing pieces of evidence in addition to those we

			identified that we plan to track and assess their impact on recommendations when they publish. This ongoing evidence is: - The review of the 2014 autism strategy on autism which will feed into the NHS Long term plan - The impact of ICD-11 when it is implemented fully in January 2022 - Sixteen ongoing trials identified during surveillance which are listed in the surveillance report 'ongoing research' section - Work in progress by NHS England and NHS Innovation (NHSE&I) to help deliver the objectives about autism services in the NHS Long-term plan. This includes 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; due to complete in 2022. NHSE&I also alerted us to the SHAPE project at the University of York. This study published post-stakeholder consultation. As you highlight, 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. We will continue to engage with the NHSE&I autism team to identify further outputs from them in order to assess its impact on recommendations on publication. We disagree that there are any people excluded from NICE guideline CG142 and hope that the responses above have addressed your concerns.

Rotherham Doncaster and South Humber NHS Foundation Trust	No	Updating guidance and evidence from practice periodically is always a good thing to support and improve practice and patient experience.	Thank you for your comment. The guidelines are reviewed approximately every 5 years unless we identify or are alerted to new event (large study, significant policy change, new guidelines or a safety alert) that may trigger an exceptional review. If this happens, we will undertake a review as soon as we can. As a result of the surveillance review we plan to track the following in progress pieces of evidence: • The review of the 2014 autism strategy on autism which will feed into the NHS Long term plan • The impact of ICD-11 when it is implemented fully in January 2022 • Sixteen ongoing trials identified during surveillance which are listed in the surveillance report 'ongoing research' section • Work in progress by NHS England and NHS Innovation (NHSE&I) to help deliver the objectives about autism services in the NHS Long-term plan. This includes 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; due to complete in 2022. We will continue to engage with the NHSE&I autism team to identify further outputs from them in order to assess impacts of their work on recommendations on publication.

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. 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. We acknowledge that there has been a large volume of comments received during consultation about implementing some of the recommendations in the guidelines due to service capacity issues. We will therefore review the guidelines again in the next 12 months to assess the impact of ongoing work, including work currently in progress by NHSE&I and DHSC.
British Association of Social Workers (BASW) – England	Yes	100% of BASW England member respondents stated 'yes'. One member said: 'The guidance states specialist MDTs for autism should be established. Given very few areas have these I think the guidance should be strengthened and it should be made clear that it is the responsibility of Clinical Commissioning Groups to fund the specialist clinical support required'	Thank you for your comment. There is a clear problem with implementation of this guideline due to insufficient service capacity. Many government reports and policy documents have highlighted autism as a priority, so services may be more able to implement the guidelines over the next few years. We plan to track the review of the 2014 autism strategy which will feed into the NHS Long term plan. We acknowledge that there has been a large volume of comments received during consultation about implementing some of the recommendations in the guidelines due to service capacity issues. We will therefore review the guidelines again in the next 12 months to assess the impact of ongoing work, including work currently in progress by NHSE&I and DHSC.
The Challenging Behaviour Foundation	No	All the guidelines were published before Building the Right Support (NHSE et al 2015) set out new approaches	Thank you for your comments. Although the guidelines were published before 2015 all have undergone subsequent surveillance

		including dynamic risk registers, CTRs/CETRs and other 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.	reviews to check they remain up-to-date, the latest in 2016 This 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. 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	- As raised in our 2019 guidance surveillance questionnaire, the guideline should 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. - NICE guideline CG128 established that a first assessment should be undertaken within 3 months of being referred. This was also included in NICE Quality Standard QS51. We also recommend a further benchmark being established for the period between referral and final diagnosis (above). It is an anachronism that both these waiting time benchmarks not also to be included in CG142 and we believe it should be.	Thank you for your comments about ICD-11 and DSM-V. We can confirm that we will track ICD-11 and assess its impact post-adoption, January 2022. CG142 recommendations do not refer to DSM-IV and it is not clear which terms are considered inappropriate for describing conditions. Thank you for your comment about assessment benchmark. NICE's autism quality standard (QS51) is based on and relevant to all autism guidelines, including CG142. QS51 quality statement 1 says that people with possible autism (no age criteria are given) who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral. These set out measurable performance metrics to enable commissioners and clinicians to benchmark and recognise good service performance, which applies to CG142.

		We raised this in our 2019 guidance surveillance questionnaire. - For the last three years, our research with thousands of autistic adults has found that mental health is the biggest challenge facing this group. We therefore believe that more explicit reference should be made to mental health support, and how mental health services can be made more appropriate for autistic people. More detail on this is provided in Question 4. - 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 guideline identified the importance of mental health in autistic people. This is reflected in recommendations on general principles of care. Recommendation 1.1.12 recommends that in order to effectively provide care and support for adults with autism, the local autism multi-agency strategy group should include representation, from adult services, including mental health and social care. The government started a review of the 2014 Autism Strategy with a public consultation calling for evidence in Spring 2019. The revised strategy is expected to support the NHS Long Term Plan, which addresses the issue of mental health with two initiatives (please see the surveillance report for more information). Thank you for your comments about the Transforming Care programme. 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. We would need to see evidence from transforming care projects before we could refer to them or assess their impact. If you can share published evidence from these projects with us that would be helpful.
Royal College of Psychiatrists	Yes	This guidance overlaps with CG128 and CG170 which go up to aged 19. This could do with being reconciled. The following text applies to all relevant guidance listed on the web page for adults and under 19s. We feel strongly that the NICE guidance listed on the web page for adults and under 19s should be revised and updated. The most recent guidance is 2013 while the oldest is from 2011 that would have been in development	Thank you for your comments about the overlap in guidelines. We acknowledge there is overlap and for this surveillance review we brought the 3 guidelines together to assess the impact of new evidence on autism as a single topic. were set during development and included consideration of what was considered the appropriate age range for each guideline. 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

		in 2009-2010 if not before and hence the guidance is ten years old by 2020. So much has happened in Autism knowledge and practice in services along with innovations and developments to support people that it is very important that NICE offers up-to-date and relevant evidence-based guidance. Some innovations include: · Recognition that Autism often co-occurs with other neurodevelopmental disorders about which more is known e.g., ADHD diagnosis, management and treatments. · More exploration of other neurodevelopmental disorders e.g., tic disorders, dyspraxias and intellectual disability that frequently co-occur with Autism. · Changes in how Autism diagnoses are made and the tools and criteria especially DSM 5 criteria and ICD 11 criteria for Autism. · Changes too in Autism diagnostic pathways in children and adults especially where the recent CQC report 'Out of sight – who cares?' recommended more widespread provision of services and measuring the services too to reduce inequalities between local areas in the quality of the diagnostic services they provide. · The innovations in services to support people with Autism to avoid being admitted to hospital. The CQC report also highlighted their concern about Autistic people being admitted to mental health hospitals and not be treated according to their needs.	can. An 'event' may be a large study, significant policy change, new guidelines or a safety alert (see the NICE methods manual Chapter 13 Ensuring that published guidelines are current and accurate for more details). NICE guideline CG142 was reviewed in 2016 and 2014 (please see the Evidence and History respectively for these surveillance reviews). In the current review of the guideline on autism in adults (please see surveillance report) we found no evidence that impacts current recommendations. 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 assess its impact on the NICE autism guidelines on publication. The guideline has recognised that autism often co-occurs with other neurodevelopmental disorders. Recommendation 1.2.10 suggests that during a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as neurodevelopmental conditions. Thank you for sharing the CQC report: Out of sight - who cares?. The document provides an overview of a review but does not provide links to evidence that we can consider in relation to the recommendations. Recommendation 1.3.2 recommends that when discussing and deciding on care and interventions for autistic adults, take into account the greater risk of altered sensitivity and unpredictable

		· The fact that the rate of mental disorders in Autistic people is high. · The evidence that physical disorders are high among Autistic people. · Autistic people use more psychotropic medication than would be expected and often the medication is inappropriate or produces intolerable side effects in people who are more susceptible to developing them. · The on-going stigma and lack of understanding of Autistic people and their needs. · Changes in attitudes toward Autism among families who are more aware of it than previously; · Changes in services for people under 19 years. For these reasons, we believe it is very important and crucial that NICE reviews its guidance along with active input from Autistic people. If not now, the guidance will be even more out-of-date than it is at present by the time NICE deems it necessary to update its guidance in five- or ten-years' time.	responses to medication. It also says that antipsychotic medication should be prescribed by a specialist and the quality of life outcomes monitored carefully; and to review the effects of the medication after 3–4 weeks and discontinue it if there is no indication of a clinically important response at 6 weeks (Recommendation 1.5.8). The recommendations on principle of care and identification, assessment were drafted considering the implication of stigma and exclusion (please see p74 full guideline) As part of the 2020 surveillance review, in addition to the published evidence from the literature we also considered the latest national level policy. We also considered the views of topic experts and patient groups (see page 16 of surveillance review for an overview). We have not yet seen any evidence that would suggest the recommendations are out of date.
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	Yes	We feel this is current and relevant.	Thank you for your comment.
PDA Society	Yes	Specifically on the question of PDA. We would hope that this remains under review as further evidence is published. 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.	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 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." 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,

		It is hoped that additional clarity can be provided following the review in January 2022	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.
Sussex Partnership Foundation Trust	No	As a multi disciplinary team of clinicians and EBEs specialising in assessing autism, we strongly disagree and believe that there has been significant recent updates in research and practice that should be included in the guidance. Identification and assessment Update needed in female presentation of autism. Increased recognition of female presentation and need for different tools to be used in assessment. Increased prevalence of autism in eating disorders patients. All should be screened for autism.	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 the NICE methods manual Chapter 13 Ensuring that published guidelines are current and accurate for more details). This guideline was reviewed in 2016 and 2014 (please see the Evidence and History respectively for these surveillance reviews). In the current review the guideline on autism in adults (please see surveillance report) we found no evidence that had an impact on current recommendations. The guideline identified that particular groups, including people with coexisting conditions, women, older people, people from black and minority ethnic groups and transgender people, were less likely to be identified by standard case identification tools (p113 full guideline) and women may be under diagnosed. Recommendation

		Our clinical work suggests a very different intervention is needed depending on how the eating problems relate to interoception, managing change, sensory needs etc. Wider screening of autism in those using mental health services. Hull, L., Mandy, W., Lai, M. et al. Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). J Autism Dev Disord 49, 819–833 (2019). https://doi.org/10.1007/s10803-018-3792-6 Westwood H, Tchanturia K. Autism Spectrum Disorder in Anorexia Nervosa: An Updated Literature Review. Curr Psychiatry Rep. 2017 Jul;19(7):41. doi: 10.1007/s11920-017-0791-9. PMID: 28540593; PMCID: PMC5443871. Update need in physical health considerations for autism: Emerging evidence suggests increased prevalence of epilepsy in autistic girls/women compared to non-autistic girls/women and to autistic boys/men. The literature also suggests increased endocrine and reproductive health conditions in autistic girls/women compared to non-autistic girls/women Relationship between hypermobility and autism.	1.8.3 recommends that the autism strategy group should develop local care pathways that promote access to services for all autistic adults, including women. NICE guideline CG142 recommendations underwent an equality impact assessment (EIA) to ensure compliance with the Act. Please see the link to the EIA form: Autism in Adults. Thank you for the reference Kassee et al., 2020; this is a narrative review about the physical health of autistic girls/women and was not eligible for inclusion. For this surveillance review we included published systematic reviews, randomised controlled trials, diagnostic studies, new and updated national policy and guidelines. Thank you for your comment about eating disorder. Recommendation 1.2.10 recommends that during a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, including mental disorders. This guideline is not covering co-existing conditions if an autistic spectrum condition is not a primary diagnosis. NICE has produced guideline for Eating Disorders: recognition and treatment (NICE guideline NG69) which recognised that 'autistic spectrum disorder and attention deficit hyperactivity disorder appear to be over represented in patients with eating disorders and might be vulnerability factors' (p23). Thank you for the references. Westwood &Tchanturia 2017 is a systematic review that included studies that assess ASD in anorexia nervosa. This guideline is not covering co-existing conditions if an autistic spectrum condition is not a primary diagnosis, therefore the study is not eligible for inclusion. The guideline identified high prevalence of epilepsy in autistic people and that attention should be paid to coexisting physical health problems such as epilepsy that may be unrecognised or not

		Testing for vitamin D deficiency. Kassee, C., Babinski, S., Tint, A. et al. Physical health of autistic girls and women: a scoping review. Molecular Autism 11, 84 (2020). https://doi.org/10.1186/s13229-020-00380-z Increased rate of joint hypermobility in autism and related neurodevelopmental conditions is linked to dysautonomia and pain Jenny L L Csecs, Valeria Iodice, Charlotte L Rae, Alice Brooke, Rebecca Simmons, Nick G Dowell, Fenella Prowse, Kristy Themelis, View ORCID ProfileHugo D Critchley, View ORCID ProfileJessica A Eccles doi: https://doi.org/10.1101/2020.09.14.20194118 Cederlöf, M., Larsson, H., Lichtenstein, P. et al. Nationwide population-based cohort study of psychiatric disorders in individuals with Ehlers–Danlos syndrome or hypermobility syndrome and their siblings. BMC Psychiatry 16, 207 (2016). https://doi.org/10.1186/s12888-016-0922-6 Baeza-Velasco C, Cohen D, Hamonet C, et al. Autism, Joint Hypermobility-Related Disorders and Pain. Front Psychiatry. 2018;9:656. Published 2018 Dec 7. doi:10.3389/fpsyt.2018.00656	treated (p138 full guideline). 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 neurological disorders (for example, epilepsy)'; and recommendation 1.2.17 advises that where epilepsy is suspected an electroencephalography and referral to a specialist epilepsy service may be considered. Similarly, specialist testing of hearing and vision may be required (p137 full guideline). With regards to your comment that there is an increase of endocrine and reproductive health condition in autistic girls and women, all research identified in relation to this is discussed in the 'Factors associated with an increased prevalence of autism' section of the surveillance report. Although we identified new evidence on possible risk factors not currently covered by the guideline, including 1 study on maternal polycystic ovary syndrome, the size of the increase in risk was lower than the threshold of 2.0 for considering an update to the guideline (except for congenital cytomegalovirus infection (which is caused by a virus), but this evidence was limited because of the small sample size of the study, so further evidence in this area is needed). Thank you for sharing the 3 articles about EDS and joint hypermobility syndrome. We found no evidence that autoimmune disorders, EDS or other connective tissue disorders are more prevalent in autistic people. Baeza-Velasco et al., 2018, is a narrative review that describes the results of studies selected by the authors that suggest EDS is associated with autism. This is a not systematic review and is therefore outside the inclusion criteria of this surveillance review. Cederlöf et al.,2016, aimed to assess the risk

		High risk group for suicide: Different considerations needed for assessment & reduction of suicide risk. Cassidy, S.A., Gould, K., Townsend, E. et al. Is Camouflaging Autistic Traits Associated with Suicidal Thoughts and Behaviours? Expanding the Interpersonal Psychological Theory of Suicide in an Undergraduate Student Sample. J Autism Dev Disord 50, 3638–3648 (2020)	of psychiatric disorders and neurodevelopmental conditions in Ehlers-Danlos syndrome (EDS) and hypermobility syndrome in a Swedish population. This study is not in scope for this surveillance review as it is not a diagnostic study, systematic review or RCT and therefore, the study was not eligible for inclusion. Csecs et al., 2020, was also not eligible for inclusion as the study population consisted of all neurodevelopmental diagnoses and did not report data on autistic people separately in the abstract results. We will flag EDS as a risk factor for autism in UK populations as an area to look for evidence when we next carry out surveillance. Thank you for your comment about vitamin D. We found evidence during the surveillance review from an observational study (surveillance report) that lower levels of neonatal vitamin D may increase risk of autism, but the evidence was insufficient for a potential impact on current recommendations. No evidence indicating the need to screen autistic people for vitamin D deficiency was identified. Vitamin D supplementation for specific populations is covered in NICE's guideline on vitamin D supplementation in specific population groups. NICE guideline CG142 recommends that any risk assessment of autistic adults should consider the risk of self-harm, in particular, in people who are also depressed or who have a moderate or severe learning disability (see recommendation 1.2.12). The guideline identified that it was important to be aware of the sensitivity of some autistic people to changes in their physical or social environment and the possibility of very rapid escalation of problems including risk-related problems (please see recommendations in 1.1 General principles of care). NICE has also published guidelines on

			Preventing suicide in community and custodial settings (NICE guideline NG105) which recognises that autistic people are a group at high risk of suicide. Thank you for the refences on camouflaging of autistic traits. Cassidy et al., 2020, is a cross sectional online survey of students with no autism diagnosis and with no data reported in the abstract, it is therefore not eligible for inclusion. Hull et al., 2019, is not eligible for inclusion because it it reports on the validity of a tool assessing camouflaging of autistic traits, not the diagnosis of autism. The authors report that 'further research is needed to identify the extent to which social skills predict camouflaging behaviours'.
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 not 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. Consultation issues	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 concluded that these did not have an impact on the recommendations. Many of the reports confirmed information 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.

		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. 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. 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 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

		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: ▪ SHAPE – We drew NICE's attention to the NIHR-commissioned SHAPE study during the initial surveillance review consultation in 2019 (which unfortunately we became aware of shortly before it's deadline). This study specifically addressed the research recommendation made by CG142 on what structure and organisation of specialist teams are associated with improvements in autistic people's experience and outcomes. Its findings are therefore of the utmost relevance to the surveillance review. Instead it appears completely absent. Although this research has not yet been formally published, confidential copies have been shared with key stakeholders, including Autistica and NHS England, and should have been available to NICE on request. www.journalslibrary.nihr.ac.uk/programmes/hsdr/131086 ▪ The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) core sets – A fundamental weakness of CG170, CG142, and current post-diagnostic support pathways	that published guidelines are current and accurate, Chapter 13 of the NICE guidelines manual. 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. 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. Therefore, we assessed current recommendations as being consistent with policy. You note in the Long term plan section 3.33's commitment to *"jointly develop packages to support children with autism…throughout*

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		for autistic people, is how skewed they are by historical biases in our understanding of autistic people's support needs. For example, CG170 says a lot about addressing "behaviour that challenges", a controversial issue with a confused and unreliable evidence base on the effectiveness of (relatively prolific) interventions. In contrast, those guidelines make few practical points about identifying, preventing or treating some of the most common causes of distress for autistic people, such as anxiety, uncertainty and sensory difficulties. These are the increasing focus of autism-specific intervention studies. For example: link.springer.com/article/10.1007/s10803-020-04442-2 trialsjournal.biomedcentral.com/articles/10.1186/s13063-019-3479-0 onlinelibrary.wiley.com/doi/full/10.1002/aur.2259 Please note this is just a sample of ongoing research we happen to be aware of. We have not been able to review the literature in the time available. The ICF core sets are the result of an international research programme to identify (through a literature review), and then agreeing clinical, community and scientific consensus on, the major causes of ability or disability among autistic people (relative to their age). That programme has published 5 papers during the period considered by the surveillance review. We cannot see any evidence that those publications were identified and considered by the surveillance review. CG170 and CG142 should arguably be structured around the core sets, as a reflection of autistic people's needs. Instead, many of the most common and impactful causes of ability or disability for autistic	*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. Thank you for also making us aware of the SHAPE project at the University of York; NHS England and NHS Innovation (NHSE&I) also alerted us to this project. This study published post-stakeholder consultation. SHAPE is a 2-stage exploratory mixed methods study

		people – the issues that are or should be the focus of intervention – are effectively absent from NICE's autism guidance. www.ncbi.nlm.nih.gov/pmc/articles/PMC6376609/ www.ncbi.nlm.nih.gov/pmc/articles/PMC5900830/ www.ncbi.nlm.nih.gov/pmc/articles/PMC5948258/ www.ncbi.nlm.nih.gov/pmc/articles/PMC5064728/ www.ncbi.nlm.nih.gov/pmc/articles/PMC6680328/ ▪ AUDIT-50 – We note that the list of ongoing research in the surveillance review does not include the AUDIT-50 project which is exploring the diagnosis of – and provision of physical and mental health care to – autistic people over the age of 50. This is a particularly underserved group. CG142 currently makes little more than tokenistic reference to older autistic people and provides no meaningful guidance on what distinctive issues they may face or how services should meet those needs. www.adaptlab.net/audit-50 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.	that investigated the experiences of service users and staff and the outcomes associated with implementing specialist autism teams (SATs). As you highlight 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.

		Misunderstanding of the policy context *"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.	Thank you for your comment about challenging behaviour. The intention of the term 'challenging behaviour' was to prevent the phrase being used as a diagnosis and to stop people feeling that they needed to 'fix' the person, so that they would instead concentrate on 'fixing' the environment. It is important to recognise that 'challenging behaviour' (as described in the glossary of NICE guideline CG142 and CG170) is rather the result of an interaction between the person and their environment, and as such is largely socially constructed. NICE has also produced a guideline on Challenging behaviour and learning disabilities (NG11) which highlights the importance of understanding the cause of behaviour that challenges and performing thorough assessments so that steps can be taken to help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers. However, we note an inconsistency in language between CG142 and CG170 and that CG170 uses 'behaviour that challenges' which was considered to be appropriately person-centred language. Therefore, we will make editorial amendments to CG142 to change the use of 'challenging behaviour' in recommendations to 'behaviour that challenges' in line with the NICE style guide and CG170. Thank you for the references you have provided. Please note that for this surveillance review the following types of evidence are eligible for inclusion: published systematic reviews, randomised controlled trials, diagnostic studies, new and updated national policy and guidelines.

		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.	In relation to the references on autism specific intervention studies: Hallett et al., 2020 is a feasibility research and therefore not eligible for inclusion. Rodgers et al., 2019 is a study protocol for an intervention feasibility trial and not eligible for inclusion. MacLennan et al., 2020 study examined the correlation between sensory reactivity differences and anxiety subtypes in 41 autistic children aged between 3 and 14 years, using parent- and self-reported measures. This study was not considered for CG142 as the population are not adults (and would have not been included due to study type and insufficient data reported in the abstract). Thank you for sharing the 5 papers from the WHO's ICF core sets. NICE guideline CG142 structured is guided by the scope, the research questions that are derived by the expert committee and subsequent public consultation including surveillance review consultations such as this one. We did identify a qualitative study (Mahdi et al., 2017a that you have shared) about the application of the WHO's ICF that concluded "the study findings support the need to understand the living experiences of individuals with Autism Spectrum Disorder (ASD) from a broader perspective, taking into account many areas of an individual's functioning and environment. The ICF can serve as foundation for exploring these living experiences." We did not find any interventional studies that applied the ICF principles to the diagnosis or management of autism. The 5 papers you have shared describe the consensus development of the ICF and are not diagnostic or interventional effectiveness studies reported in systematic reviews, randomised controlled trials or diagnostic studies, therefore, none of these studies meet the

			inclusion criteria for this surveillance review. Of the studies you have shared about the ICF: Bolte et al., 2019 is an article based on an international conference that expert consensus used to develop ICF core sets for ASD (with consideration of the evidence from four international studies). Studies based on expert's consensus are not eligible for inclusion in this surveillance review. De Schipper et al., 2015 includes a systematic review - first in a series of four empirical studies designed to develop International (ICF) Core Sets for Autism Spectrum. The objective was to use a systematic review approach to identify, number, and link functional ability and disability concepts used in the scientific ASD literature to the nomenclature of the ICF-CY (Children and Youth version of the ICF). The study does not report on the use of this tool as a means of diagnosis of autism and therefore neither meets the inclusion criteria for the surveillance review, nor is it within the scope of the guideline. De Schipper et al., 2016 is a worldwide survey of experts - second in a series of four empirical studies designed to develop International (ICF) Core Sets for Autism Spectrum. The study is based on expert's opinion, and not eligible for inclusion. Mahdi et al., 2017a is a qualitative study - the third in a series of four empirical studies designed to develop International (ICF) Core Sets for Autism Spectrum. The study was carried out via focus groups and semi-structured interviews with 19 stakeholder groups; and the study population were not autistic people, therefore the study is not eligible for inclusion. Mahdi et al., 2017b is a cross sectional study - forth in a series of four empirical studies designed to develop International (ICF) Core Sets for Autism Spectrum. This study was not considered in the

			surveillance review due to the study design, in addition no statistical results are reported in the abstract. We will add the ICF core sets to our issues log for autism in order to flag that evidence for the use of these core sets should be explicitly looked for when the guidance is next reviewed. Thank you for highlighting the Audit 50 project. The information on the website for this study describes this as a 'three-year project' which 'aims to fill important gaps in knowledge about autism in later life' but does not provide any details of the methodology being employed to achieve this. We will therefore make a note that any published evidence on this should be considered at the next surveillance review. If you are aware of any new evidence that meets the inclusion criteria for the surveillance review (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.
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 extensively changed.	Many conceptual issues which contribute to negative views of autism and which may lead to poor support, for example: • Concept of autism is professional-centred. It does not reflect how autistic people characterise their	Thank you for your comments. The social care team at NICE have produced a quick guide on Enabling positive lives for autistic adults that has a sections on tailored support for fulfilled life and, language. It has highlighted that autistic adults, experience a wide range of differences in their communication, use of language, social

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	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	own condition. This is essential for offering relevant care and support. • Impoverished concept of 'person centred care' • Minimal to no reference to autonomy, supported decision making and UNCRPD 12 • Capacity applies to individual decisions, not every decision a person makes • Focusing on 'triggers' can hide causes. • Autism is not in need of 'management', people are in need of support. The sort of thing that might be managed are, say, environments, the attitudes of others, etc. • Characterising help and support as 'interventions' is problematic • Concept of 'severity' is problematic • 1.4.1 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/ • 1.4.8 With anger look to causes not 'management'. Autism does not cause anger. • Section on behaviour needs total rethinking. Functional analysis and reinforcement of desired behaviour is widely opposed by autistic adults who have experienced it. Current guideline unintentionally recommends what many autistic people consider abuse. Importance of supporting person to be aware of and to contact the wider autistic community.	interactions and emotions. It recommends that social workers and health professional should find out how the person prefers to refer to their autism. Autism concept as profession centred: The guideline is primarily aimed at health and social care professionals working in services where they can improve outcomes for autistic people and the language reflects person cared centred. With respect to your comments about how people characterise their own autism, the guideline committee did include lay members (representing service user and carer concerns) who contributed to the development of the guideline and the recommendations. The UN Convention on the Rights of Persons with Disabilities was ratified by the UK in 2009. The UK initial report on the UN Convention Rights of Persons with Disabilities explains how the rights of disabled people as set out in the UN convention are protected by legislation and policy in the UK. It can potentially influence UK court decisions, either directly or through EU law or the European Convention on Human Rights. We do not directly list all relevant policy within guidelines, these are provided at Making decisions using NICE guidelines and we shall add a link to this information at the beginning of the recommendations section for all the autism guidelines. The guidance does not focus on triggers. The guideline covers diagnosing and managing suspected or confirmed autism spectrum disorder in people. It aims to improve access and engagement with

			interventions and services, and the experience of care, for autistic people. The guidance is called Autism spectrum disorder in adults: diagnosis and management –recommendations encompass both diagnosis and management, which includes support, which is highlighted throughout the recommendations. Help and support was not characterised as an intervention in the guideline (for example, please see recommendations in 1.1 General principles of care). Without further information, we are unable to consider making any changes. We are also unclear why the use of the term 'intervention' is considered problematic, the NICE glossary defines this as 'In medical terms this could be a drug treatment, surgical procedure, diagnostic test or psychological therapy. Examples of public health interventions could include action to help someone to be physically active or to eat a more healthy diet. Examples of social care interventions could include safeguarding or support for carers'. The concept of 'severity' in relation to identifying possible autism was used by the 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. Without further information as to why this term is considered problematic, we are unable to consider making any changes. Thank you for providing the reference (Milton 2012). The paper is a narrative review published in 2012 and predates the time period for the searches for inclusion in this review which covers the period

			January 2016 to November 2019. In addition, the article is a discussion paper and for this surveillance review the following types of evidence are eligible for inclusion: published systematic reviews, randomised controlled trials, diagnostic studies, new and updated national policy and guidelines. It is not clear in what ways you think recommendation 1.4.1 which recommends social learning programmes for improving social interaction should be changed. Recommendation 1.4.8 recommends that for autistic adults without a learning disability or with a mild to moderate learning disability, who have problems with anger and aggression, offer an anger management intervention, adjusted to the needs of autistic adults. The guideline committee identified that anger management interventions may not be suitable for all ranges of intellectual ability due to their cognitive component and thus should only be considered for individuals with no or a mild learning disability. Recommendation 1.4.8 does not say or imply that autism causes anger. We did not find any evidence to suggest that the recommendations in this guideline may be considered 'abuse' by autistic people. The guideline ensures that person-centred care genuinely promotes the autonomy of the person with autism. The following information, which is now standard for all NICE guidelines will be added to the recommendation section of the guideline: 'People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care'. Without further information and evidence as to why you have made this statement, we are unable to consider making any changes.

			With regards to your comment on the importance of supporting awareness of and contact with the wider autistic community this is addressed in, recommendation 1.1.6 about providing care and support for autistic adults, which recommends that all health and social care professionals should ensure that they are familiar with recognised local and national sources (organisations and websites) of information and/or support for autistic people and they are able to discuss and advise on how to access and engage with these resources.
Dr Ian Male, Lead of NHSE funded study: Realist evaluation of autism diagnostic service delivery for children with possible autism	Fine		Thank you for your response.

2. THIS QUESTION RELATES ONLY TO AUTISM SPECTRUM DISORDER IN ADULTS: DIAGNOSIS AND MANAGEMENT (CG142) RECOMMENDATION 1.2.3

If an adult with possible autism who did not have a moderate or severe learning disability, scored below 6 on the Autism Quotient (AQ-10), to what extent would this score change your decision to offer a comprehensive assessment? What other factors could influence your decision?

Stakeholder	Overall response	Comments	NICE response

False Allegations Support Organisation		Answer 2 - Many of this cohort, along with mental health issues of other kinds are not identified immediately at the start of the justice system, either pre/on arrest/in imprisonment and not using the individuals family and friends comments on confirmation of Autism and are treated inappropriately at arrest time and not often medically supported on the long wait until the investigations are completed (can be up to 2 years) – there is no support put in place by the criminal justice system, or in your instructions, identifying the need of support of individuals in this category. A comprehensive assessment if appropriate following triage whilst at the police station, or interceded by the solicitor/individual's Dr to be triaged at home Response	Thank you for your comment. The guideline identified that some autistic people may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised. Recommendation 1.8.3 suggests that the autism strategy group should develop local care pathways that promote access to services for all autistic adults, including people in the criminal justice system. Recommendation 1.1.12 advises that in order to effectively provide care and support for autistic adults, the local autism multi-agency strategy group should include representation from the criminal justice system. we have existing relevant NICE guidance: Mental health of adults in contact with the criminal justice system which covers assessing, diagnosing and managing mental health problems in adults who are in contact with the criminal justice system. There is also NICE's guideline on physical health of people in prison which covers mental health assessment for the prison population as part of the first-stage health assessment for people going into prison, and continuity of mental health care for people leaving prison.
2gether NHS Foundation Trust (now Gloucestershire Health and Care NHS Foundation Trust)		The team view is that any AQ 10 score can be more confusing then helpful. GAD presentations are likely to score highly and in our experience, when there is co-morbid mental illness, scores are harder to interpret. We have seen numerous clients who score 10/10 but are neurotypical. We also have the opposite issue of people possibly scoring 6 and under and not being referred. Some GPs and MHICT staff have contacted us as they felt that ASC was highly possible and, in some instances, scores were as low 3/10 – This has proven correct in that we have had had clients with scores of below 6 who have been	Thank you for your comment. The guideline suggests 'considering using the AQ-10 tool for adults with possible autism who do not have a moderate or severe learning disability. If a person scores above six on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism (CG142-1.2.3)'. The recommendation intended for the AQ-10 to be considered for use in primary care, social care and other non-specialist settings to support the decision to refer for a specialist assessment (see the full version of NICE guideline CG142, page 110). The guideline committee noted that the AQ-10 was quick to

		diagnosed with ASC. Although, we have accepted this as a measure to use, we don't tend to place much value on the AQ10 scores (1) and more emphasis on the qualitative information provided with a referral. We are also aware that this measure is available online and patients are sometimes asked to complete and return to a surgery. There could be a possibility of people seeking information about scores required to access services. 1. Wigham S, Rodgers J, Berney T, Le Couteur A, Ingham B, Parr JR. Psychometric properties of questionnaires and diagnostic measures for autism spectrum disorders in adults: A systematic review. *Autism*. 2019;23(2):287-305. doi:10.1177/1362361317748245	use and could be used without needing expertise in its administration and scoring for people in whom there was already a clinical suspicion of autism. Thank you for providing the reference (Wigham et al. 2019). This study was not included because it does not report any data in its abstract. However, the included studies, relevant to AQ-10 (Baron-Cohen et al., 2001 and Ashwood et al., 2016) in this systematic review, were already assessed and included in the original guideline (Baron-Cohen et al., 2001) and the current surveillance review (Ashwood et al., 2016). The evidence from Ashwood 2016 suggests that people referred for specialist assessment did not all meet the AQ-10 threshold, which suggests that referring clinicians did take other factors into account when deciding to refer, which is consistent with current guidance. However, the study indicates that the AQ-10 has low specificity in people with suspected autism referred for specialist assessment. As we are aware of potential limitations with the use of the tool, we consulted with stakeholders on how the AQ-10 is used in practice, by asking to what extent they rely on AQ-10 when making decisions to offer a full autism assessment. Stakeholders comments (current document) confirm that clinical judgment is a determinant factor for referral for assessment and AQ-10 is either not used or used in combination with the patient history and clinical suspicion of autism. As such, we do not think that recommendation 1.2.3 currently requires changing. This issue will be revisited in future surveillance reviews.
Surrey and Borders Partnership NHS Foundation Trust		We do not find the AQ10 a helpful screening tool and so this is not used.	Thank you for letting us know that you do not use the AQ-10.This is consistent with recommendation 1.2.3 that recommends 'considering' using the AQ-10 tool for adults with possible autism alongside clinical judgement, taking into account any past history

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			provided by an informant. Therefore, clinicians should not rely only on AQ-10 scores alone for referral for an assessment.
Autistic UK		Our response draws on various factors. The most important question to pose is whether a diagnosis would improve quality of life for the person presenting. For many, the answer is yes. The AQ10 is a flawed screening tool which doesn't lend itself to discrepancies relating to 'performance on the day'. The score even diagnosed Autistics gain from answering the questions can vary based on how their mental health and wellbeing is, and the questions do not account for masking. The questionnaire is also very stereotypical – designed for cisgender white men. It doesn't pick up on the complexities of Autistic and cultural experiences, particularly when considering other protected characteristics. Autistic respondents also ask themselves a lot of 'what if?' questions and can overthink the answers, which in turn skews the result. It also doesn't account for childhood experiences. Therefore, a comprehensive assessment is likely to be warranted in the vast majority of cases presenting to primary care. Many people at this stage have undertaken their own research to try and establish why they are experiencing the world differently to their peers, and self-identification has a low error rate once comprehensive	Thank you for your comment. The guideline recommended 'considering using the AQ-10 tool for adults with possible autism who do not have a moderate or severe learning disability. If a person scores above six on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism (CG142-1.2.3)'. Recommendation 1.2.3 is a 'consider' recommendation and suggests AQ-10 could be used alongside clinical judgement. Therefore, clinicians should not rely only on AQ-10 scores alone for referral for assessment. Stakeholders comments (current document) confirm that clinical judgment is a determinant factor for referral for assessment and AQ-10 either not used or used in combination with the patient history and clinical suspicion of autism. As such, we do not think that recommendation 1.2.3 currently requires changing. This issue will be revisited in future surveillance reviews.

		assessment and clinical diagnosis is made. If someone has requested an autism assessment, there is good reason which requires further investigation regardless of their AQ10 score.	
Rotherham Doncaster and South Humber NHS Foundation Trust		The AQ-10 is utilised to support other services and professionals when screening individuals to refer on to the autism service for the diagnostic pathway. When we receive this alongside additional ASD indicators as requested in our referral form, which requests details regarding: reason for referral, development, social functioning, interests, daily living, mental health, difficulties during childhood, we will then accept or decline the referral based on this information, the AQ-10 is not always considered necessary if there are enough suitable indicators on the referral form. Previously it was recognised within our service that the AQ-10 wasn't a sufficient screening tool alone and so other evidence based screening tools were implemented, and all patients on the pathway are screened within our service prior to an individual receiving the full diagnostic assessment. The ASD practitioners use the 3 screening tools: Autism Quotient 50, Empathy Quotient and Relatives Questionnaire to identify whether a diagnostic assessment is then warranted. As practitioners we feel that this has proven to be a more effective diagnostic pathway.	Thank you for your comment. Recommendation 1.2.3 suggests offering comprehensive assessment for autism depends on AQ-10 score or clinical suspicion of autism, therefore clinicians should not rely only on AQ-10 scores alone for referral for assessment. The current evidence suggests (see summary of evidence) that it may not be advisable to rely on any autism-specific diagnostic tool alone to suspect autism in adults and to inform decisions about referral for a comprehensive autism assessment. Stakeholders comments (current document) confirm that clinical judgment is a determinant factor for referral for assessment and AQ-10 either not used or used in combination with the patient history and clinical suspicion of autism. As such, we do not think that recommendation 1.2.3 currently requires changing, but we will consider any further evidence on screening tools at the next surveillance review.
Royal College of Nursing		I would consider offering a comprehensive assessment despite scoring below 6 and my decision would be influenced by one or more of the following factors:	Thank you for your comment confirming that recommendation 1.2.3 is being interpreted as intended and that clinical judgement as well as the possibility of the AQ-10 is being used to inform decisions

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		- Age of the service user - Gender - Educational Background - Family Background - Social Network Support Network	about referral for a comprehensive autism assessment in people with possible autism.
British Association of Social Workers (BASW) – England		One BASW member said: 'AQ-10 is a clinical assessment tool: it does not reflect the much broader duties under the Care Act. The guidance should clarify that people who are not eligible for specialist NHS clinical support may be eligible for social care support under the care act and that they are eligible for universal NHS support (and these services may need to make reasonable adjustments). As it stands there is too much risk of an all or nothing offer of support, hence the over reliance on diagnosis as opposed to need'	Thank you for your comment. Recommendation 1.2.3 suggests considering using the AQ-10 alongside clinical judgement to inform decisions about referral for a comprehensive autism assessment in people with possible autism. Therefore, clinicians should not rely only on AQ-10 scores alone for referral for assessment. The guideline has comprehensive recommendations on principles for working with autistic adults and their families, parents and carers (recommendations 1.1.1 to 1.1.11) providing effective care and support for people with autism. In addition, NICE founded on the principle that people have the right to be involved in discussions and make informed decisions about their care, which is described in NICE's information on making decisions about your care. A guideline in Shared decision making is also in progress and the expected publication date is June 2021.
National Autistic Society		The NAS Lorna Wing Centre (s) for Autism, the National Autistic Society's specialist diagnostic and assessment centre, provides a variety of assessment services relating to the understanding and diagnosis of ASDs. We do not rely on the use of the AQ-10 to make a decision about offering an assessment and it is not used to diagnose autism. Our clinical experience is that the AQ-10 is likely to result in a high false negative rate when used for screening. We believe that this is even more likely for women , as it is less	Thank you for your comment. The recommendation 1.2.3 suggests considering using the AQ-10 alongside clinical judgement to inform decisions about referral for a comprehensive autism assessment in people with possible autism. Therefore, clinicians should not rely only on AQ-10 scores alone for referral for assessment; and the replies we have received from practitioners in this consultation indicate that clinical judgement is being used to inform decisions to offer a comprehensive assessment for autism spectrum condition. As such, we do not think that recommendation 1.2.3 currently

		sensitive to the specific issues presenting in women and girls.	requires changing. This issue will be revisited in future surveillance reviews.
Cheshire and Wirral Partnership NHS FT		Clinical judgement is also important, particularly when there are indicators within the referral information that the individual may have a less visible form of autism. It's important to look specifically at the social context / demands, linguistic / cognitive skills, functional impact, and whether autism seems likely to be a possible factor. For example, there is a need to use clinical judgement to take into consideration alternative markers (e.g. a person may not 'notice small sounds when others do not', but they may be more sensitive to emotion, temperature, hunger, pain or touch and this would be equally significant). At times an informant's view on the AQ10 score is helpful.	Thank you for your comment. Recommendation 1.2.3 suggests considering using the AQ-10 alongside clinical judgement to inform decisions about referral for a comprehensive autism assessment in people with possible autism. Therefore, clinicians should not rely only on AQ-10 scores alone for referral for assessment; and the replies we have received from practitioners in this consultation indicate that clinical judgement is being used to inform decisions to offer a comprehensive assessment for autism spectrum condition.
Sussex Partnership Foundation Trust		No – we would consider other information alongside this as scoring could be influenced by masking of autism features or lack of insight in the informant. We would use more comprehensive questionnaires such as RAADS and self report tools.	Thank you for your comment confirming that recommendation 1.2.3 is being interpreted as intended and that clinical judgement is being used to inform decisions about referral for a comprehensive autism assessment in people with possible autism. Thank you for highlighting that there are other screening tools that you use. The current evidence suggests (see summary of evidence) that it may not be advisable to rely on any autism-specific diagnostic tool alone to suspect autism in adults and to inform decisions about referral for a comprehensive autism assessment. Stakeholders comments (current document) confirm that clinical judgment is a determinant factor for referral for assessment and AQ-10 either not used or used in combination with the patient history and clinical suspicion of autism. As such, we do not think that recommendation 1.2.3 currently

			requires changing, but we will consider any further evidence on screening tools at the next surveillance review.
Autistica, the UK's autism research charity		We do not provide any diagnostic services for autism and so cannot comment on how we would use the AQ-10 in practice. We have previously highlighted to NICE the evidence which indicates that the AQ-10 has poor specificity and an unacceptable risk of creating false negatives if used as a screening tool, as CG142 recommends. We believe the continued inclusion of AQ-10 in CG142 is not justified by the evidence base and could cause avoidable harm. www.ncbi.nlm.nih.gov/pmc/articles/PMC4988267/ www.ncbi.nlm.nih.gov/pubmed/29439585	Thank you for your comment. The recommendation to offer comprehensive assessment for autism depends on AQ-10 score or clinical suspicion of autism (CG142- 1.2.3) therefore clinicians should not rely only on AQ-10 scores alone for referral for assessment. Thank you for providing the references (Wigham et al. 2019; Ashwood et al., 2016). The included studies in the systematic review (Wigham et al. 2019), relevant to AQ-10 (Baron-Cohen et al., 2001 and Ashwood et al., 2016), were already assessed and included in the original guideline (Baron-Cohen et al., 2001) or the current surveillance review (Ashwood et al., 2016). The evidence from Ashwood 2016 suggests that people referred for specialist assessment did not all meet the AQ-10 threshold, which suggests that referring clinicians did take other factors into account when deciding to refer, which is consistent with current guidance. However, the study indicates that the AQ-10 has low specificity in people with suspected autism referred for specialist assessment. Therefore, we consulted with stakeholders (current document) about the impact of this new evidence on recommendation 1.2.3. by asking to what extent they rely on AQ-10 when making decisions to offer a full autism assessment. Stakeholders comments confirm that clinical judgment is a determinant factor for referral for assessment and AQ-10 either not used or used in combination with the patient history and clinical suspicion of autism. We will therefore not be amending recommendation 1.2.3 at this time. This issue will be revisited in future surveillance reviews.

Healthwatch Calderdale		Although my organisation is not involved with the assessment of adults with autism, we have done extensive engagement in our local area with a number of adults who were seeking an assessment, struggling to get an assessment, or seeking a second opinion because they disagreed with the outcome of an assessment. I can also give a personal perspective as I had a private autism assessment in December 2020 where I received the diagnosis of autism spectrum condition. While the AQ-10 was designed to be a short questionnaire appropriate to all ages to assist healthcare professionals considering referring patients for further ASD assessment, I believe it is of limited use, and is therefore not a helpful tool to help GPs who have very little knowledge or understanding about autism in general, and more specifically about how autism presents in adults and also in women. If the AQ 10 is used as part of the screening or triage process there is a danger that adults who should be assessed for autism will be denied that opportunity because the AQ 10 is not a reliable tool to use for such an important decision, as it can be misleading for the GPs who have to rely on it as a tool when they have very little experience of or understanding of autism themselves. The questions in the AQ 10, which is a shortened version of the more detailed AQ 50, do not hang together well, and some of the questions can be difficult for people to interpret, especially as they are without context.	Thank you for your comment and for sharing your personal experience. The recommendation to offer comprehensive assessment for autism depends on AQ-10 score or clinical suspicion of autism (CG142- 1.2.3) therefore clinicians should not rely only on AQ-10 scores alone for referral for assessment. The recommendation intended for the AQ-10 to be considered for use in primary care, social care and other non-specialist settings to support the decision to refer for a specialist assessment (see the full version of NICE guideline CG142, page 110). The guideline committee noted that the AQ-10 was quick to use and could be used without needing expertise in its administration and scoring for people in whom there was already a clinical suspicion of autism. However, the study indicates that the AQ-10 has low specificity in people with suspected autism referred for specialist assessment. We consulted with stakeholders (current document) by asking to what extent they rely on AQ-10 when making decisions to offer a full autism assessment. Stakeholders comments confirm that clinical judgment is a determinant factor for referral for assessment and AQ-10 either not used or used in combination with the patient history and clinical suspicion of autism. This issue will be revisited in future surveillance reviews. The guideline recommends (recommendation 1.2.8) that, to aid more complex diagnosis and assessment for adults, consider using a formal assessment tool, such as: • the following tools for people who do not have a learning disability: ○ the Adult Asperger Assessment (AAA; includes the Autism-Spectrum Quotient [AQ] and the Empathy Quotient [EQ])

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		Also one of the questions '*I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc)*' appears to display a male bias as it does not include much in the way of examples of special interests that might appeal more to women. Based on the feedback Healthwatch Calderdale has received over the last four years a number of adults have struggled to get an assessment for an autism spectrum condition (ASC) for a range of reasons, and because of this Calderdale has an exceptionally low diagnosis rate for adult autism. It is possible that the use of the AQ 10 contributes to this. At the moment access to an ASC assessment is totally dependent on their GP's input, knowledge of the patient, and understanding of autism and how it may present in adults, which may be limited. The patient, who is an expert in their condition, does not get the opportunity to input into the form, in fact if they do that it can be a reason for the triage panel to refuse to assess it. Healthwatch Calderdale has had several clients who have been unable to access an NHS autism spectrum condition assessment, sometimes because their GP has been unwilling to refer them for an assessment, possibly due to their lack of understanding of the way that autism presents in adults, or because of their lack of knowledge about the patient who is seeking the assessment. We have also had clients who have been refused an assessment because they have been turned down by the triage panel based on the information the GP submitted which includes the AQ-10.	○ the Autism Diagnostic Interview – Revised (ADI-R) ○ the Autism Diagnostic Observation Schedule – Generic (ADOS-G) ○ the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI) ○ Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R) (recommendation 1.2.8) It also recommends to organise and structure the process of a more complex assessment of an autism spectrum disorder, professionals should consider using a formal assessment tool, such as the Diagnostic Interview for Social and Communication Disorders (DISCO) the ADOS-G or the ADI-R (recommendation 1.2.9). There is some evidence (see evidence summary) to suggest that it may not be advisable to rely on any autism-specific diagnostic tool alone to diagnose autism in adults. Further research is needed to confirm any impact on the current guideline recommendations.

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		We have also had a female adult client who was refused an NHS assessment, but then obtained NHS funding for an alternative assessment with a private provider which has expertise in adult assessments including an understanding of masking and camouflaging in autistic women, and following this she received a positive diagnosis of ASC. As more is learnt about the presentation of autism spectrum conditions in adults without learning difficulties, it is important that this learning is applied to the diagnosis and assessment process. A number of new tools have been developed which can be used in these processes, for example when I had my own assessment in 2020 the following tools were used: • Diagnostic Interview for Social Communication Disorders (DISCO) • Adolescent/Adult Sensory Profile (A/ASP) • Camouflaging Autistic Traits Questionnaire (CAT-Q) I believe there needs to be leeway in the use of the AQ-10 as it is a very limited tool for supporting the diagnosis of what is a very complex condition, and if used incorrectly it can cause barriers for the very people who need help and support to access an assessment.	
Autism Rights Group Highland		This seems to be a question just for diagnosticians.	Thank you.

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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. However, FASO are limited in what their volunteers from all walks of life can do.	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 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.' NICE have provided information about how to use quality statements.
UK Society for Behaviour Analysis	1.5.3 1.1.13	We are pleased that CG142 recommends the use of behaviour analytic principles and procedures such as functional analysis and reinforcement. However, there is no mention of the underpinning science – applied behaviour analysis (see 1.5.3) – nor is there mention of the professionals trained to implement the assessment and intervention strategies it has generated, namely, behaviour analysts (see 1.1.13). In contrast, NG11 (Challenging behaviour and learning disabilities), which recommends the use of similar behaviour analytic approaches, refers both to applied behaviour analysis and behaviour analysts. With regard to CG142, we respectfully request that NICE remedies this omission by explicitly referencing the science from which approaches such as functional analysis have arisen – applied behaviour analysis – and the professionals who receive extensive training in the implementation of strategies derived from that science, behaviour analysts.	Thank you for your comments about reference to functional analysis in recommendation 1.5.3. This is based on guideline committee expertise in the absence of evidence. The full guideline says: 'the committee was conscious of the limited evidence base identified in the reviews…(and)…proposed that a functional analysis of the challenging behaviour should be the basis for the development of any psychological or pharmacological intervention for such behaviour'. Recommendation 1.1.13 lists the knowledge that health and social care professionals providing care and support for adults with autism should have. The recommendations in CG142 should be taken as whole and it is expected that those providing psychosocial interventions have the requisite skills/professions, which may include behavioural analysts. During guideline development and during this surveillance timepoint evidence about ABA was identified (surveillance review 'Psychosocial interventions for children with autism' section) that indicated its effectiveness is largely equivocal and therefore we cannot add a recommendation about ABA. Challenging behaviour and learning disabilities (NG11) recommendation 1.1.5 recommends if initial assessment and management have not been effective, health and social care provider organisations should ensure that teams providing care have access to specialist assessment, support and intervention services.

		In doing so, the guidance will protect autistic people by increasing the likelihood that they receive services from professionals who are competent in the delivery of an approach which the scientific literature has shown to be effective.	These should provide advice, from a range of staff including behavioural analysts. This term will encompass those practicing ABA-based interventions and NG11 considered evidence from ABA-based interventions (for example, PBA) and did not find sufficient evidence to make recommendations that specifically recommend named interventions based on an ABA approach, rather it makes recommendations that may encompass some ABA-based interventions, for example recommendation 1.7.5 which recommends consider personalised interventions for children, young people and adults that are based on behavioural principles and a functional assessment of behaviour. This is why NG11 makes a research recommendation to answer the following question: *are interventions based on the science and practice of applied behaviour analysis or antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges shown by adults with a learning disability?* This acknowledges that further research is needed. This research recommendation is not answered by the NIHR systematic review and is therefore still valid. During development of CG142 the guideline committee 'took the view that it was appropriate to classify interventions by the main target or focus of the intervention, rather than its particular components, as this would facilitate the implementation of the recommendations by healthcare professionals…including psychosocial interventions based on the principles of applied behavioural analysis'. CG142 contains a review question that specifically looked for evidence on applied behavioural analysis (see section 7.2.2, p.192 of full guideline) and only low quality evidence was identified. However the committee, based on their expertise, decided that behavioural therapies should be considered for life

			skills and managing challenging behaviour made recommendations 1.4.4 and 1.5.5 that accommodate ABA-based approaches.
2gether NHS Foundation Trust (now Gloucestershire Health and Care NHS Foundation Trust)	1.3.4 “consider starting with a low dose”.	‘start at low dose and consider treatment dose may be considerably lower in ASC persons’	Thank you for your comment. Recommendation 1.3.4 advises to start at a low dose because of the possibility of sensitivity to side-effects in autistic people. This is based guideline committee interpretation of evidence on the use of antipsychotics for behaviour management in adults with autism which mostly compares risperidone with placebo. This suggested that risperidone is associated with sedation and weight gain. The committee did not think it appropriate to recommend any specific antipsychotic but considered that the choice of antipsychotic medication should be influenced by a consideration of the side effect profile, a service user’s past experience of the use of the drug and their personal preferences (see page 284 of the full guideline).
Autistic UK		Comment regarding topic experts used and our response team: The topic experts used are not identified as Autistic and lived experience advisors are increasingly favoured when creating and implementing policy documents. The only patient groups involved were from NAS and Autistica, neither of whom have the full support of the wider Autistic community outside their service users. Therefore, there is a wide section of the Autistic community who haven’t been reached during the review and consultation period. We invited two independent Autistic consultants to co-produce this response with three of our Autistic board members to ensure our response covers a wide subsection of the	Thank you for your comments. Service users were included on the guidance development committee during development – please see full membership list. Additionally there is a full list of stakeholders published on the NICE website who were able to comment on the draft guideline. The same published lists are available for CG170 and CG128. For this consultation we have received responses from a number of patient group organisations who we have responded to in this consultation document and those for CG170 and CG128. We have also received responses from individual service users whose comments are given full consideration and we respond to them privately.

		community. This point stands for the other two guidance documents. Recommendation to update reasons for underdiagnosis in adults in guide: P. 9 Surveillance – Underdiagnosis in adults is due to masking in addition to capacity issues and refusal to refer to autism diagnostic pathways by primary care. Further reason we disagree with your proposal to not update the guides: P. 9 Surveillance – The Oliver McGowan Mandatory Training demonstrates that the guidelines need to be checked again using the scope of the training to ensure they are fit for purpose. This point stands for the other two guidance documents. Comment regarding the document referring to autism as a disease: P. 10 Surveillance – Your document references autism as a disease. Autism is not a disease, and calling it so is insulting to the Autistic community. NHS, (2019) What is Autism? On NHS [Online] https://www.nhs.uk/conditions/autism/what-is-autism/ (Accessed 04/11/20) This point stands for the other two guidance documents. Recommendation to update the guides to reflect the referral and diagnostic disparity for marginalised groups: P. 11 Surveillance – Only suggesting further areas of research	Thank you for your comments on masking. We did not find any evidence that masking is a cause of underdiagnosis in adults. The guideline has recommendation 1.1.14 which recommends that autism specialists should provide training to staff on the diagnosis and assessment of adults. The guidelines include recommendations about training of health and social care professionals, for example, recommendation1.1.4 recommends that the specialist autism team should have a key role in the delivery and coordination of training, support and consultation for staff who care for autistic people in residential and community settings. Similarly, recommendation 1.8.3 suggests that autism strategy groups should be responsible for developing, managing and evaluating local care pathways. Ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway for relevant health professional. Please note NICE no longer make recommendations on training of staff; and professional bodies should be developing and endorsing a training package for its members. Thank you for your comment about 'referring to autism as a disease.' This is noted and will be amended. Thank you for your comments about updating the guidelines with respect to marginalised groups. No new evidence was identified about effective interventions that addressed the needs of specific groups, a finding consistent with previous surveillance reviews.

		when provided evidence that women/trans/BAME communities are being underdiagnosed is not good enough. This is particularly pertinent when current guidance states that more boys are diagnosed as this suggests to the reader that white cisgender boys are more likely to be Autistic. This point also stands for the under 19s recognition document. Comment regarding the exclusion criteria for evidence in the review document: P. 17 Surveillance – By excluding data because it's 'not academic enough' you are not including information that's directly relevant to the Autistic community. Historically, research has been directed by non-Autistic researchers using the medical model of disability, with a focus on causes, treatments, and genetics. None of this research is designed to increase an Autistic person's quality of life (much of it actively does the opposite) and by refusing to consider the growing evidence of Autistic experience presented to you by the patient groups, you are doing the Autistic community a disservice. Co-production and lived experience advisors are increasingly being utilised in social policy review, and NICE guidelines should not differ. This point stands for the other two guidance documents. Recommendation regarding updating the guide to reflect differing access to referral for those Autistics with learning disabilities: P. 18 Surveillance – This page states that 'access to diagnostic services was reported to be better for people with learning disabilities,' yet all three guidance	Without this evidence we are unable to nuance recommendations for specific groups. As you highlight, we identified new evidence that does indicate an underdiagnosis in girls and women. However, no evidence for gender-specific diagnostic criteria were identified, and without this we cannot make recommendations. Within the suite of NICE autism guidelines, NICE guideline CG128 has research recommendation 1 on training professionals to recognise signs and symptoms of autism, which includes addressing underdiagnosis in girls, children and young peoples with parents of lower educational attainment, English as an additional language, with sensory impairments and/or with a learning (intellectual) disability; 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). We do not agree that the recommendations imply that 'white cisgender boys are more likely to be Autistic'. NICE has a commitment to reducing health inequalities and the guideline underwent an equalities impact assessment. Where there is evidence for any groups with protected characteristics this will of course be considered. Thank you for your comments about exclusion criteria. In relation to consideration of published research evidence we included systematic reviews of qualitative and quantitative research, randomised controlled trials and diagnostic studies because these were most relevant to the topics under consideration and are the most appropriate designs to establish effectiveness in this case. Therefore, we do not exclude things because 'they are not academic enough' but because it is important recommendations are based on the best available evidence. However, we also consider non-research evidence e.g., the opinions of patient groups, topic experts

		documents state that it's harder for someone with a learning disability to get a diagnosis. The guidance needs to be updated to reflect your finding. This point stands for the other two guidance documents. Recommendation regarding updating the document with suicide prevention guidance: P. 20 Surveillance – Your guidelines make no reference to suicide, yet you state that evidence pertaining to reducing suicide doesn't suggest a need to update guidelines. While there may be other NICE guidelines pertaining to suicide, these do not reflect the differing statistics found within Autistic demographics, nor are they linked on your guidance documents. It is essential that you include a cross reference to mental health guidelines, but preferably include a statement which qualifies the difference in statistics. For example, in non-Autistic populations men are more likely to complete suicide than women, whereas in Autistic populations women are more likely to complete suicide. This is an essential piece of information as mental health services often dismiss female suicide attempts as attention seeking or as self-injurious behaviour. A large number of people who complete suicide have 'at low risk of completing suicide' written on their mental health records. This practice is unsuitable. Appleby, L., et al (2018) The assessment of clinical risk in mental health services in National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH). Manchester:	and stakeholders responding to consultations like this alongside other evidence. It is the impact of this accumulated evidence that we use to make assessments about whether recommendations remain relevant or require updating. Service users were involved in the development of CG142 and there is a full list of stakeholders published on the NICE website who were able to comment on the draft guideline. The same published lists are available for CG170 and CG128. Thank you for your comments about differing access to Autistic people with and without learning disabilities. The guideline recommendations aim to ensure that all autistic people get access to diagnostic services. For example recommendation 1.2.1 recommends staff who have responsibility for the identification or assessment of autism should adapt these procedures to ensure their effective delivery. Thank you for your comments about suicide. The surveillance report notes the NHS Long-term plan aims to reduce suicides by investing in specialist community teams to help support children and young people with autism (NHS Long Term Plan page 72, 3.105). We will consider evidence on this and how it may impact recommendations.CG142 recommendation 1.2.12 recommends during a comprehensive assessment, assess the risk of self-harm (in particular in people with depression or a moderate or severe learning disability). As you highlight NICE has produced other guidance about suicide. For example, Preventing suicide in community and custodial settings (NICE guideline NG105) recommendation 1.3.1 notes that high risk groups include autistic people. Thank you for your comments about completed suicides in

		The University of Manchester [Online] https://t.co/kDcJr3iBs6?amp=1 (Accessed 04/11/20) Cassidy, S., Bradley, L., Shaw, R. et al. (2018) Risk markers for suicidality in autistic adults. In Molecular Autism Vol. 9, 42 [Online] https://doi.org/10.1186/s13229-018-0226-4 (Accessed 04/11/20) Recommendation regarding the amendment of prevalence rates in the guidance: P. 20 Surveillance – If evidence shows that the prevalence is over 1% you need to amend your guidelines to reflect this. People are being refused diagnosis and/or referral based on the 1% figure as areas 'fill their quota'. This point also stands for the under 19s recognition guide. 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 the CQC. This point also stands for the under 19s support and management document.	autistic women compared with men and for highlighting data about clinical risk by the National Confidential Inquiry into Suicide. This broadly concludes that risk tools and scales should not be relied on alone to assess suicide risk and should be used as part of a broader assessment that includes family and carers. This finding is consistent with recommendations about support immediately pre and post-discharge from mental health services in section 1.6 of transition between inpatient mental health settings and community or care home settings (NICE guideline NG53). This includes 1.6.4 which recommends if the is on the autistic spectrum, the hospital team should lead communication about discharge planning with the other services that support the person in the community. Thank you for sharing the study by Cassidy et al. which reports the results of a survey about suicidality risk factors in adults with autism. This was identified by our searches but excluded as being out of scope because it does not investigate interventions to reduce or prevent suicide. Thank you for your comments about prevalence. The surveillance review only focuses on the need to update recommendations within a guideline. The recommendations in CG142 are not contingent on prevalence nor do they quantify prevalence. While we acknowledge service capacity issues, the recommendations do not act to make these worse. 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.

		Recommendation regarding the addition of EDS and Autoimmune conditions into the co-occurring conditions list: 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. 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) 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	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 outcome and therefore we do not propose to update the guideline with any specific recommendations about inpatient care at the current time. As you note we identified 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. Thank you for your comments about Ehlers Danos Syndrome (EDS). As you highlight the surveillance proposal (p.44-45) found no evidence that autoimmune disorders, EDS or other connective tissue disorders are more prevalent in autistic people. Thank you for sharing the 3 articles about joint hypermobility. The Baeza-Velasco et al., 2018 is a narrative review that describes the results of studies selected by the authors that suggest EDS is associated with autism. This is a not systematic review and is therefore outside the inclusion criteria of this surveillance review. Cederlöf et al.,2016, aimed to assess the risk of psychiatric disorders and developmental disorders in EDS and hypermobility syndrome in a Swedish population. This study is not a diagnostic design and does meet the inclusion criteria for this review. Casanova et al. 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) and therefore does not meet inclusion criteria for the surveillance review. It reports that there

		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 anorexia into the co-occurring conditions list: P. 47 Surveillance – We disagree with your statement that there is no evidence to suggest a link between anorexia and autism and we feel this should be added to your list of co-occurring conditions. Brede, J., Babb, C., Jones, C. et al. (2020) “For Me, the Anorexia is Just a Symptom, and the Cause is the Autism”: Investigating Restrictive Eating Disorders in Autistic Women. In Journal of Autism and Developmental Disorders [Online] https://doi.org/10.1007/s10803-020-04479-3 (Accessed 04/11/20) Westwood, H., Mandy, W. & Tchanturia, K. (2017) Clinical evaluation of autistic symptoms in women with anorexia nervosa in Molecular Autism Vol. 8 No. 12 [Online] https://doi.org/10.1186/s13229-017-0128-x (Accessed 04/11/20) Huke, V., Turk, J., Saeidi, S., Kent, A. and Morgan, J.F. (2013), Autism Spectrum Disorders in Eating Disorder Populations: A Systematic Review. In European Eating Disorders Review, Vol. 21 No. 5 pp. 345-351. [Online] doi:10.1002/erv.2244 (Accessed 04/11/20)	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 together these papers do not suggest that recommendations should be amended to include recommendations about EDS as a co-occurring condition. We will flag EDS as a risk factor for autism in UK populations as an area to look for evidence when we next carry out surveillance. Thank you for your comments about anorexia and for sharing these references. As you highlight 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. The Brede, et al 2020 paper is a qualitative study and is therefore out of scope for this surveillance review. Westwood et al. 2017 is a questionnaire study of women with an eating disorder and this guideline does not cover co-existing conditions if an autistic spectrum condition is not a primary diagnosis, therefore the study is not eligible for inclusion. The study by Huke et al. 2013 predates the surveillance review search period which is from 27 January 2016 to 1 November 2019. However, please note that CG142 recommendation 1.1.9 recommends all health and social care professionals supporting autistic adults should provide information and advice about a healthy diet and refer onwards if necessary.

		Recommendation regarding excess mortality: P. 94 Surveillance – We disagree that your findings of excess mortality in Autistic populations should not be added to the guidelines due to the NHS Long Term Plan. The Oliver McGowan Mandatory Training should be used to ensure that guidance is accurate to prevent premature deaths, and it is essential that NICE monitor the quality of care for Autistic patients. This point also stands for the under 19s support and management document. Recommendation regarding the addition of music therapy and emotional support animals: P. 98 Surveillance – We disagree with your decision not to include music/animal therapy within your guidelines. Providing real quality of life is more important to the Autistic community than changing their communication to fit non-Autistic ideals. Therefore, we suggest that music therapy be included in the guidelines, and further research be conducted regarding animal therapy, particularly in reference to emotional support animals. This point also stands for the under 19s support and management document. Recommendation regarding the addition of ABA into list of therapies which should NOT be used: P. 97 Surveillance – There is a plethora of evidence demonstrating that ABA is not only ineffective, but also abusive and contributes to the high prevalence of PTSD within the Autistic community. Therefore, NICE needs to include ABA/PBS/Behaviourism in its list of therapies which should NOT be used. Autism is	Thank you for your comments about excess mortality. As you highlight the surveillance review identified evidence about excess mortality, but it did not conflict with any of the recommendations which exist to reduce health inequalities that may be associated with increased mortality for example co-existing mental health conditions and access to employment. CG142 also emphasises the importance of monitoring the effectiveness of interventions with autistic people in section 1.3. Thank you for your comments about music therapies and emotional support animals. We did not find any evidence on the impact of music therapy on autistic adults (the population for NICE guideline CG142), only evidence for this intervention in children, which reported no improvement on measured outcomes from music therapy (as the surveillance review notes on p98-100). For animal therapy, evidence was only found form 1 RCT in relation to children and horseback riding, which showed mixed results. We will therefore not currently recommend updating the autism guidelines in relation to music or animal therapies. Thank you for your comments about ABA and profound and multiple learning disability (PMLD). While we identified evidence about ABA that suggested its effectiveness was uncertain (see the NIHR study Interventions based on early intensive applied behaviour analysis for autistic children: a systematic review and cost-effectiveness analysis on p.98 on the surveillance review), we did not find evidence that it can act to cause harm and should be actively not recommended. Thank you for highlighting the Sandoval-Norton et al. 2020 paper. This is an opinion piece which makes reference to selected literature and is out of scope for this

		not synonymous with PMLD, and debased versions of techniques to support those with PMLD should not be used with Autistics. This point also stands for the under 19s support and management document. Sandoval-Norton, A. H., & Shkedy, G. (2019). How much compliance is too much compliance: Is long-term ABA therapy abuse?. In Cogent Psychology, 6(1), 1641258. [Online] https://doi.org/10.1080/23311908.2019.1641258 (Accessed 04/11/20) Comment regarding the use of the term 'challenging behaviour': P. 118 & 127 Surveillance – We again state our disagreement that the guidelines do not need updating with regard to 'challenging behaviour'. As the term is overly subjective (as previously stated) it is too easy for a medic/parent/carer to claim that other options haven't worked, leading to unnecessary medication. This point stands for all documents. Recommendations regarding support services other than behaviourism: P. 140 Surveillance – The interventions stated all describe ABA practice, and are all designed to teach Autistics how to mask, which is found to be a suicide risk factor (referenced in a previous study linked in our response document). Autistic people are not broken. Few consider themselves to be non-Autistic people waiting to be 'fixed'. We don't all need managing, but we all need	surveillance review which only considered systematic reviews, randomised controlled trials and diagnostic studies. Thank you for your comments about challenging behaviour. The intention of the term 'challenging behaviour' is to prevent the phrase being used as a diagnosis and to stop people feeling that they needed to 'fix' the person, so that they would instead concentrate on 'fixing' the environment. Users of NICE guidelines are expected to use the definition provided in a guideline's glossary, which in NICE guideline CG142 makes it clear that it is important to recognise that 'challenging behaviour' is the result of an interaction between the person and their environment, and as such is largely socially constructed. Challenging behaviour is defined in the glossary as 'a term used to describe behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour. Such behaviour is seen as challenging when it affects the person's or other people's quality of life and or jeopardises their safety'. However, we have noted an inconsistency in language between NICE guidelines CG142 and CG170: that CG170 uses 'behaviour that challenges' which was considered to be appropriately person-centred language. Therefore, we will make editorial amendments to CG142 to change the use of 'challenging behaviour' in recommendations to 'behaviour that challenges' in line with the NICE style guide and CG170. Thank you for your comments about support services other than behaviourism. CG142 does not make recommendations that try to 'fix' people. With respect to your comments about peer support

		support and equality/equity of access to services. We need support to be happily Autistic. Peer support programmes, similar to those found in mental health and addiction services, would be far more beneficial than blanket behaviourist treatments. This point stands for all documents. Recommendation regarding the addition of sensory support guidance: There is no reference in any document regarding sensory support for sensory processing differences. Support in this area needs to be added to the guidance. This should be via an adequate needs assessment in order to adapt the environment, not a desensitisation programme. This point also stands for the under 19s support and management document.	programmes CG142 makes recommendation 1.4.2 which recommends social learning programmes should typically include peer feedback for group-based programmes. Recommendation 1.3.1 in CG170 recommends considering peer mediation for psychosocial interventions with school-aged children. Thank you for your comments about sensory support. CG142 does however make several recommendations about sensory support including recommendation 1.3.2 which recommends when discussing and deciding on care and interventions with adults with autism, take into account the: • greater risk of altered sensitivity and unpredictable responses to medication • environment, for example whether it is suitably adapted for people with autism, in particular those with hyper- and/or hypo-sensory sensitivities
Fair Treatment for the Women of Wales (FTWW)	The guidelines should be updated to include more detail around sex and gender considerations including differentiated	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

	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 undergoes 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 at 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
Royal College of Nursing	Yes	Diagnosis and management should be reviewed for the deaf population as communication barriers and associated co-morbidities make it more difficult to assess and diagnose.	Thank you for your comment on diagnosis and management reviewed for the deaf population. This is addressed within NICE guideline CG142: Recommendation 1.1.5 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 (someone who does not have a personal relationship with the person with autism) if required'.
British Association of Social Workers (BASW) – England	Yes – relating to best practice in management of existing services.	**Focus on the practice examples –** From our membership perspective the components that lead to success are as follows: • Skilled workforce • Co-production • People employing autistic people • Direct service • Accessing a service because a person is an autistic adult • Providing a service for autistic people is a core issue for social work organisations. The medical model will not solve this problem, social care models can help. • Co-production as a word or term has been de-valued – this says a lot about how people and families are looked at- viewed as a free resource.	Thank you for your comments about the use of practice examples and for illustrating this with the example of North-East Lincolnshire adult autism service. The remit of CG142 is to make evidence-based recommendations that focus on improving health inequalities for people with autism. We acknowledge practice examples can be a powerful and effective means of demonstrating good practice. The example you have shared, with its focus on collaborative, multidisciplinary working, shared decision making with autistic people and the integration of diagnostic and support services is an interesting example of service delivery. If you have any published research studies that have investigated outcomes associated with the approach described, we would be grateful if you could share them with us. How you used NICE guidance to support this approach would be interesting to know more about. We suggest you consider submitting details of the service you have described to NICE's

		Organisations needs to be shown: • This is what it is • This is what it looks like • This is how you do it **Best practice example of an Autism service: Adult Autism service- North East Lincolnshire** **What is the service?** The Adult Autism Service for North East Lincolnshire was developed in conjunction with Mental Health Services and in response to feedback from people with Autism, their families and professionals who felt there was a gap in support for those over 18 years of age, the service is provided by Care Plus Group in partnership with NAViGO. Driven by CCG- vision -commissioners framework, accommodation- key providers – not in competition led by social workers and psychologists, multi-disciplinary assessment, support and accommodation needs looked at together, person, family, everyone included that is part of the person's circle of support. **What does the service look like?** • Multi-disciplinary Team (MDT)working in social care, specialist intensive support service, mental health providers- bespoke provision designed to keep people safe, agreement for cross-organisational working, pathways to prevent hospital admissions. NAVIGO are the provider of this service.	endorsement team for consideration as a potential implementation resource (more information about endorsement and how to submit can be found on NICE's endorsement page) or as an example of shared learning (see Submit shared learning example).

		• Facilitate MDT meetings support colleagues instantly involving people from the start rather having to go through a referral route to engage professionals afterwards. Not just about partnership working its about WHEN- involvement from the beginning- everybody's business • Shared decision making and shared responsibilities • Never had any hospital beds- always had to work creatively with adults with learning disabilities and mental health needs to meet people's needs in the community. • Local intensive support team- Psychology led model - commissioners knew this worked well for people with learning disabilities and complex needs and replicated this model for autism in partnership with mental health services. • The diagnostic and support services are delivered together • It is autistic people in the service that make decisions through the partnership board. The board has to have 50% representation of autistic people to be quorate. • Community Interest Companies - all service provision social care and health • Focus- provides adult social care service and is engaged in micro-commissioning	

		- NAVIGO- provides the mental health service **This is how you do it** - Drivers locally for specific autism service- referrals were going to mental health- MH were lobbying CCG saying we can't respond to people's needs - Mental Health services and local commissioners looked at a model that was already out there and working and looked to transfer this to NE Lincolnshire. - Supporting people in their local community- continuation of this at one point there was no-one placed out of area. - Commissioners: enabled delivery and adapted the model of working to support faraway CIC development – this is an added bonus- commissioners thinking creatively outside of statutory functions. This is in addition to statutory provision. - The idea is to say here's some money see what you can do with a view to replacing other provision if it works - Commissioners can invest in people who know the whole picture. - NICE guidance- how did you use it? Marry it up with what works best, important to follow, didn't used it in isolation. Just doing the diagnostic test misses the person. Augmented the guidance and	

		the diagnostic service by putting it together with an assessment and support service. • Within 6 months of having the new diagnostic and support service, cleared the waiting list and now the service operates an appointment within 4-6 weeks. • Co-production- how we involve people in service design and delivery and having this built into the system as a fundamental part of how we deliver services • Forums in North East (NE) Lincolnshire- initially autistic adults with parents has gained momentum and now 25-30 people every couple of weeks meet and have a voice • In NE Lincolnshire- autistic people can attend the board and represent the forum. At least 50% autistic people to be quorate. Moved the board meeting to be a forum and changed the time so it was outside working hours to enable people to attend and professionals also attend at this time which works better for people. • Led by autistic people, certain opportunities- autism support workers developing faraway Community Interest companies (CICS) the directors of these companies are people with autism, neuro-diverse from a leadership perspective. 12 month pot of funding- small investment to develop a scheme to develop autistic mentors. CIC's benefit the local community so demonstrate investment in community development.	

		Keys to success: • Everyone has the same aim- enabling people to thrive • Consistency and continuity of leadership – being around from the start helps • Needs led, person-centred approaches that differ from NHS medical model- identifying what the person needs to enable them to live a good life • Psychology element- leadership that comes from this perspective enables services to eb developed that are person centred and needs led, partnership working is easier. • Having a separate service for people with autism- an integrated service can be offered later down the line. Establish a separate service then get the skills that are transferable out • Operate a "You said, We did" approach and people feel listened to	
The Challenging Behaviour Foundation		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	Thank you for your comments about autism diagnosis removal and highlighting the effects this can have on an individual's access to care and support. NICE were contacted about the serious case review you describe and we considered it during this surveillance review. We did not identify any evidence that this is a system-wide issue or that the NICE autism 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.

		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 care and support. The individual and their family have been left traumatized. 2 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	It should also be noted that NICE guideline CG142 does not make any recommendations about removal of diagnosis. It does have recommendation 1.2.5 which recommends a comprehensive assessment should: • be undertaken by professionals who are trained and competent • be team-based and draw on a range of professions and skills This should act to ensure critical decisions are not taken unilaterally. Additionally, all practitioners using NICE guidelines have a responsibility to take the guidelines fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. This is described in the overview section of CG142. Thank you for your comments about medication and the STOMP initiative which, along with the STAMP initiative for children aims to stop the overmedication of people with a learning disability, autism or both. We identified STOMP-STAMP as part of this surveillance (see 'Other intelligence on drug treatments for children and young people with autism' section in surveillance proposal). We assessed the findings as being supportive of current recommendations on drug treatments for autism and that it has the potential to increase the implementation of the guideline on managing autism in children and young people, therefore an update to the guideline is not necessary. Thank you for your comment about section 1.2 and the identification of autism in women. Thank you for sharing the blog

		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. Guidance and information around medication needs updating: Although the guidance does recommend that antipsychotic medication should not be used to treat the core symptoms of autism, the guidance does not include up to date links to up to date resources/ information on inappropriate medication e.g. STOMP. which can be found here: https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/ As part of STOMP, the Challenging Behaviour Foundation created a medication pathway which can be found here: https://medication.challengingbehaviour.org.uk/ Section 1.2 Identification and Assessment should include particular information/ guidance around identifying autism in women: Currently, the number of autistic women and girls in Assessment and Treatment units is increasing.	with us 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. NICE guideline CG142 has recommendation 1.8.3 that recommends specific care pathways for women should be developed. However, 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 girls and we will highlight this to the NIHR as an area where research is needed.

		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 women than men.	
National Autistic Society	We believe the scope of the guideline could include more explicit reference to mental health support, including improved guidance on how to adapt mental health services and interventions. The guideline should explicitly reflect the work being done by NHS England and NHS Wales.	Whilst the guideline does refer to the importance of considering mental health needs in the identification and initial assessment of possible autism, as well as a comprehensive assessment, there is no explicit mention of mental health support or strategies which would benefit autistic people. NAS priority surveys show that mental health is the leading concern of autistic adults. Research suggests that around 8 in 10 autistic adults develop a mental health problem during their lifetime, and NAS surveys found that around a third of autistic adults have a serious mental illness. This is often because of, or exacerbated by, a lack of (timely) support. Our research into the *Transforming Care* programme also found that an increasing number of autistic adults are ending up in inpatient mental health hospitals – particularly those without a learning disability. Improved guidance on how to adapt mental health interventions would assist clinical professionals in tailoring therapies and avoid many mental health problems developing further.	Thank you for your comments about adaptation of mental health services for autistic people. Mental health services are already within the scope of this guideline. Thank you for sharing your research. Unfortunately, the link did not work but I think you are referring to Beyond Transforming Care What needs to change? (December 2018). This reports that data from the NHS Digital Assuring Transformation dataset shows an increase in the number of autistic people receiving mental health inpatient care between 2015 and 2018. During this surveillance review we identified two initiatives from the NHS long-term plan (see surveillance proposal document p. 22) that were relevant to inpatient mental health 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. Thank you for highlighting your findings about how mental health services can be amended including better training for therapists, shared decision making and being clear about what therapy will look like and making appropriate amendments. We think these issues are already covered by existing CG142 recommendations and we did not find any evidence to indicate that they should be amended. For

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	Developing local pathways that ensure access for specific groups, e.g. women and minority groups is considered in 1.8.3. When assessing for autism, the guideline also needs to consider the variation in profiles of autism as a result of the intersectionality with gender and ethnicity. 1.2.7 needs to include an assessment of ethnicity, cultural and gender factors and how these need to be considered within the context of the assessment and feedback.	Feedback the NAS has received about how mental health services could better support autistic people includes: more training for therapists in understanding autism, involving autistic people in the referral process, making sure autistic people are clear about what therapy will look like and what will be asked, understanding the barriers that initial assessments can pose (including the anxiety meeting a new person and describing feelings can pose), adjusting the pace and structure of sessions (including CBT) and adjusting to sensory needs. Adjustments and considerations such as these could be explicitly referred to in the guideline. As an example of a service which is working to ensure its mental health services support autistic people, Tees, Esk and Wear Valleys NHS Foundation Trust has a 'Trust-wide Autism Strategy' which has been implemented since 2016 in Adult services. Recently, this has been transferred to CAMHS and Inpatients settings in the Trust too. This includes, but is not limited to; the need for staff training in the understanding of autism, the need for clinicians to have practical skills in making reasonable adjustments and the need to understand environmental issues. The Trust is also flexible about where autistic people can wait before appointments and provides regular supervision and support to clinicians to ensure that people are not discharged if they do not engage in a phone conversation. We also believe that the guideline would benefit from reflecting the work of NHS England and NHS Wales.	example, recommendations 1.1.1 and 1.1.2 recommend that all staff that work with autistic people should work in partnership, build non-judgemental empathic relationships, and have an understanding of the course and nature of autism. Recommendation 1.6.3 recommends adaptations to the method of delivery of cognitive and behavioural interventions for adults with autism and coexisting common mental disorders, e.g., a more concrete structured approach, avoidance of metaphor and hypothetical situations, plain language, making rules explicit and explaining context, involving family, use of supporting documents like visual aids and workbooks. Recommendation 1.3.2 recommends that when discussing and deciding on care and interventions with adults with autism, to take into account the increased propensity for elevated anxiety about decision-making in people with autism. Thank you for your comments about Tees, Esk and Wear Valleys NHS Foundation Trust's mental health services for autistic people. Tees, Esk and Wear Foundation Trust could consider submitting details of the service to NICE's endorsement team for consideration as a potential implementation resource (more information about endorsement and how to submit can be found on NICE's endorsement page) or as an example of shared learning (see Submit shared learning example). Thank you for your comments about recommendation 1.8.3 which recommends developing and promoting care pathways to a number of potentially marginalised groups. The recommendation does not suggest that the populations in the groups listed are mutually exclusive. These recommendations should be implemented to take

		Currently, there is ongoing work around diagnosis, post-diagnosis and mental health. NICE should link up with teams in NHS England and NHS Wales to ensure that all guidelines and practice reflect each other.	account of the heterogeneity and potential intersectionality of the groups listed. Thank you for your comments about recommendation 1.2.7 which recommends assessing various factors during a comprehensive assessment that may indicate a person is autistic. Recommendation 1.8.3 recommends developing and promoting care pathways to a number of potentially marginalised group including women and people from black and minority ethnic groups. Thank you for your comments about NHS England NHS Wales. We have been in touch with NHS England who have highlighted ongoing work, for example, the Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD) that we plan to monitor and assess for impact when they publish. NHS England and patient groups also highlighted the SHAPE study which 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 have also responded as stakeholders to this consultation and we have considered their responses fully.
Royal College of Psychiatrists		Consideration regarding borderline personality disorder and re-diagnosis as ASD as an adult. How to tell the difference.	Thank you for your comments. NICE has produced borderline personality disorder (NICE guideline CG78) that includes recommendations about borderline personality disorder and learning disabilities in section 1.1.2.
Help for Psychology	There are problems of implementation which we feel	Through my work on the Children Commissioner's strategic oversight board and referrals from NHS England and for complex cases from Norfolk CC, I see the very significant problems of failing to assess both adults and children in an	Thank you for your comments. We are aware of implementation issues, which have been highlighted in the surveillance review and from responses to this consultation.

	NICE also needs to address	accurate and timely fashion. Guidance isn't being implemented, and I continue to press for these standards to be met. Lives can be ruined because of failures to provide appropriate support. This is especially the case for those with the PDA profile, who can require adapted management strategies. In addition, we regularly see parents accused of Fabricated and Induced Illness because their own or their child's ASD has not been properly understood. Second, There is clinical evidence of the benefit of trauma-informed and formulation-driven approaches providing the best support. I see that the hybrid approach of 'diagnostic formulation' is the right one – reporting on individual needs and strengths, while also using diagnostic criteria- but I have concerns that output from professionals is very variable. For example, Adult Psychiatrists find it especially difficult to work in this new way given their training. Consideration of standards and consistency in practice is essential. And as the Guidance has not been a driver of improvements, perhaps it needs to be reflective of the available opportunities on the ground - the lack of specialists available and lack of resource to train and employ more.	The recommendations are based on the best available evidence and expertise of service users and specialists who work to support people with autism. We did not identify any evidence that the guidelines act to cause implementation issues. We identified several government initiatives including a review of the 2014 Autism Strategy with a public consultation calling for evidence in Spring 2019. The revised strategy is expected to support the NHS Long Term Plan (which notes 'Across the NHS, we will do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives' (NHS Long Term Plan page 41, 2.31). We will monitor the autism strategic review and asses its impact on publication. Thank you for your comments about pathological demand avoidance (PDA). 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. Thank you for your comments about trauma-informed and formulation-driven approaches. We did not find any evidence about these approaches during surveillance. If you have any evidence from

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			systematic reviews, randomised controlled trials or diagnostic studies that you could share with us that would be helpful.
PDA Society	Given that there is a significant problem with **implementation** of existing guidance, can additional and updated 'tools and resources' be provided? The report describes an inadequate Government response to issues of capacity and highlighting of 'lack of training and competency by healthcare	Information on good implementation of the needs and strengths assessment process in relation to issues such as 'demand avoidance', co-morbid 'eating disorders', 'assessment in inpatient units' and 'masking' should help to improve practice. 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	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. We will share your 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.

	staff and specialists' Need for assessments to be integrated	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 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. 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?	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 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 the provision of training to staff. Thank you for your comments about borderline personality disorder. All of the guidelines advocate the involvement of multidisciplinary teams with appropriate training to ensure a correct diagnosis. NICE also has produced Borderline personality disorder: recognition and management CG78.

	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. 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.	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 in NICE guideline CG128, for 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 diagnostic services. In NICE guideline CG142, for 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 (NICE guideline CG170) 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 can be found here: Diagnosis in children (CG128) Management in children (CG170) Diagnosis and management in adults (CG142)
Sussex Partnership Foundation Trust		EBEs & Co-production very important. Neurodivergent clinicians and EBE input provides a better service as there is a greater depth of understanding of individuals experiences.	Thank you for your comments about co-production expert by experience (EBE) input and neurodivergent clinicians. CG142 recommendation 1.1.1 recommends all staff working with adults with autism should work in partnership with adults with autism and, where appropriate, with their families, partners and carers.

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		Consideration of interoception differences need to be highlighted in guidance. ADIE project in process. Profs Garfinkel, Critchley University of Sussex. https://doi.org/10.1186/ISRCTN14848787 The way in which a diagnosis is given to someone and the nature of post-diagnosis support is important in helping an individual to understand their strengths and to be able to articulate the reasonable adjustments that are required for an individual to participate in life as they would hope. We have been using an autism care plan to elicit specific individualised reasonable adjustments A diagnosis given in a negative way can impact on an individual if they do not have an understanding of Neurodiversity rather than a deficits based model. Safeguarding issues Consideration of higher risk of exploitation, radicalisation, neglect. Can be linked to mental capacity issues and need for information to be presented in the right way to support understanding and decision making.	Recommendation 1.1.14 recommends specialist multidisciplinary autism teams should have responsibility for diagnosis and care and for training other health and social care practitioners. Thank you for highlighting ADIE to prevent development of anxiety disorders in autism. We identified this during surveillance. We will track its progress and assess its impact on publication of results. Thank you for your comments about post-diagnostic support and autism care plans. Recommendation 1.2.6 recommends at the beginning of a comprehensive assessment, discuss with the person the purpose of the assessment and how the outcome of the assessment will be fed back to them. Recommendation 1.2.18 recommends offering all adults who have received a diagnosis of autism (irrespective of whether they need or have refused further care and support) a follow-up appointment to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require. Thank you for your comments about consideration of higher risk of exploitation, radicalisation, neglect and the link to mental capacity. Recommendation 1.1.2 recommends during assessment to assess the risk of abuse or exploitation by others. Recommendation 1.1.15 recommends discussing with autistic adults if and how they want their families, partners or carers to be involved in their care, and to take into account any implications of the Mental Capacity Act (2005). The Act is cross referred to from this recommendation.

Autistica, the UK's autism research charity	Yes. We cannot develop a substantive response to this question in the time available, however, we are concerned about the scope and structure of the existing guidance.	We cannot develop a substantive response to this question in the time available. However, as per our earlier comments, we are concerned that the guidance does not reflect the range (and relative frequency of) the many difference causes of ability and disability among autistic adults (as described in work like the ICF core sets for autism). As a result, CG142 fails to guide (and potentially discourages) public service providers and commissioners in intervening to support those issues. NICE should be playing a leading role in ensuring those needs are recognised by public services and that there is clarity over the evidenced interventions available to meet them. Within many issues, there may not be interventions with robust evidence of feasibility, acceptability and effectiveness/efficacy available; however, recognising and signalling that lack would be immensely valuable in dissuading bad practice and in stimulating research on those topics.	Thank you for your comments about the timescale of the consultation. 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). Thank you for your comments about the range of frequency of the many different causes of ability and disability. We thank you for drawing to our attention to the ICF core sets, but we did not find any relevant evidence that met the inclusion criteria and would impact recommendations (i.e. from systematic reviews, randomised controlled trials or diagnostic studies). NICE's role is to produce evidence-based recommendations and we cannot do that if the evidence is not available. We signal lack of evidence by making research recommendations. For CG142 they can be seen on the research recommendations page. We will add the ICF core sets to our issues log for autism in order to flag that evidence for the use of these core sets should be explicitly looked for when the autism guidance is next reviewed.
Takeda UK Ltd	Yes	Screening for common comorbidities as part of assessment: We would suggest that consideration is given to adding specific advice on *screening* for Attention-deficit/hyperactivity disorder (ADHD) within the autism guidance. This is based upon the high levels of comorbid	Thank you for your comments about ADHD and for describing the findings of studies about the prevalence of ADHD in autistic children and adults. NICE guideline CG142 already recommends considering an assessment for possible autism when a person has a history of ADHD (see recommendation 1.2.2). While this implies that ADHD has been identified prior to referral, the guideline does

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		ADHD and autism, and the benefits of screening at the earliest opportunity. As you will be aware, in clinical settings, studies involving children with autism report a co-occurrence with ADHD ranging between 53-78% (Lee & Ousley, 2007; Sinzig et al, 2009). In community samples of children, the co-occurrence has been between 28–31% (Leyfer et al, 2006; Simonoff et al, 2008). In adults with autism, ADHD has been found to present in 30-45% of autistic adults who do not have an intellectual disability (Polderman et al., 2014). Given these high levels we concur with the current autism guidance on considering ADHD during the diagnostic assessment. However, there are benefits to earlier screening in the pathway, eg screening by a GP at point of referral or by an autism service on receipt of referral, rather than waiting until an assessment has commenced. Firstly, where autism and assessments are delivered by separate services/clinics, earlier identification of the potential presence of ADHD would enable referrals to be made to both the autism and ADHD pathways, avoiding the delay if they were considered sequentially. Secondly, where ADHD and autism are assessed within the same service, screening prior to assessment would potentially enable both autism and ADHD to be considered as part of the same diagnostic assessment appointments. This would avoid individuals and their families going through two separate assessments, and the duplication of evidence gathering and prolongation of the assessment	not preclude screening for ADHD by a GP at the point of referral to a specialist autism team. Where a diagnosis of ADHD is made, practitioners would be expected to also refer to NICE guidance on Attention hyperactivity disorder (NICE guideline NG87) which makes several recommendations about recognition and referral. For example, recommendation 1.2.1 says 'Be aware that people in the following groups may have increased prevalence of ADHD compared with the general population: … people with neurodevelopmental disorders (for example, autism'). Additionally, recommendation 1.2.5 recommends that referral from the community to secondary care may involve a number of different actors and the person making the referral to secondary care should inform the child or young person's GP. Additionally, recommendation 1.2.6 recommends when a child or young person presents in primary care with behavioural and/or attention problems suggestive of ADHD, primary care practitioners should determine the severity of the problems and if they persist refer to secondary care for assessment (recommendation 1.2.7). It should be noted that the papers you have highlighted are out of scope for this surveillance review because they all predate the surveillance search period (published from January 2016) and are not systematic reviews, randomised controlled trials or diagnostic studies.

		that could entail. This would enable smoother, quicker, and therefore potentially more cost-effective services. Lastly, earlier identification of potential comorbidities would allow individuals and their families to be provided with information on all potential conditions. This could enable them to be more fully engaged and informed about the assessment process. In addition, they may be able to find resources and support that would allow them to potentially reduce the impairment from their presenting difficulties. For example, where they can identify traits of behaviours suggestive of ADHD symptoms, they may be able to engage with support groups or make environmental modifications to reduce their symptoms/impairments whilst they await an assessment. References Lee DO, & Ousley OY. Attention-deficit hyperactivity disorder symptoms in a clinic sample of children and adolescents with pervasive developmental disorders. J Child Adolescent Psychopharmacol. 2007;16(6):737–46. Leyfer OT, Folstein SE, Bacalman S, Davis NO, Dinh E, Morgan J, et al. Comorbid psychiatric disorders in children with autism: interview development and rates of disorders. J Autism Dev Disord. 2006;36(7):849–61. Polderman, TJC, Hoekstra RA, Posthuma D and Larsson H (2014) The co-occurrence of autistic and ADHD dimensions in adults: an etiological study in 17770 twins. Translational Psychiatry, 4: e435. Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism	

		spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. J Am Acad Child Adolesc Psychiatry. 2008;47(8):921–9. Sinzig J, Walter D, Doepfner M. Attention deficit/hyperactivity disorder in children and adolescents with autism spectrum disorder: symptom or syndrome? J Atten Disord. 2009;13(2):117–26.	

5. Do you have any comments on equalities issues?

Stakeholder	Overall response	Comments	NICE response
False Allegations Support Organisation	Yes	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 autistic children and adults, their families and healthcare professionals. The primary objectives are to help these groups with recognising, diagnosing and managing autism spectrum disorder. The recommendations are based on the best available evidence and should assist with robust diagnostic processes. However, the role of those involved in the justice system who may come into contact with autistic people is outside of the scope of this guideline. National recommendations for the police and courts, for example, for how to ensure people with neurodevelopmental conditions are not discriminated against will be produced the remit by of organisations that support the justice system, e.g. The Ministry of Justice. 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.

Surrey and Borders Partnership NHS Foundation Trust		Use of melatonin in adults - whilst evidence not there in adults it does not stop in post 19 and that we support it.	Thank you for your comments. We did not find evidence about the use of melatonin in autistic adults with insomnia. The BNF notes 'Melatonin is used for insomnia in patients with learning disabilities but is not licensed for this indication.'
Autistic UK		Comment relating to gender equality issue within the guidelines: GENDER: p. 77 Surveillance – Despite stating that recommendations do not differ by sex (and we agree that autism isn't gendered) women are more likely to have an a-typical presentation of autism, particularly due to masking, which needs to be added to the guidance. The Lorna Wing centre is specifically set up as a female diagnostic centre for this reason, and evidence states that DISCO is more able to assess a-typical (often related to female) autism presentations. This point also stands for the under 19s recognition document. Comment relating to gender equality issue within the guidelines: GENDER: p. 78 Surveillance – The most commonly used diagnostic tools (including AQ50) are not designed to spot repetitive and restrictive behaviour in girls. The tools mention elements which relate to male socialisation (cars, numberplates, trains). These issues also extend to the trans community and a-typically presenting boys. The guidance needs to be updated to advise that other tools such as DISCO should be used.	Thank you for your comments and for highlighting Diagnostic Interview for Social and Communication Disorders framework (DISCO). DISCO is recommended in CG142 recommendation 1.2.9 which recommends using a formal assessment tool to organise and structure the process of a more complex assessment, such as DISCO, but also refers to other tools: the ADOS-G or the ADI-R. We did not identify any evidence during surveillance that DISCO is specifically more effective with women and girls. Additionally, recommendation 1.2.8 lists various tools as options for diagnosis. Thank you for your comments about autistic women. The use of the word 'emotional' is taken directly from a study that was identified during the surveillance review (p.78) that reports: compared with boys (n=106), girls with autism (n=24) are less likely to have repetitive and restricted behaviour (OR 0.41, 95% CI 0.18 to 0.92, p=0.03), and are more likely to have emotional and behavioural problems as reported by parents (OR 2.44, 95% CI 1.13 to 5.29, p=0.02). We will clarify in the report that this is a parent-reported measure. It might be helpful to know that NICE has produced guidance on borderline personality disorder (NICE guideline CG78) which includes recommendations about BPD and learning disabilities.

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		Comment relating to gender equality issue within the guidelines: GENDER: p. 78 Surveillance – Suggesting that female Autistics are more 'emotional' is medical misogyny. This conflation between emotional women and being Autistic often leads to a misdiagnosis of Borderline Personality Disorder. This point also stands for the under 19s recognition document. Autism Research Trust (ND) Are autistic people being misdiagnosed with Borderline Personality Disorder? on Autism Research Trust [Online] https://www.autismresearchtrust.org/news/borderline-personality-disorder-or-autism (Accessed 04/11/20) Dudas, R. Lovejoy, C., Cassidy, S., Allison, C., Smith, P., & Baron-Cohen, S. (2017) The overlap between autistic spectrum conditions and borderline personality disorder in Plos One [Online] https://doi.org/10.1371/journal.pone.0184447 (Accessed 04/11/20) Comment relating to ableism equality issue within the guidelines: ABLEISM: p. 100 Surveillance – Stating that 'without an improvement of symptoms, it is unclear how the improvement in quality of life was achieved' is ableist and insulting to the Autistic community. Autistic people are absolutely able to have a good quality of life while still being (and presenting as) Autistic. Feedback informed treatment works in a similar way to co-production and is a	Thank you for sharing the paper by Dudas et al. 2017. This is however out of scope for this surveillance review which only considered systematic reviews, randomised controlled trials and diagnostic studies. Thank you for your comments about 'ableism' and 'symptoms'. The term 'symptoms' is taken from a study that uses quality of life and 'symptom severity' as outcomes. It notes a very small increase in quality of life but 'no additional effects were observed for symptom severity decrease [$F\,(2{,}158) = 0.19$, $p = 0.825$].' The study authors conclude 'Adding FIT (feedback informed treatment) in a child psychiatric setting may increase QoL but does not appear to decrease symptom severity as compared with CAU (care as usual). It is suggested that FIT positively changes parents' expectations. Results should be replicated in other child psychiatric samples and with an extended theoretical model'. Thank you for highlighting this issue, we will amend the conclusion in the surveillance report to more fully reflect the study conclusions. Thank you for your comments on accessibility of the guidelines and language used. Information for the public based on all 3 guidelines are available for CG142, CG128 and CG170. NICE endeavour to make their products as accessible as possible. The accessibility page gives more details about how to provide feedback about accessibility issues. If there are other uses of language used within NICE guidelines on autism that are considered damaging to the mental health of autistic people, we would like to be informed of this so that we can consider

		good way of improving trust in therapeutic relationships. This is crucial for a community which has been failed so regularly by unsuitable mental health services and therapies which do not consider Autistic experience. This point stands for all documents. Comment relating to ableism equality issue within the guidelines: ABLEISM: All documents provide accessibility issues for those who also have learning difficulties/disabilities as they are difficult to read and are presented academically – easy read versions and plain English versions should be available. Comment relating to ableism equality issue within the guidelines: ABLEISM: All documents (and those received from services) and discourse surrounding autism are damaging to the mental health of Autistics due to the language used and the way our experiences are described. We have pointed some of these examples out in this consultation response, however, these examples are not the limit of our findings.	what changes could be made. Details of how NICE uses and considers the importance of language are also provided on the NICE language page and style guide.
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	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,

		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.	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 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

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			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	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

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		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.	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 increased risk of premature mortality.	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 may face. We would be happy to discuss these further with you.	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 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.
Royal College of Psychiatrists		Recognition in women.	Thank you for your comment. CG142 recognises issues with diagnosis and care of autistic females and makes recommendation 1.8.3 which recommends the autism strategy group should develop local care pathways that promote access to services for all adults with autism, including women.
PDA Society	More needs to be done	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.	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.

		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)	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.
Sussex Partnership Foundation Trust	Female autism as above must not be missed from accessing a diagnosis. More in guidance re reasonable adjustments to promote equal access to	Misdiagnosis – especially with EUPD and misunderstanding of this can lead to increasingly restrictive inpatient environments which create a vicious cycle.	Thank you for your comment about female autism. CG142 recognises issues with diagnosis and care of autistic females: recommendation 1.8.3 recommends that the autism strategy group should develop local care pathways that promote access to services for all adults with autism, including women. Thank you for your comments about having more recommendations about adjustments to enable equal access to healthcare. Recommendation 1.2.1 recommends staff who have responsibility for the identification or assessment of adults with autism should adapt procedures, if necessary, to ensure their effective delivery, including modifications to the setting in which assessment is

	healthcare. Evidence of poorer health outcomes due to access and lack of reasonable adjustments/understanding.		delivered. NICE has a commitment to equality as described in NICE equality scheme and CG142 has undergone a full equalities impact assessment which includes consideration of access to healthcare interventions. Thank you for your comments about misdiagnosis and emotionally unstable personality disorder (EUPD). CG142 recommendation 1.2.7 recommends that a comprehensive assessment should consider behavioural problems and past and current physical and mental disorders. Recommendation 1.2.8 recommends specific instruments to support a more complex diagnosis.
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 about the timescale of the consultation. 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');
Healthwatch Calderdale	Yes	There needs to be a greater understanding that women and girls with autism can present in a very different way males. Therefore, assessment and diagnosis need to take into account a much higher likelihood that females with autism will use camouflaging and masking strategies as their way to cope. Some diagnostic services don't appear to take this into account.	Thank you for your comments about underdiagnosis in women and girls. 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

		There are specific tools that can be used to help diagnose females use masking and camouflaging strategies, such as the Camouflaging Autistic Traits Questionnaire (CAT-Q). While GPs can't be expected to have an up-to-date knowledge about this, I would expect any diagnostic services to take this into account and to use appropriate tools to help diagnose females who are on spectrum.	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'. Autism in adults (CG142) recommendation 1.8.3 recommends that local autism strategy groups should develop pathways specifically for women. We did not identify any evidence reporting on the predictive accuracy of the Camouflaging Autistic Traits Questionnaire (CAT-Q) for autism in either women or men. Please let us know if you are aware of any diagnostic studies published since 27 January 2016 on the CAT-Q.

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
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.	Thank you for your comments. We appreciate that this is a difficult time. 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 comment on the interface with other services but it does not include recommendations relating to services provided by these agencies,

		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.	except relating to care provided in those settings by healthcare professionals funded by the NHS. Therefore, we are unable make recommendations about the Ministry of Justice.
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 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	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 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 making choices about your care'. 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

		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 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)	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. 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

		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)	(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	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

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		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.	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.
Rotherham Doncaster and South Humber NHS Foundation Trust	Require guidance for using telephone and virtual technology.	Currently there is limited guidance for assessing and diagnosing individuals when face to face contact is not possible for observing individuals, therefore causing further increased waiting times.	Thank you for your comments we will share them with NICE's COVID-19 team. We have received similar comments about the use of virtual assessments and consultations.
Royal College of Nursing	Yes	• 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.	Thank you for your comments; however we are not sure if these refer to getting a diagnosis of COVID-19 or autism; or access to services for addressing the needs of autistic people with or without COVID-19.
British Association of Social Workers (BASW) – England		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 desensitisation through the rather unpleasant swab test, as well as support to adjust and accept social distancing'.	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. 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

		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'.	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 adjustments to ensure any barriers to diagnosis and	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. 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.	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 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

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	provision of appropriate support caused by Covid 19 are removed.	Research by the National Autistic Society has found the negative impact of Covid 19 has been felt most strongly by those with higher support needs, autistic women and non-binary people. https://www.autism.org.uk/what-we-do/news/coronavirus-report#:~:text=We%20found%20that%3A,**%20(comparisons%20using%20ONS%20data) An additional focus should be included in the guidelines to make sure appropriate support is in place for these groups of individuals, especially as Covid 19 restrictions are likely to continue for a long time.	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. Thank you for sharing the National Autistic Society's research. Left stranded: The impact of coronavirus on autistic people and their families in the UK 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 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.
National Autistic Society	The current COVID-19 pandemic has left many autistic people and their families without access to education, occupational and	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.

	speech therapy, mental health and social care support. This is particularly relevant to mental health, which should be a key consideration for the guideline.		We are aware of the impact 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.	Thank you for your comments. We have received similar comments on the use of digital technologies during the pandemic from other stakeholders and will share these with NICE's COVID-19 team.
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. Confidentiality can be an issue with people working from home. The key would be to continue to offer options. 2. Due to sensory issues a lot of autistic people are unable to wear masks, as they are already stigmatised, victimised and bullied, this could increase risks to autistic people which has detrimental effects on autistic people's mental health.	Thank you for your comments. It might be helpful to know that NHS England have produced Managing capacity and demand within inpatient and community mental health, learning disability and autism services for all ages which contains some information about remote consultations. Thank you for your comments about autistic people with sensory issues and COVID-19. 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.
PDA Society	Not sure	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	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.

		implemented in many areas anyhow, trying to identify the possibility of flexibility that could be adopted in times of crisis is probably meaningless.	
Sussex Partnership Foundation Trust	Virtual appointments can be a reasonable adjustment over a face to face appointment	We have successfully moved to majority virtual diagnostic appointments for adults and this has made the process less stressful for many individuals.	Thank you for your comments on being able to move to virtual diagnostic appointment.
Autistica, the UK's autism research charity	Yes, there are lasting issues from the pandemic that CG142 should address.	The evidence available on the impact of the pandemic on autistic adults has obviously been limited by the timeframes it has been around, as well as the impact of COVID-19 on the sectors ability to fund and run research projects. However, the evidence that is available strongly suggests that COVID-19 (and the necessary public health measures to contain it) will have a serious and disproportionate impact on autistic adults mental health and employment status. www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Impact-of-COVID-19-on-autistic-people.pdf The impact of poor mental health and employment difficulties on autistic people will persist long beyond the end of the pandemic. Currently CG142 provides little guidance for clinicians and public services on how practically to identify and address those issues.	Thank you for your comments and sharing your action briefing which includes several research recommendations including investigating: the impact of emergency changes on autistic people's mental health; the acceptability of digital assessment, treatment and care amongst neurodivergent people and across different platforms; and development of effective neurodevelopmental and mental health service models that can vary capacity in response to lockdowns and changes in national public health guidance. 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 note your comment about Department of Health and Social Care (DHSC) commissioned research about the impact of COVID-19 on autistic people. We will contact them for more information as suggested.

		For reference, the Department of Health and Social Care (DHSC) has commissioned ongoing research, led by the London School of Economics, about the impact of COVID-19 on autistic people. NICE should approach the DHSC for the findings of that research.	
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 will share these issues and your comments related to autism services with NICE's COVID-19 team.

7. Additional comments

Stakeholder	Overall response	Comments	NICE response
Autistica		Additional comment from Autistica There are three particular points I want to highlight from our response: We strongly recommend that NICE urgently discusses the risks of not updating it's Autism Guidance with NHS England's Autism Team. We are concerned that critical context was missing for the surveillance review, and that the decision not to update the guidance could result in a damaging disconnect between NICE and NHS England's work.	Thank you for your comments. We had contact with representatives of NHS England and NHS Improvement (NHSE&I) early in the surveillance review 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. 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

		We are not confident that the surveillance proposal's conclusions accurately reflect the evidence base. 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.	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 concluded that these did not have an impact on the 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. 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.

Further Comments:

Asperger's Voice

Asperger's Voice is a registered stakeholder but given the extremely short timescale and the complexity of the information involved in this consultation only one of our members (who are all people with Asperger's) has been able to comment on any of the guidelines and he only had the time to look at and comment on the Introduction to the guidelines. As he has taken the time to review an aspect of the guidelines I hope you will be able to include it in responses, even though I cannot readily fit it into the form provided. His comment is copied below:

" I was struck by the Introduction to the Guidance. This refers to the 'persistent difficulties' that those on the ASD spectrum have to deal with, which is indeed correct. But the whole of the Introduction follows on from this, in that it highlights and emphasises difficulties and problems - it's all down-sides. There is no reference to any up-side.

There is no reference that I can find to any of the positive aspects that those on the ASD spectrum may have because we look at, and experience, the world differently from those not on the spectrum. For example, we can solve problems in ways not available to others through our ability to see patterns and connections that others can't; our senses can work in different ways to others, allowing us to experience and interpret the natural world or arts and crafts differently from others; the attention to detail that some of us have can provide intricate and important detail that others may miss. The list is endless.

I realise that the purpose of NICE is to provide health and medical practitioners with guidance to help them help others improve their health and wellbeing, so it is bound to focus on such interventions. But the tone of the Introduction is that those on the ASD spectrum are problematic and live lives that are all, and always, challenging. Whilst this may be true for some, it is not true for all, and I think that the Introduction needs to be better balanced in also making reference to up-sides, emphasising that life on the ASD spectrum is about **difference** as well as about **disability**.

On a less important point, the last paragraph of the Introduction refers to prescribers and drugs. It seems a strange place to have this paragraph, which bears no relation to what has gone before. But it is also strange that such a paragraph makes no mention of other non-drug therapies which may be prescribed. I think that, if this paragraph is needed, it should be a footnote to some other detailed part of the document."

Response

Thank you for your comments about the timescale of the consultation. 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.

Thank you for your comments about the introduction section of the guideline, however this section is not considered as part of the surveillance review. Surveillance reviews only focus on the content of recommendations and whether these require updating or remain current. The introduction attempts to outline reasons why autistic adults might need support from health and social care services. The guidelines themselves specify that health and social care staff have an understanding of the nature and development of autism and work with autistic people (recommendation 1.1.2). The paragraph about prescribing is contained within all NICE guidelines to ensure patient safety and to make prescribers aware that the guidelines do not preclude clinical judgement.

Institute for Food, Brain and Behaviour

Nutrition & Autism

The apparent prevalence of autism has increased 50 fold in the last 75 years. Most people agree that this is largely due to widening of the diagnostic criteria to include milder cases together with the profound social changes that have reduced stigma and increased public knowledge of its characteristics. But even allowing for these changes it is probable that the underlying 'true' prevalence has also increased. The heritability of autism is c. 50% and its genetic background is unlikely to have changed over such an evolutionarily short period. This leaves a substantial role for environmental influences to be causing the increase in prevalence, and there is some evidence that it is the interaction between these and the genes that is the main contributor. Of all the changes in the human environment that have occurred over the last 75 years in the West the largest likely to affect the developing brain are probably dietary. Yet the only references to nutrients in current NICE guidance are negative: in CG142 section 1.4.15 the advice is 'do not use dietary supplements', despite a large literature suggesting that dietary improvements can help manage autism and in section 1.6.3 'Do not use omega-3 fatty acids to manage sleep problems in children and young people with autism' as if there were some special risk of all omega 3s (alpha-linolenic, eicosatetraenoic, eicosapentaenoic. docosapentaenoic and docosahexaenoic acids) causing problems with sleep, for which there is absolutely no evidence at all.

Instead there is a growing evidence base, exemplified by some recent publications shown below, indicating that autism is associated with nutrient deficiencies whose correction may be helpful. This is particularly relevant because so many autistic children have very difficult dietary habits and preferences, such that nutrient deficiencies are relatively common. The deficiencies are unfortunately found not only in the children but often established prior to birth in their mothers, where they probably contributed to their child's maldevelopment. The strongest evidence for nutrient deficiencies affecting autism concerns the 1 Carbon metabolic pathways (folate, vitamin B12, cysteine, homocysteine and

DNA methylation) together with recently discovered roles for the Omega 3 fatty acids and Vitamin D in these. We would therefore like to draw your attention to four papers in particular.

Fraguas et al. (2019) carried out a meta-analysis of 27 randomised control trials that assessed the efficacy of nutrient supplements for improving autism symptoms. These compared placebo with Omega-3 polyunsaturated fatty acids (a-linolenic acid, eicosapentaenoic acid, docosahexaenoic acid, or a combination of them) and vitamins (B6, B9 (folic acid), B12, C, D) and showed that either or both together were significantly superior to placebo. Effect sizes were moderate (1/2 standard deviation, Hedges' g c.0.5) for anxiety-affect, behavioral problems and impulsivity, and small (g c.0.3) for core symptoms (social-autistic, stereotypies, restricted and repetitive behaviors). But these compare well with most pharmacological treatments that have never been shown to be effective at all.

Li et al (2019) reviewed 20 articles on ASD. They found that children's risk of ASD was significantly reduced if the mother took folic acid or multivitamin supplements before and during pregnancy with an estimated risk reduction of 46%.

Lee et al (2019) measured Vitamin D in over 4000 mothers and children from the Stockholm Youth Cohort Study. They found that maternal Vit D insufficiency (25 – 49 nmol/L) in the mothers at ~11 weeks gestation was associated with 1.58 times higher odds of Autism Spectrum Disease (ASD) compared with sufficiency (≥50 nmol/L). In the babies Vit D < 25 nmol/L was associated with 1.33 times higher odds of ASD as compared with sufficiency. These results confirm that low Vit D in mothers and babies is indeed a potent risk factor for Autism.

Steenweg et al. (2016) used the Generation R Rotterdam Cohort Study of nearly 10,000 urban mothers and children to determine whether prenatal maternal folate insufficiency, high total homocysteine levels and low vitamin B12 levels are associated with altered brain morphology, and cognitive problems in school-aged children. The imaging sample consisted of 256 Dutch children aged between 6 and 8 years from whom structural brain scans were collected using MRI. The mothers of sixty-two of these children had insufficient (<8 nmol/l) plasma folate concentrations in early pregnancy. These low prenatal folate levels were associated with smaller brain volumes, and poorer performance in language and visuospatial domains. High homocysteine levels (>9·1 µmol/l) also predicted poorer performance in language and visuospatial domains. Thus folate insufficiency in early pregnancy has a long-lasting, global effect on brain development and is, together with homocysteine levels, associated with poorer cognitive performance. Although this study is not specifically addressed to autism, it emphasizes the importance of the one carbon pathways for the development of children's brains.

Refs

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Response

Thank you for your comments and for the overview of some recent studies about dietary supplements and autism. Please note that for this surveillance review, only published evidence from 27 January 2016 to 1 November 2019 from systematic reviews, randomised controlled trials or diagnostic studies were included.

We identified the Fraguas study during surveillance and excluded it because the abstract contained very little data which could be directly related to specific outcomes. The study compares the effects of dietary supplements to placebo in children less than 18 years of age on clinical domains and symptom/functional domains. The study reports dietary supplements including omega-3 and vitamin supplementation were superior to placebo and produced small to moderate effects sizes for a number of outcomes. The authors report a subgroup analysis by location showed the effect of dietary supplements on social-autistic, and stereotypies, restricted and repetitive behaviours and core and associated symptoms remained significant only for studies conducted in the United States, but not in those conducted in Europe. This suggests some of the results may have limited applicability for a UK setting. Also, effects sizes are relative to an inactive placebo and the study does not compare supplements to pharmacological interventions, to use your example. During surveillance we did not find convincing evidence to suggest adding recommendations about dietary supplementation is appropriate. The Fraguas study compares supplements to placebo and reports only moderate to small effects sizes, which is not sufficient to recommend an update of recommendations.

As the Lee study is a retrospective case-control study and the Steenweg-de Graaff study is a cohort study, these do not meet the inclusion criteria for the surveillance review; and the remaining studies you have provided (Ooi et al., Gao et al., Neggers et al. and Schmidt et al.) all predate the surveillance search period.