

Appendix B: Stakeholder consultation comments table

2021 surveillance of [Patient experience in adult NHS services: improving the experience of care for people using adult NHS services \(2012\)](#)

Consultation dates: 21st June 2021 to 2nd July 2021

1. Do you agree with the proposal to not update the guideline?			
Stakeholder	Overall response	Comments	NICE response
Centre for Health and Society, Aston University	No	No, we do not agree with the proposal that the guidelines should not be updated. While the ethos of the guidelines is well-intended, they currently offer no concrete ways to either patients or healthcare professionals to ensure the guidelines are operationalised in practice. This is a significant concern as there exists a body of evidence to show that shared decision-making rarely occurs in practice and that the tailored, individualised adult care the guidelines promote is experienced by patients as ad hoc, dependent on individual trusts and further dependent on the ethos and availability of the individual health care professionals interacting with the patient on any given day (McMullen, 2012; Frongillo et al., 2013;	<p>Thank you for your comments.</p> <p>The NICE guideline CG138 is intended to cover the components of a good patient experience. It aims to make sure that all adults using NHS services have the best possible experience of care.</p> <p>NICE has also published a guideline on shared decision making (NG197) that describes how healthcare professionals can work with people using services to share decisions about care. That guideline was published recently in June 2021. The current review does not cover shared decision-making as that section was replaced by NG197.</p> <p>Both CG138 and NG197 guidelines provide general guideline</p>

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	<p>Mackintosh et al., 2017; Diamond-Brown, 2018; Paton, 2017; Paton, 2018a; Paton, 2018b; Paton, 2019; Paton et al., 2020). As such the guidelines represent an ideal that is not currently experienced consistently by patients across the NHS services.</p> <p>References: Diamond-Brown, L. (2018) "It can be challenging, it can be scary, it can be gratifying": Obstetricians' narratives of negotiating patient choice, clinical experience, and standards of care in decision-making". <i>Social Science and Medicine</i>, 205: 48-54. Frongillo, M., et al. (2013) "Is there shared decision making when the provider makes a recommendation?" <i>Patient Education and Counseling</i>, 90: 69–73. Mackintosh, N. et al. (2017) "Working for patient safety: a qualitative study of women's help-seeking during acute perinatal events". <i>BMC Pregnancy and Childbirth</i>, 17: 232. McMullen, L.M. (2012) "Discourses of Influence and Autonomy in Physicians' Accounts of Treatment Decision Making for Depression". <i>Qualitative Health Research</i>, 22(2): 238–249. Paton, A. (2017) "No Longer Handmaiden: The role of social and sociological theory in bioethics". <i>IJFAB</i>, 10(1), 30-49. Paton, A. (2018)a. "'It's not just about having babies': A socio-bioethical exploration of older women's experiences of making oncofertility decisions in Britain.", in Riesch, H., Emmerich, N. & Wainwright, S. (Eds). <i>Philosophies and Sociologies of Bioethics</i>. Springer. Paton, A. (2018)b. "About time: how time influences and</p>	<p>recommendations that can be applied in every area of healthcare.</p> <p>Implementation of NICE guidelines in local settings is the responsibility of commissioners and service providers. Whilst we recognise that there can be variation in local practices, if the guideline recommendations are implemented it is anticipated that services will be effective and cost effective – and this will help to reduce variation in local practices.</p> <p>NICE also provides quality standards. Patient experience in adult NHS services quality standard [QS15] covers improving the quality of the patient experience for people who use adult NHS services. It describes high-quality care in priority areas for improvement.</p> <p>Thank you for forwarding references to these articles. While they provide insights to patient experience, they would not meet the inclusion criteria of the current review (see the section headed 'overview of 2020 surveillance methods').</p>
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		<p>facilitates patient autonomy in the clinical encounter”, Monash Bioethics Review, 36: 68-85.</p> <p>Paton, A. (2019). “Being Guided”: What oncofertility patients’ decisions can teach us about the efficacy of autonomy, agency and decision-making theory in the contemporary clinical encounter, IJFAB: International Journal of Feminist Approaches to Bioethics, 12(2), 18-35.</p> <p>Paton. A. et al. (2020). Parents’ decision-making following diagnosis of a severe congenital anomaly in pregnancy: Practical, theoretical and ethical tensions. Social Science and Medicine. https://doi.org/10.1016/j.socscimed.2020.113362</p>	
The Challenging Behaviour Foundation	No	<p>It is well known and evidenced that people with learning disabilities experience significant health inequalities and die prematurely of preventable causes, with over 50% of deaths being avoidable as found by LeDeR 2021. Any NICE guidance relevant to providing care and treatment for individuals with learning disabilities which can acknowledge this and ensure improvements are made in access to effective healthcare must do so. This guidance can be significantly improved to include meeting the needs of patients who have a learning disability, expanding on guidelines surrounding meeting healthcare needs, making reasonable adjustments, and effectively communicating with the individual and their family/carers. NHSE has a workstream on this and should provide evidence and suggestions about how it can be improved.</p> <p>P8 1.1.2 Ensure that factors such as physical or learning</p>	<p>Thank you for your comments.</p> <p>The remit for the CG138 guideline is general patient experience in the NHS and the needs of specific groups were not addressed within the development of this guideline. As you note, the guideline does however highlight areas where certain considerations should be taken into account; it also recommends that service providers recognise individuality and the unique way in which each person experiences a condition, services and its impact on their life.</p> <p>When developing the guideline, it was recognised that people with learning disabilities would be key beneficiaries of the NICE guideline CG138, and they may have multiple-morbidities or be socially vulnerable. The guideline covers patient experience for all people who receive healthcare for all adult age groups.</p> <p>In addition, NICE guidelines exist which cover people with learning disabilities: care and support of people growing older with learning disabilities, mental health problems in people with learning</p>

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	<p>disabilities, sight, speech or hearing problems and difficulties with reading, understanding or speaking English are addressed so that the patient is able to participate as fully as possible in consultations and care.</p> <p>Ensuring that people with learning disabilities are able to participate fully in consultations and care may require enhanced provisions around communication needs. While translators and interpreters are provided for people whose primary language is not English, Acute Liaison Learning Disability Nurses and/or family carers often perform this role for people with learning disabilities, ensuring that behavioural presentation and communication needs are taken into account. Stronger recommendations should be introduced for hospitals to have such an individual available to ensure that communication needs for people with learning disabilities are met.</p> <p>There are multiple practical methods to ensure that health needs are communicated and that patients' express preferences are considered in the delivery of care. This can include the use of Health Passports, Communications Passports, and communication aids such as MyComPass</p> <p>1.1.2/1.1.3 Ask the patient about and take into account any factors, such as their domestic, social and work situation and their previous experience of healthcare, that may: • impact on their health condition and/or • affect their ability or willingness to engage with healthcare services and/or affect their ability to manage</p>	<p>disabilities, and challenging behaviour and learning disabilities. These guidelines cover many of the themes outlined in CG138 for these populations. NICE has also published a guideline on shared decision making (NG197) that describes how healthcare professionals can work with people using services to share decisions about care. As is the case with CG138, recommendation 1.1.8 specifies: health and social care practitioners must understand and take into account the Mental Capacity Act 2005 when working with people with learning disabilities. There is a hyper-link between the 2 NICE guidelines to support end-users.</p> <p>The CG138 guideline provides recommendations on patient experience that are relevant to underserved groups to address inequalities in healthcare. The guideline also recommends that healthcare professionals should take into account the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using adult NHS services (recommendation 1.1.6). Additionally, an equality impact assessment was carried out during the development of the guideline. This document confirmed that the recommendations have been developed to promote equalities for all people who receive healthcare within the adult NHS services, irrespective of age, gender, ethnicity, disability, religion or beliefs, sexual orientation and gender identity or socio-economic status.</p> <p>Whilst the NICE guideline CG138 cannot anticipate all people's experience of using NHS services it is intended to cover the components of a good patient experience. It aims to make sure that all adults using NHS services have the best possible experience of care.</p>
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	<p>their own care and make decisions about self management and lifestyle choices.</p> <p>Ensure that a range of ways, according to the patients individual needs and using reasonable adjustments, are utilised to find out about their needs. This will require more methods than asking the individual alone, including involvement of family and carers, employment of communications passports and expressly stated preferences, and support from a Learning Disability Nurse, amongst other methods.</p> <p>It must also be recognised that many people with learning disabilities, autistic people, and their families have had negative experiences of hospital, inpatient and other healthcare settings/services, and may have been traumatised by these experiences. Delivery of healthcare services must be sensitive to this factor and in particular to the risks of re-traumatising an individual, as is noted in CQC's 'Out of Sight – Who Cares?' report.</p> <p>P9 1.1.6 Take into account the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using adult NHS services</p> <p>Families in contact with CBF regularly report that the Equalities Act is not universally upheld in hospitals – necessary reasonable adjustments are not made (either as families are not aware of how to request them, as there is no available Learning Disability Nurse to co-ordinate them, or they are simply not adhered to)</p>	
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		<p>P11 – 1.2.8 If a patient is unable to manage their own pain relief: • do not assume that pain relief is adequate • ask them regularly about pain • assess pain using a pain scale if necessary (for example, on a scale of 1 to 10) • provide pain relief and adjust as needed.</p> <p>Make adjustments according to the individual. Many people with learning disabilities are unable to indicate pain or pain levels in the ways suggested. Include specialist assessment tools such as DisDat as example Disability (betterlives.org.uk)</p> <p>The recommendation ‘do not assume that pain relief is adequate’ should be expanded to ‘do not assume that pain relief is adequate or appropriate’. The aims of the STOMP programme should be integrated into relevant guidance such as this to ensure that all involved in care are aware of the issues surrounding overmedication/inappropriate medication of individuals with learning disabilities, which is often done with aims of pain relief, behaviour management or sedation.</p> <p>P11 1.2.9 Ensure that the patient's personal needs (for example, relating to continence, personal hygiene and comfort) are regularly reviewed and addressed. Regularly ask patients who are unable to manage their personal needs what help they need. Address their needs at the time of asking and ensure maximum privacy.</p> <p>People with learning disabilities may be unable to communicate through speech whether their personal</p>	
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		<p>needs are being met. It is important that the recommendations set out in 1.1.1 acknowledge this – the gathering of information should involve finding out what support that will be required to meet a person’s needs, what behavioural presentations may occur when needs are not met, and this information should be shared with all involved in delivering care.</p> <p>P12 1.3.4 Hold discussions in a way that encourages the patient to express their personal needs and preferences for care, treatment, management and self-management. Allow adequate time so that discussions do not feel rushed.</p> <p>Above points on communication are reiterated, with further/different methods of communication needing to be employed if these discussions are to be effective and a patient’s needs and preferences are to be represented.</p> <p>P13 1.3.10 Clarify with the patient at the first point of contact whether and how they would like their partner, family members and/or carers to be involved in key decisions about the management of their condition. Review this regularly. If the patient agrees, share information with their partner, family members and/or carers.</p> <p>1.3.11 If the patient cannot indicate their agreement to share information, ensure that family members and/or carers are kept involved and appropriately informed, but be mindful of any potentially sensitive issues and the duty of confidentiality.</p>	
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		Treatment and support of patients with severe learning disabilities will likely require the involvement of family or paid carers. For this reason, it is necessary to ensure that these family members or support workers are kept informed not only about the patient's condition and treatment, but are also supported to be involved in decisions and provision of support. This may involve providing accessible information and/or support from a Learning Disability Nurse.	
Kent Community Health	No	There are some areas of the guidance which require updating in relation to ensuring that patient experience feedback is gained from all service users and that methods used to not discriminate - only allowing the voices of a few people to be heard	<p>Thank you for your comments.</p> <p>Without clarification of the areas of the guideline and evidence to support an update we are not able to change the guideline.</p> <p>The guideline currently covers patient feedback in recommendations 1.3.12 and 1.3.13.</p> <p>The current surveillance review considered new evidence and intelligence in this area (see appendix A for more details). Overall, the new evidence was consistent with CG138 recommendations which cover different forms of patient feedback. In addition, the guideline clarifies the need to make sure services are equally accessible to, and supportive of, all people using adult NHS services.</p>
2. Do you have any comments on areas excluded from the scope of the guideline?			
Stakeholder	Overall response	Comments	NICE response

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Centre for Health and Society, Aston University	Yes	<p>The guidance needs to better foreground and acknowledge the impact of multimorbidity on individual health care. Multimorbidity is increasingly becoming a normal state of health for the UK population (NIHR, 2018). Perhaps the greatest challenge of multimorbidity to care provision, and therefore an individual's experience of care, can be the polypharmacy and multiple sources of information regarding management and self-care which accompany having multimorbidity. The negative impacts of multimorbidity are also not equally felt within our society, as individuals living in deprived communities, who make up more than 20% of the UK population, are the ones most likely to be living with multimorbidity (King's Fund, 2021). As a result, a significant proportion of adults in NHS care will present or be diagnosed with multimorbidity.</p> <p>The collection of health conditions acquired throughout the life course also has far reaching implications for how contemporary healthcare is organised. Multimorbidity gives rise to multiple sources of clinically relevant information, providing advice on lifestyle changes and healthy behaviours aimed at improving an individual's health. In practice, emerging evidence suggests guidance is often confusing and conflicting, and may lead to suboptimal health for those living with these conditions (Whitty et al., 2020). This provision of contradictory advice is consistent with the confluence of several short and long range factors including: the single-disease framework by which most health care, medical research, and medical education is configured (Barnett et al., 2012); the emphasis on protocol-based care (Ilott et al., 2006); the impact of increased specialisation within</p>	<p>Thank you for your comments.</p> <p>As you acknowledge, multimorbidity is an issue which affects all areas of patient healthcare. As you also acknowledge, this important issue has been addressed in a NICE guideline specifically about multimorbidity (NG56). This guideline covers optimising care for adults with multimorbidity (multiple long-term conditions) by reducing treatment burden (polypharmacy and multiple appointments) and unplanned care. It aims to improve quality of life by promoting shared decisions based on what is important to each person in terms of treatments, health priorities, lifestyle and goals. The guideline sets out which people are most likely to benefit from an approach to care that takes account of multimorbidity, how they can be identified and what the care involves.</p> <p>The multimorbidity (NG56) guideline complements patient experience in adult NHS services, and the 2 guidelines should both inform patient services.</p> <p>We have reviewed the language in NICE guideline CG138 and acknowledge that usually it refers to patient condition (singular). To address your point we will refresh the language within CG138 to mention 'condition (or conditions)', thereby acknowledging multimorbidity is an issue for many patients. We will also include a link from NICE guideline CG138 recommendation 1.1.1 to NICE's guideline on multimorbidity to raise awareness of this other guideline.</p>
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		<p>medicine (Whitty et al., 2020); and the gradual fragmentation of publicly funded health care in the UK (The King's Fund, 2015). These developments entrench the compartmentalisation of disease, which prioritises organ systems over considering how conditions affect the person as a whole (Whitty et al., 2020). In practical terms, patients may find themselves faced with a plethora of health information, coming from different healthcare professionals in separate care sectors, often not working together, nor fully aware of what information and advice has previously been given and taken up (Rosbach and Andersen, 2017).</p> <p>Recent guidance by NICE on the management of multimorbidity (N.I.C.E., 2017) suggests a measure of institutional recognition of the problem, however neither this nor ongoing work educating primary care clinicians about managing multimorbidity (Swancutt et al., 2021), address the impact of historical experiences of disease accumulation, where life events and experiences at the time of each diagnosis may influence a patient's prioritisation of disease and adjustments in their behaviour. This current consultation is an opportunity for NICE to bring these concepts together and explicitly acknowledge the impact of multimorbidity on care and good clinical practice.</p> <p>Recommendation: By including multimorbidity in section 1.1.1, this would formally acknowledge and signal to both healthcare professionals and patients the impact that multimorbidity has on health. 1.1.1 could accomplish this by adding a sentence that makes explicit the need to include cross-</p>	
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	<p>speciality consideration of the effect of multimorbidity on health and wellbeing of the patient, and the need to recognise the relationship between multimorbidity and the “patient as an individual”. This could also include better co-ordination of care or by improved communication or inter-speciality working to support the health needs and objective of individuals. Further, section 1.3.1 provides no guidance on who should be ensuring that all conditions are known and considered when caring for a patient. At present evidence shows that it is in fact patients who are left with the burden of trying to ensure all their healthcare providers are aware of their multiple conditions, not the healthcare professionals themselves as indicated in the guidance (Rosbach and Andersen, 2017).</p> <p>References: Barnett, K., Mercer, S.W., Norbury, M., Watt, G., Wyke, S., and Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. <i>The Lancet</i>, 380(9836): 37-43 Ilott, I., Rick, J., Patterson, M., Turgoose, C., and Lacey, A. (2006). What is protocol-based care? A concept analysis. <i>Journal of Nursing Management</i>, 14(7): 544-552. N.I.C.E. (2017). Multimorbidity and polypharmacy. Available at: https://www.nice.org.uk/advice/ktt18/resources/multimorbidity-and-polypharmacy-pdf-58757959453381 NIHR (2018). Available at: https://evidence.nihr.ac.uk/alert/multi-morbidity-predicted-to-increase-in-the-uk-over-the-next-20-years/</p>	
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		<p>Rosbach and Andersen (2017). Patient-experienced burden of treatment in patients with multimorbidity—A systematic review of qualitative data. PLoS ONE 12(6): e0179916</p> <p>Swancutt, D.R., Jack, E., Neve, H.A., Tredinnick-Rowe, J., Axford, N., and Byng, R. (2021). GP trainee responses to using SHERPA for multimorbidity consultations. Education for Primary Care, DOI: 10.1080/14739879.2021.1888662</p> <p>The King’s Fund. (2015). Available at: https://www.kingsfund.org.uk/projects/verdict/how-far-has-government-gone-towards-integrating-care</p> <p>The King’s Fund (2021). Available at: https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity</p> <p>Whitty, C.J.M., MacEwen, C., Goddard, A., Alderson, D., Marshall, M., Calderwood, C., Atherton, F., McBride, M., Atheron, J., Stokes-Lampard, H., Reid, We., Powis, S., Marx, C. (2020). Rising to the challenge of multimorbidity. BMJ, 368: 16964.</p>	
The Challenging Behaviour Foundation	No	No additional comments	Thank you.
Kent Community Health	Yes	Accessible methods of feedback for all services users and patients to ensure that services understand the patient experience from the population it serves and not from a limited range of patients.	<p>Thank you for your comment.</p> <p>The guideline currently covers patient feedback in recommendations 1.3.12 and 1.3.13. In addition, the guideline clarifies the need to make sure services are equally accessible to, and supportive of, all</p>

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			people using adult NHS services.
3. Do you have any comments on equality issues affecting the guideline or the surveillance review?			
Stakeholder	Overall response	Comments	NICE response
Centre for Health and Society, Aston University	Yes	While section 1.1.6 calls for consideration of the Equalities Act, this does not explicitly lay out how health inequalities are experienced across the patient population, and the impact that deprivation has on health in the UK. Over 20% of the UK population live in poverty (UK Parliament, 2021), therefore are further disadvantaged by structural and economic barriers which reduce their ability to access timely healthcare. In areas of higher social deprivation, the number of health impacted years, where quality and function of life is reduced in some way are often increased. Therefore, this can have the net effect of individuals living shorter and less healthy lives (ONS, 2021). As financial resources limit or facilitate a person's access to services which promote and support healthy aging, the lack of resources in these groups is cause for concern in Britain's rapidly aging population (Hornsten et al., 2004; Christensen et al., 2014). Collectively, these limitations have accumulated through individual lives, and in some cases generations, to create an unequal distribution of wealth and health, resulting in an inequity in healthy (Christensen et al., 2014), with white, well-off, Britons living longer and healthier lives (including living less years with disability) than their poorer, non-white counterparts. Section 1.1.6 must overtly address the role of inequalities in health, so	<p>Thank you for your comments. The issues that you raise concerning health inequalities are relevant to all areas of healthcare and therefore relevant to all NICE guidelines.</p> <p>The CG138 guideline provides recommendations on patient experience that are relevant to underserved groups, and if implemented should support relevant groups and help improve their experience and use of services. As you note, the guideline also recommends that healthcare professionals consider the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using adult NHS services (recommendation 1.1.6). As such, there are overt references to ensuring access to services.</p> <p>Additionally, an equality impact assessment was carried out during the development of the guideline (this is true for all NICE guidelines). This document confirmed that the recommendations have been developed to promote equalities for all people who receive healthcare within the adult NHS services, irrespective of age, gender, ethnicity, disability, religion or beliefs, sexual orientation and gender identity or socio-economic status.</p>

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		<p>as to draw explicit attention to the impact of deprivation on health, which will help fulfil the requirement to consider the “patient as an individual”.</p> <p>References: Christensen, U., Krolner, R., Nilsson, C.J., Lynebye, P.W., Hougaard, C.O., Nygaard, E., Tielen, K., Holstein, B.E., Avlund, K. and Lund, R. (2014). Addressing Social Inequality in Aging by the Danish Occupational Social Class Measurement. <i>Journal of Aging and Health</i>, 26(1): 106-127. Hörnsten, Å., Sandström, H. and Lundman, B. (2004), Personal understandings of illness among people with type 2 diabetes. <i>Journal of Advanced Nursing</i>, 47: 174-182. Office for National Statistics. (2021). Health state life expectancies, UK: 2017 to 2019. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/latest UK Parliament. (2021). Available at: https://researchbriefings.files.parliament.uk/documents/SN07096/SN07096.pdf</p>	
The Challenging Behaviour Foundation	Yes	<p>People with learning disabilities face significant health inequalities and as such are at a great risk of illness or death if health needs are not effectively met. People with learning disabilities have a 27 years younger life expectancy than the general population for women and 23 years for men, while over 50% of deaths of people with learning disabilities that occur are from avoidable</p>	<p>Thank you for your comments.</p> <p>As noted above, the remit for the CG138 guideline is general patient experience in the NHS and the needs of specific groups were not addressed within the development of this guideline. The CG138 guideline provides recommendations on patient experience that are relevant to underserved groups to address inequalities in healthcare.</p>

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		<p>causes. Furthermore, the high rate of co-morbidities place individuals with learning disabilities at high risk of severe illness or death from illnesses less fatal to the general population, with the rate of death from COVID-19 having been 6.2 times higher amongst people with learning disabilities than amongst the general population. It is therefore crucial that all relevant guidance expressly notes the importance of identifying and treating illness, injury or change of condition at an early stage, using methods of care and communication which are appropriate for the individual.</p> <p>As has been mentioned previously in this submission, necessary reasonable adjustments are often not made for individuals with learning disabilities, meaning that healthcare provision in adult NHS services often falls short of the Equality Act. This guidance should include more robust details around making reasonable adjustments in order to better reflect the inequalities and typical experiences which hinder the meeting of healthcare needs for individuals with learning disabilities in adult NHS services. This has been done more effectively in other NICE guidelines, in particular NG96.</p>	<p>The guideline also recommends that healthcare professionals should consider the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using adult NHS services (recommendation 1.1.6).</p> <p>Thank you for acknowledging care and support of people growing older with learning disabilities (NG96). This guideline covers a relatively narrow population, unlike CG138 which covers all adult NHS service users. Both guidelines, nevertheless, require that adjustments are made to accommodate the individuals in line with the Equality Act 2010.</p>
Kent Community Health	Yes	<p>Yes, as above. How do we learn from patients who may not have equitable access to care, and how this affects their experience and outcomes if we do not ensure we hear their voice?</p>	<p>Thank you for your comment.</p> <p>We acknowledge that there are barriers to service access for some groups. The guideline currently covers patient feedback in recommendations 1.3.12 and 1.3.13. Where the recommendations in CG138 are implemented it is anticipated that services will be equally accessible to, and supportive of, all people using adult NHS services.</p>

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