NICE National Institute for Health and Care Excellence

Appendix B: Stakeholder consultation comments table

2021 surveillance of service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services (NICE guideline CG136)

Consultation dates: 17/09/2020 to 30/09/2020

1. Do you agree with the proposal to not update the guideline?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Royal College of Psychiatrists	No	Given the community mental health framework has now been published by NHSE/I – shouldn't that mean that both this guidance and that on service user experience are reviewed in light of that? The framework is not referred to in this consultation document. It contains extensive recommendations that would be relevant to this guideline and necessitate revisions to it. CG 136 and NG 53 are both very broad pieces of guidance and the College feels that the complex psychoses rehabilitation ones shows how narrowing the focus enables improved care.	Thank you for your comments. The framework supports local and regional provider planning to enable providers to realise the NHS long-term plan for community mental health. Both the impact of the NHS Long Term Plan and also the NHS Mental Health Implementation Plan, are considered on p. 11-13 of the consultation document. This notes that these plans were developed in line with NICE guidance and that recommendations in CG136 are consistent with their aims and objectives. It is therefore not considered that the community mental health framework has an impact on the recs. Thank you for your comments on complex psychoses in relation to NICE guidelines CG136 and NG53. the remit NICE received from

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			the Department of Health and Social Care for CG136 was to 'produce a quality standard and guidance on patient experience in adult mental health'. For NG53 the remit was to 'develop a guideline on the transition between inpatient mental health settings and community or care home settings for children, young people and adults… (to) provide recommendations about actions to improve practice'. The recommendations are primarily about service delivery and are necessarily broad. The quality standard derived from this guideline provides quality statements designed to improve the quality of care.
Statica Research Ltd t/a PEP Health	No	It is acknowledged that "people's experience of mental health care still remains poor" and "that mental health services are still struggling to meet even basic demands". Therefore, we believe that an enhanced and more sophisticated approach to listening to the voice of users and their families/carers needs to be adopted urgently. Technology is evolving quickly and it is now possible to remotely monitor in near real-time what people think of their care received and the themes and trends underpinning it. These insights would significantly improve service design in the future as well as supporting immediate quality improvement projects. As an example, www.pephealth.ai could offer a national overview and local insights into how mental health services are performing across the country.	Thank you for your comments and for highlighting the Patient Experience Platform (PEP). CG136 makes recommendations about enabling service users in improving care. For example, recommendation 1.1.22 recommends that service managers should commission reports on experience of care that includes data from multiple sources. The PEP tool and comparable technologies are accommodated by these recommendations. Further, we did not find any evidence during this surveillance review that suggested that this recommendation required amending.
Royal College of Nursing	No	We think that the guidance is still relevant, however could do with updating in respect of the reality of Mental Health	Thank you for your comments. We have acknowledged implementation issues in the surveillance proposal (p.3). I have

		services and contingencies that are in place due to a lack of staff and impact on care. There are several omissions that could be corrected, and we have highlighted a few below. However, we understand during the COVID-19 Pandemic why the decision not to update may have been the option. However, this may have an impact for day-to-day practitioners treating service users in services – this is something for NICE to consider.	responded below about the omissions you have highlighted. The decision to not update was not based on the COVID-19 pandemic but on evidence gathered from searches and feedback from topic experts and stakeholders. An overview of the reasons to not update the guideline are on p.1 of the surveillance proposal and more detail is contained in appendix A of the proposal. Thank you for sharing your comments about COVID-19 and day to day impact on services. We are aware of the impact that the pandemic has had on mental health services from a number of sources including stakeholders. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio.
Gender Identity Research and Education Society (GIRES)	No		Thank you for your response.

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

Stakeholder	Overall response	Comments	NICE response
Royal College of Psychiatrists	Yes	At present there is no NICE guidance for community or crisis/ home treatment teams (for example). CG136 touches on some important aspects, but falls short in terms of recommendations on how services should be organised.	Thank you for your comments. CG136 makes recommendations about crisis management under section 1.5 assessment and referral in a crisis, which include recommendations about choice of location for assessment and avoidance of admission. CG136 scope does not

		However, the new Rehabilitation for adults with complex psychosis NICE guideline [NG181] says: 'It includes recommendations on organising rehabilitation services, assessment and care planning, delivering programmes and interventions, and meeting people's physical healthcare needs.' https://www.nice.org.uk/guidance/ng181 Adult mental health services would really benefit from something similar, especially given the funding coming to them in the Long Term Plan, and as new models are being developed as part of the 12 early implementer sites. NHS England state: 'These early implementer sites will test how the barriers between primary and secondary care can be dissolved. They will lead transformation of community mental health services in England in partnership with Primary Care Networks (PCN) and Clinical Commissioning Groups (CCGs), as well as local authorities and the Voluntary, Community and Social Enterprise sector (VCSE), service users, families and carers, and local communities themselves.' https://www.england.nhs.uk/mental-health/adults/cmhs/	include service organisation, its main aim is to 'develop recommendations and quality standards to provide a framework that describes the key requirements for providing a high quality service user experience.' As stated in your comments, and identified in this surveillance review, long-term changes are planned which aim to break down barriers between primary and secondary care. The impact of these policy changes on CG136 recommendations and scope will be monitored and assessed at the next surveillance timepoint. We also 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.
Statica Research Ltd t/a PEP Health	No		Thank you for your response.
Royal College of Nursing	Yes	1.3.1- This section should be updated. We think it is important to offer a food/drink beverage as a standard	Thank you for your comments. Recommendation 1.3.1 recommends that 'service users should be greeted…in a warm, friendly, empathic,

		upon arrival to Mental Health Services or be given access to drinks. From a service user's perspective being greeted is important, but if you have not eaten for days or have not had a drink - this could hinder the assessment. 1.3.2- We accept that the guideline may not be overly prescriptive on healthcare personnel involvement. However, we consider that student nurses should be encouraged and allowed to be involved in the assessment process, this is fundamental to the development of the Mental Health Nurse and the future care of Mental Health Services. In clinical practice, we are perplexed when mental health student nurses lack the option to attend an assessment as a result of the service user refusing this access - the benefits of mental health student nurses' participation in the assessment process should be promoted and encouraged and service users encouraged and enabled to allow mental health student nurses to take part in the assessment process. This is something to consider in the next update. 1.3.3- As a Mental Health Nurse it is also important to consider the appropriateness and timing of the assessment face-to-face. There should be an option to revisit the assessment within a suitable period of time if a service user is in distress or confusion or agitated. This will show empathy and understanding that 'now is not the time' and 'let's explore this later'.	respectful and professional manner, anticipating possible distress.' This advice does not preclude offering food and drink if it is appropriate to do so. As advised in the overview section of CG136 practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences, and values of their patients. Thank you for your comments about student nurses. The extent of involvement of student nurses in the assessment process would be a decision taken by senior staff and those mentoring students in mental health services. Thank you for your comment about recommendation 1.3.3. Recommendation 1.3.3 makes recommendations about the process of carrying out an assessment and should be considered alongside clinical judgement. If a patient becomes distressed, then it is the decision of the practitioner whether or not to continue. 'Access to care' recommendations in section 1.2 make recommendations about organising assessment that include recommendations to minimise potential distress, e.g. by providing information about the assessment process. On the advice of topics experts we also plan to add a cross-referral from section 1.3 to the NICE guideline on decision-making and mental capacity (NICE guideline NG108) which contains recommendations about managing patient's distress that may occur during assessments of mental capacity. Thank you for your comment about 'No health without Mental Health'. 'No health without mental health' was published in 2011 and it was considered as part of 2016 surveillance when it was assessed as having no impact. This current surveillance review

		1.4 - No Health Without Mental Health: A Cross-government Mental Health Outcomes document focuses on how to initiate early intervention and combat stigma - why not consider this in an update? 1.5. There should be mention of 111/ option 2 specifically and most importantly the 'crisis hubs' that are being initiated across the South East of England. 1.6. Complex needs assessment? Safeguarding of Vulnerable Adults legislation? Stigma? Homelessness? Abused? Domestic Violence? Also need to mention NHS Long Term Plan in this section to enhance quality of care. 1.7. Care Programme Approach (CPA)? Community Treatment Order? Care-coordination? This seems to lack the fundamentals of what is expected under the Mental Health Act 1983/2007. Not sure why it is this later discussed in the next section – discharge = CPA.	considered evidence and information from November 2013 to February 2020. We have considered recent policy docs as part of this surveillance including the Final report of the Independent Review of the Mental Health Act 1983, NHS Long Term Plan and NHS Mental Health Implementation Plan. Thank you for comments about section 1.5. Section 1.5 makes recommendations for healthcare staff carrying out crisis assessments. It does not make recommendations aimed at patients therefore inclusion of 111 in this section would not be appropriate. Also, we try to future proof recommendations and this level of detail would therefore not be provided. Thank you for your comment about crisis hubs. We did not identify any evidence about crisis hubs during this surveillance timepoint. Thank you for your comments about recommendation 1.6. Recommendations in section 1.6 should be implemented in the context of recommendations in earlier sections of the guideline. These include recommendation 1.1.13 which makes recommendations about safeguarding procedures and assessment of vulnerable adults, and recommendation 1.6.3 which advises shared decision making whenever possible with users subject to the Mental Capacity Act. Also, recommendation 1.1.7 makes recommendations about awareness of stigma and discrimination that can be associated with people using mental health services. The currency of recommendations in CG136 in light of the impact of the NHS plan on mental health services was considered during this surveillance review. The recommendations were assessed as being supportive of the aims and objectives of the plan and we do not

			think it would be helpful for users for NICE to cross-refer to such a large strategic document. Thank you for your comments about the Care Programme Approach (CPA) and recommendations in 1.7. Section 1.7 makes recommendations about the principles of good discharge planning and transfer. The original guideline development group took account of the CPA approach when writing recommendations and while 1.7 does not specifically mention CPA the recommendations are in line with CPA principles to assess, plan, review and co-ordinate treatment and care For example, 1.7.1 recommends that changes are discussed and planned carefully beforehand with the service user and are structured and phased. Recommendations in section 1.7 should be implemented in the context of recommendation 1.1.10 which recommends that health and social care professionals should ensure that they: understand and can apply the principles of the Mental Capacity Act (2005), and how the Mental Health Act (1983; amended 1995 and 2007) and the Mental Capacity Act (2005) relate to each other in practice.
Gender Identity Research and Education Society (GIRES)	No		Thank you for your response

3. Do you have any comments on equality issues?			
Stakeholder	**Overall response**	**Comments**	**NICE response**

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Royal College of Psychiatrists		The Equalities Act 2010 is referred to, but when referring to protected groups, only some, not all, are mentioned. There is a need to review this guideline to ensure it is in line with the Equalities Act 2010.	Thank you for your comments. Recommendation 1.2.4 says to take into account the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using mental health services. In addition, recommendation 1.1.7 says be 'respectful of and sensitive to service users' gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and any disability'. The Act was in force when the guideline was developed and an equality impact assessment was carried out during development to ensure guideline recommendations are in line with the Act.
Statica Research Ltd t/a PEP Health	No		Thank you for your response
Royal College of Nursing	Yes	We think that the current guidelines do not explicitly consider LGBT, however it does consider BAME communities which is positive in this document. – with supporting evidence, we commend the reviewers. We, however, think it is also important to consider homelessness and people who use illicit substances in terms of service users going through recovery and becoming well in their Mental Health well-being, what chance do the homeless have in recovery if there is no housing or support package set up in the discharge plan?	Thank you for your comments. Recommendation 1.2.4 indicates to consider the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using mental health services. Recommendation 1.1.7 recommends be respectful of and sensitive to service users' gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background). and any disability The Act was in force when the guideline was developed and it was developed and equality impact assessment was made to make sure it was in line with the Act. People who are homeless were specifically considered as part of the impact assessment to ensure recommendations did act to exclude them. CG136 recommendation acknowledges illicit drug use in recommendation 1.6.2 but specific interventions for Illicit drug

			users are covered by Drug misuse in over 16s: psychosocial interventions (July 2007) CG51. It might also be useful for you to know that NICE is currently consulting on the draft scope of Integrated health and care for people who are homeless through being roofless which includes mental health care. As there is existing and on-going NICE guidance that does or will address the mental health needs of people who are homeless, including those who use illicit substances, NICE guideline CG136 will not be updated to consider recommendations specifically for this group.
Gender Identity Research and Education Society (GIRES)	Yes	'1.2.5 Access to care' refers to some of the protected characteristics under the Equality Act, 2010 which are, of course, applicable to public services. These should be listed in their entirety, and in alphabetical order to indicate that no characteristic is more important than any other: age, disability, gender reassignment, marriage/civil partnership, pregnancy/maternity, race, religion/belief, sex, sexual orientation. Of course, others mentioned, such as socio-economic background may still be included, but must not displace the legally protected characteristics. Service providers should also be alerted to 'intersectionality' and its implications for some of their service users, that is, who have more than one protected characteristic.	Thank you for your comments. All protected characteristics are considered during development of recommendations and detailed in the equality impact assessment. NICE develops guidance in line with principles described in the document 'The principles that guide the development of NICE guidance and standards'. Principle 29 says: 'we think about equality in relation to the protected characteristics stated in the Equality Act 2010. We also take into account inequalities arising from socioeconomic factors and the circumstances of certain groups of people.' This principle includes consideration of people with more than one protected characteristic.

		1.6.1.Using ‘preferred’ names and titles, is good, except that for trans people, the name they are using is not a matter of ‘preference’ in the same way as it is for cis-gender people. The post transition name of a person who has socially transitioned, is just their ‘name’, not their ‘preferred’ name. This applies to titles and pronouns also. 1.6.13 Providing ‘feedback’ to other clinicians must not include gratuitous information about a trans person’s history. This must only occur if it is directly relevant to their treatment and, prior to the disclosure, the reasons for this are explained to the individual, and preferably with the consent of the person concerned. 1.7, 1.8 As under 1.6.13, transfers of care, for instance to crisis houses or other facilities, clinicians and other service providers should also be aware that revealing irrelevant gender identity histories is not appropriate, unless absolutely necessary and preferably with their consent.	Thank you for your comments about use of ‘preferred’ names. Recommendation 1.6.1 recommends ‘When a service user enters hospital, greet them using the name and title they prefer’. This implies that the service user will be asked what name they would like healthcare staff to use. Therefore, recommendations 1.6.1 is advising that the choice of name is left entirely up to the service user. Thank you for your comment about providing feedback. Recommendation 1.6.13 should be implemented in the context set by recommendation 1.1.4. This says ‘when working with people using mental health services: • make sure that discussions take place in settings in which confidentiality, privacy and dignity are respected • be clear with service users about limits of confidentiality (that is, which health and social care professionals have access to information about their diagnosis and its treatment and in what circumstances this may be shared with others).’ It is also expected that the guidelines are implemented by healthcare providers with’ due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities’ as stated in the overview section. It is also expected that health care staff should adhere to professional principles of practice and ethics set out by their professional bodies. In relation to your comments on recommendations 1.7 and 1.8, please see response above.

4. NICE acknowledges that services may be affected by the current COVID—19 situation. Please tell us if there us any particular issues we should be considering?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Royal College of Psychiatrists		The Royal College of Psychiatrists in collaboration with NHS England and NHS Improvement has produced extensive guidance for the current COVID-19 situation. Details of the guidance, much of it which is relevant to NG53, can be found here: https://www.rcpsych.ac.uk/about-us/responding-to-covid-19/responding-to-covid-19-guidance-for-clinicians	Thank you for sharing this guidance. We will share these resources with colleagues in the NICE COVID-19 team and discuss if cross-referrals can be made to them from relevant COVID-19 guidelines. We recommend that you also submit these to NICE's endorsement team for consideration as potential NICE implementation tools. More information about endorsement and how to submit can be found on NICE's endorsement page. We also 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.
Statica Research Ltd t/a PEP Health	Yes	Remote monitoring of patients and the services provided is even more important during this time. The role of technology to support this has not yet been fully explored and is worthy of more focus and innovation.	Thank you for your comment about remote monitoring of patients we will share them with colleagues in NICE's COVID-19 rapid guidelines team. We also 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 Nursing	Yes	Changes in the Mental Health Act as a result of COVID-19 pandemic. It is worth exploring the use of personal protective equipment (PPE), deep cleaning, infection control in services and service user in-patient hospitals and prison transfer as a result of the pandemic. As mentioned earlier, student Mental Health Nurses are the next generation after the pandemic - Invest in students and invest in service user and Mental Health services. Consider the barriers experienced by student mental health nurses and the need to keep contact with service users. In community Mental Health settings, communication is hindered as a result of the pandemic among healthcare professionals and this has influenced student learning and engagement with service users in the community. Attention is needed for community psychiatric nurses to have access to psychological support if their debriefs are being affected by the pandemic and the usual ways of working in the healthcare system.	Thank you for your comments. 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 student nurses and difficulties engaging with service users during the pandemic and for your comments about psychological support for community psychiatric nurses during the pandemic. Other organisations have produced guidance about mental health services and staff wellbeing during COVID-19. For example, the Royal College of Psychiatry COVID-19: Guidance for clinicians includes COVID-19: Wellbeing and support for healthcare staff .

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Gender Identity Research and Education Society (GIRES)		1.6.13 Providing feedback to other clinicians must not include gratuitous information about a trans person's history. This must only occur if it is directly relevant to their treatment, and a proper explanation for the disclosure is given to the individual, before it occurs. COVID-19 has resulted in more medical appointments being carried out by phone or other means, such as Zoom. There is a higher risk of breaching confidentiality in these circumstances. Guidance already exists to help staff avoid making such privacy breaches, but further awareness training may be advisable with regard to contact with a trans person whose home circumstances are not fully known.	Thank you for your comments. Please see above for the response to comments on recommendation 1.6.13. With regards to your comments on the impact of COVID-19 leading to online consultations, recommendation 1.4 recommends when working with people using mental health services: • make sure that discussions take place in settings in which confidentiality, privacy and dignity are respected • be clear with service users about limits of confidentiality These recommendations apply to all appointments, including those via media including web conferencing and telephone. However, we will share these comments with colleagues in the COVID-19 team at NICE who produce rapid guidelines about services during COVID-19. We also 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.