

Appendix B: Stakeholder consultation comments table

2021-2022 surveillance of CG155 Psychosis and Schizophrenia in children and young people: Diagnosis and management

Consultation dates: 08th December 2021 to 12th January 2022

1. Do you agree with the proposal not to update the guideline? Please provide reasons for your answer.			
Stakeholder	Overall response	Comments	NICE response
Royal College of Paediatrics and Child Health	Yes	<p>Yes, however, please see comments below.</p> <p>There should be some acknowledgement that mental health problems are more prevalent in d/Deaf children.</p> <p>Reference</p> <p>Mental health problems in deaf children</p> <p>Hindley, Peter A,</p> <p>Current Paediatrics, Volume 15</p>	<p>Thank you for your comments about the prevalence of mental health problems in deaf children and for providing the overview paper by Hindley (2005). This paper is outside the scope of this surveillance review which covers the period 01 June 2016 to 31 October 2021.</p> <p>Deaf children with psychosis and schizophrenia are acknowledged in CG155's equality impact assessment which assesses the appropriateness of recommendations in relation to protected characteristics including sensory disabilities. This notes the importance of relaying information in an individually appropriate manner including for people with hearing problems. CG155 makes</p>

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		<p>Issue2, 114-119</p> <p>This is a useful summary and includes the difficulty that children with psychotic disorders may have disordered language which even through signing may be misinterpreted.</p> <p>COVID-19</p> <p>The difficulties faced by deaf children and young people regarding communication during COVID could be acknowledged. The barriers presented by the use of face masks i.e., lack of access to visual communication, facial expression and lip reading. Also, the effect on speech making it difficult to use residual hearing.</p> <p>Remote consultations need to consider any potential barriers to communication but can facilitate use of BSL interpreters.</p>	<p>recommendation 1.1.13 that recommends when communicating with children and young people with psychosis or schizophrenia and their parents or carers to take into account the child or young person's sight or hearing problems or delays in language development and to use communication aids such as sign language if needed. Recommendation 1.3.27 also recommends taking into account hearing problems when delivering psychological interventions.</p> <p>During this surveillance and previous surveillance of CG155 in 2016 we did not identify any evidence about the effectiveness of interventions aimed at deaf children and are therefore unable to make specific recommendations in this area. As highlighted in the surveillance proposal we plan to monitor several areas where evidence suggests practice is changing. The searches will include all children and young people with schizophrenia including deaf children. If we identify new evidence for this group, we will assess this immediately for impact on CG155's recommendations.</p> <p>Thank you for your comments about the impact of COVID-19. We acknowledge that personal protective equipment (PPE) can present a barrier to communication. The recommendations contained in recommendation 1.1.13 which includes checking that the child or young person and their parents or carers understand what is being said, still applies in situations where people are wearing face masks. If a child has hearing impairments this recommendation accommodates adaptations to PPE where appropriate, e.g., the use of transparent masks or visors.</p>
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		<p>Adverse drug reactions (information for young people prior to initiation/change of therapy, baseline measurements to monitor weight gain/etc, and professionals' duty to check for them) are major features of the current NICE guidance. But there is nothing about reporting suspected ADRs to the MHRA national spontaneous reporting scheme (or even encouraging young people to report their own suspected ADRs). The reviewer thinks that this is an oversight and this should be highlighted.</p>	<p>Thank you for your comment about remote consultations, communication barriers and the use of British Sign Language (BSL) qualified interpreters. We are aware of the issues around the use of digital resources and telemedicine, particularly in relation to mental health and learning disability services. In line with the NICE 5-year strategy we are currently prioritising which parts of the guidelines portfolio will be actively maintained. We plan to look at all the mental health guidelines in NICE's portfolio together in order to explore the implications of system drivers including the NHS Long Term Plan and the impact of COVID-19 on service delivery on our recommendations.</p> <p>Thank you for your comments about health and social care professionals reporting adverse drug reactions (ADRs) to the MHRA reporting scheme or encouraging young people to do the same. On the CG155 overview page the section called 'your responsibility' says: 'All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.' Additionally, CG155 recommends that choice of treatments should be a shared decision and that their benefits and side-effects should be discussed with the young person and their carers, including side-effects they do not find tolerable. For example, recommendation 1.3.18 recommends that from a discussion with the child or young person and their parent or carer, record the side-effects the child or young person is most and least willing to tolerate.</p> <p>NICE have also produced babies, children and young people's experience of healthcare (NICE guideline NG204) which contains recommendations to ensure good patient experience for babies,</p>
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			children and young people including their involvement in decision making about their healthcare.
Royal College of Nursing	No comment	N/A	Thank you.

2. Do you agree with the proposal to monitor the areas outlined in the surveillance proposal? Please provide reasons for your answer.

Stakeholder	Overall response	Comments	NICE response
Royal College of Paediatrics and Child Health	Yes	N/A	Thank you.
Royal College of Nursing	No comment	N/A	Thank you.

3. Are you aware of important evidence relevant to CG155 that we have not considered in the Evidence summary? (If yes please provide details)

Stakeholder	Overall response	Comments	NICE response
Royal College of Paediatrics and Child Health	No	N/A	Thank you.
Royal College of Nursing	No comment	N/A	Thank you.

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4. Do you have any comments on equalities issues?

Stakeholder	Overall response	Comments	NICE response
Royal College of Paediatrics and Child Health	Yes	<p>Yes:</p> <p>Section 1.1.13 page 8</p> <p>The importance of sign language and the use of trained BSL interpreters could be specified. This method of communication may be required by the child, parents, or both.</p> <p>Reference</p> <p>Vicci Ackroyd & Barry Wright (2018) Working with British Sign Language (BSL) interpreters: lessons from child and adolescent mental health services in the U.K., Journal of Communication in Healthcare, 11:3, 195-204.</p> <p>Any reference to specialist mental health services should include National Deaf Children and Young People Mental Health Services (CYPMHS), previously Deaf CAMHS.</p> <p>Section 1.1.14 pages 8-9</p>	<p>Thank you for your comments and for highlighting the paper by Ackroyd and Wright (2018). The paper makes recommendations about how CAMHS (child and adolescent mental health services) can work with BSL interpreters to improve communication between clinicians and children and their families and carers. The paper uses an audit of a deaf CAMHS service in 2012 and expert opinion to derive broad recommendations. The paper makes several recommendations including having BSL trained interpreters, using visual aids, and using plain language and that the clinician should make time to meet with the interpreter.</p> <p>Many of these recommendations are included in or accommodated by CG155. For example, recommendation 1.1.13 includes using sign language if needed to communicate with children and their parents and carers. Implementation of this recommendation by local services should include the availability of reliable and suitably qualified interpreters, including BSL qualified interpreters where this is appropriate. The recommendation does not specify BSL as this will act to exclude some groups who's sign language is not BSL. CG155's 'your responsibility' section sets out the responsibilities expected of healthcare providers and commissioners when implementing recommendations in CG155, which includes advancing equality of opportunity and reducing health inequalities.</p>

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		Reference to written information. Suggest signposting to internet and especially sign language interpreted video information to enable equality of access.	<p>Thank you for your comment about reference to specialist mental health services. 'Specialist mental health services' is a generic phrase used to describe services employing staff who specialise in treating children and young people with mental health problems including those working with deaf children.</p> <p>Thank you for your comments about recommendation 1.1.14 provision of written information. The recommendation accommodates signposting to internet resources and sign language video information as it says that any information should be in an 'appropriate format.' The implementation of the recommendation by local services should also take account of recommendation 1.1.22 which recommends NHS mental health services and third sector organisations work together to ensure equal access to services irrespective of any disability.</p>
Royal College of Nursing	No comment	N/A	Thank you.

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