

National Institute for Health and Care Excellence

4-year surveillance 2016 – Patient experience in adult NHS services (2012) NICE guideline CG138

Appendix B: stakeholder consultation comments table

Consultation dates: 25 April to 18 May 2016

Proposal not to update the guideline:

Type	Stakeholder	Do you agree with the proposal not to update the guideline?	Comments Insert each new comment on a new row	Comments on equality issues or areas excluded from the original scope Insert each new comment on a new row	NICE response
SH	Hindu Council UK	Disagree	In light of the current implementation of the Equality Act 2010 and the Social Care Act 2012 the guidance should be updated, including evidence on personalised risk communication, decision aids for patient-practitioner communication, midwife-led continuity models of care and interventions to communicate. This will need further breakdown (and engagement) in terms of who is reporting any benefits, who is not reporting any benefits. This will help to identify and reduce any	Yes. Cochrane identified blatant equality issues and the updates include a direct impact on Protected Characteristics e.g. maternity and pregnancy, age, race and disability. Analysis of the reporting will show bias as many groups of patients will not have been engaged. Patient's experience, who's experience (white, middle class, middle aged, male who will respond) needs to be identified according to the Protected Characteristics. Human rights of patients will also need consideration.	Thank you for your comment. The guideline 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 (1.1.6). The guideline also recommends that healthcare professionals should avoid making assumptions about the patient based on their appearance or other personal characteristics (1.1.5). During

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			health inequalities and create better outcomes for patients		<p>development of the guideline the committee considered that it was essential for healthcare professionals to have a non-judgemental attitude towards the patient. The Equality Act 2010 covers nine protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. The guideline committee considered that a good patient experience should not be compromised because of any patient's physical and mental characteristics, for example appearance or dress. For that reason, the committee felt it was important for clinicians to be supportive but not patronising, and to describe to patients the pertinent options and tools available to support them.</p>

Type	Stakeholder	Do you agree with the proposal not to update the guideline?	Comments Insert each new comment on a new row	Comments on equality issues or areas excluded from the original scope Insert each new comment on a new row	NICE response
					<p>Additionally, an equality impact assessment was carried out after development of the guideline recommendations. This document confirmed that the recommendations and quality statements have been formulated to promote equalities for all people who receive healthcare within the adult NHS services, irrespective of gender, ethnicity, disability, religion or beliefs, sexual orientation and gender identity or socio-economic status. No information was identified through this surveillance review to change those conclusions.</p> <p>In terms of social care, the Health and Social Care Act 2012 was a major piece of over-arching legislation that led to significant reorganisation of services. The guideline does discuss the importance of social care provision in patient experience,</p>

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					<p>particularly around continuity of care and recommends the following with reference to the Health and Social Care Quality Act 2015 which is specifically about the safety of health and social care services (1.4.3):</p> <p>Ensure clear and timely exchange of patient information:</p> <ul style="list-style-type: none"> • Between healthcare professionals (particularly at the point of any transitions in care) • Between healthcare and social care professionals in line with the Health and Social Care Safety and Quality Act 2015. [QS] <p>Additionally, NICE is currently developing a social care guideline on People's experience in adult social care services which is expected to publish in January 2018. This new guideline will complement NICE guideline</p>

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					CG138. The NICE Pathways will bring all relevant guidance together.
SH	Patient Experience Network	Disagree	The omission of Children and Young People (CYP) in the current guideline/ no specific guideline for CYP	As before the omission of CYP	Thank you for your comment. The guideline specifically covers people who use adult NHS services. The guideline recognised that some people or groups may have had poor experiences of healthcare and need additional consideration in the delivery of high quality care (for example, because of their age, disability, race, religion or belief). Although the specific needs of such people or groups were not addressed within this guidance, the Guideline Committee considered the principles may be of use in local strategies to narrow inequalities in patient experience.

Type	Stakeholder	Do you agree with the proposal not to update the guideline?	Comments Insert each new comment on a new row	Comments on equality issues or areas excluded from the original scope Insert each new comment on a new row	NICE response
					<p>The scope of this guidance covers users of adult services which could include young people. NICE has produced other guidelines focusing on service user experience for children including NICE guideline NG43: Transition from children's to adults' services for young people using health or social care services (2016). Other individual guidelines that include children cover general principles of care for the population covered by the guideline. We did not find any evidence in the surveillance review to justify extending the scope of the guideline to cover children and young people. This area will be examined again at the next surveillance review of the guideline.</p>

Call for evidence:

		Response	References and supporting information	NICE response
	Is there new evidence (not identified through the surveillance) in the following areas that may impact on current recommendations or address research recommendations in this guideline?			
<p>Knowing the patient as an individual</p> <p>Recommendations</p> <p>1.1.1 – 1.1.7</p>	Hindu Council UK	Yes	<p>1.1.6. – “services are equally accessible to, and supportive of, all people using adult NHS services.”</p> <p>Services should be inclusive and provide equitable outcomes</p>	<p>An equality impact assessment was carried out after development of the guideline recommendations. This document confirmed that the recommendations and quality statements have been formulated to promote equalities for all people who receive healthcare within the adult NHS services, irrespective of gender, ethnicity, disability, religion or beliefs, sexual orientation and gender identity or socio-economic status. No information was identified through this surveillance review to change those conclusions.</p>

	Response	References and supporting information	NICE response
Patients Experience Network		<p>Topic: Infant, Children and Young People’s Experience of Care</p> <p>Source:</p> <ul style="list-style-type: none"> • NHS England • Public Health England • Department of Health • Care Quality Commission • Health Education England • Parliamentary & Health Service Ombudsman • NHS Youth Forum • Royal College of Paediatrics and Child Health • Royal College of Nursing • Contact a family • National Children’s Bureau • Office of the Children’s Commissioner • Young People’s Strategic Health Partnership (AYPH, Youth Access, CLIC Sargent, NCYVS, Street Games, Adaction) <p>Background</p> <p>NICE Quality Standard 15 addresses adult experience of care, no such guidance currently exists for infants, children and young people which is impacting on the focus given to infants, children and young people’s experience of care by commissioner and provider organisations.</p> <p>The National Children and Young People’s Experience of Care Survey was conducted via the Care Quality Commission in 2015, highlighting that whilst there is much to be celebrated about children and young people’s experience of care there</p>	<p>Thank you for your comment.</p> <p>The scope of this guidance covers users of adult services which could include young people. NICE has produced other guidelines focusing on service user experience for children including NICE guideline NG43: Transition from children’s to adults’ services for young people using health or social care services (2016). Other individual guidelines that include children cover general principles of care for the population covered by the guideline.</p>

		Response	References and supporting information	NICE response
Essential requirements of care Recommendations 1.2.1 – 1.2.13	Patients Experience Network	[Yes / No]	Please see above	See response above.
Tailoring healthcare services for each patient Recommendations 1.3.1 – 1.3.13	Patients Experience Network	[Yes / No]	Please see above	See response above.
Continuity of care and relationships Recommendations 1.4.1 – 1.4.6	Patients Experience Network	[Yes / No]	Please see above	See response above.
Enabling patients to actively participate in care Recommendations 1.5.1 – 1.5.29	Patients Experience Network	[Yes / No]	Please see above	See response above.