NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

QS14 and QS15 refresh: consultation summary

Contents

1 Introduction

At the QSAC meeting on 17 October 2018, NICE outlined plans to refresh:

- QS14 Service user experience in adult mental health services
- QS15 Patient experience in adult NHS services.

The purpose of the refresh was to ensure they continue to be fit for use and as easy to use as possible until full updates take once the NICE guideline on shared decision making publishes in 2021. The intention is to:

- merge quality statements that focus on similar or overlapping actions
- amend language to align with current editorial style
- align with the current template (for example, adding sections that were not originally included such as 'rationales').

Proposals to refresh the two quality standards were made available on the NICE website for a 3-week public consultation period between 19 November 2018 and 7 December 2018. This was not an opportunity to include new areas for quality improvement (i.e. new quality statements). Around 750 stakeholders were notified by email and invited to submit comments on proposals to merge existing quality statements. All stakeholders were sent a reminder during the consultation period.

Following the close of consultation, 19 of the organisations that had not responded were sent a follow-up email giving them until 18 December 2018 to supply comments. This time extension was given to organisations that support the current quality standards, and those potentially important for the topic (such as those identified by the NICE Public Involvement Programme team). Some organisations reported that they could not respond to a lack of capacity. To try and elicit a response, they were contacted again and informed that they could still submit late comments up until the date committee met. [Two responses were received following the production of the original version of this paper. These comments were reported to members at the committee meeting and have been included as appendix 3 in this final version of the consultation summary report.]

Comments were received from 30 organisations and individuals in response to the consultation. These included service providers, national organisations, professional bodies, patient organisations, QSAC members and individuals.

This report provides the QSAC with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee.

Consultation comments that may result in changes to the proposals to merge quality statements have been highlighted within this report. Comments suggesting changes that are outside of the purpose of the refresh have not been included in this summary. The types of comments typically not included are those suggesting new areas for quality improvement, broadening the scope of the refresh and combining the two quality standards. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

Note that appendix 1 includes comments from organisations, QSAC members, individuals and internal comments from NICE teams. For completeness, all pre-consultation comments received from QSAC members can be found in appendix 2.

2 Questions for consultation

Responses to the following questions were sought at consultation:

1. Given QS14 and QS15 will not be fully updated until the NICE guideline on shared decision making is published, do you support an interim refresh?

2. Do you agree with the proposals for merging existing statements?

3. Are there more statements that could be merged because they focus on similar or overlapping actions?

Responses to each question are summarised in a separate section below.

3 Consultation question 1 responses

Given QS14 and QS15 will not be fully updated until the NICE guideline on shared decision making is published, do you support an interim refresh?

Consultation comments

Almost all responses to question 1 expressed support for the refresh. Reasons for the support included:

- Many existing statements overlap and could be worded more clearly.
- A refresh can make standards fit for purpose, simpler to understand, easier to access and use.
- Guidance needs to be concise and focussed.
- No new guideline will be published for several years.

Some comments suggested the refreshed quality standards:

- Need a comprehensive definition of shared decision making.
- Should not weaken the standard of care or the provision of information to support shared decision making.
- Risk losing detail that that is critical for ensuring the quality of care by merging some statements.

One response did not support the refresh saying it is not clear why it is needed. The response added that there is a danger that changes will not take account of needs of service users as the language of policy and research has changed in recent years.

4 Consultation question 2 responses: QS14

Do you agree with the proposals for merging existing statements?

Five responses agreed with all the proposals made for merging the statements. Most of those who responded to question 2 agreed with some of the proposals but suggested changes to specific statements. These comments are summarised below.

Respect and empathy

Quality statement from QS14 Service user experience		Proposed merger
2	People using mental health services, and their families or carers, feel they are treated with empathy, dignity and respect.	People using mental health services, and their families or carers, are treated with empathy, dignity and respect.
15	People using mental health services feel less stigmatised in the community and NHS, including within mental health services.	

- One response agreed with the proposed merger, but questioned if the wording should be the same as QS15 statement 1?

Decision making

Quality statement from QS14 Service user experience		Proposed merger
1	People using mental health services, and their families or carers, feel optimistic that care will be effective.	People using mental health services are involved in shared decision-making and supported in self-management.
3	People using mental health services are actively involved in shared decision-making and supported in self-management.	
11	People in hospital for mental health care, including service users formally detained under the Mental Health Act, are routinely involved in shared decision-making.	
7	People using mental health services understand the assessment process, their diagnosis and treatment options, and receive emotional support for any sensitive issues.	

- Two responses stated that one of the merged statements should remain as a standalone statement:
  - Statement 1 as optimism is an important and discrete concept in mental healthcare, which is not covered by a broad statement about shared decision-making.

  - Statement 7 as it is about people having the necessary information and advice so they can get involved and make informed decisions.
- Several comments suggested the proposed merged statement needs extra detail:
  - Reference to 'families and carers' as this has been lost from quality statement 1.
  - Change wording "and supported" to "and comprehensively supported, considering physical and mental health needs".
  - The need for health and care professionals to proactively involve people in shared decision-making should not be lost.
  - Understanding should be made explicit as the merged statement does not highlight the importance of people understanding the process, diagnosis and treatment options.
- Shared decision making was the subject of several comments:
  - Some people may make an informed choice not to engage in shared decision-making. The statement should focus on people being involved in their own care as much as they like.
  - Shared decision-making needs to be defined.
  - The concept of shared decision-making in the statement is not a relation where power is symmetrical; psychiatrists or other mental health professionals set the agenda, decide on the options and can override the decision of the person. The concept should be replaced by supported decision-making in alignment with the United Nations Convention on the Rights of Persons with Disabilities.
- The proposed statement should clearly apply to people who are formally detained under the Mental Health Act.

Involvement

Quality statement from QS14 Service user experience		Proposed merger
5	People using mental health services feel confident that the views of service users are used to monitor and improve the performance of services.	No change

- One response agreed this cannot be merged with other statements.

Continuity

Quality statement from QS14 Service user experience		Proposed merger
4	People using community mental health services are normally supported by staff from a single, multidisciplinary community team, familiar to them and with whom they have a continuous relationship.	People using mental health services are supported by a multidisciplinary team with whom they have a continuous relationship.
12	People in hospital for mental health care have daily one-to-one contact with mental healthcare professionals known to the service user and regularly see other members of the multidisciplinary mental healthcare team.	

- Two respondents supported the merger but:
  - Queried if the wording should align more closely to statement 11 on continuity in QS15?
  - Said that 'continuous relationship' needs to be defined.
  - Asked if it captures the element of time as indicated in the 2 existing statements (such as daily one-to-one contact)?
- One response did not support the merger of these statements but gave no reason.

Access

Quality statement from QS14 Service user experience		Proposed merger
6	People can access mental health services when they need them	People can access mental health services when they need them.
10	People accessing crisis support have a comprehensive assessment, undertaken by a professional competent in crisis working.	

- Two responses questioned if the 2 statements can be merged as:
  - Statement 6 relates to whether people can access services at all, whereas statement 10 relates to how care should be delivered once services have been accessed.
  - The statements are about different issues; having a comprehensive assessment supports people's access to services, but access does not always lead to an assessments being done.
- Several comments related to the lack of reference to crisis support:
  - It is important to stress the crisis situation specifically.
  - Statement should reference crisis care as proposed for statements 8 & 9.

- Merger not supported as people in crisis need specific support.
- The importance of a comprehensive assessment, especially at points of crisis, has been lost.

Information

Quality statement from QS14 Service user experience		Proposed merger
8	People using mental health services jointly develop a care plan with mental health and social care professionals, and are given a copy with an agreed date to review it.	People using mental health services have an agreed care plan, including a crisis plan if they may be at risk of crisis.
9	People using mental health services who may be at risk of crisis are offered a crisis plan.	

- One response agreed with the merger but noted that the review element of the existing statement 8 is removed.
- Several comments suggested amendments to the statement wording:
  - Should be changed from “have an agreed care plan” to “jointly agree a care plan with their care team”.
  - Needs to say that care should be agreed with the service user rather than among the health and care professionals.
  - Needs to address the issue of access by patients or their families/carers to said care/crisis plans and agreement on review dates etc.

Environment

Quality statement from QS14 Service user experience		Proposed merger
13	People in hospital for mental health care can access meaningful and culturally appropriate activities 7 days a week, not restricted to 9am to 5pm.	No change

- One response agreed this statement cannot be merged with other statements.

Treatment

Quality statement from QS14 Service user experience	Proposed merger

Quality statement from QS14 Service user experience		Proposed merger
14	People in hospital for mental health care are confident that control and restraint, and compulsory treatment including rapid tranquillisation, will be used competently, safely and only as a last resort with minimum force.	No change

- One response agreed this statement cannot be merged with other statements.

5 Consultation question 2 responses: QS15

Do you agree with the proposals for merging existing statements?

Five responses agreed with all the proposals made for merging the statements. Most of those who responded to question 2 agreed with some of the proposals but suggested changes to specific statements. These comments are summarised below.

One comment recommended that the language of all statements in QS15 should be changed by using “people” instead of “patients”.

Respect and empathy

Quality statement from QS15 Patient experience		Proposed merger
1	Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.	No change

- Comments described statement 1 as broad and containing 7 descriptors which are more or less synonymous. One response suggested using wording similar to QS14 statement 2 instead: "Patients are treated with empathy, dignity and respect".

Communication

Quality statement from QS15 Patient experience		Proposed merger
2	Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.	No change

- One response considered statement 2 vague. It asked if it is about continuity, effectiveness or communication; and whether it could be merged with statement 12?

Contacts

Quality statement from QS15 Patient experience		Proposed merger
3	Patients are introduced to all healthcare professionals involved in their care, and are made aware of the roles and responsibilities of the members of the healthcare team.	Patients are introduced to all healthcare professionals involved in their care and know how to make contact about their healthcare needs.
14	Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs.	

- One response agreed with the merger.

Continuity

Quality statement from QS15 Patient experience		Proposed merger
11	Patients experience continuity of care delivered, whenever possible, by the same healthcare professional or team throughout a single episode of care.	No change

- Agree that this statement cannot be merged with others.
- Could statement 11 be worded more like the proposed merged statement about continuity of support in QS14?

Information exchange

Quality statement from QS15 Patient experience		Proposed merger
12	Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals.	No change

- Agree that this statement cannot be merged with others.

Support

Quality statement from QS15 Patient experience		Proposed merger
4	Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.	Patients experience care that is tailored to their needs and preferences.
9	Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.	
10	Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety.	

- Several comments suggested that some of the existing statements need to be retained as separate statements:
  - Statement 4 is concerned with a different aspect of individuality from statements 9 and 10 and should be retained as a separate statement.
  - Statement 10 should be a separate statement. Statements 4 and 9 are about activities done at specific points in the treatment pathway of a patient, whilst 10 is about continued assessments during a particular treatment. Statement 10 also has specific areas (anxiety, pain relief, personal hygiene) that are missing from the proposed statement.
- Other comments related to detail being lost in the merged statement:
  - Reflect elements listed in the current statement 10 (such as pain relief, help to eat meals and hydration) in the measures of the new, merged statement.
  - Risks, benefits and burdens of treatment need to be considered.
  - Physical and psychological needs have been omitted.
  - Change “needs” to “physical, emotional, and psychological needs”.
  - The wording assumes people will know that it includes the detail of the existing statements such as health beliefs, concerns and preferences, physical and psychological needs, including nutrition, hydration, pain relief, personal hygiene and anxiety.
  - The specific needs of service users in the existing statements are replaced with jargon.

Information sharing

Quality statement from QS15 Patient experience		Proposed merger
13	Patients' preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.	No change

- One response agreed that the statement cannot be merged with other statements.

Decision making

Quality statement from QS15 Patient experience		Proposed merger
5	Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.	Patients are involved in shared decision-making.
6	Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.	
7	Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.	
8	Patients are made aware that they can ask for a second opinion.	

- Some responses stated that a comprehensive definition of shared decision-making is needed:
  - As ‘patients are involved in shared decision making’ does not have a commonly understood meaning in healthcare.
  - To ensure that important aspects of the approach (especially relating to choice) are not missed.
- Several comments considered that important detail was being lost on patients being supported to be involved in decision making, and being advised or given information on their rights in relation to treatment, on options etc.
- Many responses stated that the merger weakens the emphasis on patient choice; of declining treatment and having a second opinion.
- Some comments wanted understanding to be added to the statement as shared decision making rests upon an individual’s ability to understand and communicate.
- The need to respect patient decisions has been lost in the merged statement.

- One response said the statements should not be merged as each supports an important principle which is not reflected in the merged version.

6 Consultation question 3 responses

Are there more statements that could be merged because they focus on similar or overlapping actions?

Consultation comments

Most responses made in relation to question 3 said there were no further statements that could be merged. A small number of responses made the following suggestions for QS15:

- Statements 1 & 2 could be merged and simplified using the wording of QS14 statement 2: “Patients are treated with empathy, dignity and respect, by staff who have demonstrated competency in relevant communication skills”.
- Statement 2 about effective interactions and communication skills could be merged with statement 1 about how people are treated overall. Alternatively, statement 2 could be considered part of merged statement on shared decision-making.
- Include a statement like QS14 statement 5: “People using health care services feel confident that the views of service users are used to monitor and improve the performance of services”.
- QS15 should include statement 5 of QS14 amended to cover all service users: “People using health care services feel confident that the views of service users are used to monitor and improve the performance of services”.

Appendix 1: Quality standard consultation comments table

General comments		
ID	**Comment from**	**Comments[1]**
1	Individual 1	My personal comments on NICE QS15 Patient experience in adult NHS services 1 I have very recently been a user of 111, A & E, Assessment ward and an Oncology ward so I feel comfortable in making my comments. 2 I have looked at the document and appreciate that such documents need to exist but I find it startling that this document is suggesting a wonderful five star service for every patient and that NICE have had majority of these standards in place since 2012. From my experience the service falls a long way short of these targets. If the basic targets are not being met then why are you trying to enhance them? 3 I had a 7:30hrs wait in A & E, 11 hours on a trolley in A & E, a few hours in an assessment ward and during that time my blood results were misread by three doctors. How does that relate to the standards set by NICE? 4 I feel very strongly that the money being spent on this consultation would be far better going towards resourcing the existing system to a basic standard. If once the basic standards are being met then we should look to enhance. Every patient would love to receive a gold standard service but in today's climate that is a dream from what I experienced. All staff were extremely pleasant, hard working and over stretched. It took me 7:30 hrs to be discharged and I was not waiting for any medication, just a discharge letter. Is that a NICE standard? 5 It is not the staff that are working, it is the staff that are missing that is an issue. I saw that in practice. Three bank staff failed to show up on the ward. How can your dream be meet with this level of staff? Four bedridden patients out of five were not washed and did not have their teeth brushed until after lunch. 6 I would love to be more supportive and discuss the finer points of the document but given my experience of using a very broken system I am unable to assist.
2	Individual 2	[This response included images that have not been copied in to this table]

[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

General comments		
ID	**Comment from**	**Comments[1]**
		I think NICE should take feedback in which ever for people wish to present it …. I hallucinate and hear voices but I am not ill and I do not take psychiatric drugs ... Some people would like more Crisis centres somewhere peaceful to stay for a few days... Some of my friends are homeless and sectioned under the Mental Health Act ... Some of my friends are being bullied by the DWP this bullying is affecting their health … Some of my friends are in very poor housing and have been for months, which affects their well-being …. Some of my friends are being forced to take depot injections which they think are unhealthy for them … Some of my friend would like to reduce their psychiatric drugs but there is no medical support for them to do this … Some of my friends have said they would like therapeutic communities for their loved ones ... Some of my friends have problems raising funds for good community ideas: - https://www.nesta.org.uk/blog/felicitations-madame-mayor-participatory-budgeting-in-paris-hits-new-highs https://www.kingsfund.org.uk/audio-video/donna-hall-wigan-story Experts by experience that are paid and peer support are vital. [Image of Peer Support Charter] https://discover.dc.nihr.ac.uk/content/signal-000673/mental-health-crisis-readmissions-may-reduce-with-peer-support Please be aware of the following: - https://www.youtube.com/watch?v=zDZFcDGpL4U Dr James Davies: The Origins of the DSM: https://www.youtube.com/watch?v=6JPgpasgueQ Pat Braken's work: https://www.youtube.com/watch?v=cV5RKT6Q8qU Jo Moncrieff's work… https://www.youtube.com/watch?v=FjTisLX4q1Y Joanna Moncrieff and The Radar project FEEL (Friends of East End Loonies) hosted this event at Kingsley Hall with Joanna Moncrieff critical psychiatrist... https://www.youtube.com/watch?v=eAnVi3Zuay4 Hearing Voices Network: https://www.hearing-voices.org/ nsun (national survivor user network), network for mental health in England, UK. Independent: https://www.nsun.org.uk/ national paranoia network: http://www.nationalparanoianetwork.org/ Zero tolerance to suicide alliance: https://www.zerosuicidealliance.com/ https://discover.dc.nihr.ac.uk/content/signal-000672/guided-online-interventions-can-help-people-recover-from-depression http://www.suicidecrisis.co.uk/ Micheala Amering's work … https://news.liverpool.ac.uk/2014/04/25/viewpoint-the-medicalisation-of-human-distress/ https://www.shapingourlives.org.uk/wp-content/uploads/2016/05/FROM-MENTAL-ILLNESS-PDF-2.pdf

General comments		
ID	**Comment from**	**Comments[1]**
		Ben Goldacre's Bad Pharma and Bad Science that Doctors and academics made up illnesses for money ! Then there is the BBC series The doctor how gave up drugs https://www.bbc.co.uk/programmes/b0b578bd https://www.thetimes.co.uk/magazine/the-times-magazine/is-there-a-cure-foralzheimers-disease-f9tp8st9w Universal citizen wage Jon Stone The UK's welfare system should be replaced with a single universal basic income paid to all citizens https://www.independent.co.uk/news/uk/politics/replace-the-benefits-system-with-a-universal-basic-income-paid-to-all-citizens-think-tank-recommends-a6777101.html A no-strings basic income? If it works for the royal family, it can work... Don't choke at the idea of a universal basic income. It benefits many – from beggars to entrepreneurs https://www.theguardian.com/world/2015/dec/26/dutch-city-utrecht-basic-income-uk-greens [images] The Royal College of Psychiatrists booklet "Schizophrenia" (page 26) states: - "...if there is an inaccurate or abusive item about schizophrenia in the press, a radio talk show or a TV, don't get depressed, get active. Write a letter, e-mail them, phone them up and tell them where they are wrong. It works! …" Why just restrict this to the media? How can this be? things need to change .... pay ratios idea? Titans of industry earn more than average annual wage in three days By Tom Knowles, Economics Correspondent: https://www.thetimes.co.uk/edition/news/titans-of-industry-earn-more-than-average-annual-wage-in-three-days-wllxdm3w7 Green Party | Green Party calls for wealth tax to tackle soaring inequality: https://www.greenparty.org.uk/news/2017/01/16/green-party-calls-for-wealth-tax-to-tackle-soaring-inequality/ If I am lucky enough to never need surgery, then a road sweeper is more important to me than a surgeon? Or should I sweep the road myself? The Mental Health act needs to be repealed it is one of the few areas of law where you can be locked away for something you may do! Restraints, ECT and serious incidents in the Mental Health system needs to be reviewed by members of the public. https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf Not just me? https://www.theguardian.com/world/2018/oct/01/police-stun-guns-mentally-ill-patients-health-uk https://www.theguardian.com/society/2018/oct/04/secure-hospitals-are-not-penal-institutions https://www.theguardian.com/society/2018/oct/08/ptsd-rates-increase-in-uk-military-personnel https://www.independent.co.uk/news/health/depression-withdrawal-symptoms-antidepressants-side-effects-nice-prescription-drugs-a8565066.html Some things I have known for years … https://www.theguardian.com/society/2018/sep/09/nhs-land-earmarked-for-sale-to-developers

General comments		
ID	**Comment from**	**Comments[1]**
		https://www.theguardian.com/society/2018/sep/11/nhs-care-regulator-says-sexual-incidents-commonplace-in-mental-health-units Mental Health is one of the few areas where you cannot refuse treatment. Mental health hospitals need to be closed as per Italy and a move to respite implemented: - http://www.richmondandtwickenhamtimes.co.uk/news/14778547.Police_officer_tells_how_new_mental_health_haven_spares_people_trauma_of_being_sectioned_and_saves_colleagues_hours_of_work/ https://www.nuffieldtrust.org.uk/news-item/reinventing-the-hospital https://www.theguardian.com/books/2015/aug/19/man-who-closed-asylums-franco-basaglia-review https://youtu.be/aOtFYMDiOtI https://youtu.be/d8eqWBVtD2g https://www.youtube.com/watch?v=wPHXx8VMhMM https://www.bbc.co.uk/sounds/play/m0000mkd [image] https://www.youtube.com/watch?v=EHkozMIXZ8w https://www.youtube.com/watch?v=dvba62gObhw https://www.youtube.com/watch?v=t4LwS5GPgEA Hope this information is useful.
3	Loughborough University Design School	I have carried out Human Factors systems mapping on: • Nice Guideline CG138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services • Nice Guideline CG190: Care of women and their babies during labour and birth • Nice Pathway: Care throughout labour • NHS Trust policies on Care throughout labour from 2 Trusts My comments are: 1. The patient experience guideline CG138 currently did not interface smoothly with CG190 2. Each Trust seems to re-interpret NICE guidelines (moving from Work-as-Imaged, to Work-as-Prescribed), often as a response to an SUI or other local 'trigger' 3. This leads to considerable potential for variance in patient experience (Work-as-Done) which then contributes to misunderstanding and confusion during SUIs Medical Devices are now required to undergo usability testing https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/645862/HumanFactors_Medical-Devices_v1.0.pdf

General comments		
ID	**Comment from**	**Comments[1]**
		Can I suggest that clinical staff would find it very useful for guidelines to be tested to improve usability?
4	Patient Experience Library	NICE has invited comments on its proposed changes to QS14 Service user experience in adult mental health services and QS15 Patient experience in adult NHS services. We welcome both the proposed changes and the opportunity to comment. Our response comes from the perspective of our work in running the Patient Experience Library - the UK evidence base on patient experience.
5	Patient Information Forum	We believe it is important to protect people's right to information particular those who are most vulnerable and in crisis.
6	QSAC 1	I think it is a pity that there is no QS that includes or focuses on children and young people. It would be good if this could be developed.
7	Royal College of Speech and Language Therapists	We are concerned that the proposed merges all lead to a lack of focus on the importance of patient understanding of process, diagnosis and treatment options. Understanding of information, and expression of information are fundamental to shared decision making thereby omitting this focus may lead to a substantial oversight in shared decision making practice.

Consultation question 1: Given QS14 and QS15 will not be fully updated until the NICE guideline on shared decision making is published, do you support an interim refresh?		
ID	**Comment from**	**Comments**
8	Diabetes UK	Yes While the guideline on shared-decision making is being developed, each Quality Standard should include/refer to a comprehensive definition of shared decision-making, outlining the extensive range of elements included in the approach, so that important aspects of the approach (especially relating to choice) are not missed.
9	East and North Hertfordshire NHS Trust	I have been asked to review the consultation proposals for NICE QS15 and would like to confirm my support for the interim refresh and the proposals for merging existing statements.
10	Elcena Jeffers Foundation	Yes
11	Healthwatch Birmingham	Healthwatch Birmingham welcomes the opportunity to respond to NICE's proposal for merging existing statements in QS14 and QS15. Our key role is to make sure that patients, the public, service users, and carers (PPSuC) are at the heart of service improvement in health and social care. We welcome that NICE is taking steps to ensure that Quality Standard 14 and 15 are still fit for purpose and are easy to use. At Healthwatch Birmingham, we know through our listening exercise that issues around dignity and respect, involvement, information,

Consultation question 1: Given QS14 and QS15 will not be fully updated until the NICE guideline on shared decision making is published, do you support an interim refresh?		
ID	**Comment from**	**Comments**
		access, treatment, choice, decision-making and continuity, continue to be important to service users, the public and carers accessing health and social care in Birmingham. The feedback (2018) we have heard from service users, the public and carers highlights the importance of these issues: *They keep you on hold for ages and don't pick up. I have been in crisis twice and no one has helped at all. I think that this centre should be closed down and the staff should get dismissed.* *The whole team is poorly run [redacted in accordance with moderation policy], PALS have received many other reports of the team being vindictive and uncaring, and advise that patients apply to transfer to another team.* *I feel that there is no continuity at the [name deleted by NICE] Centre. We have been going there for the past two years only now we feel we have a psychiatrist who understands my husband. We have had to find out things for ourselves. Not happy, he feels disturbed like he has to keep explaining himself at sessions.* *I did a self-referral in February and heard back within a few weeks that I was on the waiting list for an appointment. It is now June and haven't heard anything further.* *I went through Birmingham Healthy Minds but they referred me to something I wasn't comfortable with. I went to the Pause in Birmingham City, where it's a walk in but you would see someone different every time. This gave me a choice to when I can talk and see someone when I really need to.* *Sometimes the treatment I am receiving from the mental health trust is working and sometimes it is not. I am seeking treatment, however, I feel if I had more support it would help.* *They need to put more money into mental health and the NHS as there are longer waiting times for A&E and other departments. Doctors and nurses should explain things more clearly to patients who have disability, mental health issues and learning difficulties.* *My experience was horrible. You wait two months for appointments - how are you meant to access quick help when appointments are not regular? How can you have a diagnosis and then be told it isn't right but still not get the right support even on medication? If it isn't working you still have to wait two months plus, to ask for different medication or help to solve the problem. If I'm having a bad day I can't wait to be seen. Where do I go in an emergency? I've called them in an emergency and*

Consultation question 1: Given QS14 and QS15 will not be fully updated until the NICE guideline on shared decision making is published, do you support an interim refresh?		
ID	**Comment from**	**Comments**
		they say there's no doctors and they don't give me other places to go. I don't like my male doctor but if I want another male doctor I need to travel across the City. I am questioning my sexuality and have never told anyone as I can't talk to my doctor. I didn't get any help filling in the personal income payments (PIP) form even though I am autistic. I asked my Mental Health Team to refer me to anger management "they didn't. Mental Health told me I needed a social worker but I've never had any contact since. *I have struggled to get support for my mental health issues. I have attempted to contact several mental health support units and have been put on hold or ignored. I have also reported not receiving appropriate support for my PTSD needs.* *They ([name deleted by NICE] Centre) don't follow through on promises. They are difficult to contact. Their admin is useless.* Service users and their carers have also told us positive stories of accessing mental health services in the community and in a hospital setting. These experiences highlight the issues that they consider important in their care including involvement in decision-making around care, access to information and advice, dignity and respect, and good quality care. *I was referred to the service after my anxiety and depression had been managed locally by my GP for many years. Due to the recurring nature and length of time I was having to take off work I got a referral. Once in the system I was seen by a lovely Psychiatric Nurse, who spent the time to go through my history, what I was feeling and asked me what I wanted out of this referral. I was started on a new course of treatment, given out of hours contact details if I was worried about anything and booked for a return review. I also saw a clinical psychologist who took an overview of my case. This was all a year ago. I am now back at work. I have a couple more tweaks to my meds and some counselling (in the community).* *My wife had a fall, and after that her behavior deteriorated rapidly. She was then sectioned. Initially, she did not want to stay but they were looking after her really well. She has now been moved to a residential centre. The Consultant at the hospital was great and kept me informed of any changes or improvements. The transition to the residential home went really well as my wife had built relationships with staff at the hospital. The hospital staff have also visited her at her new place.* *Consultant psychiatrist of [name deleted by NICE] outreach team has been my doctor for years. The Doctor has shown strong care during home visits and more stronger care at times of my crisis in hospital admissions. He is a very good listener. His communication is outstanding when he speaks to me. Doctor and his team at [name deleted by NICE] outreach team are such good people when it came to delivering a community service as a mental health trust service. When I need to access services via telephone to the team my calls are handled with care and respect which is maintained on every call that I have ever made to*

Consultation question 1: Given QS14 and QS15 will not be fully updated until the NICE guideline on shared decision making is published, do you support an interim refresh?		
ID	**Comment from**	**Comments**
		Doctor or my CPN. I would trust Dr with my life. I have known Dr for 9 years. His care and compassion and high expertise is nothing like I have known as I am a service user for the last 15 years. 10 out of 10 award goes to [name deleted by NICE] outreach team from me as an experienced service user of other community outreach services. *They are very good at patient's care and the doctor is willing to have informal chats when needed* In addition to the above experiences, Healthwatch Birmingham carried out research on the experiences of people with a serious mental health illness in relation to care plans. Our study found that despite stated policy by Birmingham and Solihull Mental Health Foundation Trust to provide care plans to 100% of its patients that this was not the case. Our findings highlights the importance of understanding the disparity between stated objectives and implementation. Therefore, quality standards such as the ones under discussion are essential in ensuring that service users and carers are involved in various aspects of their care and access good quality care. The experiences above have guided our comments below on the proposed merged statements.
12	Hounslow and Richmond Community Healthcare Trust	Yes
13	National Maternity Voices	Overall, it is not clear why this 'interim refresh' is needed, pending publication of the forthcoming shared decision-making guideline. There is a real danger of making changes that do not take into account the needs, wishes and lived experiences of service users in all areas of healthcare – simply because the language of policy and research, and therefore that of public discourse in health, has changed somewhat in recent years. Copying in maternity colleagues who, having been alerted to this consultation only this week, who may wish to endorse or add to my comments on behalf of National Maternity Voices by replying to this email. [names of individuals deleted by NICE]
14	NHS England Patient Experience Team	Yes
15	NICE A&I	Yes. We agree that many of the current statements overlap and could be worded much more clearly.
16	NICE M&P	Yes
17	Patient Experience Library	We welcome the goal of ensuring that the standards continue to be fit for use and as easy to use as possible. Healthcare staff work in complex and busy environments, so guidance needs to be concise. It is good to see standards being merged, so that checklists are shortened and duplication is reduced.

Consultation question 1: Given QS14 and QS15 will not be fully updated until the NICE guideline on shared decision making is published, do you support an interim refresh?		
ID	**Comment from**	**Comments**
		[Summary of all comments submitted by Patient Experience Library] To sum up: a more concise and focused set of guidance statements on patient experience is welcome. Our comments above are offered in a spirit of constructive support. We appreciate the opportunity to contribute to this consultation and are happy to offer further information or clarification if required:
18	Patient Information Forum	We think an interim refresh could make it simpler for patients to understand and access the quality standard but this should not weaken the standard of care or the provision of information to support shared decision making in community and in-patient settings.
19	QSAC 1	Yes
20	QSAC 3	I fully support this
21	QSAC 4	Yes, I would support an interim refresh as the SDM guideline isn't due to be published for a few years yet.
22	QSAC2	Yes
23	Royal College of Nursing	Yes, we support an interim refresh.
24	Royal College of Speech and Language Therapists	We agree that it is important to review content in the standards and are looking forward to seeing the published guideline on shared decision making in the future. However, while we appreciate that there are advantages to refreshing these standards by aligning the language and format of the document to current practice, we have substantial concerns around the merging of some of the quality statements. We feel some of the proposed merges risk losing critical detail for ensuring quality care. These are detailed below.
25	The Pelvic Partnership	Yes
26	University Hospital Southampton NHS Foundation Trust	I do support refreshing the guideline since it simplifies it.
27	University Hospitals Bristol NHS Foundation Trust	Yes

Consultation question 2: Do you agree with the proposals for merging existing statements?		
ID	**Comment from**	**Comments**
28	Elcena Jeffers Foundation	Yes
29	Hounslow and Richmond Community Healthcare Trust	Yes
30	QSAC 2	Yes
31	Royal College of Nursing	Yes, we agree with the proposals for merging existing statements.
32	University Hospital Southampton NHS Foundation Trust	Yes

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS14		
ID	**Comment from**	**Comments**
33	Diabetes UK	Yes, please see our suggestions for amendments to proposed language below. [QS14 statements 8, 9] People using mental health services *jointly agree a care plan with their care team*, including a crisis plan if they may be at risk of crisis. [QS14 statements 1,3,11,7] People using mental health services Are involved in shared decision-making and *comprehensively supported, considering physical and mental health needs*, in self-management.
34	Healthwatch Birmingham	Quality statement 7: We do not believe this statement belongs under this proposed merger. Although having information supports involvement, this is about people having the necessary information and advice that helps them to get involved and make informed decisions. The proposal does not capture this element effectively. Information and advice should be a standalone statement. Quality statements: 4 and 12: Whilst we agree with the proposed merger, we are unsure whether this captures the element of time that is indicated in the two quality statements. In particular, statement 12 has 'daily one-to-one contact' for people receiving mental health

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS14		
ID	**Comment from**	**Comments**
		care in hospital. Quality statements: 6 and 10: We do not believe that these two statements are about similar issues, whilst having a comprehensive assessment supports people's access to services, access does not always lead to an assessments being done. Quality Statements: 8 and 9: We do agree to the proposed merger, however we do not believe that it is complete. This quality statement needs to address the issue of access by patients or their families/carers to said care/crisis plans and agreement on review dates etc.
35	NHS England Patient Experience Team	Yes except: In the proposals for QS14, in the proposed merged statement 'People using mental health services are involved in shared decision-making and supported in self-management' the previous reference to 'families and carers' in quality statement 1is lost. Whilst the existing quality statement 1 implies rather than explicitly supports family and carer involvement, it would be preferable to either retain or include some element of the existing standard (which is different from the proposed merged standard on empathy, dignity and respect) in the proposed merger.
36	NICE A&I	QS14 comments Merging statements 2 & 15; we agree with this merger. However, we note that the wording of the proposed statement differs from statement 1 in QS15 and wonder if these should be aligned. Merging statements 1, 3, 11 & 7; we do not support the merger of statement 1 into a statement about shared decision-making. We believe that optimism is an important and discrete concept in mental healthcare, which is not covered by a broad statement about shared decision-making, and that this statement should be preserved. We do agree with merging the remaining statements. We would note that the data we have mapped to the existing statements include survey questions such as "were you as involved as much as you wanted to be in decisions about your care?" and "were you given information in a way you could understand?" As proposed, a statement about patient involvement in shared decision-making is very broad and could cover many of the statements in both QS. We would therefore suggest that a new statement should focus on people being involved in their own care as much as they like, as this is what is measured in practice. Merging statements 4 & 12; we agree with this merger. We note that the proposed new statement is worded differently from statement 11 in QS15 and wonder if these should be more closely aligned. We also note that it would be useful to have 'a continuous relationship' defined if this term is to be retained in the combined statement. Merging statements 6 & 10; we do not support this merger. We believe that the existing statement 6 relates to whether people can access services at all, while statement 10 relates to how care should be delivered once services have been accessed. Merging statements 8 & 9; we agree with this merger. However we currently map data relating to whether plans have been reviewed and note that the proposed new statement removes the review element of the existing statement 8. Statements 5, 13 and 14; we have no mapping against these statements. We agree that, if they are to be retained, they cannot be merged with other statements.
37	NICE M&P	Yes, broadly. See specific comments below:

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS14		
ID	**Comment from**	**Comments**
		QS14 service user experience in adult mental health services **Proposed merger of statements 1, 3, 11 and 7**: it is important that the need for health and care professionals to proactively involve people in shared decision-making is not lost, bearing in mind also that some people may make an informed choice not to engage in shared decision-making. The statement should also clearly apply to people who are formally detained under the Mental Health Act. Suggest: *People using mental health services, including service users formally detained under the Mental Health Act, are encouraged to engage in shared decision-making to the extent they wish and are supported in self-management.* It will be necessary to explain what is meant by shared decision-making. A widely used definition is: 'a process in which healthcare professionals and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.' (Coulter and Collins King's Fund 2011). **Proposed merger of statements 8 and 9**: the proposed wording doesn't make clear with whom the care plan is agreed; that is, it is not obvious that this should be agreed with the service user rather than among the health and care professionals. The phrasing about the service user jointly develop a care plan with mental health and social care professionals should be retained. Suggest: *People using mental health services jointly develop a care plan with mental health and social care professionals, including a crisis plan if they may be at risk of crisis*.
38	Patient Information Forum	Comments relate to specific statements 1.Merger of support 1, Involvement 11 and Involvement 7 – We think the needs of people detained under Mental Health Act need specific reference Proposed merger: (PIF suggestion in italics) People using mental health services, *including those detained under the Mental Health Act*, are involved in shared decision-making and supported in self-management. *They understand the assessment process, their diagnosis and treatment options and receive emotional support for any sensitive issues.* 2. Continuity 4 and 12 – We do not support the merger of these statements 3. Merger of access standard 6 and 10 – We do not support the merger of these statements. People in crisis need specific support.
39	QSAC 1	Mostly but I have concerns about the areas described below. Mental Health: I think merger of 6 & 10 needs reference to crisis care as is proposed for 8 & 9
40	QSAC 4	Yes, with the following exception: • QS14 - In merging access 6 and 10, I think it would be important to stress the crisis situation specifically, i.e. "People can access mental health services when they need them, including in crisis situations"
41	Royal College of Speech and	We have particular concerns regarding the following proposals for merging existing statements: Table one - QS14

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS14		
ID	**Comment from**	**Comments**
	Language Therapists	Merging 1,3,11,7 The RCSLT is concerned that the proposed merger of these quality statements focuses on shared decision making and fails to highlight the importance of people understanding the process, diagnosis and treatment options. This recommendation is dependent on an individual's ability to understand. We recommend that understanding is explicitly mentioned in the proposed merger wording. Merging 6,10 The RCSLT is concerned that the importance of a comprehensive assessment, especially at points of crisis, has been lost. We seek clarification that this proposed merger will continue to highlight this.
42	Service User Research Enterprise	[QS14 statements 1, 3,11,17] I don't support the merging of standards 3, 11 and 7. I also don't agree with the concept of 'shared decision-making' as this is not a relation where power is symmetrical and psychiatrists or other mental health set the agenda, decide on the range of options and can override the decision of the person in distress. I know this from personal experience and research. I recommend: that the concept of 'shared decision-making' be replaced with 'supported decision-making' in alignment with the UN CRPD

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS15		
ID	**Comment from**	**Comments**
43	Diabetes UK	Yes, please see our suggestions for amendments to proposed language [QS15 statements 4,9,10] Patients experience care that is tailored to their *physical, emotional, and psychological needs and individual preferences*. [QS15 statements 5,6,7,8] Patients are involved in shared decision-making Comprehensive definition needed outlining the extensive range of elements included in the approach, so that important aspects of the approach (especially relating to choice) are not missed.
44	Healthwatch Birmingham	Quality Statements: 4, 9 and 10: We do not believe that these three statements are effectively captured by the proposed statement. Whilst 4 and 9 can be merged under this new proposed statement we do not believe that statement 10 should be included. Statement 4 and 9 seem to be about activities done at specific points in the treatment pathway of a patient, whilst 10 is about continued assessments during a particular treatment. In addition, statement 10 has included specific areas (anxiety, pain relief, personal hygiene) that are missed out under the new statement. We believe that statement 10 should be a standalone statement. Quality Statements: 5, 6, 7, and 8: These statements are not only about decision-making and the new proposed statement does not capture the content of these statements effectively. There needs to be a separation between decision-making and information/advice. The four statements capture issues around the information people need in order to make informed decisions. Whilst people may be involved in decision-making, they could do so without having the necessary information stipulated within these statements. It is therefore important that there is a statement that makes it clear that people are informed or advised on their rights in relation to treatment, second opinions, and that they understand relevant options etc.
45	National Maternity Voices	I refer to Table 2 and your proposal to merge Statements 5,6,7 and 8. It would be a mistake to assume that the phrase ‘patients are involved in shared decision making’ has a commonly understood meaning in healthcare. The reason that what this jargon phrase ‘means’ was spelled out in the guideline, and therefore the quality standard, is surely that the lay people involved, supported by the clinical committee members, knew it needed to be spelled out in detail: what is not explained clearly will not happen. And that remains the case nearly 10 years on. In maternity a new charity – Birthrights – has been set up in the intervening time to remind healthcare professionals of women’s human rights in childbirth (including the right to have evidence-based care, and their options and rights explained) and to train healthcare professionals in understanding what that means: demand for the training from

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS15		
ID	**Comment from**	**Comments**
		Trusts is high – it is needed. The Academy of Royal Colleges has only just launched its 'choosing wisely' 'BRAN' – Benefits, Risks, Alternatives, do Nothing for while – campaign – and it is seen in many areas of health as new and a bit radical to think of patients asking these questions, or having explanations of options framed in this way: that was the clear message at the launch conference this year – it is not obvious to professionals how to do shared decision making, nor what it means. Most importantly of all, the phrase 'patients are involved in shared decision-making' will not necessarily mean to most patients and services users all of the things that statements 5 to 7 encompass. People do not understand that they have the right to choose, accept or decline treatment and that these decisions should be respected and supported, nor that they can ask for a second opinion. They typically will not know about as ask the BRAN questions, nor understand their right to set the boundaries on who among their family and carers knows about their health issues and treatment. So a statement in a hospital leaflet, for example, that 'this Trust follows the NICE Standard on Shared Decision Making' would mean little – and local Healthwatch would have difficulty holding that Trust to account to say more without the existing wording of standards 5,6, 7, 8. Similarly, the proposed merger of standards 4, 9 and 10 makes the same error in supposing that care being 'tailored to [patient] needs and preferences' automatically and obviously encompasses the detail of the existing standards, which includes health beliefs, concerns and preferences, physical and psychological needs, including nutrition, hydration, pain relief, personal hygiene and anxiety. With an aging population, the specific reference to coexisting conditions is surely valuable: the current focus on 'integrated care' would not be necessary if people's needs typically were being looked after at the moment in a person-centred, holistic way. It remains necessary to describe in specific detail the ideal situation towards which services aspire. Please reconsider – it would be especially important for you to have consulted both Healthwatch England and National Voices on these proposals. While mental health care is not within the remit of National Maternity Voices, the reservations expressed here about Table 2 would appear to be equally applicable to the proposals in Table 1, where what is proposed is the substitution of jargon in place of statement of the specific needs of service users.
46	NICE A&I	QS15 comments Statement 1; this statement is extremely broad and, as noted, differs in wording from statement 2 in QS14. We can see the value in retaining it, so that it is not necessary to include an overarching statement about how people should be treated in condition-specific quality standards. Our current mapping includes a lot of data about whether people felt they were treated with respect and dignity, which appear to be the terms from this statement most commonly used in national surveys and audits. We have also mapped data about staff talking in front of people as if they weren't there, whether people felt they were given enough privacy, whether they felt listened to, were given enough time and were treated with care and concern. It could be argued that all of these elements are also covered by the terms respect and dignity. Merging statements 3 & 14; we agree with this merger.

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS15		
ID	**Comment from**	**Comments**
		Merging statements 4, 9 & 10; we agree with this merger. We note that much of our mapping relates to the specific elements listed in the current statement 10, such as pain relief, help to eat meals and hydration, and we would therefore support reflecting these elements in the measures of the new, merged statement. Merging statements 5, 6, 7 & 8; we agree with this merger. Much of our mapping against statement 5 relates to treatment options, risks and benefits being clearly explained (also see our response to statement 2 in the next section of this response). The mapping against statement 6 relates to people reporting being as involved as they would like to be in decisions about their care. Our comments above relating to the use of the term shared decision-making in this merged statement are equally relevant here. Statements 12 and 13; we agree that, if these statements are to be retained, they cannot be merged with other statements. Statement 11; as above, we note that this statement is worded differently to the proposed merged statement about continuity of support in QS14 and wonder whether these should be more closely aligned.
47	NICE M&P	Yes, broadly. See specific comments below: **QS15 patient experience in adult NHS services** **Proposed merger of statements 4, 9 and 10**: statement 4 is concerned with a different aspect of individuality from statements 9 and 10. I suggest statement 4 is retained unchanged and statements 9 and 10 are combined into the proposed wording. **Proposed merger of statements 5, 6, 7 and 8**: it is important that the need for health and care professionals to proactively involve people in shared decision-making is not lost, bearing in mind also that some people may make an informed choice not to engage in shared decision-making, and also that their decisions should be respected if the healthcare professional disagrees. Suggest *Patients are encouraged to engage in shared decision-making to the extent they wish and their decisions are respected and supported.* It will be necessary to explain what is meant by shared decision-making. A widely used definition is: 'a process in which healthcare professionals and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.' (Coulter and Collins King's Fund 2011).
48	Patient Experience Library	We broadly agree with all the proposed mergers, and would just question the following: QS15 - Need - 1: "Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty." This sentence contains seven descriptors which are more or less synonymous. We would suggest a match with QS14 - Support - 2, perhaps something like: "Patients are treated with empathy, dignity and respect". QS15 - Continuity - 2: "Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills." This seems a little vague. Is it about continuity, or effectiveness, or communication? How would anyone judge the "effectiveness" of the interactions? What are the "relevant communication skills" and what level of competency should be demonstrated? We wonder whether Continuity - 2 could be subsumed within Continuity - 12.

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS15		
ID	**Comment from**	**Comments**
		QS15 - Choice - 9: We see a need to keep "second opinion" as a separate, specific statement. Shared decision-making is a good aim. But in cases where agreement is problematic or impossible, the patient should be explicitly supported in exploring other options.
49	Patient Information Forum	4. Proposed merger of individuality 4 and 9 and need 10 – Risks, benefits and burdens of treatment need to be considered. Suggest rewording so that a patient receives enough information to make a shared decision as follows: Patients *receive information and care tailored to their physical and psychological* needs and personal preferences. 5. Choice 6, 6, 7 and 8 We do not support the merger of these statements – patients or their advocates need to be informed of their rights to choose treatment and to ask for a second opinion. We also think any update to statements relating to patients detained under the Mental Health Act should include the use of advanced directives.
50	QSAC 1	Mostly but I have concerns about the areas described below. Adult health: 5, 6 & & merger – I think saying 'involved in shared decision making' significantly weakens the element of choice including second opinion, rejection and I think this should remain explicit
51	QSAC 3	Generally yes but the statement 'Patients are involved in shared decision-making' should include reference to their decision being respected as I and others have recently found it to be an issue
52	QSAC 4	Yes, with the following exception: • QS15 – in merging choice 5, 6, 7 and 8, I think it's important not to lose the point about patients being supported to be involved in shared decision making as not all patients can do so effectively without support, i.e. "Patients are supported to be involved in shared decision making" or "Patients are involved in shared decision making, including having support to do so if required".
53	Royal College of Speech and Language Therapists	We have particular concerns regarding the following proposals for merging existing statements: Table two - QS15 Merging 4,9,10 The RCSLT is concerned that physical and psychological needs has been omitted from the proposed merger wording. We seek clarification that this will be clearly represented in the proposed merger. Merging 5,6,7,8 The RCSLT is concerned that the importance of an individual's ability to understand and to make informed choices has been omitted from the proposed merger. Whilst shared decision making is essential, this rests upon an individual's ability to understand and communicate. Shared decision making must highlight the importance of communication and understanding to make sure that both parties can equally participate. We recommend that understanding is added to the proposed merger as a priority.

Consultation question 2: Do you agree with the proposals for merging existing statements? Comments relating to QS15		
ID	**Comment from**	**Comments**
54	The Pelvic Partnership	[QS15] Yes, in principle – I think this simplifies and minimises duplication. However, I have concerns about some of the statements that are to be merged, particularly Choice 5, 6, 7 and 8. I think these should not be merged as each supports an important principle which is not reflected in the merged version. I think the wording of the mental health standards is good as it refers to "people" and would like to see this reflected in the QS15 statements by changing the language and removing reference to "patients" from these. The use of "patient" is particularly problematic in maternity settings where there has been a significant move to woman-centred language, and so the use of "people" instead of "patient" for the QS15 recommendations would be preferable. I think that the same principles of care should apply across all types of service, including mental health, primary and secondary healthcare and maternity services.
55	University Hospitals Bristol NHS Foundation Trust	Yes – but I would be more specific in focussing the following statement on care and treatment (if that's what it is): Patients are involved in shared decision-making = Patients are involved in shared decision-making about their care and treatment. Unless, you want to take this Standard further and include something around shared decision making in respect of NHS services (i.e. patient and public involvement / engagement territory)

Consultation question 3: Are there more statements that could be merged because they focus on similar or overlapping actions?		
ID	**Comment from**	**Comments**
56	Elcena Jeffers Foundation	Yes
57	Hounslow and Richmond Community Healthcare Trust	No

Consultation question 3: Are there more statements that could be merged because they focus on similar or overlapping actions?		
ID	**Comment from**	**Comments**
58	NHS England Patient Experience Team	Not that we have identified
59	NICE A&I	QS15 comments Statement 2; we considered whether this statement, about effective interactions and communication skills, could be merged with the very general statement 1 about how people are treated overall. Alternatively, since most of our mapping against this statement is about treatments and options being explained in a way people can understand, we believe it could be considered part of shared decision-making, as is made clear in the current statements 5 & 6. Statements 3, 11 & 14; we would note that some of our mapping potentially applies across these statements, particularly relating to whether cancer patients were allocated a named nurse specialist to support them throughout their care and whether their nurse was easy to contact.
60	NICE M&P	No
61	Patient Information Forum	No
62	QSAC 1	No
63	QSAC 2	In QS15, Statements 1 & 2 could be merged and simplified as follows. There is a lot of overlap between the list of words and fewer could be selected to still convey the same meaning. These are the same words that were chosen in QS14: 'Patients are treated with empathy, dignity and respect, by staff who have demonstrated competency in relevant communication skills' I would like to suggest including the statement as worded in QS14 in QS15. Feedback from patients is equally applicable to all healthcare, not just mental health 'People using health care services feel confident that the views of service users are used to monitor and improve the performance of services.'
64	QSAC 3	None
65	QSAC 4	No.
66	Royal College of Nursing	No, we do not believe there are any more statements that could be merged.
67	Royal College	No

Consultation question 3: Are there more statements that could be merged because they focus on similar or overlapping actions?		
ID	**Comment from**	**Comments**
	of Speech and Language Therapists	
68	The Pelvic Partnership	No, but I think using the same terminology facilitates all the QS to apply to all settings.
69	University Hospital Southampton NHS Foundation Trust	None immediately obvious to me
70	University Hospitals Bristol NHS Foundation Trust	Not in my view

No comment responses		
ID	**Comment from**	**Comments**
71	Department of Health and Social Care	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.
72	Mind	First our apologies for not being able to get back to you within the deadline. Unfortunately this has been an exceedingly busy time for our team (with the Review of the Mental Health Act, upcoming NHS Long Term Plan, etc.) we simply didn't have the capacity. Because of this we won't be able to get comments to you by Dec 18th. This is a really important issue and so sorry we weren't able to contribute at this time.
73	QSAC 5	Have looked at this a few times and it seems so sensible to tidy them up pro tem that I cannot think of anything sensible to say. So no comment.
74	The Patients Association	Thanks for checking in with us. I'm afraid we won't be responding to either of these consultations, owing to a lack of capacity.

Comments submitted by:

- Department of Health and Social Care
- Diabetes UK
- East and North Hertfordshire NHS Trust
- Elcena Jeffers Foundation
- Healthwatch Birmingham
- Hounslow and Richmond Community Healthcare Trust
- Individuals 1 & 2
- Loughborough University Design School
- Mind
- National Maternity Voices
- NHS England Patient Experience Team
- NICE internal comments: Adoption and impact team
- NICE internal comments: Medicines and prescribing team
- Patient Experience Library
- Patient Information Forum
- QSAC members 1 to 5
- Royal College of Nursing
- Royal College of Speech and Language Therapists
- Service User Research Enterprise
- The Patients Association

- The Pelvic Partnership
- University Hospital Southampton NHS Foundation Trust
- University Hospitals Bristol NHS Foundation Trust

Appendix 2: Pre-consultation comments from QSAC members

Notes:

1. Many of the comments shown in the table were submitted as tracked changes or comment boxes within the proposed consultation document. Additional text has been added by NICE in square brackets to help explain what each comment is referring to.
2. Comments have been linked to a consultation question by NICE or assigned to a general category.
3. Some comments relate to the refresh and consultation process.
4. The label CM refers to committee member.

Comment category	Comment from	Comments
General	CM1	It would be useful if the stakeholders consulted include carer organisations such as Carers UK.
General	CM2	My comments are mainly about the " process" to ensure that this consultation and the end outputs of refreshed QS can be a real opportunity to engage with stakeholders and to promote / reinforce the very purpose of and for QS I can see the value in merging statements which do now seem to be overlapping. I guess if NICE can in communicating the reason for change make reference to the evidence that much of what needed to be stated at the point of origin for the QS has now become embedded in practice that would be assuring. I do understand that retaining the underpinning measures provides this but wonder if the subtlety of this may be lost on some stakeholders. Should be interesting to see how key stakeholders respond particularly given changes between NHS and LA in the ways of working in the community particularly re Mental Health.
General	CM3	My overriding point is to challenge the need for 2 different QS covering MH and adult NHS experience. Could it be possible to make an exception to the usual process in the light of the key MH policy objective of Parity of Care? QS 15 more than adequately covers mental health user experience and overall is more inclusive. It is particularly stark in the context of QS14, 2 and 15 and QS15, 1. Both include dignity and respect, but only if you are an adult experiencing NHS care do you get kindness, honesty and understanding etc! On the basis we probably won't have one overarching QS at this stage my other points are as follows: [comments can be found later in the table]
General	CM3	Overall QS feels as if it has a secondary care focus. Finally, could we have one additional consultation question - ' Would you like to see a future amalgamation of these 2 QS in line with the policy imperative of Parity of Care' or similar
General	CM2	[Comment inserted in document] These QS form the backbone of all QS and I think you need to acknowledge and reinforce this a bit more as part of the reason to refresh. I assume that you are going to promote awareness of the "consultation" to ensure that we can demonstrate that we have sought and hopefully will receive robust feedback from "key" stakeholders who need to buy into and "promote" the refreshed

Comment category	Comment from	Comments
		standards. This refresh is a great opportunity to increase awareness and reinforce the use of QS if NICE look to use the “process” for consultation which is being adapted from the topic specific given the place and importance of these particular standards being fit for purpose and used. Communication throughout the “refresh” is key. When you have set out the Background and technically what you have written is accurate but whether it’s in this document or to accompany it I think this needs a little more explanation and assurance (not just the measures but the intent) for the range of external stakeholders one wants to own and use these QS
General	CM2	[Comment inserted in document] Are you able to x ref to some process by which NICE capture and subsequently review suggested new areas which are currently out of scope at the time of “ full update “? I am simply mentioning this as I would anticipate a level of sensitivity and concern even with our best efforts in relation to QS14 in particular.
Consultation question 1	CM4	Yes, I support an interim refresh as suggested.
Consultation question 1	CM1	Many thanks for the opportunity to comment on the refresh. I think an interim refresh makes a lot of sense and it will be interesting to see what responses are returned by stakeholders.
Consultation question 1	CM3	I’ve no problem with the majority of the ‘mergers’ as the basis for consultation.
Consultation question 2	CM1	The proposed merger will obviously simplify some of the statements, however my initial reaction is that this does risk losing some important concepts which are particularly important to patient choice.
Consultation question 2	CM4	[QS14 statement 15 “…the community…”] Is this covered in the proposed merger? Respect in the community is a different thing from respect in NHS services and may be beyond the scope of the QS as it implies culture change in the wider world.
Consultation question 2	CM4	[QS14 statement 1] This sounds like a different issue from the other 3 that are being merged here. It’s more about confidence in the medical professionals and the models of care/treatment they use than it is about shared decision-making
Consultation question 2	CM2	[QS14 Statement 15 “the community”] Need to understand if there was some further info re the use of “community” in the original.
Consultation question 2	CM3	[QS14 statements 2 & 3] That said I have a problem with the theme for QS14 2 and 3 and QS15 1, ‘support’ and ‘need’ respectively. For me they are both about attitude and approach to patients.
Consultation question 2	CM3	[QS14 statements 4 & 12] The merger of QS14 4 and 12 seems to suggest on-going dependence. QS15 , 11 and 12 apply equally to people with MH problems and provide a better standard around continuity.
Consultation	CM3	[QS14 statements 2 & 3; QS15 statement 1]

Comment category	Comment from	Comments
question 2		That said I have a problem with the theme for QS14 2 and 3 and QS15 1, 'support' and 'need' respectively. For me they are both about attitude and approach to patients.
Consultation question 2	CM3	[QS14 statements 6 & 10] The merger of 6 and 10 in QS 14 omits the assessment part of the latter.
Consultation question 2	CM3	[QS14 statements 1,3,11 &7] The merger of 1,3,11, and 7 in QS 14 is a very general statement which loses any emphasis on patient rights to accept or decline treatment
Consultation question 2	CM5	[QS14 Statements 2 and 15. Proposed merged statement wording "families or carers, are treated"] Suggest this should say "… families or carers, feel they are treated…"
Consultation question 2	CM5	[QS14 statements 1,3,11&7: Proposed merged statement wording "…and supported in self-management"] Suggest changing to "… are supported in self-management; and feel optimistic that care will be effective. Is 'shared decision-making' defined elsewhere for stakeholders?
Consultation question 2	CM4	[QS14 statement 10] There is a review underway at the moment of a young man who committed suicide a few days after being admitted to a mental health unit. It turns out that the assessment he had on admission was just a generic one undertaken by a nurse, not comprehensive and personalised. Does losing this statement dilute the QS?
Consultation question 2	CM1	[QS15 statements 5,6,7&8] …the proposed merger of statements 5, 6, 7, and 8 into 'Patients are involved in shared decision-making' takes out: 'active involvement in decision making, right to choose, right to ask for a second opinion'. I think it is really important these principles aren't lost.
Consultation question 2	CM3	[QS15 statement 1] That said I have a problem with the theme for QS14 2 and 3 and QS15 1, 'support' and 'need' respectively. For me they are both about attitude and approach to patients.
Consultation question 2	CM5	[QS15 statements 4,9 & 10] Is 'shared decision-making' defined elsewhere for stakeholders?
Consultation question 2	CM4	[QS15 statements 4, 9 &10: "regularly assessed and addressed" from statement 10] This element of review of changing needs is missing from the proposed merger.
Consultation question 2	CM4	[QS15 statement 12] Possible merger here?

Appendix 3: Comments received after report was sent to members

Comment category	Comment from	Comments
QS14 & QS15	Mind	Thank you for extending the period for us to comment on the proposed refresh of QS14 and QS15, we really appreciated that and I'm very sorry not to have responded before the extended deadline. Here are some comments in case you can still use them. The way you have merged quality statements looks logical and I think the main question for us would be what the implications of the merges are for the quality measures. It would be important not to lose too much specificity. For example in QS14, under 'Involvement' we'd want you to continue to include a focus on people detained under the Mental Health Act as they risk being excluded or overlooked otherwise and (as highlighted in the recent review of the Mental Health Act) are very likely not to be involved in decisions. We also wouldn't want to lose one-to-one contact with mental healthcare professionals in hospital as this is a core aspect of therapeutic experience (and was also picked up in the independent review of the MHA). However it isn't only (or perhaps primarily) about continuity and with a merged statement could disappear altogether. It's not that we want to focus overly on inpatient settings or detention, but the more generic quality statements need to be applied to these contexts as well as to community services and this may involve different actions and measures. It's good that you are including rationale. We're very conscious that a lot of these statements are a long way from being widely implemented, despite being established so long, and hope the refresh will bring renewed attention to them. While you're not proposing new statements, I'd just point out that there are statements in QS15 that are relevant to adult mental health services and perhaps that could be considered when the standards are fully updated.
QS14	Former QSAC member	**Respect and empathy -** No comment **Decision making** - I agree that a definition of shared decision making is needed and that statement 1 is a discrete concept. I think the comment re understanding being made explicit is a good point as this would allow people to make informed shared decisions. I also agree and think it is important that this statement be applied to those detained under the mental health act. Whilst some decisions will be made without their input, it would be good to see them involved in other decisions where/if possible.

Comment category	Comment from	Comments
		Could the statement be - "People using mental health services, including those detained under the Mental Health Act, understand the assessment process, their diagnosis and treatment options, and are actively involved in shared decision making and supported in self management"? Otherwise, can it be something similar to that I've stated for QS15: "People using mental health services, are actively involved in shared decision making and supported to make fully informed choices about treatment, including self management". Whilst I acknowledge that some people may choose not to engage in shared decision making, would such a clause minimise the likelihood that practitioners will involve the majority in shared decision making. Can this be noted in the rationale or elsewhere, but not the statement itself? **Continuity** - I believe it is important to capture the element of time in this statement. Is it possible to word the statement: "People using mental health services have regular contact and are supported by a multidisciplinary team with whom they have a continuous relationship"? As NICE propose, it would help if continuous relationship is defined and ideally, the QS would stipulate how regularly contact should occur in an inpatient setting **Access** - I agree with all of the comments and believe also that it is important to highlight crisis in particular. Recent research I have conducted has emphasised the fact that many in need of crisis support are not able to access this treatment when they try to. This is addressed in the statement people can access mental health services when they need them, however given the comments noted, I wonder whether the statement could be: "People can access mental health services when they need them, including crisis support services, Those accessing crisis support should have a comprehensive assessment, undertaken by a professional competent in crisis working"? Is it possible to have a two-part statement? **Information** – Again, I agree with all comments. Can the statement be: "People using mental health services jointly agree and have access to a care plan, including a crisis plan if they may be at risk of crisis, both of which have an agreed review date. **Environment** – No comment **Treatment** – No comment
QS15	Former QSAC member	As suggested by one individual, is it possible to use the term people, rather than patients. i.e. people using adult NHS services … I would vote for this **Respect and empathy -** No comment

Comment category	Comment from	Comments
		Communication – No comment **Contacts -** No comment **Continuity** – No comment **Information Exchange** – No comment **Support** – I would suggest that this statement is worded as follows: “Patients (people using adult NHS services) experience care that is regularly reviewed and tailored to their physical and psychological needs and preferences.” I wouldn’t have thought it mattered that nutrition etc isn’t listed and hopefully a regular review would identify a persons circumstances, concerns etc. **Information Sharing** – No comment **Decision Making** – I agree with most comments, in particular the one about the emphasis on patient choice. Can the statement be: “Patients are actively involved in shared decision making and supported to make fully informed choices about treatment, including the right to decline treatment or ask for a second opinion”?

- An informal response was also received from The Patient’s Association. It is not reported here as had not been through their formal sign-off process.